

FACTORS ASSOCIATED WITH MAMMOGRAPHY SCREENING DECISION AMONG RURAL WOMEN IN KIULU, SABAH

BY

FARHANNIDALINE BT GODULUS

Dissertation submitted in partial fulfillment of the requirements of the degree of Bachelor of Health Sciences (Nursing)

June 2012

TABLE OF CONTENT

| LIST (| DF ABBREVIATIONS | i | | | |
|--|--|--|--|--|--|
| LIST OF FIGURES AND TABLES ii | | | | | |
| ABSTRACTiii | | | | | |
| DECL | ARATION | vii | | | |
| CERTIFICATEviii | | | | | |
| ACKNOWLEDGEMENTix | | | | | |
| DEFIN | ITION OF KEY TERMS | x | | | |
| СНАР | TER 1: INTRODUCTION | 1 | | | |
| 1.0 | Introduction | 1 | | | |
| 1.1 | Background of the Study | 2 | | | |
| 1.2 | Rationale for the Study | 4 | | | |
| 1.3 | Problem Statement | 5 | | | |
| 1.4 | Purpose of the Study | 6 | | | |
| 1.5 | Aims of the Study | 7 | | | |
| 1.5.1 | General Objective | 7 | | | |
| 1.5.2 | Specific Objectives | 7 | | | |
| 1.6 | Research Questions | 7 | | | |
| 1.7 | Research Hypothesis | 8 | | | |
| 18 | Justification for and Significance of the Study | 0 | | | |
| 1.0 | Sustification for, and Significance of the Study | | | | |
| CHAP' | TER 2: LITERATURE REVIEW | | | | |
| 2.0 | TER 2: LITERATURE REVIEW | | | | |
| 2.0 2.1 | TER 2: LITERATURE REVIEW Introduction Breast Cancer | | | | |
| 2.0 2.1 2.2 | TER 2: LITERATURE REVIEW Introduction Breast Cancer Incidence and Prevalence of Breast Cancer | | | | |
| 2.0 2.1 2.2 2.2.1 | TER 2: LITERATURE REVIEW Introduction Breast Cancer Incidence and Prevalence of Breast Cancer Breast Cancer: Incidence and Prevalence in Malaysia | | | | |
| CHAP ⁷ 2.0 2.1 2.2 2.2.1 2.2.2 | TER 2: LITERATURE REVIEW Introduction Breast Cancer Incidence and Prevalence of Breast Cancer Breast Cancer: Incidence and Prevalence in Malaysia Breast Cancer: Incidence and Prevalence in Sabah | | | | |
| CHAP' 2.0 2.1 2.2.1 2.2.2 2.3 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP⁷ 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP' 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 | TER 2: LITERATURE REVIEW | | | | |
| CHAP⁷ 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP' 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP' | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP⁷ 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP⁷ 3.0 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP⁷ 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP⁷ 3.0 3.1 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP⁷ 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP⁷ 3.0 3.1 3.2 | TER 2: LITERATURE REVIEW. Introduction. Breast Cancer Incidence and Prevalence of Breast Cancer | | | | |
| 1.3 CHAP' 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP' 3.0 3.1 3.2 3.3 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP' 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP' 3.0 3.1 3.2 3.3 3.3.1 | TER 2: LITERATURE REVIEW Introduction | | | | |
| CHAP 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP 3.0 3.1 3.2 3.3 3.3.1 3.3.2 | TER 2: LITERATURE REVIEW. Introduction. Breast Cancer | 10 10 10 10 10 10 10 10 10 12 | | | |
| CHAP' 2.0 2.1 2.2 2.2.1 2.2.2 2.3 2.3.1 2.3.2 2.4 CHAP' 3.0 3.1 3.2 3.3 3.3.1 3.3.2 3.3.3 | TER 2: LITERATURE REVIEW | 10 | | | |

| 3.4.1 | Instrument | | | |
|---|---|--|--|--|
| 3.4.2 | Measurement of Variables | | | |
| 3.4.3 | Translation of Instrument | | | |
| 3.4.4 | Issue of Rigor, Validity and Reliability of the Data Collection | | | |
| Instrur | nent | | | |
| 3.5 | Ethical Considerations27 | | | |
| 3.6 | Data Collection Methods28 | | | |
| 3.7 | Data Analysis | | | |
| CHAP | TER 4: RESULTS | | | |
| 4.0 | Introduction | | | |
| 4.1 | Demographic Data | | | |
| 4.2 | Socio-Demographic Data of Rural Women on Mammography | | | |
| Screen | ning | | | |
| 4.3 | Knowledge of Mammogram and Mammography Screening | | | |
| 4.4 | Health Belief Model Factors in Relation to Mammography | | | |
| Screer | ning Decision | | | |
| CHAP | TER 5: DISCUSSION 40 | | | |
| 5.0 | Introduction | | | |
| 5.1 | Knowledge of Mammogram with Mammogram Screening40 | | | |
| 5.2 | Health Belief Model Factors in Relation to Mammography | | | |
| Screen | ning Decision | | | |
| CHAP | TER 6: CONCLUSION & RECOMMENDATION | | | |
| 6.0 | Introduction43 | | | |
| 6.1 | Recommendations43 | | | |
| 6.1.1 | Nursing Practice | | | |
| 6.1.2 | Nursing Education | | | |
| 6.1.3 | Nursing Research | | | |
| 6.2 | Strengths and Limitations | | | |
| 6.3 | Conclusion | | | |
| 6.4 | Contribution to the Theory Development | | | |
| REFEI | RENCES | | | |
| APPE | NDIX 1 - RESEARCH INFORMATION FOR PATIENTS 54 | | | |
| LAMP | IRAN 1 - MAKLUMAT KAJIAN BAGI PESERTA 57 | | | |
| APPEN | NDIX 2 - PARTICIPANT INFORMATION AND CONSENT | | | |
| FORM | | | | |
| LAMP | IRAN 2 - BORANG KEIZINAN PESERTA | | | |
| APPENDIX 3 - QUESTIONNAIRE ON FACTORS ASSOCIATED WITH 62 | | | | |
| MAMMOGRAPHY SCREENING DECISION AMONG RURAL | | | | |
| WOM | EN IN KIULU, SABAH | | | |
| | | | | |

