

Self-directed learning experiences of women with breast cancer: preliminary findings

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ABSTRAK

Kanser payudara ialah penyakit kanser yang paling banyak dihadapi oleh wanita di Malaysia. Mempelajari dan memahami penyakit ini adalah penting bagi wanita-wanita tersebut dalam menangani situasi krisis yang dialami. Pembelajaran arahan sendiri adalah satu kaedah pembelajaran yang dapat memudahkan wanita-wanita tersebut dalam mempelajari dan memahami secara lebih mendalam tentang penyakit tersebut. Kajian ini berpandukan kepada soalan-soalan berikut: (1) Apa yang mendorong mereka untuk terlibat dalam pembelajaran (2) Apa strategi yang digunakan dalam pembelajaran arahan sendiri mereka; dan (3) Apa cabaran yang dihadapi oleh mereka. Kajian kualitatif ini menggunakan kaedah temubual secara mendalam (in-depth interview) untuk mendapatkan data mengenai pembelajaran wanita-wanita yang mengidap kanser payudara. Data dirakam secara verbatim, dan analisis dijalankan dengan menggunakan teknik pengkodan dan pengkategorian. Dapatan setakat ini menunjukkan bahawa terdapat tiga kategori dorongan untuk mereka terlibat dalam pembelajaran iaitu dorongan untuk mendapatkan maklumat tentang penyakit; dorongan yang berkaitan dengan keluarga; dan dorongan yang berkaitan dengan perasaan. Strategi pembelajaran utama mereka ialah menggunakan media cetak dan bertanyakan doktor. Dapatan ini masih pada peringkat awal dan beberapa lagi temubual akan diadakan untuk mendapat dapatan yang lebih konklusif. Data yang diperolehi setakat ini menunjukkan bahawa pembelajaran arahan sendiri wanita-wanita yang mengidap penyakit kanser payudara dipengaruhi oleh faktor-faktor kontekstual seperti keluarga, keyakinan terhadap doktor dan emosi.

INTRODUCTION

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. In regards to breast cancer, the issue of education and learning

has been regarded as important in dealing with the situation. The specific issue that the author would like to address is the learning process as experienced by women with breast cancer. Bouchard (1994) categorizes learning into two: self-directed and other-directed.

Self-directed learning means taking personal responsibility in learning (Brockett & Hiemstra 1991). The concept of personal responsibility implies the learner's role in accepting the responsibility to undertake the process of learning, which includes planning, implementing and evaluating. The importance of self-directed learning for adults is well documented in the literature (Brockett & Hiemstra 1991, Brookfield 1985; Merriam & Caffarella 1999).

Rager's (2003) study underlines the importance of self-directed learning in breast cancer context. Diagnosed with breast cancer, the woman left with no choice but to learn in order to survive. Brockett & Hiemstra's (1991) notion of self-directed learning as a matter of survival can appropriately describe the self-directed learning in the context of personal crisis situation.

Understanding the potential of self-directed learning as an important element in the context of breast cancer, the learning effort of self-directed learners need to be encouraged and facilitated. The desired state that we would like to see is the existence of learning environment conducive to the self-directed learners. In order to attain the desired state, the following issues need to be noted: (1) the lack of literature that could enhance our understanding of the phenomenon; and (2) our limited understanding of the phenomenon have been translated into the lack of attention given to the learning needs of breast cancer patients.

Despite the richness of literature on self-directed learning, most of them have not been focusing on self-directed learning in personal crisis situation. The only studies on self-directed learning and cancer from patients' perspective have been Rager (2003), Alexander (1997), and Murphey-Ende (1996).

Previous line of inquiry is developed by Rager (2003) who investigated self-directed learning of thirteen women with breast cancer in Wichita, Kansas, United States. The study offers an insight into the phenomenon in a culturally different setting. As the study cannot be generalized into a culturally different context, an investigation of the phenomenon in Malaysian context is needed. The investigation will be able to offer a rich description of how the self-directed learning of Malaysian women with breast cancer is influenced by contextual factors such as culture and religion. Studies on self-directed learning in Malaysia have been focusing in non-crisis situation (for example: Abu Daud *et al.* 1998; Daing Zaidah & Abu Daud 2002; Norzaini *et al.* 2004, Rozhan 1992).

