



UNIVERSITI PUTRA MALAYSIA

***LEARNING EXPERIENCES OF MALAY MUSLIM WOMEN BREAST
CANCER SURVIVORS AT A CANCER RESOURCE CENTER, MALAYSIA***

MARIANA BINTI MOHD YUSOFF

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BERILMU BERBAKTI

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By

MARIANA BINTI MOHD YUSOFF

**Thesis Submitted to the School of Graduate Studies,
Universiti Putra Malaysia, in Fulfillment of the Requirements for the
Degree of Doctor of Philosophy**

January 2015

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Abstract of thesis presented to the Senate of the Universiti Putra Malaysia in partial fulfillment of the requirement for the degree of Doctor of Philosophy

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January 2015

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The purpose of the study was to understand the learning experiences at a Cancer Resource Center (CRC) from the perspective of Malay Muslim women breast cancer survivors. This study also explored how the context of culture shaped their experiences with the CRC.

Previous studies from Western and Malaysia have shown that cancer resource centers played an important role in assisting cancer patients and survivors. However, research on the relevance of information and learning on cancer has been predominantly conducted in the Western countries. This research was guided by the six following research questions: (1) Why breast cancer survivors visit CRC?; (2) What do they learn from CRC?; (3) How do they learn through CRC?; (4) How do they find their experience using CRC: Benefits and Challenges?; (5) What is the ideal CRC?; and (6) How does the context shape their experience with the CRC?

A qualitative design using purposive sampling technique was used to collect and analyze the in-depth interview of 10 women breast cancer survivors who fit the inclusion criteria. Each interview was audio taped and lasted approximately 60 minutes. All audio tapes were transcribed verbatim and field notes taken during the interview were added to the transcript. The qualitative analysis employed an ongoing, constant comparative process.

The findings indicated that CRC played a vital role in helping people affected by terminal illness such as breast cancer. Informants engaged in learning at CRC for various reasons such as to get more information on cancer, to share knowledge and experiences with others and to socialize. Through CRC they learned on cancer diagnosis, treatment and side effect, food practices and coping strategies. They learned from printed and non-printed education materials, utilizing internet, from peers and the CRC nurses, as well as from the educational activities. From CRC, the informants gained knowledge and information, received psychological support and shared their experiences. However, they faced internal and external challenges that deterred them from learning at CRC. The findings also suggested three major aspects to establish

an ideal CRC: (1) the location; (2) the human resource; and (3) the design of CRC. Based on these findings, it was concluded that the establishment of CRC in Malaysia was very beneficial to breast cancer patients and survivors as a place for learning. The findings also revealed that culture influenced the breast cancer survivors learning experience at CRC. The learning was self-directed, non-formal and experiential and collectivist/communal. However, the bigger challenges to expand and sustain the CRC were very much related to minimal support from policy makers as well other administration issues.

This study contributed to the growing research in adult education, experiential learning, information need and information seeking behavior especially within the field of Adult Education, Health Education and Health Communication. Furthermore, it also provides evidence that CRC played a significant role as an effective learning platform towards improving the quality of life of breast cancer patients and survivors.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia
sebagai memenuhi keperluan Ijazah Doktor Falsafah

**PENGALAMAN PEMBELAJARAN BEKAS PESAKIT KANSER PAYUDARA
WANITA MELAYU DAN BERAGAMA ISLAM DI PUSAT SUMBER KANSER,
MALAYSIA**

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Tujuan kajian ini adalah untuk memahami pengalaman pembelajaran di Pusat Sumber Kanser (PSK) dari perspektif bekas pesakit kanser payudara wanita, berbangsa Melayu dan beragama Islam. Kajian ini juga ingin meneroka bagaimana konteks budaya membentuk pengalaman pembelajaran mereka dengan PSK. Kajian terdahulu dari Barat dan Malaysia telah menunjukkan bahawa PSK memainkan peranan penting dalam membantu pesakit kanser. Walau bagaimanapun, kajian mengenai perkaitan maklumat dan pembelajaran mengenai kanser kebanyakannya dijalankan di negara-negara Barat. Kajian ini dipandu oleh enam soalan berikut: (1) Mengapakah bekas pesakit kanser payudara mengunjungi PSK?; (2) Apakah yang mereka belajar daripada PSK?; (3) Bagaimanakah cara mereka belajar melalui PSK?; (4) Bagaimanakah pengalaman mereka menggunakan PSK: Kebaikan dan Cabaran ?; (5) Apakah PSK yang ideal?; dan (6) Bagaimanakah konteks membentuk pengalaman mereka dengan PSK?. Reka bentuk kajian kualitatif menggunakan teknik persampelan bertujuan digunakan untuk mengumpul data melalui temubual mendalam bersama 10 orang bekas pesakit kanser payudara wanita Melayu yang menepati kriteria. Setiap temubual dirakam dan berlangsung kira-kira 60 minit. Semua rakaman disalin kata demi kata dan dianalisa menggunakan kaedah *constant comparative*.

