

RESEARCH ARTICLE

Understanding the Breast Cancer Experience: a Qualitative Study of Malaysian Women

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Abstract

Breast cancer is the most common and leading cause of cancer mortality among Malaysian women. Despite good survival rates, the diagnosis of cancer still invokes the feeling of stress, fear and uncertainty. Because very little is known about the experiences of Malaysian women with breast cancer, a qualitative study using semi-structured interviews to explore the lived experience of newly diagnosed breast cancer. Using a purposive sampling method, 20 Malaysian women newly diagnosed with breast cancer, including Malays (n=10) and Chinese (n=10) were recruited in two main public hospitals in Kelantan. Similarities and divergence in women's experience were identified through thematic analysis of interview transcripts. Three themes emerged from the data: uncertainty experience of the illness, transition process and fatalistic view of breast cancer. In many ways, these findings were parallel with previous studies, suggesting that the experience of breast cancer is to a certain extent similar among women newly diagnosed with breast cancer. This study adds to the sparse literature concerning the experience of illness following breast cancer diagnosis among the Malays and Chinese. More importantly, this study addressed areas that were previously lacking, specifically in depth information on breast cancer experience from a developing country with a multi-ethnic population. The results of this investigation provide preliminary information to healthcare professionals on the impact of illness and cultural influence on survivorship to plan for appropriate education and supportive programme in order to meet the needs of breast cancer women more effectively.

Keywords: Malaysian women - breast cancer - new diagnosis - illness experience - transition - uncertainty - fatalism

Asian Pacific J Cancer Prev, 14 (6), 3689-3698

Introduction

Breast cancer is the major health problem and cause of death worldwide (World Health Organization, 2012). Among female, breast cancer is the most frequently diagnosed cancer and the leading cause of cancer mortality in developed and developing countries (Jemal et al., 2011; Zainal Ariffin and Nor Saleha, 2011). Malaysia is a developing country of 28.3 million populations with the Malays and Chinese as the major ethnic group (Department of Statistics Malaysia, 2010). The National Cancer Registry reported that the most common cancer among Malaysian population regardless of sex and ethnicity were breast 18.1%; followed by colorectal 12.3%; and lung 10.2% (Zainal Ariffin and Nor Saleha, 2011). Breast cancer corresponds to 32.1% of all female newly diagnosed with cancers and 58% presented at early stages (Stage I and II) while 42% presented with late breast cancer, Stage III and IV (Zainal Ariffin and Nor Saleha, 2011). The incidence of breast cancer in Malaysia

was highest among Chinese with age standardized rate (ASR) of 38.1 per 100,000 population followed by Indian 33.7 per 100,000 population and Malay 25.4 per 100,000 populations (Zainal Ariffin and Nor Saleha, 2011).

The difference in the incidence rates across ethnicity could be explained in terms of risk factors known to be associated with breast cancer such as limited breast feeding practice, lifestyle, nutrition, reproductive and genetic factors (Yip et al., 2006; Musa et al., 2011). Generally, Chinese women have fewer children, breast feed for shorter period and have their first child later compared to the Malay and Indian. Although the incidence rate is lower among the Malays, they present at advanced stages, with larger tumour and consequently, their survival is the worst compared to other ethnic groups in Malaysia (Yip et al., 2006; Taib et al., 2011a; 2011b; Ibrahim et al., 2012; Mujar et al., 2012). The reasons for late presentation and getting treatment were inattention to routine breast cancer screening; poor knowledge on symptom, disease and treatment; denial; fatalistic view of cancer

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and perceived benefit and compatibility on alternative therapies (Mohamed et al., 2005; 2011; Farooqui et al., 2011; Norsa'adah et al., 2011; Taib et al., 2011b)

Previous studies reported that survival rates is improving from 59.1% to 75.7% among breast cancer patients in all stages and ethnicities attending University Malaya Medical Centre (Taib et al., 2008; 2011a). While early detection and treatment together with treatment advancement has indicated an increment in survival rate, yet the diagnosis of breast cancer still conjures feelings of fear, stress and uncertainty (Taib et al., 2011b; Yusoff et al., 2011; Norsa'adah et al., 2012). Doumit et al. (2010a) found that Lebanese women regard their breast cancer journey as a continuous battle of fears, anxiety, stress and uncertainty even after completed treatment. The few studies involved non-white women with breast cancer reported that women experience psychological distress, sexual and marital concern, poor knowledge on symptom and treatment and fatalistic view as a result of breast cancer diagnosis and treatment (Montazeri, 2008; Taib et al., 2011b; Norsa'adah et al., 2012). Starting from the time of diagnosis, women received loads of new and unfamiliar information about their illness, treatment and often were given limited time to make decisions. Moreover, decisions that they have to make are the major decisions which can have lasting effects on their lives. It has been suggested that women regards that initial phase after receiving breast cancer diagnosis as stressful and full of emotional turmoil (Coyne and Borbasi, 2006).

