



UNIVERSITI PUTRA MALAYSIA

**SELF-DIRECTED LEARNING AMONG SELECTED MALAYSIAN
WOMEN WITH BREAST CANCER**

AHMAD ZAMRI MANSOR

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**SELF-DIRECTED LEARNING AMONG SELECTED MALAYSIAN
WOMEN WITH BREAST CANCER**

By

AHMAD ZAMRI MANSOR

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

March 2009



DEDICATION

TO

My Dear Wife

Rosita Mohd Yusof

And our children

**Wajahah, Najwa, Umairah, Muzakkir, Mardhiah, and
Insyirah**



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

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March 2009

Chairman: Mazanah Muhamad, PhD

Faculty: Educational Studies

Breast cancer is the most frequent cancer among Malaysian women. Learning and understanding the disease is important for the women in order to deal with the crisis situation. Self-directed learning is a learning mode that can facilitate a woman with breast cancer in learning and understanding more about the disease.

The purpose of this qualitative study was to explore the phenomenon of self-directed learning among selected Malaysia women with breast cancer. The study is guided by the following research questions:

1. Why did they learn?
2. How did they learn?
3. What challenges did they face in their learning?



This qualitative study used in-depth interview technique with ten Malaysian women with breast cancer. Participants were selected using purposeful sampling and snowballing techniques. Interviews were tape-recorded and transcribed verbatim. The validity of data analysis was assured through triangulation, member check, and peer review, and researcher's bias and assumptions were declared in the study.

The findings can be presented in terms of motivation, strategies, and challenges. In terms of motivation, the participants were motivated by the need to confirm information, the need to understand how to deal with their disease, and the need to help the learning of other patients and survivors. Two aspects that emerge under strategies are learning phases and activities. The learning phases involved were coping with the results, seeking information about treatments, preparing for personal life changes, and learning outcomes. The participants used learning activities such as reading Internet articles, books, other printed materials, consulting doctors and asking other survivors. Doctors are generally regarded as the credible learning source. Participants faced two main challenges in their self directed learning, i.e. the emotional effects of exposure to information and the reliability of information.

This study presents new understanding of self-directed learning in crisis situations in Malaysian context. This study concluded that self-directed learning of Malaysian women with breast cancer is contextualized by the dimensions of source credibility, cognition, and spirituality.



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

**PEMBELAJARAN ARAHAN KENDIRI DI KALANGAN WANITA
MALAYSIA YANG MENGIDAP PENYAKIT KANSER PAYUDARA**

Oleh

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Kanser payudara ialah penyakit kanser yang paling kerap dihidapi oleh wanita-wanita di Malaysia. Pembelajaran dan pemahaman tentang penyakit tersebut adalah penting agar wanita tersebut dapat menangani keadaan krisis yang dihadapi. Pembelajaran arahan sendiri ialah kaedah pembelajaran yang dapat membantu wanita tersebut dalam mempelajari dan lebih memahami penyakit tersebut.

Tujuan kajian kualitatif ini ialah untuk memahami fenomena pembelajaran arahan sendiri di kalangan wanita Malaysia terpilih yang menghidap kanser payudara.

Kajian ini adalah berdasarkan kepada soalan-soalan kajian seperti berikut:

1. Mengapakah mereka belajar?
2. Bagaimanakah mereka belajar?
3. Apakah cabaran yang mereka hadapi dalam pembelajaran?



Kajian kualitatif ini menggunakan kaedah temubual mendalam ke atas sepuluh orang wanita Malaysia yang mengidap kanser payudara. Informan dipilih menggunakan kaedah-kaedah persampelan bertujuan dan *snowballing*. Temubual direkodkan menggunakan pita rakaman dan dibuat transkripsi secara verbatim. Kesahihan analisis data dipastikan dengan menggunakan kaedah-kaedah triangulasi, *member check* dan *peer review*, dan bias dan andaian pengkaji dinyatakan dalam kajian ini.