| LAMPIRAN 3 - BORANG KAJI SELIDIK FAKTOR-FAKTOR | |
|--|----|
| BERKAITAN DENGAN MEMBUAT KEPUTUSAN MENJALANI | |
| SARINGAN MAMOGRAFI DALAM KALANGAN WANITA LUAR | |
| BANDAR DI KIULU, SABAH | 64 |
| APPENDIX 4 – SAMPLE CALCULATION | 67 |
| APPENDIX 5 – GANTT CHART | 68 |
| APPENDIX 6 – PERMISSION TO USE QUESTIONNAIRE | 69 |
| APPENDIX 7 – APPROVAL LETTER | 70 |

LIST OF ABBREVIATIONS

- USM Universiti Sains Malaysia
- HBMS Health Belief Model Scale
- CHBM Champion's Health Belief Model
- KRK Klinik Rawatan Keluarga

LIST OF FIGURES AND TABLES

| Figure 2.1 | - | Health Belief Model |
|------------|---|--|
| Figure 3.1 | - | Flow Chart of Study |
| Figure 4.1 | - | Age frequency among rural women in Kiulu |
| Figure 4.2 | - | Ethnicity of rural women in Kiulu |
| Figure 4.3 | - | Marital status among rural women in Kiulu |
| Figure 4.4 | - | Highest educational level among rural women in Kiulu |
| Figure 4.5 | - | Family members with breast cancer |
| Table 4.2 | - | Socio-demographic characteristics among rural women in Kiulu |
| Table 4.3 | - | Socio-demographic data of rural women on mammography |
| | | screening |
| Table 4.4 | - | Knowledge of mammogram among women who had mammogram |
| | | and no mammogram |
| Table 4.5 | - | Relationship between Health Belief Model factors and |
| | | mammogram screening practice |
| Table 4.6 | - | Barriers items scale across mammography screening practice |
| | | |

FACTORS ASSOCIATED WITH MAMMOGRAPHY SCREENING DECISIONS AMONG RURAL WOMEN IN KIULU, SABAH

ABSTRACT

Breast cancer is the common cancer and the leading cause of death among women in Malaysia. Mammography screening behavior has not been well studied among rural women in Sabah. Knowledge about breast cancer and screening were associated with mammography utilization. The objective of this study was to identify factors associated with mammography screening decision among rural women in Kiulu, Sabah. This study had a cross-sectional design with purposive sampling (n=200). A self-administered structured questionnaire was done. Data was analyzed using IBM Statistical Package Social Science (SPSS) software version 19.0. Of 200 participants, only 40 (20%) women had a mammogram done and 80% reported not had a mammogram. Chi-Square test revealed that age, ethnicity and marital status were associated with mammography screening decision with (p<0.05). Women 30 to 40 with mean age 41.86 years old were the highest respondents. 25 from 40 women 30-40 years old more likely had a mammogram. Women who had reporting a mammogram were likely to be a Dusun woman, and were married. Meanwhile, the educational level and family history of breast cancer were found not associated with mammography screening decision (p>0.05). Using the Independent t-Test, perceived seriousness and barriers found was associated with mammography utilization. Women who had a mammogram score fewer on barriers (14.07). Specific barriers were identified among rural women in this study were embarrassment due to mammogram, causing pain, unpleasant and cost of mammogram. The findings also revealed that there was no association of knowledge about breast cancer screening and mammography utilization (p=0.884). This study provides valuable information for future study and research about belief and attitude toward breast cancer screening among rural women.

KEYWORDS:

Breast, Breast Cancer, Mammography Screening, Decision-Making, Rural Area

FAKTOR-FAKTOR BERKAITAN DENGAN MEMBUAT KEPUTUSAN MENJALANI SARINGAN MAMOGRAFI DALAM KALANGAN WANITA LUAR BANDAR DI KIULU, SABAH

ABSTRAK

Kanser payudara adalah kanser yang paling meluas dan penyebab utama kematian dalam kalangan wanita di Malaysia. Tingkahlaku menjalani saringan mamografi tidak dikaji sepenuhnya dalam kalangan wanita luar bandar di Sabah. Pengetahuan tentang kanser payudara dan saringan payudara adalah berkaitan dengan penggunaan mammogram. Objektif kajian ini adalah untuk mengenalpasti faktor-faktor yang berkaitan dengan keputusan menjalani saringan mamografi dalam kalangan wanita luar bandar di Kiulu, Sabah. Kajian ini dilakukan secara tinjauan dengan persampelan secara bertujuan (n=200). Kajian soal-selidik telah dilakukan. Data dianalisis menggunakan IBM Statistik Pakej Sains Sosial (SPSS) versi software 19.0. Daripada 200 peserta, hanya 40 (20%) orang wanita sahaja yang pernah menjalani mammogram dan 80% wanita tidak pernah menjalani mammogram. Ujian Chi-Square menunjukkan bahawa faktor umur, kumpulan etnik dan status perkahwinan adalah berkaitan dengan keputusan menjalani mammogram (p<0.05). 25 wanita berumur 30 hingga 40 tahun dengan umur min 41.6 tahun ialah responden yang mempunyai peratusan paling tinggi dan mereka pernah menjalani mammogram. Etnik Dusun dan telah berkahwin menjadi faktor dalam keputusan menjalani mammogram. Sementara itu, tahap pendidikan dan keluarga yang mempunyai sejarah kanser payudara didapati tiada perkaitan dengan keputusan untuk saringan mamografi (p>0.05). Dengan menggunakan ujian Kebebasan t, keseriusan penerimaan dan halangan didapati mempunyai perkaitan dengan penggunaan mamografi. Wanita yang menjalani mammogram mempunyai kurang halangan (14.07). Halangan spesifik dikenalpasti dalam kalangan wanita luar bandar yang terlibat dalam kajian ini adalah malu untuk menjalani mammogram, kesakitan disebabkan prosedur ini, ketidakselesaan dan perbelanjaan menjalani mammogram. Keputusan juga membuktikan bahawa tiada hubungan di antara pengetahuan tentang saringan kanser payudara dengan penggunaan mamografi (p=0.884). Kajian ini memberikan informasi yang bernilai untuk kajian yang lebih lanjut pada masa akan datang.