Nonetheless, another finding frequently found in the literature is positive personal growth following breast cancer diagnosis. Studies have shown that individuals diagnosed with breast cancer often grow as a result of the experience particularly regarding spirituality, appreciation of life and personal relationships (Ashing-Giwa et al., 2006; Ahmad et al., 2011; Swinton et al., 2011; Tighe et al., 2011).

Several studies have been performed to explore aspects of living with breast cancer with much research has been focused on social support, body image, quality of life and psychological reactions using standardized questionnaires in developed countries (Drageset et al., 2010; Sammarco and Konecny, 2010). However, few have explored women's experiences with breast cancer especially in Asian countries such as Malaysia (Redhwan et al., 2008b; Yusoff, 2009). There is paucity in qualitative investigation specifically aimed at capturing personal experience and views of Malay and Chinese women newly diagnosed with breast cancer in Malaysia. Therefore, this qualitative study was conducted to explore the experience of Malay and Chinese women newly diagnosed with breast cancer in the East Coast of peninsular Malaysia. Research in this area is very important as it involved multi-ethnic participants; the Malay and Chinese women and may provide some insight on the experiences of illness and treatment from the lowest urbanization state in Malaysia.

Materials and Methods

Study design

Due to the paucity of information about breast cancer

experiences of Malaysian women from various ethnicities, this study employed qualitative phenomenology to guide the investigation. This method will allow us to explore 'lived experience' of the newly being diagnosed with breast cancer and an insight into women's understanding, interpretation and beliefs about breast cancer and its treatment (Heidegger, 1996; McWilliam, 2010). The purpose is to understand a person's experience from their point of view and acknowledges the existential nature of understanding (Streubert and Carpenter, 2011). As the dimensions of this experience may reflect beliefs, attitudes and behaviours, they are difficult to measure in a quantitative way. Thus, qualitative approach can allowed an understanding on how people interpret their experience and the meaning of actions and reactions of people within their social context. This study explores the experiences of Malaysian Malay and Chinese women newly diagnosed with breast cancer.

Participants

Purposive sampling was used in this study to capture broad variation in demographic and clinical characteristics such as age, ethnicity, house location and stage of breast cancer for better understanding of the phenomenon being studied (Sandelowski, 2000; Kemper et al., 2003; Kelly, 2010). Participants were recruited from surgical outpatient clinics at two main public hospitals in Kelantan, Malaysia who satisfied the study's inclusion criteria: all women with confirmed histological diagnosis of primary breast cancer within November 2010 to April 2011. There were no restrictions on patient selection with regard to histology of breast cancer, breast cancer stage, and demographic characteristics. The exclusion criteria were women with previous history of breast cancer, terminally ill condition, and mental health illness.

The data collection was based on the principles of data saturation. According to Bryman (2008) and Sandelowski (2000), numbers are not important in ensuring adequate samples as the concern in qualitative sampling is about the depth of the data; not with the empirical generalization. Therefore, the final number of participants was not predefined. After the 15th interviews, there were no new themes generated from the interview. It was therefore deemed that the investigation had reached a preliminary saturation point, and the collection of data was discontinued after the 20th interview. Data from 20 participants was also viewed as a sensible number with which a degree of data saturation might be achieved (Morse, 2000; Green and Thorood, 2004).

Ethical considerations

The study was granted an ethical approval from the Clinical Research Centre, Ministry of Health, Malaysia; KKM/NIHSEC/08/0804/P10-332 and Human Ethics Committee, Universiti Sains Malaysia; USM/KK/PPP/JEPeM[231.4.(1.11)]. The women were informed about the study both orally and in writing. Written consent was obtained from the women when they agreed to participate in the study. They were informed that they can withdraw from the study at any time, without any implications on their future treatment and follow-up. In addition, women

were assured of anonymity and confidentiality such as pseudonyms was given to each participants.

Procedure

This study utilizes qualitative longitudinal data as Mandelblatt et al. (2003) pointed out that there are significant gap in existing qualitative data in exploring the trajectories experience of people with illness. In this study, we aim to explore the experience of illness within six months following the diagnosis of breast cancer. Thus, recruitment and data collection for the Phase 1 was from November 2010 to April 2011 and follow-up interviews for Phase 2 were scheduled from May 2011 to October 2011.