Dapatan kajian ini dapat dijelaskan berdasarkan aspek-aspek motivasi, strategi dan cabaran. Dalam aspek motivasi, informan didorong oleh keperluan untuk mengesahkan kebenaran maklumat, keperluan untuk memahami bagaimana untuk menangani penyakit mereka, dan untuk membantu pembelajaran pesakit dan survivor lain. Dua aspek yang muncul di bawah aspek strategi ialah fasa-fasa dan aktiviti pembelajaran. Fasa-fasa pembelajaran yang terlibat ialah menghadapi keputusan diagnosis, mencari maklumat tentang rawatan, bersedia untuk perubahan kehidupan diri, dan hasil pembelajaran. Para informan menggunakan aktiviti-aktiviti pembelajaran seperti membaca artikel Internet, buku-buku, bahan bercetak lain, membuat rujukan dengan doktor dan bertanya kepada survivor lain. Doktor secara umumnya dianggap sebagai sumber pembelajaran yang berwibawa. Informan-informan kajian ini menghadapi dua cabaran utama dalam pembelajaran mereka, iaitu kesan emosi hasil daripada pendedahan pelbagai maklumat dan kebolehpercayaan maklumat yang diperolehi.

Kajian ini memaparkan kefahaman baru tentang pembelajaran arahan sendiri dalam situasi krisis dalam konteks Malaysia. Kajian ini merumuskan bahawa pembelajaran arahan sendiri dalam kalangan wanita Malaysia yang menghidap kanser payudara adalah ditentukan oleh dimensi-dimensi kebolehpercayaan sumber, kognisi dan spiritualiti.



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I certify that a Thesis Examination Committee has met on 13 March 2009 to conduct the final examination of Ahmad Zamri Mansor on his thesis entitled "**Self-Directed Learning Among Selected Malaysian Women With Breast Cancer**" in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the Doctor of Philosophy.

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DECLARATION

I declare that the thesis is my original work except for quotations and citations which have been duly acknowledged. I also declare that it has not been previously, and is not concurrently, submitted for any other degree at Universiti Putra Malaysia or at any other institutions.

AHMAD ZAMRI MANSOR

Date: 12 August 2009



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LIST OF ABBREVIATIONS

BCWA	Breast Cancer Welfare Association
CaEd	Cancer Education and Social Research Project
CESGA	Cancer Education and Support Group Association
HINTS	Health Information National Trends Survey
HUKM	Hospital Universiti Kebangsaan Malaysia
KanWork	Cancer Network Association for Selangor and Wilayah Persekutuan
MAKNA	National Cancer Council
MBCEP	Malaysian Breast Cancer Education Project
MTA	Malaysian Translator's Association
NCR	National Cancer Registry
NCS	National Cancer Society
PRO	Personality Responsibility Orientation
SDL	Self-directed Learning
SDLR	Self-directed Learning Readiness
SSDL	Staged Self-Directed Learning
UMMC	University of Malaya Medical Centre
UMMC BCRC	UMMC Breast Cancer Resource Centre



CHAPTER 1

THE PROBLEM AND ITS CONTEXT

Having been diagnosed with breast cancer, Salmah (not her real name) felt that her days are numbered. She asked herself, “Why me?” Days after days, weeks after weeks, she then began to realize that she did not have to surrender. She must struggle to keep her alive. She began to actively involve in learning by looking for more information about her disease from doctors, nurses and other survivors. She felt that learning is important and a life-or-death matter. Without learning, she would not be able to understand her situation, and she would not be able to cope with her situation well.

She understood that treatment for her disease is costly. But she did not see this as a major problem. What is more important is to learn everything she needs to know about the disease. She heard that there are several organizations offering information about breast cancer on the Internet. Driven by her desire to get access to information, she learned how to search for information on the Internet.

The story of Salmah is a common experience faced by thousands of Malaysian women with breast cancer. Her engagement in learning is triggered by a crisis situation and she hopes that by learning to understand more about her disease, she is able to continue her own life.



This study represents an inquiry into learning experience of breast cancer survivors. In order to build the worthiness of such inquiry, the following sections present the background of the study, statement of the problem, research questions, research significance, and definition of terms used in the study.

Background of the Study

This section aims to provide background information that enable us to understand the breast cancer situation. First, brief information on origin of cancer is presented. This is followed by an illustration of common phases that a woman with breast cancer has to go through. Then the breast cancer situation in Malaysia is presented. The next focus is on learning and self-directed learning in breast cancer context. The part on learning opportunities is presented in order to demonstrate the resources that women with breast cancer can draw upon in their pursuit of learning.