KATA KUNCI:

Payudara, Kanser Payudara, Saringan Mamografi, Membuat Keputusan, Kawasan Luar Bandar

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Farhannidaline Godulus, Student of Degree of Bachelor Health Sciences (Nursing), School of Health Sciences, Health Campus, Universiti Sains Malaysia, 16150 Kubang Kerian, Kelantan Date: 19 July 2012

ACKNOWLEDGEMENT

First of all, I am very thankful to God, the One who makes all things possible for me and in giving me strength and guidance in through tough time that I have been encounter.

I also would like to take the opportunity to express my gratitude to my supervisor, Dr. Soon Lean Keng, for her guidance, support, valuable suggestion throughout the completion of this thesis. Special thanks to Dato' Dr. Zaidun Kamari, the Hospital Director, Hospital Universiti Sains Malaysia (HUSM) for approving to do data collection. I also want to express my sincere gratitude to all the respondents that had participated in my study in hospital and also in Sabah. Without them, this research cannot be complete. I am most grateful to Professor Victoria L. Champion for allowing me to refer to her published survey questionnaire. Without her permission, I could not complete this research.

Besides that, I would like to give warmest appreciation to my beloved family; my parents Godulus Sogunting, Jomini Agu, and my siblings for their love, prayer, financial support, patience, encouragement and understanding; and to my beloved partner, Peter Nyambang for his personal support and great patience at all times. I would like to acknowledge all of my lecturers, tutors and my senior, Lai Sue Yi for all help, advice and support they gave to me. I owe sincere and earnest thankfulness Miss Ernest Mangantig, Master students from Department of Biostatistics, School of Medical Science for her guidance in research methodology and data analysis even though she was busy with her works.

At last but not least, I thank you to my friends who accompanied me and giving me support and encouragement. Thank you everyone who made this research successful.

ix

DEFINITION OF KEY TERMS

- Breast The breasts are made up of a combination of glandular and adipose tissue that determines breast size and shape, while glandular tissue makes lactation possible (Hormann, 2007).
- Cancer Cancer is the uncontrolled growth of abnormal cells in the body. Cancerous cells are also called malignant cells (American Cancer Society, 2011).
- Breast cancer
 It refers to cancer that forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). This cancer is caused by an uncontrolled growth of cells within the breast tissues (American Cancer Society, 2011).
- Mammography Mammography is a low-dose x-ray that allows visualization of the internal structure of the breast (American Cancer Society, 2011).
- Decision-making Decision-making is a complex process involving the consideration of many alternatives as the act of choice following deliberation and judgment (Gillian, 1993). In this study, it is the woman's decision on mammography screening and the value/belief of the outcome to herself.
- Rural area Rural area is area that have characteristic of farming or country life. The area is not urbanized, though when large areas are described. They have low population density, and typically much of the land is devoted to agriculture (The World Bank, 2011).

CHAPTER 1: INTRODUCTION

1.0 Introduction

Cancer is a significant cause of mortality and morbidity affecting human around the world. While diagnoses may be increasing, this has not obscured any of the realities, the lives that have been taken by cancer. The American Cancer Society (2007) reports in its 2007 Cancer Facts and Figures published in 2008, that nine in eight deaths worldwide is due to cancer. According to Judd (2004), breast cancer is a complex disease and is the second-most common type of cancer, causing an increasing number of deaths annually (Judd, 2004). An estimated 1.3 million new cases of invasive breast cancer are expected to occur among women in 2007 (American Cancer Society, 2008).

In many cases, if breast cancer is detected early, and treatment is begun immediately, a patient's prognosis and survival rate is statistically very good (Lum, 2011). One of the interventions used to reduce the risks of breast cancer is through mammography screening. There is a strong association between survival and early detection of breast cancer through regular mammography.

This chapter will outlined the background to this quantitative study into factors associated with mammographic screening decision among Sabahan rural women in Malaysia. It also details the study aims, objectives, intended outcomes, including methodology and methods. It also provides an outline of the thesis structure. The definitions of key terms used throughout this thesis in relation to this study will be provided.

1.1 Background of the Study

According to the World Health Organisation's International Agency for Research on Cancer, regular mammogram screening could reduce deaths from breast cancer by 35%. Breast cancer is the most common cancer in women in most parts of the world. According to the Malaysian Second Report of the National Cancer Registry, there were 3,738 cases in 2003. It was the commonest cancer in all ethnic and age groups of Malaysian women, comprising 31% of all cases reported (Lum, 2011).

The peak incidence was in the 50 to 59 years age group, with a decline in older age groups. About 64.1% of all cases were diagnosed in women aged between 40 and 60 years. Many women regard the breast as a badge of their feminity, and they can be markedly affected psychologically if they have breast cancer. Studies worldwide have shown that its early detection and treatment helps in making possible a high cure rate. Mammograms play an important role in the screening and diagnosis of breast cancer and other breast conditions (Lum, 2011).

The World Health Organization's International Agency for Researcher on Cancer (IARC) had concluded that only limited evidence of reductions in breast cancer. According to researchers, the recently reported age trial suggested benefit among women who begin to screening from the age of 40. Although early detection improves the likelihood of survival, breast cancer typically diagnosed at advanced stages of disease progression in limited resource countries (Anderson et al., 2003; Benjamin et al., 2006).