Once a participant was screened for eligibility and had verbally consented to the interview, an appointment for a face-to-face interview was arranged by telephone. The interview in Phase 1 was conducted within the first week after women received their breast cancer diagnosis, while Phase 2 interview was scheduled at six months following the first interview. Most of the women preferred to meet and conduct the interview at their house. Nevertheless, some of them requested to meet somewhere else at their convenience.

All interviews were done by the first author either in Malay or English language according to the women's preference. This option allows the participant ease in narrating their views. Each interview took approximately 45-60 minutes. All interviews were audio-recorded, with the consent from the participants. All ambiguous notes or interview segments on the audiotape were clarified in the field notes. When the interviews were transcribed, they were kept in both languages, the Malay and English for analysis by the researchers who are fluent in both languages.

Each interview followed a self developed interview guide to ensure that all the interviews are conducted in a similar manner and that an identical set of questions was discussed. Probes and follow-up questions were used to ensure specific dimensions are explored in all interviews and allowing fuller explication of topics of interest (Rubin and Rubin, 2005; Kelly, 2010). In the first phase, at the start of each interview, the woman is asked to tell the story from the point when she first suspected that there was something wrong. The researcher may then ask for clarification or expansion of some of the issue arose, before using a set of additional semi-structured questions and prompts to explore about the following topics: (i) Presenting symptom of breast cancer, (ii) Ideas about the causes of breast cancer, (iii) Experience of breast cancer illness and (iv) Thoughts about the future.

In the second phase, the women were encouraged to talk about their illness and treatment experience for the last six months from the first meeting. In addition, women were encouraged to talk about all aspects of their experiences that have mattered to them. This allowed exploration of women's experiences without imposing pre-determined ideas as to what should be assessed. Due to the sensitive issues may arise from the interview; women were offered consultation after the interview with the counsellor at the oncology clinic according to the women's

Data analysis

Data analysis took place concurrently with data collection and as the initial coding is done, subsequent interviews were adapted to include issues coming from the preliminary analysis (Marshall and Rossman, 2011). To facilitate data analysis, verbatim transcriptions of audio-recorded interviews were prepared by the first author. Transcriptions of qualitative interview were entered into NVivo 9 software. This software provided a better overview, management and facilitation the analysis of themes and systematic comparisons across transcripts (Green and Thorogood, 2004; Streubert and Carpenter, 2011). Following the principle of the constant comparative method, each transcript was repeatedly compared across and within the participants to identify common themes. To ensure validity, another co-author was continuously involved in the coding process. Particular attention was paid to deviant or contradictory cases by the authors.

Results

Participant's characteristics

The socio-demographic and clinical data of the women involved in this study are shown in Table 1. In this study, 20 Malaysian women with 10 Malay and 10 Chinese participated in the interviews. The age range was 34-59 years old. Most of the Malay and Chinese women were married. Majority of the Malay women were at later stages of breast cancer while Chinese women at early stages. One of the Malay women refused conventional therapy and opted for traditional treatment after receiving breast cancer diagnosis. Two of the Chinese women defaulting chemotherapy after underwent surgical treatment. Most of the women received combination therapy of mastectomy surgery and chemotherapy. Thirty-nine interviews were conducted over two phases within one year since one of the Malay women was loss to follow-up due to death. We present extracts from respondents' narratives to illustrate these themes (for each quotation, we give the respondent's pseudonym to ensure anonymity followed by 'M' to indicate the speaker is a Malay or 'C' to indicate a Chinese).

Overall, the study findings highlighted important aspects of the complexities women's stories about their struggle when they were newly diagnosed with and living with breast cancer. Illness meanings are exemplified as evolving, dynamic phenomena changing with situational and life contexts and the experiences generated by the illness and treatment process. Three themes emerged that describe the Malaysian women's personal experience after diagnosis of breast cancer which were uncertainty, transition and fatalistic.