This study seeks to contribute to the theoretical understanding of self-directed learning in a personal crisis situation. Although self-directed learning is a popularly researched theme in adult education, an inquiry in the

context of a crisis situation is relatively new. So far theoretical framework developed have not addressed the discussion of self-directed learning in a personal crisis situation. Two of the closely related frameworks are Brockett & Hiemstra's Personal Responsibility Orientation and Garrison's Model (Rager 2003). These models highlight the centrality of personal responsibility in learner's self-directed learning, but do not specifically address the situations in which the learners learn. This study aims to provide a foundation for theory building related to self-directed learning in a personal crisis situation.

In terms of research implication, findings of this study will enrich our understanding about the phenomenon of self-directed learning among breast cancer survivors in Malaysia. The issue of chronic illnesses and other personal crisis situations has not been discussed in detail in the literature (Rager 2003). As this study is conducted using qualitative paradigm, the in-depth understanding of the phenomenon under investigation can be derived. The unexplored richness of information regarding contextually influenced factors such as sociocultural and religious factors makes this investigation contributive to the new knowledge. Findings of this study enable researchers to understand the phenomenon from the perspective of the patients. The context is also relatively new and this represents a new contribution of knowledge in the context of Malaysian breast cancer patients. Merriam & Caffarella (1999) suggest the inquiry of "how contextual factors interact with the personal characteristics of self-directed learners" (p. 313) as one of the research areas that need further attention.

Findings from this study can guide policymakers in the related ministries and non-governmental organizations in order to provide conducive learning environments for breast cancer patients who are self-directed learners. Examples of areas of improvement as an implication of these findings are: (1) provision of learning materials such as books, leaflets, and computer-based learning materials; (2) planning for breast cancer education programs; and (3) provision of services that supports the needs of the breast cancer patients, for example, library, counseling services.

Among policymakers identified as beneficiaries of this research include the Ministry of Health, the Ministry of Women and Family Development, National Cancer Council (MAKNA) and National Cancer Society (NCS). The other parties that will gain benefit from this study are the breast cancer patients themselves and their family, and various support groups throughout the country.

METHOD

The purpose of sample selection is not to achieve statistical generalisation, but rather to gain the perspective of participants (Merriam 1998). The selection of participants is therefore based on the potential of each participant to contribute to researcher's understanding of the phenomenon under investigation. Merriam (1998) presents an interesting analogy in this regard. She posits that medical consultants are selected due to their expertise. In solving our medical problems, we do not seek "their average opinions". They are consulted due to their expertise, which in qualitative research context means they are resource-rich. Merriam's analogy found support from Morse & Richards (2002) who argue that, "average experience are difficult to explore, as the characteristics of the phenomenon of interest are diluted and mixed in with other characteristics from other experience" (p. 173).

In this study, purposive sampling is used. According to Merriam (1998), the criteria used should reflect the research question and guide in identification of information-rich cases. The criteria for the sampling are summarized in the following table:

TABLE 1: Criteria of the selection of participants

Item	Criteria	Rationale
Learning mode	Being a self-directed learner	Self-directed learning is the phenomenon under investigation.
Gender	Female	Most of the diagnosed with breast cancer are female.
Language spoken	Malay and/or English	The languages are the most widely spoken in Malaysia.
Survivorship	1-5 years after being diagnosed with breast cancer	Period of 0-1 year marks the emotional adjustment period. The limit of fifth year of survivorship is to ensure the recentness of information.

The first criterion is the participants must be self-directed learners in the context of learning about breast cancer. In order to qualify them as a self-directed learner, Tough's (1971) conception of learning projects is used. Tough (1971) defined a learning project as "a series of related episodes, adding up to at least seven hours" (p. 7). A learning episode is "a period of time devoted to a cluster or sequence of similar or related activities" (Tough 1971: p 7). Examples of activities are reading books, newspaper articles, and attending classes.

In the context of this study, potential participants are asked about their learning efforts in order to ensure that their total hours spent on their self-directed learning total up at least seven hours. The seven hours spent are in any or any combinations of the following activities: reading books or articles, browsing the Internet, consultation with doctors and other survivors, discussion in support groups, and other related learning activities.

Participants for the study are Malaysian women diagnosed with breast cancer within the last five years from the time of interview with them is conducted. There are two reasons for the limit of five years, firstly it is the post-diagnosis period before a patient is declared disease-free, and secondly, the period of five years is to ensure the recentness of experience. The researcher does not select those of within one year after diagnosis with breast cancer because this period represents the most difficult phase in their life. During this period, the women diagnosed with breast experience emotional adjustment which will not enable the researcher to elicit any meaningful information. As this study is still in data collection stage, the paper only reports the first two in-depth interviews involving the first two participants.