Dapatan kajian menunjukkan PSK memainkan peranan penting dalam membantu mereka yang mengidap penyakit terminal seperti kanser payudara. Wanita-wanita ini mengunjungi PSK adalah untuk mendapatkan maklumat lanjut mengenai kanser, ingin berkongsi pengetahuan dan pengalaman serta bersosial. Melalui PSK mereka belajar tentang kanser, rawatan dan kesan sampingan, amalan makanan dan strategi *coping*. Mereka belajar daripada bahan-bahan pendidikan bercetak dan bukan bercetak, dari rakan-rakan dan jururawat di PSK serta daripada aktiviti pendidikan. Di PSK, mereka mendapat banyak pengetahuan, sokongan psikologi dan dapat berkongsi pengalaman. Walau bagaimanapun, mereka menghadapi cabaran dalaman dan luaran yang menghalang mereka daripada mengunjungi PSK. Hasil kajian mencadangkan tiga aspek utama untuk menubuhkan sebuah PSK yang ideal: (1) lokasi; (2)

sumber manusia ; dan (3) reka bentuk PSK. Berdasarkan penemuan ini, dapat disimpulkan bahawa penubuhan PSK sangat bermanfaat kepada pesakit dan bekas pesakit kanser payudara sebagai tempat pembelajaran. Hasil kajian juga menunjukkan bahawa budaya mempengaruhi pengalaman pembelajaran wanita-wanita ini di PSK. Pembelajaran mereka lebih bersifat pembelajaran sendiri, tidak formal dan berbentuk kolektif. Namun begitu, cabaran utama untuk mengembang dan mengekalkan PSK adalah kerana kurangnya sokongan daripada penggubal dasar di samping isu-isu pentadbiran yang lain.

Kajian ini menyumbang kepada penyelidikan yang semakin berkembang berkaitan pendidikan dewasa, pembelajaran pengalaman, keperluan dan tingkahlaku pencarian maklumat terutama dalam bidang Pendidikan Dewasa, Pendidikan Kesihatan serta Komunikasi Kesihatan. Lebih daripada itu, ia juga membuktikan bahawa PSK memainkan peranan penting sebagai salah satu platform pembelajaran yang berkesan ke arah meningkatkan kualiti hidup pesakit dan bekas pesakit kanser payudara.

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- the research conducted and the writing of this thesis was under our supervision;
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LIST OF ABBREVIATIONS

BSE	Breast Self-Examination
CaEd	Cancer Education and Research Project
CIS	Cancer Information Seeking Model
CMIS	Comprehensive Model of Information Seeking
CRC	Cancer Resource Centre
HUSM	Universiti Sains Malaysia Hospital
IT	Information Technology
KanWork	Cancer Network
MOH	Ministry of Health
NCSM	Malaysia National Cancer Society
NGO	Non-Government Organizations
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TSR	Transformative Service Paradigm
UKMMC	Universiti Kebangsaan Malaysia Medical Centre
UMMC	University Malaya Medical Centre
UPM	University Putra Malaysia
VCRC	Victoria Cancer Resource Centre
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

This chapter provides an overview of the cancer scenario around the world including Malaysia, addresses the importance of education and information in helping people to cope with cancer; describing the cancer education in Malaysia which relates to the establishment of Cancer Resource Centre; identifying the significance for conducting this study and the research questions and indicating the definitions used in the study.

1.1 Background of the Study

Cancer is a leading cause of death around the world (Gerard, 2002). The World Health Organization (WHO) estimates that 84 million people will die of cancer between 2005 and 2015 without intervention (WHO, 2010). According to WHO (2007), cancer is the world's second biggest killer after cardiovascular disease, but one of the most preventable non-communicable chronic diseases. Cancer killed 7.6 million people in 2005, three quarters of whom were in low- and middle- income countries. By 2015, that number is expected to rise to 9 million and increase further to 11.5 million in 2030.