Additionally, there is a strong association between survival and early detection of breast cancer through regular mammography. Although mammography used has substantially increased over the past two decades, women with low-socioeconomic

status continue to underutilize this life-saving screening resulting in a disproportionate cancer burden. Poverty, with its inherent class inequities and associated social conditions, is the dominant factor contributing to this cancer burden A poignant social justice issue emerges warranting the pursuit of the reduction of health inequities (Purtzer, 2007).

Although the evidence is that breast cancer was the commonest cancer among Malaysian women (Taib, Yip, & Mohamed, 2008), the incidence of breast cancer among women still prevail (Yahaya & Lim, 2004). For instances, a total of 3738 female breast cancer cases were reported in 2003 and accounted for 31.0% of all cancers; with an overall age-standardized risk of 46.2 per 100,000 (Yahaya & Lim, 2004).

Sabah, also known as North Borneo, is part of East Malaysia is recognised as 'The Land Below The Wind' or 'Land Of The Sacred Mountain'. Sabah is the second largest state in Malaysia. Sabah's population is heterogeneous and culturally diverse, with more than 30 different ethnic races and over 80 local dialects spoken. The largest indigenous ethnic group is the Kadazan-Dusun (17.8 %), followed by Bajau (13.5 %), Malay (11.5%), Murut (3.3%) and others with 14.6 %. The largest non-indigenous group is the Chinese (9.6%) while other groups consist of 4.8% of the population. Nearly 25% is made up of non-Malaysian populations which are Filipinos and Indonesian (Leong et al., 2009). Breast cancer was a cancer of the affluent countries, and the incidence rate increases with industrialization and economic development (Yip, Taib, & Mohamed, 2006). Hence, survival rates for breast cancer patients may increase when the disease is detected in its earliest stage through mammography. Reducing health inequities related to breast cancer is the

foundational issue for this inquiry. This area of study is pursued through a quantitative methodology. Study findings may offer a new theoretical explanation specific to the mammography-screening decision-making processes of rarely or never-screened women. Therefore, ruling out the factors associated with mammography decision making is critical.

1.2 Rationale for the Study

Breast cancer is among the leading causes of deaths in women worldwide. Its incidences have been rising at an alarming rate. More and more women have been subjected to the misery, suffering and pain caused by the disease. In Malaysia alone, approximately one in 20 women will be afflicted with breast cancer by the age of seventy, and by the age of 85, women have a one in eight chance of developing breast tumor (Leong et al., 2009).

Sabah, formerly known as North Borneo, is part of East Malaysia. Leong and colleagues (2009) performed a two-year prospective study looking at the treatment trends of breast cancer in Sabah. They found that 52.2 % of patients with breast cancer in Sabah presented at advanced stages and up to 20.4 % of patients defaulted proper treatment, opting for traditional therapy.

Breast cancer is the commonest cancer among Malaysian women with an overall age-standardised risk of 46.2 per 100,000 (Yahaya & Lim, 2004). A Malaysian woman has a one in 20 chance to develop breast cancer in her lifetime. As with most Asian countries, there is no national breast cancer mammographic screening programme in our country. In Sabah, women with breast cancer present and discovered when the cancer metastasized. 52.2% of patients presented with advanced disease (36.6% with locally advanced and 15.6% with metastatic disease) and they

are more likely to be non-Chinese, poor, uneducated and from a rural area (Leong et al., 2009).

Despite being the second largest state in the country, Sabah has the poorest healthcare service in Malaysia with a doctor to population ratio of 1:2,938 in 2005 (Sabah State Health Department, 2006). According to the latest published National Cancer Registry of Malaysia data on breast cancer did not include data from Sabah due to underreporting of cases. In addition, mammography screening is not available in under developed area in rural health center in Sabah. Hence, limited or no exposure to women especially in rural area. To improve mammography utilizations among rural women in Sabah, there is a need of information concerning on how they make decision and attitude towards mammogram. Thus, there is a higher need of mammography adherence in rural women in Kiulu, Sabah. Therefore, this study was important to fill these gaps by investigating the factors associated with mammographic decisions of rural women in Kiulu, Sabah.

1.3 Problem Statement

As mentioned earlier in the previous section, Sabah has the poorest service of healthcare in Malaysia (Leong et al., 2009). The incidence and prevalence of breast cancer is on the rise worldwide and in Malaysia. As reported by researchers, lack of awareness of breast cancer among women in Sabah with a wrong social and cultural perception of breast cancer has been associated with advanced disease at present. They also reported that strong influence of traditional and cultural beliefs among women is the main attributing factors (Hisham & Yip, 2004; Leong et al., 2009).

As in West Peninsular Malaysia, Leong's (2009) epidemiology study also indicates that a significant portion of women defaulted proper treatment. Their study showed that 20.4% defaulted proper treatment. Lack of breast cancer awareness leading to

late presentation, adherence to strong belief in the effectiveness of complementary alternative and traditional treatments and refusal of treatment, coupled with insufficient health service funding were reasons for defaulted proper treatment and follow-up (Hisham & Yip, 2004; Leong et al., 2009).

The first report of Malaysian National Cancer Registry (NCR) was published in 2002 and the latest is the third report which is NCR 2005 (National Cancer Registry, 2008). All Malaysian NCR were merely descriptive in nature and there was no morbidity and mortality data. All reports were also confine to Peninsular Malaysia and did not include data from East Malaysia (i.e Sabah and Sarawak) (Rushdan, 2008).

Although many researches had focused on factors associated with mammography adherence, few studies have addressed how rural women in Sabah with a breast cancer family history make decisions about whether or not to have mammograms. Furthermore, studies had shown that Malaysian women have a 1 in 20 chance of developing breast cancer in their lifetime (Hisham & Yip, 2004; Leong et al., 2009). The researcher conduct this study to provide unreported data of the mammography screening decision from this part of the world and to investigate which particular factors associated with mammographic decisions of rural women in Sabah.