Uncertainty

Both Malay and Chinese women in this study described their experiences of uncertainties during their illness journey; before diagnosis, after diagnosis, and even after

Table 1. Description of the Breast Cancer (BC) Participants in Qualitative Interview

Name	Age	Marital status	Children	Education level	Occupation	BC stage	Treatment
Aminah M	40	Married	2	Secondary	Clerk	III	Mastectomy, Chemotherapy
Zaharah M	36	Married	4	Tertiary	Officer	III	Reconstructive mastectomy, Chemotherapy, Tamoxifen
Salmah M ^a	43	Married	4	Secondary	Odd job	IV	Traditional treatment
Safiah M	39	Married	4	Secondary	Clerk	IV	Palliative chemotherapy
Maryam M	54	Single	2 ^b	Secondary	Police	II	Mastectomy, Radiotherapy, Chemotherapy
Jamilah M	35	Married	3	Tertiary	Nurse	II	Mastectomy, Radiotherapy, Chemotherapy
Suzilah M	49	Married	5	Secondary	Odd job	III	Mastectomy, Chemotherapy
Rosie M	35	Married	2	Tertiary	Teacher	II	Mastectomy, Chemotherapy, Radiotherapy, Tamoxifen
Rahmah M	40	Married	6	Secondary	Odd job	III	Mastectomy, Chemotherapy
Halimah M	51	Married	5	Tertiary	Teacher	II	Mastectomy, Chemotherapy
Tang C	45	Married	3	Secondary	Manager	II	Lumpectomy, Chemotherapy
Lim C	50	Married	3	Secondary	Odd job	IV	Chemotherapy, Reconstructive mastectomy
Khor C	56	Married	2	Secondary	Manager	II	Wide local excision, defaulted Chemotherapy & opt for alternative treatment
Cheng C	45	Widowed	1	Tertiary	Executive	II	Mastectomy, defaulted Chemotherapy & opt for alternative treatment
Kim C	47	Married	4	Secondary	Housewife	II	Mastectomy, Chemotherapy
Law C	34	Married	4	Secondary	Odd job	IV	Mastectomy, Chemotherapy
Khoo C	49	Married	2	Secondary	Housewife	II	Mastectomy, Radiotherapy
Quek C	59	Widowed	0	Tertiary	Retiree	I	Wide local excision, Radiotherapy, Chemotherapy, Tamoxifen
Chow C	59	Married	4	Tertiary	Retiree	II	Mastectomy, Chemotherapy
Lee C	38	Married	1	Secondary	Clerk	IV	Chemotherapy, Radiotherapy

*All names are pseudonyms, ^aLoss to follow up during second interview due to death, ^bAdopted

treatment. In the beginning, they were uncertain about their breast presenting symptoms of cancer. For some, they had mistaken the symptoms of breast cancer as benign diseases such as cysts or milk duct clot. In addition, there was no pain or affecting their routine activities.

"I first noticed about the lump on my right breast when I was having my morning shower. Then, I thought may be the lump is from the milk clot as I breastfed my daughter only on the right breast. In addition, I'm in the weaning process of breast feeding. Then, I told my husband; he also guessed that is normal" (Zaharah M)

"Actually I noticed about a lump as big as a small round marble for quite some time. Then, I asked my friend. She said it could be swelling from the milk duct as I was just weaning off breast feeding for my younger daughter. When I heard it just a swelling milk duct, I ignored the symptom. I thought that after three months, I will check again. But it (the lump) has no pain, so I just ignore it. Then, I don't know how, suddenly I touched it again [the lump] and it feels like it is getting bigger and hard. And that was about one year a part" (Law C)

After receiving the diagnosis, especially among Malay women, they were in dilemma about their treatments in order to survive and continue to live a quality life. They were confused whether to receive conventional or alternative treatments. Traditional treatment is strongly embedded in Malay culture. People surrounding them (including their parents, family, in-laws, siblings and friends) were more in favour of alternative treatments, even bringing them to the places where alternative treatments are performed. They believed that traditional treatments would cure breast without the need to remove their breast and suffering the side effects of conventional treatments. They have strong believes that with conventional therapy, they will definitely lost their breast besides suffering dreadful side effects such as nausea and vomiting resulted

from chemotherapy.

"...my cousins bring me to the place for traditional treatment. I did everything including applying self-made herbal cream and massage to the breast (as suggested by the traditional healer)" (Maryam M)

"I went for the alternative treatment first because if possible, I don't want to remove [my breast]. If possible I don't want to go for chemo (therapy) because people said the effect was terrible like hair loss, vomiting ..." (Safiah M)

As they faced uncertainty about making decisions for their treatment, they turned to their spiritual beliefs and asked Allah to help them make the best decisions:

"When I want to make decision for the operation, I am in dilemma... because my family are against it... My parent is not agreeing on my decision to operate... Now I pray to Allah and asked Him to show me which way should I choose...? (Am) afraid that I will make a wrong decision. We don't know which way [is the best]. So, I pray to Allah to guide me the best decision" (Zaharah M)

Chinese women are more concerned about what would happen to them during their breast cancer treatments:

"When the doctor told me that I need to go through chemotherapy, I feel scared thinking of the people stories about the side effects of it. I have a friend who said that she wouldn't wish any of her friends or even her enemies to go through chemo(therapy). That is the extend of the unbearable side effects of chemotherapy that I heard that made me terrified" (Quek C)

"At first, they (the doctor) told me that I don't have to undergo chemotherapy. Later, I was told that I need to do. I wasn't protesting (to the doctor), I was just in doubt, why do I need to do chemo(therapy) now" (Chow C)

After their breast cancer treatments, the women were uncertain about their health, future, and being breast cancer survivors:

“...I don't know how long will I live with this illness, I don't know how my illness is (now)? Should I ask the doctor?” (Maryam M)

“Sometimes I am worried that the other side (of the breast) might have cancer also... I do worry about the future, after operation and all that [treatment], about the recurrence” (Chow C)

For some who were still young, they worried about menopausal symptoms as a result from breast cancer treatments:

“... Eh, am I pregnant?... then I went for the urine test, but the result came out negative... Will I lost my menstruation permanently? My husband still wants me to conceive after this...” (Rahmah M)

Transition

The participants in this study experienced a transition from health to illness after being diagnosed with breast cancer. This transition affected almost all aspects of their life: physical, psychological, social, and spiritual. They felt that their lives had moved and changed so suddenly, and had to make immediate and important decisions about their illness. At the same time, they were over-loaded and confusing with unfamiliar medical information. The following are examples of how a cancer diagnosis affected women's transition:

“When the doctor said ‘You have breast cancer and we will do the operation’. By the time they said operation, I cried... I asked them ‘is there any other way?’ the doctor said ‘No’ as mine (lump) is quite big. Then, I asked ‘What will happen after the operation?’ Doctor said I have to accept that one of my breasts is gone and my (affected) hand might be weak. After that is the follow-up treatment of all sort of therapy... With all that sudden and new information, I am so confused” (Maryam M)

“Before I know about my condition (breast cancer), I feel a little bit healthier. But, after (the result) I feel weak... I think a lot and feel sad” (Lee C)

For some women, this illness had an impact on their financial status. For example, most of the Chinese women were working in the private sector before the illness, and were unable to work either due to the illness or their treatment side-effects. Thus, they suffered financial difficulties:

“My work definitely affected. I am thinking very hard about my job, my income and my treatment. I am a single mother, if I don't have an income, how to take care of my daughter?” (Cheng C)

“I'm not able to work for half a year already. I cannot work much with my health like this. I am scared that it will give some effect on my health. If possible, I want to work but where got people want to hire me anymore?” (Lee C)

In addition, both Malay and Chinese women in this study also experienced dietary changes after their illness. Dietary change was a result of their physical condition or as part of their way of controlling and treating breast cancer:

“Dietary pattern has changed a lot. My appetite is good but I cannot eat much because of my condition whereby I can only lie down all the time. Thus, I eat with lying down position. With this position, I only can tolerate soft food

“I started with not taking red meat, but still taking chicken and fish... and I consumed plenty of vegetables... I changed into this habit with the hope for quick recovery” (Halimah M)

For some, especially among Chinese women, changed in dietary pattern was difficult for them. They felt stressed about it:

“My diet pattern has changed tremendously. This is very difficult. The fried one which I like before such as banana fritters, I cannot eat. I also reduced the amount of salt and sugar in my food. I only eat organic chicken and it's quite hard to get. I already start planting my own vegetable. I have to do my own cooking as I cannot expect my family to eat the same food that I'm eating” (Quek C)

“Now I felt stress because I am a person who likes delicious food. When I cannot eat almost everything ... I feel difficult. Now, I can only eat yellow tail scads [one kind of fish that is eaten for ‘pantang’ practice among the Malay] starting after the operation until now. I ate lots of vegetables. I did not take red meat at all. So, my diet has totally changed. I like to eat seafood like prawn and crab... But now I cannot eat all of those. That makes me feel tension” (Cheng C)

Fatalism

Most of the women in this study did not have much knowledge about breast cancer. Even they have access to the information, some of them even refused to know or read about breast cancer. They believed breast cancer to be terrifying and dangerous.

“... I never take notes about cancer. Normally, during health exhibition... they showed some scary pictures about cancer... In addition, I also heard that there was no cure for cancer. Therefore, I don't want to know, I'm scared to see that condition, I don't want it to happen to me” (Maryam M)

“Before I get this illness, I don't want to hear about cancer disease because I don't want it to come to me. So, I don't want to know at all” (Lim C)

They were interested in knowing the causal factor for the breast cancer that they get. They claimed that they adopted healthy life-styles besides no history of breast cancer in the family.