Cancer has a significant impact upon the lives of a vast number of people including patients, family and friends, work colleagues and the greater community (Jefford, Black, Grogan, White & Akkerman, 2005). A diagnosis of cancer can give major impact on the physical, psychosocial as well as economic, not only on the patients, but also members of families and so forth. In Malaysia, cancer is one of the common causes of death (National Cancer Registry, 2007). Under Primary Goals of the health sector for the 11th Malaysia Plan, cancer is one of the diseases that have been given priority to be researched on in Malaysia. A third report from National Cancer Registry (2003-2005) stated that a total of 67,792 cancer cases were diagnosed in Peninsular Malaysia in the year 2003-2005 comprising 29,596 males (43.7 percent) and 38,196 females (56.3 percent). The annual crude rate for males was 100.2 percent per 100,000 population, and 132.1 percent per 100,000 for females. The most frequent cancer during this period in Malaysia was breast cancer (18 percent) followed by large bowel cancer (11.9 percent) and lung cancer (7.4 percent). A study conducted by Ministry of Health (MOH) collaborated with World Health Organization (WHO) in 2004 found that the five leading diseases in Malaysia were ischemic heart disease followed by mental illness, cerebrovascular disease/stroke, road traffic injuries and cancers. The incidence of cancer is expected to rise with an increase in aging population. The proportion aged more than 60 years was 4.6% in 1957, increased to 5.7% in 1990 and is projected to be 9.8% in 2020.

Over recent years research has shown that communication and information have increasingly been considered important in helping people to cope with cancer (Leydon, 2000). Previous research have also shown that patients want to be informed about cancer (Daniels, James, Rahman, Young, Derry & Mc

Conkey, 2007; Grahn, 1996) and want to know about what would happen to them (Mossman et al., 1999). Leadbeater, cited in Daniels et al. (2007) suggested that 80 percent of patients want more involvement in decisions about their treatment, particularly in the context of long-term illness. Once diagnosed with cancer, the person needs to deal with the disease, to decide on a treatment option, to deal with the side effects of treatment and with the emotional challenges of the disease and to have a quality of life after treatment (Mazanah & Noraini, 2008). Coping with cancer can be overwhelming and requires patients to learn about their disease, make treatment decisions and manage physical and psychological consequences (Kuhrik, 2009). By seeking information may provide needed knowledge about the disease, treatment and self-care management (Mayer et al., 2007). Lack of information may lead to increased anxiety and distress, may impact negatively on the patient's satisfaction and may influence patient's treatment choices (Mossman et al., 1999). With an increasing burden in reducing incidence and mortality due to cancer, there is a strong need for the care provider to educate patients, family and the public with all the relevant information and skills.

1.2 Cancer Education in Malaysia

Health education has been widely accepted as an important tool in the control of cancer because of increased recognition of the behavioral and socio-cultural factors involved in their prevention, early diagnosis and treatment. Medical and organizational measures by themselves have proved to be unsatisfactory. The purpose of cancer education is to inform people and thus help them make decisions and take actions to improve their own health and the health of their community. Education will also initiate changes in beliefs, cultural views and social norms. The Non Communicable Disease Division of Ministry of Health (MOH) Malaysia collaborated with Health Education Division played an important role to educate the public related to cancer prevention, detection and control besides the other Non-Government Organizations (NGOs). This phase identifies strategies and potentials to influence and enhance the promotion of healthy life-style of individuals as well as communities. This takes into consideration the religious, cultural and ethnic practices of individuals or groups, while providing and demonstrating leadership and role model for the community. Some of the programme are National Healthy Lifestyle Campaign - Prevention and Control of Cancer in 1995 which produced the cancer education material (printed and non- printed), media campaign and other educational materials. However, the focus of the programmes were more towards the health/community setting regardless of the hospital setting.

In the hospital, the education materials for cancer are very limited and yet there is no specific education programme for cancer patients and family. In order to educate the patients, family, caregivers and public regarding cancer, Universiti Putra Malaysia (UPM) in collaboration with Cornell University has set up the Cancer Resource Centre (CRC) in Hospital X as a pilot project under the Cancer Education and Research Project (CaEd). The idea was to set up the centre based on Peter Mac Patient Information and Support Centre, at Peter Mac Callum Cancer Centre in Australia. The ground work started on 29 May 2004 and was officially launched to the public on 26 October 2007. The CRC in

Hospital X was funded by Exxon Mobile Malaysia to provide support service mainly for cancer survivors and public, including family members and staff. This centre is unique because it was set up by a collaboration effort of Ministry of Health (MOH), Universiti Putra Malaysia (UPM), Cornell University, Exxon Mobile and one support group association which can be considered the first in Malaysia. It becomes a model for other hospitals like Universiti Malaya Medical Centre (UMMC), International Islamic Universiti Malaysia, Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and Universiti Sains Malaysia Hospital (HUSM) to set up their own Cancer Resource Centre. Recently there are six CRCs in Malaysia, of which four are in the teaching hospital, one under Ministry of Health and the other one is under Universiti Putra Malaysia. All the Cancer Resource Centres focusing more on breast cancer education as it is the most common killer among women in Malaysia. The establishment of CRC at Hospital X is in line with the requirement of the New Policy of the Patient Education & Promotion Centre in all hospitals under the Ministry of Health, Malaysia (2008) which emphasize on improving the services of patient education in the hospital setting.