The interviews conducted were based on open-ended questions. To assist the data collection process, an interview guide outlining general interview and probing questions was prepared. The interview data was recorded using an Olympus Pearlorder microcassette recorder. In order to prepare for technical problem, a second tape recorder was made available during the interviews. The data were then transcribed verbatim. Data collection and data analysis should be run simultaneously. For the purpose of data analysis, the researcher kept a research diary, fieldnotes and interview transcripts in printed and electronic forms. The printed copies were kept in several folders, with each folder representing each participant.

As for electronic version of the document, there were two copies to be kept. The working copy was kept in the researcher's thumb drive. To guard against possible loss of data due to viruses and other computer problems, a second electronic copy was kept in researcher's external disk. To allow easy retrieval of documents, all electronic documents were kept in various folders representing different participants. The next step was to analyse the data. The data analysis strategies that are going to be used are: (1) coding (2) concept mapping; and (3) constant comparative method.

PRELIMINARY FINDINGS

The study is guided by the following research questions: (1) what are motivating factors in their learning? (2) what strategies they used in their learning? and (3) what are challenges that they encounter in their learning?

Based on the first two in-depth interviews conducted so far, there were three common categories of motivating factors, two common categories of learning strategies, and a common category of challenges in learning. The findings are organized according to predetermined themes: motivating factors (theme 1), strategies in learning (theme 2), and challenges in learning (theme 3). A summary of the common categories is listed as in the followings:

TABLE 2: Summary of common categories

Theme 1: Motivating factors

1. Disease-related factors
 - a. Triggered by suspicion of having breast cancer
 - b. The need to cope with breast cancer
 - c. The desire to be free from breast cancer
2. Family-related factors
 - a. Encouragement of learning effort by family members
 - b. Learning in order to be alive and able to care for family
3. Thoughts and emotions
 - a. The need to gain emotional strength
 - b. The need to fight negative thoughts

Theme 2: Learning strategies

1. Utilizing of print media
 - a. Read to learn
 - b. Role of popular print media
2. Doctors as trusted referent persons
 - a. Learn through consultation
 - b. Perceived credibility of doctors

Theme 3: Challenges

1. The challenge of managing emotion
 - a. Consequence of being diagnosed with breast cancer
 - b. Stress and uncertainty
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MOTIVATING FACTORS

DISEASE-RELATED FACTORS

Triggered by suspicion of having breast cancer. Participants' learning efforts are triggered by their suspicion of having breast cancer. Their learning effort was by consulting doctors in hospitals. Therefore the referent persons who are authoritative in diagnosis are doctors. For Puan Normala, she waited for two weeks before she got the result:

“Jadi dia kata dalam masa dua minggu lah, jadi bila saya confirmkan, pergi balik pada doctor, lepas dua minggu, doktor mengesahkan itu kanser”.

(He said it would be in two weeks time, so to get that confirmed, I got back to the doctor, and after two weeks, the doctor confirmed, it is cancer).

The need to cope with breast cancer. Participants search ways to cope with their situation. One of the ways is learning about complementary medicine as illustrated by Puan Rosilah:

“Sebab ubat dia tu pemakanan .. bukan ubat dia .. anti ...anti-barah dia kata elakkan daripada merebak penyakit elakkan merebak ke tempat penyakit”.

(Because her medicine is for dietary purposes, it is not medicinal, but it is rather, anti cancer to prevent the spread of the disease).

The desire to be free from breast cancer. For the participants, they learn in order to seek treatments to free themselves from the disease. For Puan Normala, for instance, her desire is to remove any traces of the disease from her vein:

“Kakak cuma nak tahu, bila dah dibuat operation, nak sembuh saja, tak nak penyakit tu berada, makna baik dalam darah, baik dalam apa dalam saluran apa pun”.

(I only wanted to know, after completing the operation, I would like to get well, I would not want the disease in my blood, in any of my veins).