1.4 Purpose of the Study

In Sabah, research about mammography screening decision among rural women was limited and only a few exploration done on the trends of breast cancer treatment in Sabah (Leong et al., 2009). Furthermore, although evidence points to a significant problem that the rate of breast cancer continued to rise, little or no investigation that has been undertaken into the factors associated with mammography decisions among rural women in Sabah whose culture is obviously different from women of West Peninsular Malaysia background (Leong et al., 2009; Sabah State Health Department, 2006). Therefore, subjective data and information from this study can provide valuable input to healthcare provider or public factors that influence the decision making of mammography decision. The survival rates for breast cancer patients may increase when the disease is detected in its earliest stage through mammography.

1.5 Aims of the Study

1.5.1 General Objective

The study aims was to investigate the factors associated with mammography decisions among rural women in Sabah.

1.5.2 Specific Objectives

- To assess the knowledge about mammography screening among rural women in Kiulu, Sabah.
- To identify the demographic factors influencing mammography screening frequency among rural women in Kiulu, Sabah.
- iii. To determine relationship between factors associated with screening decision and mammography screening frequency.

1.6 Research Questions

- What is the knowledge of mammography screening among rural women in Kiulu, Sabah?
- Are there significant mean differences of mammography screening frequency based on demographic factors among rural women in Kiulu, Sabah?
- iii. Is there significant relationship between factors associated with screening decision and mammography screening frequency?

1.7 Research Hypothesis

- Hypothesis 1 There are significant mean differences of mammography screening frequency based on demographic factors and knowledge of breast cancer among rural women in Sabah.
 (H_{o≠}H_A)
- Hypothesis 2 There are significant relationship between factors with screening decision and mammography screening practice. $(H_{o\neq}H_A)$

1.8 Justification for, and Significance of the Study

In spite of mammography benefits, a significant 20.4% of women in Sabah defaulted treatment and follow-up. Lack of breast cancer awareness leading to late presentation, adherence to strong belief in the effectiveness of complementary alternative and traditional treatments and refusal of treatment, coupled with insufficient health service funding were reasons for defaulted proper treatment and follow-up (Leong et al., 2009) reported by researcher, mammography studies have found that health care provider can make a difference in terms of intervention in increasing the mammography utilization (Champion, Skinner, & Foster, 2000). To promote informed decision about mammography screening, investigating the contributing factors that influence women's decision to have mammography screening is important. Despite evidence points that the rate of breast cancer continued to rise, little or no investigation has been undertaken into the factors associated with mammography decisions among rural women in Sabah whose culture is obviously different from women of West Peninsular Malaysia background. In addition, study has shown that the expectation that healthcare providers can effectively communicate information to their patients is based on a number of key assumptions and patients think about cancer and screening is similar; and breast cancer is almost never treatable (Silverman et al., 2001).

Although countless efforts to teach women facts about breast cancer and mammography, little attention has been devoted to investigate the contributing factors that influence mammography-screening decision among the rural women in Sabah. Most of the research on this topic has been conducted in developed countries, and very few studies have been conducted among indigenous minorities. Research on this topic is important for healthcare providers to have a better understanding of how to manage patients so that policy makers can implement strategies and program activities to prevent delay in breast cancer diagnosis. Therefore, this study was important to elicit better understanding of the rural women's current knowledge of mammography and contributing factors that influence their screening decision. Subjective data and information from this study can provide valuable input to healthcare provider.

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

Before conducting a research study, it was a common practice to conduct a review of the literature on the topic. The ultimate goal of the research were to develop, refine, and expand a body of knowledge (Beck & Polit, 2006). It can help researchers to be familiar with the current body of the knowledge on the topic before the research is carried out. Importantly, these reviews can provide a comprehensive understanding of the topics which help the researcher to be more aware of what was known and what questions need to be answered (Gorard, 2004). Besides, it was also important to locate and include previous evidenced-based papers that have examined the evidence of a particular intervention, because the conclusions of these authors are highly relevant.

As discussed in the introductory section of this proposal, Malaysian women have a 1 in 20 chance of developing breast cancer in their lifetime (Hisham & Yip, 2004; Leong et al., 2009). The purpose of this literature review was to provide the background and context for the research problem. The remaining sections of this literature review will be presented under the major headings of breast cancer, incidence and prevalence of breast cancer, mammography, perception and decision of mammography screening. This chapter also details the conceptual framework that forms a basis in connecting all aspects of inquiry in this study.

2.1 Breast Cancer

Genetic diseases are widespread. Cancer is a genetic disease and is a major cause of death. Cancer is caused by mutations within the genome that result in the development of oncogenes or tumor suppressor genes which both cause the uncontrolled proliferation of cells in opposed ways. The oncogenes are mutated genes that in their pre-mutated state, promote cell replication. However, due to the mutation, these oncogenes cause either enhanced expression or altered nature of protein products. Tumor suppressor genes (TSG) are mutant genes that normally restrain cell growth. It is the most common cause of death for women in Malaysia as well as in the most parts of the worlds (Academy of Medicine of Malaysia, 2008). In breast cancer, the proliferated cells form a hard mass of cancer that can sometimes be felt upon breast self-examination (BSE). The proliferated cells can detach from the tumor and invade other tissue in a process called metastasis. Most breast cancers are invasive, or infiltrating. These cancers started in the lobules or ducts of the breast but have broken through the duct or glandular walls to invade the surrounding tissue of the breast (American Cancer Society, 2011).

2.2 Incidence and Prevalence of Breast Cancer

Many studies have documented that routine mammography and regular clinical breast exams (CBE) are effective at reducing mortality from breast cancer in women between 50 and 69 years of age (Kerlikowske, Grady, Rubin, Sandrock, & Ernster, 1995). Despite early detection improves the probability of survival, breast cancer is typically diagnosed at the advanced stages of the disease progression at the low income of countries that account for 23% (1.38 million) of the total new cancer cases and 14% (458,4000) of the total cancer deaths in 2008. Thus, this makes the incidence of breast cancer in less developed countries to about 19.66 per 100,000 (Rafi, Subramaniam, Chandrasegar, & Mehmood, 2011).