“... I gave exclusive breast feeding to all my children. I did not give them formula milk at all. As for the food factor, I did not take any junk food... If it is work stress, I don't think so...” (Zaharah M)

“... I always think that this (breast cancer) is a rare disease since none in my family have it. So, it won't happen to me” (Jamilah M)

Both Malay and Chinese women in this study have negative perception about breast cancer. They viewed breast cancer as a death penalty. They associate breast cancer with death and thought they would be approaching death very soon:

“... When they said that I have a disease that has no cure, I felt like my world has fallen apart. It's like I am going to die tomorrow” (Maryam M)

“I feel sad and scared... I am thinking of the future of my children. They are not even finished their school, if

I'm not around, how are the children..." (Tang C)

Sometimes, they tried to negotiate with God about their illness. Women with young children used this as a reason to continue with treatments and survive their breast cancer:

"If Allah (God) willing me to recover, I want to stay longer with my children ... all my children are still schooling, they are still small to live without their mother" (Salmah M)

"Although I know that I cannot be 100% cure, but I hope that I can stay healthy, live longer so that I can see my daughter growing.. she is still young" (Cheng C)

Later, they learnt to accept their illness and positively cope with their illness. They described that their priority was their family:

"...I know that with early treatment, that thing (breast cancer) can be treated and I can lead a normal life. Second, I 'm thinking for the children sake, I know that I have a chance to cure, so I still have time to be with my children...I want to recover for my husband and children" (Zaharah M)

"I never think of surrendering this treatment, because I always think of my husband and my son. I want to continue my life with them (cried). I want to treat my illness, I want to see my son growing up, I want to take care of my family..." (Lee C)

Others who did not state family as a reason for maintaining a positive attitude cited a high chance of recovery, and described themselves as having a strong will and fighting spirit to cure their illness:

"I want myself to cure. Because I know if I stop halfway through the treatment, the chance of recovering is slim.... I already gone through half way, might as well finished the (full) course. Furthermore, I was diagnosed at stage I, therefore the chances (of recovery) is high, So, I don't want to give up. I still have that fighting spirit, I won't give up... I must continue to fight and be positive about it" (Chow C)

Finally, they restructured their life's priorities. They learnt to appreciate the people and world around them. They narrated:

"I become closer with my children because I know that I will leave them someday [cried]. So, I take this opportunity to spend more quality time with them, they also enjoying this moment" (Zaharah M)

"As a motivation for me, I've made a promise to myself. I'll go for a holiday trip after completed this treatment. I will make a frequent visit to see my children and grandchildren. I also want to attend my son's convocation. I am look forward for all these trips. So, I must make sure that I am healthy" (Chow C)

Discussion

We conducted this qualitative study among Malay and Chinese women in Kelantan, the lowest urbanization state in Malaysia. The study findings found that in general, there were no differences in the narratives of experiences, perceptions and beliefs among the Malay and Chinese women newly diagnosed with breast cancer. A possible explanation for this finding is that all Malaysian;

regardless of ethnicity shared a common cultural values as Malaysian while preserving their own identity as Malays, Chinese and Indian in terms of physical appearance and religion (Abdullah, 1996; Merriam and Mohamad, 2000; Pue and Shamsul, 2011). In addition, 90% of the Chinese in Kelantan is Peranakan Chinese where they assimilated extensively to the Kelantanese rural Malays culturally as well as linguistically since they are living in the community with over 90% Malay ethnicity (Teo, 2003). Thus, the similarities in the narrative of breast cancer experience as a result of the assimilation among the Malay and Chinese in terms of ways of thinking, preference and culture including the aspect of health and illness.

The first theme found in the current study is women experiencing different kinds of uncertainty throughout breast cancer trajectory. This finding supports previous studies finding on uncertainty and unknown future in the breast cancer trajectories (Doumit et al., 2010a; Drageset et al., 2010; 2011; McCann et al., 2011). Uncertainty has been identified as one of the variables that influence the quality of life and caused psychological reactions that influence woman's experiences during cancer trajectory (Shaha et al., 2008; Tobin and Begley, 2008; Sammarco and Konecny, 2010; Drageset et al., 2011). Most women in this study were uncertain about their breast cancer symptoms and severity of their symptoms. Previous studies shown that limited knowledge about breast changes, symptom of cancer and its treatment besides poor understanding of information from the hospital, add to women's uncertainty which can contribute to delay in help seeking and consequently affecting their survival (Taib et al., 2011b; Norsa'adah et al., 2012). Landmark et al. (2008) reported that especially after being diagnosed, unpredictability of the disease and treatment cause various emotional reactions such as fear, stress and anxiety. However, our findings revealed that positive support especially from family; friends and healthcare professionals have helped the breast cancer women to endure uncertainty and psychological distress. In addition, support groups comprising of breast cancer survivors have assist in reassuring newly diagnosed women especially during challenging moment such as at earlier phase. Thus, continuous and individually tailored support is essential for the women to ensure they adjust well to their new and changed life sequel.

