

## RESEARCH ARTICLE

# Understanding Barriers to Malaysian Women with Breast Cancer Seeking Help

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### Abstract

Delay in help-seeking behaviour which is potentially preventable has a major effect on the prognosis and survival of patients with breast cancer. The objective of this study was to explore reasons for delay in seeking help among patients with breast cancer from the East Coast of peninsular Malaysia. A qualitative study using face-to-face in-depth interview was carried out involving 12 breast cancer patients who had been histo-pathologically confirmed and were symptomatic on presentation. Respondents were selected purposely based on their history of delayed consultation, diagnosis or treatment. All were of Malay ethnicity and the age range was 26-67 years. Three were in stage II, seven in stage III and two in stage IV. At the time of interview, all except one respondent had accepted treatment. The range of consultation time was 0.2-72.2 months with a median of 1.7 months, diagnosis time was 1.4-95.8 months (median 5.4 months) and treatment time was 0-33.3 months (median 1.2 months). The themes derived from the study were poor knowledge or awareness of breast cancer, fear of cancer consequences, beliefs in complementary alternative medicine, sanction by others, other priorities, denial of disease, attitude of wait and see and health care system weakness. Help-seeking behaviour was influenced by a complex interaction of cognitive, environmental, beliefs, culture and psycho-social factors. Breast cancer awareness and psychological counselling are recommended for all patients with breast symptoms to prevent delay in seeking clinical help.

**Keywords:** Breast cancer - delay - help-seeking behaviour - qualitative study - in-depth interview

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### Introduction

Breast cancer is the most common cancer among women of all major ethnic groups in Malaysia (Zainal and Nor, 2011). The distribution of breast cancer among ethnic groups is in accordance with their socio-economic status which was highest in Chinese, followed by Indians and Malays (Zainal and Nor, 2011). There were 3292 cases of newly diagnosed breast cancer in Malaysia in 2007 that contributed to 32.1% of all women cancers (Zainal and Nor, 2011). The lifetime risk of having breast cancer in Malaysia was 1 in 20 women (Yip et al., 2006). The estimated mortality rate for breast cancer was 11.4 in 100 000 population (Globocan, 2002), and has been found to be the highest among the Malays (Hisham and Yip, 2003). This was contributed by factors such as presentation at advanced stage of disease, poor compliance and high refusal rate for treatment among the Malays (Hisham and Yip, 2003).

Late presentation is common in Malaysia, the National Cancer Registry reported that 24% presented in stage III and 18% in stage IV (Zainal and Nor, 2011). Delays in case presentation and detection was partially responsible

for the advanced stage at diagnosis (Richards et al., 1999; Thongsuksai et al., 2000) and advanced stage of disease is a poor prognostic factor for breast cancer. The current breast screening programs in Malaysia are still not effective in encouraging people to come early for consultation.

Studies have categorised delays into patient delay and provider delay (Richards et al., 1999; Arndt et al., 2003). It has been reported that delay between recognition of symptom and consultation [patient delay] was related to knowledge on breast cancer, accessibility to health care and psychological factors such as fear and denial (Arndt et al., 2003). Whereas delays between first consultation to specialist referral and definitive treatment [provider delay] were mostly related to health care services, including failure of general practitioners to take action, false negative diagnostic tests or inaccessible health care services.

Grunfeld et al. (2003) explained the processes that patients experience from the recognition of symptoms to treatment. When a woman first notices a breast symptom, she would interpret the symptom, assesses risks for potential ill health and starts analysing reasons

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for seeking diagnosis. The decision to seek help is influenced by knowledge of the disease. Burgess et al. (2001) conducted a qualitative study among 46 breast cancer patients in the United Kingdom and reported five common themes that influenced help-seeking behaviour after symptoms' discovery. The themes were symptoms interpretation, attitude on medical consultation, fear of cancer consequences, perception on competing priorities and triggers to action.

A review of 104 narrative studies of 80 breast cancer among ethnic minorities in United States showed that the predictor factors for advanced stage at diagnosis were attributions and risk estimations, reluctance to consider symptoms as a threat, failure to confide symptom to other person, expectations of abandonment by male partners, fear of deportation, prejudice and refusal of treatment due to poverty (Facione and Giancarlo, 1998). The study also reported other factors such as reliance on complimentary and alternative therapies, worries about finance and modesty which resulted in refusal of physical examination.

This study was conducted to explore the reasons of delaying seeking help among symptomatic patients with breast cancer in the East Coast of peninsular Malaysia. To date, most research in this area have been conducted in developed countries, particularly among minorities, and very few have been carried out in developing countries which have limited resources. There has been limited research on this issue in Malaysia that has been published. There are socio-cultural influences on help-seeking behaviour for disease symptoms and the Malaysian population is known for its strongly held traditional beliefs. Research in this area is very important so that clinicians can be more understanding when managing patients and policy makers can formulate strategies and implement activities that can prevent delay in the diagnosis and treatment of breast cancer.

## Materials and Methods

This was a qualitative study using in-depth interview. Respondents were breast cancer patients with histopathological confirmation and were on follow-up in any of the three government hospitals in the East Coast of peninsular Malaysia. The respondents were selected and approached because they had all manifested delay in either consultation or diagnosis or treatment. The respondents were briefed about the research and voluntary consent was asked for. None of the invited respondents refused interview. All information has been kept confidential and ethical clearances were obtained from the Ethic Research Committees of each hospital, with the reference numbers: USM/KK/PKK/JK EP(M)-191 USM, Bil(43)HRPZ II.71/20 Jld.8, HSNZ.KT.100-22/15(27) and (4)KKM/NIHSEC/08/0804/P07-13.