In general, incidence rates are high in the developed countries such as Western and Northern Europe, intermediate in South America, Caribbean, and Northern Africa and low in sub-Saharan Africa and Asia. The breast cancer incidence increases as well as an increase screening intensity (Jemal et al., 2011). Approximately 10 in hundred women are at a risk of developing breast cancer. This includes many African and Asian countries. The incidence and mortality rates have been rising over the past 25 years, while the rates of breast cancer in other developed countries decrease because of early detection by mammogram (Parkin, Nambooze, Wabwire-Mangen, & Wabinga, 2010; Parkin, Whelan, Ferlay, & Storm, 2005). Many overseas studies reported that women from minority ethnic backgrounds are less likely to participate in screening programs than their Anglo-Caucasian counterparts. The Australian Institute of Health and Welfare (1996) reported that incidence rate of breast cancer is lowest in Chinese-Australian women as compare to other Australian women; however breast cancer still remains the most common cause of cancer morbidity among them (McAllister & Bowling, 1993). Kwok, Cant & Sullivan's (2005) qualitative study on twenty Chinese-Australian women in Australia found that barriers identified were fear perceptions of mammography, modesty and fear of stigmatization (Kwok, Cant, & Sullivan, 2005).

2.2.1 Breast Cancer: Incidence and Prevalence in Malaysia

Breast cancer is among the leading causes of deaths in women worldwide. Its incidences have been rising at an alarming rate when more and more women have been subjected to the misery, suffering and pain caused by the disease. According to consultant surgeon Professor Yip Cheng Har's study, there is an increased in breast cancer situation in Malaysia, almost 4,000 newly diagnosed cases emerged in the country in the year 2000. Of these, nearly 45% result in deaths, making it the number one cause of cancer related deaths among Malaysian women (Sunday Star, 2003). The most recent report of the National Cancer Registry in Malaysia in 2003 reported 3,738 new cases of breast cancer, giving an age-adjusted rate of 46.2 per 100,000 (Lim & Halimah, 2004). This translates to a lifetime risk of one in 20, that is, one in

20 Malaysian women will develop breast cancer in her lifetime. This means that approximately one in 20 women will be afflicted with breast cancer by the age of seventy. In addition, by the age of 85, women will have a one in eight chance of developing breast tumor (Lim, Halimah, & Lim, 2003).

In a technical report drafted by the Ministry of Health Malaysia in 2001, 20% of patients afflicted by all kinds of the 1392 cancer cases died from breast cancer alone. In its first report, the National Cancer Registry stated that 26,089 people were diagnosed with cancer in Peninsular Malaysia in 2002, of which 14,274 (55%) cases were cancers among women and 30.4% of it were cancer of the breast (Mat Sakim, 2004).

There were 3525 cases of female breast cancer that were registered in the National Cancer Registry Malaysia in 2006, accounting for 16.5% of all cancer cases registered that year. The overall age-standardized rate was 39.3 per 100,000 populations (Zainal, Zainudin, & Saleha, 2006). The cancer incidence in Malaysia is expected to increase because of increasing life expectancy, better socio-economic status and changes in lifestyle. Patients with breast cancer in Malaysia commonly present with advanced disease. The Kelantan Cancer Registry reported that 19.0% of patients presented in stage I, 25.5% in stage II, 20.7% in stage III and 34.9% in stage IV (Fauziah, Hamizah, Norazmi, & Lila, 2006). It was previously reported that the 5-year survival rate in Kuala Lumpur was 59.1% (Taib et al., 2008) whereas this rate was 25.8% in Kelantan (Leow, 2007). The delay in the presentation and detection of patients with breast cancer is partially responsible for the advanced stage at presentation and low survival rates in Malaysia.

According to Lim and Halimah (2004), Malaysia women have the overall agestandardized risk of 46.2 per 1000, 000. The incidence rate of breast cancer in 1996

was 23.8 per 100,000 (Penang Cancer Registry, 1996). Chinese had the highest agestandardized rate (70.1 per 100,000), compared to Malays (41.00 per 100,000) and Indians (61.7 per 100,000) (Lim et al., 2003). In the year 2000, about 3825 new cases of breast cancer were reported in Malaysia, with deaths of about one thousand and seven hundred women. The incidence was estimated to be 34.86 per 100,000 populations.

2.2.2 Breast Cancer: Incidence and Prevalence in Sabah

The latest published National Cancer Registry of Malaysia data on breast cancer did not include data from Sabah due to underreporting of cases. Similar report on underreporting was also indicated in Malaysia (Leong et al., 2009; Sabah State Health Department, 2006). Despite breast cancer is the most common form of cancer among women in the world and in Malaysia; and is a major public health issue, underreporting of breast cancer is noted. The Malaysian Ministry of Health was still unaware of the actual incidence rate of breast cancer (Ferlay, Bray, & Pisani, 2001). Several researchers reported that previous studies of breast cancer screening behavior in Malaysia were conducted on relatively small samples that were not nationally represented, hence limiting the generalizability of results (Dunn & Tan, 2011).

2.3 Mammography

Mammography is an X-ray technique that is used to aid diagnosis and detect impalpable tumors of the breast. In Malaysia, mammography screening programs operate in a national health care system but mammograms are not used for screening except for high-risk women who have had previous breast cancer or a strong family history of breast cancer. It is not used for screening because of the high cost and limited expertise in Malaysia. In Malaysia, there are clinical practice guidelines for breast cancer management, but the use and implementation of the guidelines are

unknown. More widespread implementation of these guidelines may increase the quality of care for breast cancer patients and shorten the diagnosis delay (Norsa'adah, Rampal, Rahmah, Naing, & Biswal, 2011).

2.3.1 Perception of Mammography Screening

Data from 1989–90 show that in New South Wales (the largest state of Australia in terms of population, of which Sydney is the capital) Chinese women are 50% less likely to have breast examinations compared to Australian-born women, which puts their screening participation rate among the lowest of all ethnic groups (Dollis, Gifford, Henenberg, & Pirkis, 1993). Such findings suggested that there are factors which discourage ethnic women, particularly Chinese women, from participating in screening programs. Many overseas studies reported that women from minority ethnic backgrounds are less likely to participate in screening programs than their Anglo- Caucasian counterparts (McAllister & Bowling, 1993).