Understanding Breast Cancer

To study the origin of cancer, one needs to understand how cells work. Cells are “the building blocks that make up tissues” (Understanding Cancer, 2005). Cells grow, divide and when the body does not need them, they die and are replaced by new cells. The problem occurs when the old cells refuse to die and they eventually form ‘tumors’. There are two forms of tumors: benign and malignant. Unlike the former, malignant tumors are cancerous and characterized by the followings:



1. Malignant tumors are generally more serious than benign tumors. They may be life-threatening.
2. Malignant tumors often can be removed. But sometimes they grow back.
3. Cells from malignant tumors can invade and damage nearby tissues and organs.
4. Cells from malignant tumors can spread (*metastasize*) to other parts of the body. Cancer cells spread by breaking away from the original (*primary*) tumor and entering the bloodstream or *lymphatic system*. The cells invade other organs and form new tumors that damage these organs. The spread of cancer is called *metastasis*. (Understanding Cancer, 2005)

As for breast cancer, the cancer cells spread in lymph node i.e. the area near the breast. To make things worse, the cells can spread to other parts of the body such as the bones, liver, lung, and brain. The cells originated from the breast found in other parts of the body are called ‘metastatic breast cancer’.

Coping With Breast Cancer

Four common phases that a cancer patient has to go through are: the phase before the diagnosis, the acute phase, the chronic phase, and recovery or death (Gonzaga, 2004).



The phase before the diagnosis begins when a woman has a suspicion that she is developing a breast cancer. The woman experiences stress and anxiety as she waits for doctor's confirmation of her illness.

In the acute phase, the diagnosis is made and the patient has to make decisions about further treatment. In the course of searching for information related to breast cancer treatments, the woman has to face problems such as difficulties in accessing the required information (for example, situational and institutional barriers), and the emotional effect of being diagnosed with breast cancer.

Situational and institutional barriers are two of Cross' (1982) classifications in describing obstacles faced by adults in pursuing their learning. In the context of breast cancer, among the situational barriers are: not having enough time for learning due to job and home commitments, no transport to go to breast cancer resource centres or support group meetings, or there is no resource centres or resource persons available within learners' geographical location. "Institutional barriers" in the context of the study means practices and procedures imposed by public health system, for instance, inconvenient time for programs and absence or very limited support services offered by hospitals.

The chronic phase is the period between diagnosis and the results of treatment. This phase is described by Gonzaga (2004) as "extremely demanding" (para. 12) as the patient needs to cope with unwanted side effects of treatment as well as to



manage her everyday business. Among the common side effects of the treatments are hair loss, weight loss, nausea, and fatigue.

In the recover phase, the patient has to manage herself in order to maintain her well-being as well as to prevent the recurrence of cancer. The four phases can be best summarized as in Figure 1.

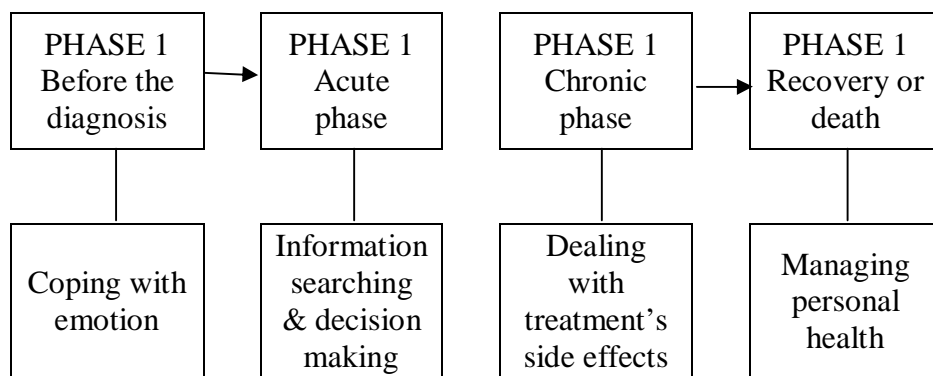


Figure 1: Phases of breast cancer experience

Source: Adapted from Gonzaga, 2004, para 10.

Breast Cancer Situation in Malaysia

According to National Cancer Registry Report, in the year 2002 (Lim, et al., 2003), a total of 26,089 cancers were diagnosed in Peninsular Malaysia, comprising 11,815 males and 14,274 females. Among all cancers in females, breast cancer is top of the list as illustrated in Figure 2.