The role of CRC is to provide an information for all types of cancer especially breast cancer. The development of CRC is in line with the role of the hospital as a centre of excellence in breast and endocrine. This centre is managed by nurses from Hospital X and collaborates with volunteers from one established support group in Klang Valley. The CRC vision is to be an excellent reference centre for cancer disease by giving quality services to the customers through excellent work process and active community participation.

The objectives of CRC are : (1) to provide a one stop centre for support services, education and counseling for those who have experienced cancer disease directly or indirectly; (2) to educate public about the disease, treatment, medication and self-care before and after treatment; (3) to provide advice and opportunity for sharing their problems and experience as well as ways to cope with it; (4) to provide a conducive space for learning and support services; and (5) to be a centre for patient data collection and related issues regarding cancer. The CRC provided the information, reference and health education materials especially breast cancer in the form of CDs, books, journals, leaflets and fact sheet. It also provides conducive space for cancer patients to read and rest while waiting for treatment, organize individual and group counseling/support group activity, provide internet access facility, and as a centre for data collection and distribution of cancer education materials. The main CRC users are the cancer patients, cancer survivors, family members and public. In the context of cancer disease, the CRC can be the platform for the patient, family and public to learn and gain support on cancer.

In Western countries, cancer support centre or cancer information centre like CRC has been well established to provide information and support for cancer patients, caregivers and also for the community. One of the successful examples is The Lorán Smith Center for Cancer Support in Northeast Georgia. The centre has become useful to cancer care and support available in Northeast Georgia (Nemetz, Giarelli and Throckmorton, 2002). Other example is National Cancer Information Center of the American Cancer Society which provides telephone / personal contact 24 hours per day to answer questions

about cancer, link callers with resources in the communities, provide information on local events and send printed cancer information (Powe et. al, 2005). This kind of centre need to be set up more in Malaysia. However, in Malaysia the establishment of CRC was piloted by Hospital X which is the only one under Ministry of Health, Malaysia. Research in explaining the learning experiences of cancer survivors at cancer resource centre and the learning needs among cancer patients in Malaysia is still limited. Therefore, further research needs to be done in the local context.

1.3 Statement of the Problem

Cancer has become a worldwide killer. A diagnosis of cancer may invoke uncertainty, fear and loss that can be alleviated by information (Leydon et al., 2000). Research has shown that cancer patients demand information, not only to assist them to understand the disease and its treatment, but also to allow them to interpret the aversive events and actions taken (Lee, Francais, Walker & Lee, 2004). After a diagnosis of cancer, patients and their families and friends experienced a significant need for information about the illness, treatment and prognosis, as well as support.

Structured education and support group-based programs play a major role in meeting these needs (Roberts & Black, 2002). In addition to other sources of information like printed and non-printed materials, medical and health professional advice, the internet and so on, Cancer Resource Centres (CRC) play a role as one of the key sources for delivering information and health education for cancer patients, caregivers and the public in Malaysia. Through education provided by Resource Centres, patients have the opportunity to gain a better understanding of their disease process and treatment options, reducing fear and allowing them to make informed choices about their care (Deborah, 2006).

In Western countries, this type of centre is well-established. It has become a useful and effective adjunct to cancer care because patients and family members need educational, psychosocial and spiritual support during time of crisis (Nemetz, 2002). Previous literature on Cancer Resource Centers in Western countries showed this type of centre was useful to empower patients become familiar with medical terminology, increase their understanding of proposed treatments and develop the confidence to become active participants in their healthcare (Eddlemen & Warren, 1995). Another very long study on resource centre was done by Peterson, Michas Villejo (1989) entitled evaluation of a learning resource centre for cancer patients. The findings stated respondents who had used the learning resource centre indicated a stronger preference for receiving information about cancer through written materials than those who had not used the centre. The study offered recommendations for the practitioner regarding the establishment and evaluation of a learning resource centre for cancer out-patients and addressed these issues in a unique program setting. However in non-western countries, little is known about the information needs of women with breast cancer (Raja Lexchimi, et.al, 2005) include Malaysia. Only little study found to support the fact that cancer patients felt a resource centre gave benefit to them. For example, a study by Loh et al.,