This study findings on breast cancer is a family affair rather than the women's personal concern is consistent with previous studies finding (Lam et al., 2005; Coyne and Borbasi, 2006; Hasan et al., 2009; Muhamad et al., 2011). In Malay culture, family especially husband and parent plays an important role in the decision making process for the women. Such role is critical in the Islamic culture where an effort will not be blessed without family, particularly parent and husband sanction (Muhamad et al., 2011; Norsa'adah et al., 2012). A literature review done by O'Cathain et al. (2007) found that one of the barrier for breast cancer screening in Asian women was "inability to act without husband permission". As permission from husband and parent is very crucial in decision making, healthcare professionals should include them in health education and information giving programme to encourage

mutual understanding and support among patients, husband and family.

The current study supports previous literature that women experience change in their life after breast cancer diagnosis (Drageset et al., 2011; McCann et al., 2011). Our study shows how the diagnosis of breast cancer has changed the whole of women's life; from caregiver to care receiver; changed in work and social role; changed in body and personal image, changed in personal relationship; either positive or negative. As most of the women in this study were at advanced stages of their breast cancer, their surgical treatment was mastectomies and chemotherapy as adjuvant treatment. Physical changes such as mastectomy scar and hair loss have clear implications on identity for women in this study; either intra or interpersonal.

This study supports previous findings on the meaning and experiences after breast cancer diagnosis where surgery and treatment had changed their bodies, self esteem and altered a symbol of femininity. The women themselves thought that they are imperfect, no longer attractive and needed by their husband due to the physical changes of the body. They were worried that their husband will withdraw from their relationship. This attitude could create strained relationship with their husband. Similar thoughts among breast cancer women in previous studies at various places were pointed out in countries such as in Taiwan, Iran, England as well as Malaysia (Lindop and Cannon, 2001; Taleghani et al., 2008; Doumit et al., 2010b; McCann et al., 2011; Chen and Chang, 2012; Yusoff et al., 2012). Nevertheless, the women in this study were mostly young; 10 years younger than those in Western countries, hence special attention to this problem is warranted.

The finding of this study among Chinese women that physical body change such as hair loss can signal to their social network that she is sick. They believed that being sick and labelled as someone with cancer is inexcusable as it will bring bad luck to the whole family. This finding is consistent with a study conducted among Chinese women in Hong Kong (Fielding and Lam, 2004). Bad luck to the family is due to the possibility genetic inheritance of cancer to their future generation as well as difficulty among the daughters in getting a husband as the mother is not healthy and having a disease.

Consistent with previous studies, this study found that there were positive transition in women's lifestyles in term of their dietary habits and physical activity after breast cancer diagnosis (Salminen et al., 2000; Maunsell et al., 2002; Redhwan et al., 2008a; Chen and Chang, 2012). The most common changes were increments of physical activity and consumption of fruits and vegetable. This positive changes is aligned with recommendation by the American Cancer Society that cancer survivors should increase fruit and vegetable intake beside increasing physical activity and maintain an ideal body weight to increase overall survival and decrease risk of recurrent (Kushi et al., 2007; 2010). However, the women in this study also reported that especially during chemotherapy, they feel very weak and can barely walk. Thus, the issue of promoting physical activity and exercise for patients undergoing treatment to beat the symptom of fatigue is a

concern among these breast cancer women. In addition, the importance of recognition and management of treatment related side effects for breast cancer patients receiving adjuvant therapy is an important issue since such side effects negatively affect quality of life and adherences to the therapy.

This study shows that maintaining a positive and optimistic perspective seemed to be very important to young women who are married with relatively young or school age children. The women emphasized that they have young children and family to take care and had to survive the cancer. This result is in line with other studies that mentioned the primary concern of breast cancer women was to survive and combat the illness for the sake of their children and loved ones (Henderson et al., 2003; Tam Ashing et al., 2003; Boehmke and Dickerson, 2006). In addition, positive adaptation, optimism and hopefulness seemed to do better in enduring the cancer experience and symptom distress associated with breast cancer treatment.