FAMILY-RELATED FACTORS

Encouragement of learning effort by family members. The husbands play very influential role in encouraging their wives to learn more about their disease, especially by consulting doctors. Puan Rosilah's husband talked about the need to consult the doctor and Puan Normala's husband went a step further by highlighting doctor's authority in dealing with the disease:

“Lepas tu saya kata bila balik kita bincang macam mana, saya cakap dengan suami saya, dia kata. Ikutlah dia kata, pandangan macam mana pun, makna doctor lebih arif, dia kata”.

(After that we were going to discuss that when we got home, that's what I told my husband. He said, just follow what he (doctor) said, no matter what others say, it is doctors who are more knowledgeable).

Learning in order to be alive and able to care for family. Concern for their family, especially for their children is always in their mind. For Puan Normala, if she did nothing, she would trouble not only herself but also her children:

“Maknanya kalau saya orang kata, mendiamkan diri, tak tentu hala, saya akan menyusahkan diri saya, menyusahkan anak saya, sebab anak saya perlukan perhatian saya”.

(If I were to do nothing and without any direction, I would trouble myself and my child, because she needs my attention).

THOUGHTS & EMOTIONS

The need to gain emotional strength. To gain emotional strength, Puan Normala looked for counseling service offered by one of the support groups in Kuala Lumpur. She treasured this very much as it enliven her spirit and motivation:

“Jadi semangat, bila saya mendengar daripada Puan Azura tadi dia boleh sampai dah sepuluh tahun, mengapa saya tak boleh, makna kekuatan, makna semangat tu datang daripada diri saya sendiri”.

(In regard to my inner strength, when I listened to Puan Azura, if she could survive for ten years, why not me? The inner strength has come from within myself).

The need to fight negative thoughts. As breast cancer is a life-threatening disease, the participants found it necessary to fight any negative thoughts that demotivate them. They have to learn how to fight the negative thoughts. Puan Normala, for instance, had to persuade herself to stand against the negative self-talk. She learns how to battle her own fear, i.e. by emulating other survivors:

“Yalah bak kata tadi saya takut nak melawan perasaan tu, saya nak pujuk diri sendiri. Kenapa orang tu boleh hidup sampai sekarang. Saya yang baru disahkan, belum operate lagi, saya dah berasa takut?”.

(Yes, as what I have said just now, I was scared to fight my own feeling, I wanted to persuade myself. Why the person survives up until now? I have been confirmed (as having breast cancer), and haven't been operated yet, so why I need to have fear?).

LEARNING STRATEGIES

UTILIZING PRINT MEDIA

Read to learn. Participants look for information about their disease by reading printed materials such as books, newspaper and magazines. For Puan Rosilah, reading is her habit and she happened to read about breast cancer before she was diagnosed. The materials helped very much in dealing with the situation. For Puan Normala, she reads not only to learn but also to help other patients.

Role of popular print media. Participants reported that they appreciate the role of popular print media such as newspapers and women magazines in highlighting relevant information about breast cancer.

DOCTORS AS TRUSTED REFERENT PERSONS

Learn through consultation. The participants utilize consultation with doctors as a valuable source of learning. They take the opportunity to ask questions relating to the disease, for example, side effect, chances of recurrence, etc. For example, Puan Normala asked:

“Adakah bila saya dah dibuang sebelah ni kesan dia untuk mendapat, dia akan menyerang sebelah kiri, ada ke chance untuk itu? Dia kata, berkemungkinan, tetapi dia kata, bila dah buat operation, kita akan buat chemo, kita akan buat apa tu aaa radioterapi ni untuk membantu”.

(Is there any chance that, after this side is removed, cancer will get to the other side? He (the doctor) said, after completing operation, we go for chemo, we go for, aaa, radiotherapy, and these will help).

Perceived credibility of doctors. The participant share their non-preference for bomoh’s treatment. They put their trust in doctors and regard them highly. The doctor’s perceived credibility is in terms of their medical expertise. Puan Rosilah put full trust in doctors,

“Saya terserah pada doktor aje lan, kita tak pandai kan, tak arif. Terserah pada doktor ajelah, dia kata makan ubat, makan ..pergi buat fisioterapi , pergi”.

(I put my trust in doctors, as we are not knowledgeable..We trust the doctor, if he asks us to take medicine, do it, if he asks us to go for physiotherapy, go).

Puan Normala’s perception is not much different, she views doctor’s authority in terms of medical expertise highly:

“Bila saya pergi pada doktor, makna doktor lebih arif, makna dia lebih faham kan daripada saya”.

(When I see a doctor, it means that the doctor knows more, he understand much better that I do).