In Australia, a National Screening Program (BreastScreen) has been in place since 1991 providing free mammograms for all women over the age of 50 (National Breast Cancer Centre, 1998; National Health and Medical Research Council, 2001). Despite the benefit from mammograms and the known fact that breast cancer is a killer, several researchers like Schettino and colleagues suggested that minority populations in particular have many misconceptions about breast cancer, which may have a negative impact on preventive behaviors (Schettino, Hernández-Valero, Moguel, Hajek, & Jones, 2006).

Acculturation factors such as language, length of residency in the host country and also financial barriers are commonly reported as significant causes of the low utilization of mammographic screening services among ethnic women, including Chinese (Hoare et al., 1994; Kung, Chan, Chong, Pham, & Hsuhage, 1997; Yu, Hong,

& Seetoo, 2003). Although the evidence is that women of Chinese ancestry have a lower breast cancer incidence rate than other Australian women (Australian Institute of Health and Welfare, 1996) breast cancer still remains the most common cause of cancer morbidity among Chinese-Australian women (McCredie, Coates, Duque-Portugal, Smith, & Taylor, 1993).

The strongest predictors of participating in cancer screening are having usual source of medical care and recommendation of a physician (Breen, Wagener, Brown, Davis, & Ballard-Barbash, 2001). However, even with physician recommendation, patient non-acceptance or non-completion of screening is high (O'Malley, Forrest, & Mandelblatt, 2002). Researchers also state that the misconceptions about screening or preventing cancer may compromise the quality of patient decisions around screening. Increasingly, informed decision-making rather than simple adherence to physician recommendation is the dominant paradigm, especially when the benefits of a screening test are uncertain, or when downstream testing or treatment is controversial (Whitney, McGuire, & McCullough, 2004).

Denberg, Sabrina and Angela (2005) stressed in their study that the misconceptions of patients have about screening, whether unrecognized or overlooked by clinicians that might influence informed decision-making. They also said that, for our knowledge, the relationship between patients' misconceptions and informed decision-making has received little systematic attention. In their study, which is the range of age is from 50 to 80 years old; several women perceived that screening is only indicated with symptoms or family history or something is perceptibly wrong with one's body. Lack of knowledge pre-malignancy became the perception of other women (Denberg, Sabrina, & Angela, 2004). Some researchers indicated that women were fearful of having mammography. Women were afraid that there might be a physical damage and can result in developing cancer (Kwok et al., 2005) and the procedure was reported to aggravate pain, embarrassment, and fear of detection of cancer (Soskolne, Marie, & Manor, 2006).

2.3.2 Decision Making in Mammography Screening

Prevention by mammography screening plays an important role in efforts to reduce breast cancer mortality. In spite known mammography benefits, a study of 10,000 women age 65 and older found 60% of these women have not undergone screening mammography or had received only one mammogram in the past five years (Harrison et al., 2003).

According to a researcher, decision aids facilitate people to make informed decisions by provide information on the alternatives and the outcomes that are relevant to their situation. They perform better than usual care in improving patients' knowledge about the alternatives, reducing decisional conflicts and encouraging users to take more active role in decision making without increasing their anxiety (Jepson, Forbes, Sowden, & Lewis, 2001; O'Connor et al., 1999). Decision aids contain information on the entire screening process- including follow-up tests and treatment and in the chances of having on consequential disease found and treated (Barratt, Howard, Irwig, Salked, & Houssami, 2005). Decision aids also must allow the user to classify the pros and cons of screening, as they perceived them. Mathieu and colleagues' (2007) study about decision aids for women 70 years old considering whether continue or stop screening, reevaluated the decisions aid in the year 2010 demonstrated that it is an effective intervention in improving knowledge of mammography screening and increase inform decision making, without discouraging women from screening participation (Mathieu et al., 2010).

Kwok and colleagues (2005) also found that there are two facilitators of mammographic screening which are organizational factors. This factor involve written invitation for regularly check-up. It is effective in introducing screening services and the attractive point is that the service is made free of charge. Other than that, transportation and language skills act as facilitator to persuade some Chinese-Australian women to accept screening.

The second facilitator is influence of 'significant others'. Family members played a vital role whether to encourage and spent time with patient for screening (Leong et al., 2009). According to Leong's study (2009), many rural women were ignorant about mammogram. They reported that factors such as afraid, deficit knowledge and far from health care center were barriers that made women refusal for mammogram. In similar thread with Leong and colleagues (2009) and Kwok colleagues (2005) points out that barrier in mammography screening identified were fear of perceptions of mammography. They also presented modesty and fear of stigmatization as barriers that deter the women decision for mammography (Kwok et al., 2005; Leong et al., 2009).

2.4 The Health Belief Model (HBM)

In determining the associated contributed factors that influence mammography decision in rural women in Kiulu, Sabah, the Health Belief Model (HBM) is the conceptual framework applied in this study (Figure 2.1). The HBM is by far the most commonly used theory in health education and health promotion (Glanz, Rimer, & Lewis, 2002); and is used to theoretically explicate direct and indirect effect of knowledge on benefits, barriers, and cues to action. The HBM is a health behavior change and psychological model developed by Irwin M. Rosenstock in 1966 for studying and promoting the uptake of health services (Rosenstock, 1966). It is also to

explore the social and cultural factors which involved in women's health behaviors. The model consists of four constructs: (i) perceived susceptibility or vulnerability to a health condition (in this case breast cancer); (ii) perceived seriousness or severity of the condition; (iii) perceived barriers of an action (in this case, mammography screening); and (iv) perceived benefits of an action (Janz, Champion, & Stretcher, 2002). On the next page, Figure 2.1 shows HBM concepts by Rosenstock. Two other concepts were later added to original HBM; general health motivation, which was defined as beliefs and behaviors that related to the state of general concern about health; and confidence which was defined as a belief that one can successfully perform a behavior that will then lead to desirable outcome (Rosenstock, Stretcher, & Becker, 1966).