In this study, women had worst expectations at the time when they heard about the cancer diagnosis. Anxiety and fear that death is approaching was clearly apparent among the women in this study. This confirmed previous studies finding that women associate breast cancer with death (Taleghani et al., 2008; Taib et al., 2011b; Norsa'adah et al., 2012). However, an important finding was that, whilst experiencing breast cancer, they reappraised the challenges as an opportunity. Then it becomes positive, less stressful and enables them to appreciate life to the fullest. They started to reflect on their priorities in life, establishing better social relationships and appreciate the simple joys of life that were unrecognized before. Hence, for most of these women, they discovered that their cancer implied a reminder to live for the moment and change their perspectives in important areas of their life. As reported in the literature, many of these women reconceptualised the meaning of breast cancer from a negative to a positive event especially after the treatment has commenced (Lam and Fielding, 2003; Luoma and Hakamies-Blomqvist, 2004; Coyne and Borbasi, 2006).

However, the belief that death is inevitable when cancer is present also has been identified as a barrier to participation in cancer screening, detection and treatment (Spurlock and Cullins, 2006; Florez et al., 2009). This may be explained by the negative influence that uncertainty has on their life and many perceived that breast cancer as a terminal illness with no hope for a cure even when detected in early stages. Therefore, health care professionals need to demystify about these conceptions via health education and health promotion. In addition, nurses and other health care professionals need to be cognizant of the presence of these factors in their patients and the significant influence that these factors have on breast cancer survivors.

While this study has contributed to a preliminary understanding of psychosocial impact and experiences of newly diagnosed with breast cancer among Malay and Chinese women in Malaysia; it has a number of restrictive elements that affect generalizability.

Firstly, as the small sample size with 10 Malays and 10 Chinese was used, results should not be generalized beyond the sample of this study. The ethnic make-up of the

sample might be reflective of the local population from which this sample was drawn but does not represent the ethnic makeup of the general population of breast cancer survivors. However, this finding could be used as basis for further research on the area of experience and coping with chronic illness. It is suggested that further studies should recruit participants in multi-states with varying demographics characteristics, cultural backgrounds taking into account on families' perspectives. As individuals and their families living with breast cancer, a chronic illness; the experience of family becomes a critical issue thus needing future research.

Secondly, although our study locations are the main referral centre for breast centre in the east coast of peninsular Malaysia that offered oncology and radiotherapy services, but not all breast cancer cases are managed here. These government hospitals are subsidized and only charge minimum for the service provided. Thus, most patients have to queue for an appointment, diagnosis test or treatment because there was an excess of demand for service. There is other private hospital that diagnosed and provides treatment for breast cancer elsewhere in the country. Those with higher income might go to the private hospital for their treatment where they can get fast and better services. This could have affected the representativeness of the sample as most of the patients seeking treatment in the study location are those from the lower to middle income group. Therefore, it may not be possible to generalize the finding across the entire population and various cultures.

In conclusion, this qualitative study was conducted among Malay and Chinese women since these two groups are the main ethnic in Malaysia. The Malays has been reported to present at advanced stages of breast cancer with poor compliance and lowest survival. On the other hand, the incidence of breast cancer was highest among Chinese but they normally present at early stages with high survival.

This study explored personal experience and views of multi-ethnic women; Malay and Chinese newly diagnosed with breast cancer in the east coast of peninsular Malaysia. The results of this study provided in-depth understanding on women's experiences of living with newly diagnosed breast cancer. Their experience was related to several uncertainties during their illness journey; before and after the diagnosis, and even after the treatment; a transition from health to illness and fatalistic view of illness. There was inadequacy of breast cancer awareness and symptom knowledge besides misconception on the treatment and future of breast cancer. Overall, this study found this Malay and Chinese women were optimistic about their experience as they benefited from positive coping and supports from family and friends. Nevertheless, the results of this investigation could provide preliminary information on multi-ethnic experience to healthcare professional about the impact of illness and cultural influence on survivorship. In addition, the knowledge gained from this study can be used to assist healthcare professionals such as doctors, nurses as well as counsellors in their provision of appropriate information, continuous care and supporting interventions as patients who accept

their illness positively are better able to manage the illness and the side effects of the treatment they received.

Acknowledgements

This study would not have been possible without the financial support from the Universiti Sains Malaysia (304/PPSK/61311016) and all the individuals directly or indirectly involved in this study, specifically to the women who shared their experience. Special thanks to David Pickles, of University of Ballarat, Australia for his support and professional editing of this manuscript.

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