(2007) on Perceived Barriers to Self-Management in Malaysian Women with Breast Cancer mentioned that a resource centre at the University Malaya Medical Centre (UMMC) offers networking with survivors and health professional, a potent “pipeline” for comfort, emotional-physical support and hope. Based on previous studies from Western countries and Malaysia, we knew that cancer resource centre played a role in assisting cancer patients learned about cancer. However, the gap was we do not know what and how was the learning experience at CRC and how the context of culture shaped their experience with CRC. Therefore, this study filled the gap and offered an insight into the phenomenon in a culturally different setting. As a study cannot be generalized into a culturally different context, an investigation of the phenomenon in the Malaysian context is needed. The investigation will be able to explain a rich description on what and how was the learning experience at CRC from the perspective of women, Malay, muslim breast cancer survivors.

1.4 Purpose of the Study

The main purpose of the study was to understand, describe and explain the learning experiences at a cancer resource centre from the perspective of Malay Muslim women breast cancer survivors.

This study also explored the information and support needs of breast cancer survivors from CRC and how the context of culture shaped their experiences with the CRC.

1.5 Significance of the Study

This study was significance for three reasons. Firstly, it contributes to the existing knowledge in adult learning, health education and communication fields as well as contributes to the learning needs related to breast cancer. Very few studies have explored the learning experience of breast cancer survivors in the local context compared to the West. Therefore this study contributes towards the theoretical explanation on experiential learning through CRC in different culture context and the process of information seeking behavior from the CRC and not from the traditional sources such as medical and health professionals, books, magazines and internet. Secondly, this research provides detailed explanation to which the service provider should tailor the information and the services accordingly. This may help improve the effectiveness of the services for those living with cancer as well as improve cancer education to those immediately affected by the disease.

Finally, from the practical perspective, the themes obtained can serve as input for the policy maker or the service provider like MOH Malaysia, KanWork and UPM towards designing an ideal CRC and establishing more CRC or other resource centres which is made in Malaysia and for Malaysians. Furthermore, it can also provide the leadership on providing better cancer health education system to the patients, caregivers and public at the hospitals or health care settings.

1.6 Scope of the Study

This study explored the learning/ information needs and support among the breast cancer patients and survivors from CRC in Hospital X. Thus, the scope of the study was within the boundaries of breast cancer patients/survivors, their learning/information needs/information seeking and their experiences on using the services at CRC in Hospital X. Since the study was designed to investigate the breast cancer patient and survivor's needs and experiences from respondent's point of view, the qualitative approach was the most appropriate design. The informants of the study were selected based on certain criteria determined by the researcher that best fit the purpose of the study.

1.7 Assumptions

The following assumptions were made for the purpose of this study:

- a. The breast cancer patients and survivors identified as potential candidates for the study will participate in the study.
- b. Participants will share their experience and give comments about CRC honestly and openly.
- c. Breast cancer patients and survivors who come and visit CRC were voluntary (volunteer to visit).
- d. The learning experience at CRC was non-formal and more towards self-directed learning

1.8 Definitions of Terms

Information needs: According to Odongo and Mostert (2006), information need is a requirement that drives people into information seeking. In terms of information seeking about cancer, the individuals' needs for information can either consist of cognitive needs (obtaining more factual information about cancer prevention, detection and treatment) or affective needs (obtaining information that aids in dealing with cancer emotionally) (Daniels et al., 2007).

Cancer patient: Persons who have been diagnosed of having cancer and still undergoing the process of treatments (Cancer net, 22/9/2008).

Cancer Survivor: A cancer survivor is someone who has been "living with or beyond cancer", namely someone who has completed initial cancer management and has no apparent evidence of active disease, is living with progressive disease and may be receiving cancer treatment, but is not in the terminal phases of illness or has had cancer in the past-(Macmillan Cancer Support).

Caregiver: Caregivers are typically family members and friends who provide vital and constant physical and emotional care of a person with cancer. Caregivers provide support and encouragement, administer medications, help control symptoms and side effects, provide proper nutrition, and report any problems to the doctor or health care team. (Cancer net, 22/9/2008).

CRC: Cancer Resource Centre: the non-medical place which provides information, education and support to people lives or affected by cancer.

MAKNA: Majlis Kanser Nasional or the National Cancer Council is a not-for-profit social enterprise mainly tasked to pool and utilizes every effort, expertise and financial aid from every faction of society, and to fight cancer and reduce the related pain, suffering and morbidity that cancer patient and their families often experience.



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