Victoria Champion had revised and validated this model. The revised Champion's HBM Scale includes six concepts which were 'susceptibility' that evaluates individual's opinion about breast cancer and her general health, 'severity', 'health motivation', 'benefits', 'barriers', and 'confidence in one's ability'. According to Champion's HBM, women with perceived seriousness and susceptibility to breast cancer are more likely to participate in breast cancer screening. On the other hand, women must perceive benefits to screening and perceive few barriers. This CHBMS had been tested widely in Western cultures (Champion & Scott, 1997). Significant increases in breast cancer screening rates have been shown in intervention studies based on HBM.

Understanding Malaysian women, especially rural women in Sabah about their beliefs related to breast cancer screening behavior will help other healthcare professionals to implement health education programmes with the potential in increase screening practices.



Figure 2.1: The Health Belief Model (Rosenstock, 1966)

CHAPTER 3: METHODOLOGY & METHODS

3.0 Introduction

The research design and method is the most imperative part of a study as a weak design and method retracts from the value of research findings (Heppner, 2004). This chapter outlined how the study will be carried out. It includes the methodology and methods used along with the rationale behind these decisions. A flow chart of the study is provided within this proposal. Together with the methodologies and approach used, research design, population and study setting, sample, gaining access, sample selection, instrument, ethical consideration, data collection, data analysis and expected research outcomes will be described. Cormack and Benton (1996) recommended that it is important for the researcher to know the research methods necessary for the study undertaken but also the methodology in which the research aims, objectives and research questions will be detailed. It is the science of studying how research is to be carried out which also includes the various procedures, schemes, and algorithms, used by a researcher during a research study to search for knowledge (Cormack & Benton, 1996).

In this chapter, methodology and methods were carried out along with the rationale behind these decisions. Research design, population and study setting, sample, gaining access, and sample selection were described through this chapter. According to the researchers, research aims, objectives and questions are mentioned in detail to guide in designing a coherent and focused study. Hence, to notify the flow of this study, the objective of the study is restated along with the research questions. This was followed by ethical consideration, the data collection method and data analysis that had been used in this research.

The objective of the study:

 To identify factors and barriers that influenced these women in Kiulu, Sabah to undergo mammography screening.

In achieving the objective, the following research questions were chosen:

- What is the knowledge of mammography screening among rural women in Sabah?
- 2. What are the factors that influenced in decision making of mammography screening?

3.1 Research Design

A descriptive cross-sectional design will be used to achieve the aim of this study. The quantitative perspective was favoured because of its flexibility and broadness of scope.; and can be applied to many populations focusing on a wide range of topics while its information obtained can be used for many purposes (Beck & Polit, 2004).

Within the quantitative paradigm, there are three subtypes of research, i.e. descriptive, correlational and experimental (Carter & Hurtado, 2007). Descriptive research aims to describe the characteristics of individuals or groups or to determine the frequency with which a variable occurs. Descriptive statistics reduces a large quantity of data into information that is more easily comprehended while correlational attempts to describe the statistical relationship between two or more variables. With this in mind, the researcher decided that this study will be mainly a correlational survey as it attempted to measure the nature of relationship and the strength of the relationship between variables (Dyer, 1995; Goodwin, 2008).

3.2 Population and Setting

The study aims to investigate the factors associated with mammography decisions among rural women in Sabah. Most of people in Sabah's rural or remote areas depend heavily on agriculture produce to survive and are inaccessible by road. Many communities in the rural or remote areas remain trapped in poverty. In addition, Sabah has the poorest healthcare services in Malaysia (Sabah State Health Department, 2006) and has the highest poverty rate of all states in Malaysia whereby 6.5% of Sabahan households are categorized as 'hardcore poor' (The Ninth Malaysia Plan, 2007). Kiulu was chosen as a study setting as it was one of the rural areas in Sabah. It was located 60 km from Kota Kinabalu.

3.3 Sample

The sample in this study was women from Kiulu, Sabah. According to the statistic in Malaysia, there are a total 20, 522 rural Sabahan women (Newmond, 2011).

3.3.1 Sample Size

The sample size was calculated to give a confidence level of 99% and a margin error of 5% as well as to estimate the accuracy of a sample (sampling error) while determined the representatives and parameter of the sample (Naing, 2010), the Raosoft Sample Size Calculator (Raosoft, 2004) was used and deemed appropriate. The sample size calculated was 378 (Appendix 4). To counter for the dropout rate of this study, 10% of the calculated sample size was added. Therefore, the total participants required for this study was within the range from 340 to 416 rural women in Kiulu.

> n = $378 \pm \text{drop out of } 10\%$ = 378 ± 38 = 340-416 participants

3.3.2 Sampling Method

Convenience sampling was used in this research study. This sampling was used because subject was convenient and approachable in the targeted areas.

3.3.3 Inclusion and Exclusion Criteria

In conducting a research, certain inclusion and exclusion criteria were applied.

Inclusion criteria

Subjects will be eligible for inclusion in the study if they were:

- Rural women in Sabah
- Age from 30 to 60 years old
- Willing to participate in this study.

Exclusion criteria

Subjects will be excluded in the study if they were:

- Urban women in Sabah
- Age less than 30 and more than 60 years old
- Not willing to participate in this study

3.4 Instrumentation

This study is a quantitative study and thus data will be collected by self-administered questionnaire. Questionnaire is relatively quick to collect information and the respondents that gather are more standardized and tend to be fairly structured, involving the use of a formal instrument that elicits the same information from every subject (Beck & Polit, 2004). The use of questionnaire can eliminates the effect of researcher over the subject (Moore & Price, 2004). Using structured question can reduce the risk of researcher's bias (Sajiwandani, 1996). Therefore, to gain similar information from every participant, a survey questionnaire was deemed appropriate