CHALLENGES (THE CHALLENGE OF MANAGING EMOTION)

Fear, depression, emotional stress and uncertainty are among emotional consequences of being diagnosed with breast cancer. The common question asked is “Why me?” The presence of these aspect of emotion can disrupt learning. Regarding this Puan Rosilah recalled that:

“Perasaan saya tu memang sedihlah .. aaa .. saya balik pada operation tu saya tak campur apa-apa aa saya masa tu memang buat kelas tuition lah kat sini kaan .. budak-budak

.. kaan .. saya tak nak mengajar, saya kata .. suami saya tutuplah kelas saya tak nak mengajar lagi”.

(My emotion at that time was really sad, when I got home from the operation, did not care to interact with others, at that time we were organizing tuition classes here for the schoolchildren, I did not want to teach, I said to my husband, close down the classes, I do not want to teach anymore).

Puan Normala's feeling was characterized by emotional uncertainty:

“Perasaan pada masa tu saya tak tentu arah, saya menangis, saya menjerit, saya tanya doktor, mengapa saya, doktor, saya yang Allah Taala pilih. Mengapa saya?”.

(My emotion at that time, I was disoriented, I cried, I asked doctor, why me, why Allah chose my, why me?).

DISCUSSION

MOTIVATION FOR LEARNING

Motivation to learn is characterized by factors related to breast cancer, family and emotion. Being diagnosed with breast cancer, a patient needs to understand her disease in order to help her coping with the chronic situation.

Role of family is important, especially in Asian societies (Hisham & Yip, 2003; Lee & Wu 2002, Muller & Desmond 1992, Ruhnke *et al.* 2000; Sent *et al.* 1998). The presence of family related factor as found in this study supports our earlier findings of focus group discussion (Zalilah *et al.* 2005), especially in regard to the desire to live in order to care for the well being of their family.

Impact of diagnosis on emotional well being of breast cancer patients is well-documented in the literature (for example: Rager 2003, Rabinowitz 2002, Weinberg & Schmale 1996). According to Hack & Degner (1999), adaptation to breast cancer situation is about building self-esteem in dealing with the situation.

STRATEGIES FOR LEARNING

The findings so far suggest that women with breast cancer utilize print materials and consultation with doctors as their main source of learning. The former is due to the popularity of the print media materials such as daily newspapers and women magazines. This supports Yahaya & Taranjit's (2003) study which

indicates that 92% of respondents surveyed learn from mass media such as newspaper. In Davis *et al.* (2003) Australian study, however, television was found to be the most effective means of communicating health messages to the public.

In coping with life-threatening situation such as in breast cancer situation, the role of trusted persons is important. In terms of learning, the trusted persons are those who have the medical knowledge to treat their disease, i.e. the doctors. According to Fogarty (1996), perceived credibility of physicians is an important factor in influencing patients' treatment decision-making. In a recent survey of 2,074 respondents conducted by Business Ethic Institute of Malaysia (Rajah 2006), doctors were voted as the most trusted professionals.

CHALLENGES OF LEARNING

The findings so far indicate that the common challenge of learning is the presence of emotional factors. The women reported that they felt disoriented and uncertain about their future life. Their feeling of disorientation and uncertainty about their future life disrupted their pursuit of learning as evidenced by Rager's (2003) investigation. A Thai study indicates that female cancer patients experienced more anxiety in comparison with their male counterparts. This finding can be best described by Francabandera (1992) who posits that learning in chronic situation is not just about acquiring disease-related information, but also dealing with other issues such as relationship and stress coping skills.

CONCLUDING NOTES

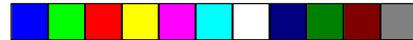
These findings are at still preliminary stage and more in-depth interviews will be held in order to arrive at more conclusive findings. At this stage, we could conclude that self-directed learning experiences of women with breast cancer is influenced by contextual factors such as family, trust in doctors, and emotion. These factors need to be taken into consideration in facilitating learning efforts of the women.

Involvement of family in the learning of women with breast cancer needs to be supported with proper guidance. The trust that they put in doctors underlines the need for the doctors to continue their professional duty in professional manner. The trust does not mean that the women do not have to learn about their disease anymore as the doctors are there to help them. The challenge of managing emotion needs to be addressed as it has the potential of disrupting the learning. In regard to this, the role of cancer support services is of utmost important (Othman & Mazanah 2005).

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