A pre-test was conducted on five respondents to test for logistics as well as rehearsals for the researcher. The results of pre-test were not included in the final results. Each session took about 45-60 minutes. The first author conducted all the interviews in clinics after the respondents' consultation with oncologist or surgeon in a quiet and controlled environment and free from disturbance. The

first author introduced herself as a medical doctor who conducted research but was not involved in the clinical management of their disease. During the interview session only the interviewer and respondent would be present seated side-by-side. A detailed explanation of the purpose of the interview was given to initiate the session followed by an ice-breaking general conversation about respondents' background, disease staging, progress and general health. After ensuring the respondents were comfortable and at ease, the respondents were asked about their help-seeking behaviour starting from the recognition of the first symptom to treatment. Open ended questions were asked regarding the chronological events [onset of symptoms, first consultation with a healthcare provider, definitive diagnosis and treatment] and explanations for their behaviour. A checklist of questions was used to ensure that all interviews covered all the relevant areas.

The entire interview was digitally audio-recorded and a transcription was written immediately after the interview. The transcription was checked line-by-line by another co-author to ensure it was accurate especially for participants who spoke local dialect. Data was analysed manually and the transcription was read repeatedly, summarised and coded into categories. The categories then were sorted into potential themes. Data analysis was done immediately after the transcription so that the researcher could make improvements for the next interview. The researcher also took notice of the control of interview, usage of leading questions and whether cues were taken or ignored, were respondents given enough time to respond to questions or whether researcher had explored the raised issues in sufficient depth. Reflection was done so that more themes could be developed for the subsequent interview. To ensure internal validity of study, further analyses were also carried out by two independent data analysers who were also co-authors. After both had examined the transcripts independently, discussions were held to identify and come to a consensus about the drawn themes. Translated verbatim passages are reported in total or part thereof depending on the cases and the meanings. Another bilingual co-author cross-checked the translation to assure its validity.

## Results

The data collected was saturated after twelve respondents were interviewed. The background characteristics of the respondents are shown in Table 1. The age range was 26-67 years old. All respondents were of Malay ethnicity and this was not surprising since 90% of the study population were Malay. One respondent did not have formal schooling, two had primary schooling, one had completed lower high school, five had completed high school and three had diplomas. All were married except one, two were post-menopausal, none had a family history of breast cancer and 11 had taken complementary alternative medicine [CAM]. One had undergone lumpectomy, eight had mastectomy, two were inoperable and one refused surgery. Three were in stage II, seven in stage III and two in stage IV at the time of diagnosis. The range of consultation time was 0.2-72.2 months with

**Table 1. Socio-Demography of Respondents**

Res-pondents	Age	Occupation	Stage	Median time (month)		
				X	Y	Z
A	35	Housewife	IIIA	0.8	1.4	5.7
B	67	Housewife	IIIB	72.2	95.8	0
C	43	Teacher	IIB	1	3.1	0.5
D	43	Teacher	IIIA	0.6	19.5	1.2
E	45	Housewife	IIA	3	4.9	5.2
F	30	Supermarket worker	IV	1.4	3.5	0.9
G	43	Housewife	IIIB	0.3	3.2	33.3
H	47	Housewife	IIA	0.2	6	1.1
I	42	Housewife	IV	6.1	6.5	0.2
J	59	Housewife	IIIA	2	3.3	Refused
K	49	Traditional midwife	IIIC	24.1	29.7	1.2
L	26	Student	IIIB	12.1	13.5	5.1

<sup>x</sup>Consultation, <sup>y</sup>Diagnosis, <sup>z</sup>Treatment

median 1.7 months, diagnosis time was 1.4-95.8 months with median 5.4 months and treatment time was 0-33.3 months with median 1.2 months.

This analyses of the data suggested that help-seeking behaviour was influenced by poor knowledge and awareness of breast cancer, fear of cancer consequences, beliefs in CAM, sanction by others, other priorities, denial of disease, attitude of 'wait and see' and weaknesses of the health care system or provider.

#### Lack of knowledge about breast cancer

There was a lack of knowledge or awareness about breast cancer. Many respondents misinterpreted the presenting symptoms as benign diseases such as cyst, slime, knot or a sign of menses. Some did not suspect cancer and thought that cancer would never happen to them.

*"I never thought about it at all... I had no knowledge about breast cancer... never thought it would happen to me. I thought it was normal like incoming menses or milk collection"* (A)

*"...people said cyst. My siblings said if it was cancer surely I could not sleep, had throbbing pain. But I was well, could sleep at night..."* (B)

*"I thought it was the skin... itchy skin. Swelling... only itchiness... normal growth... not cancer... not a serious disease..."* (C)

Most respondents did not think that the symptom might be due to cancer because there was no pain and it did not cause any ill health to them. Most of the symptoms were minor and did not prevent them from working and going about with their usual activities. There was a lack of perception of the symptoms and its seriousness.

*"I let it be... no pain... I could plant trees, continue farming, plucking coconuts without any problems."* (B)

*"...I ignored it... it was not painful at all... so I did not do anything."* (D)

*"It was small. It was mobile..."* (E)

*"No pain. Only slight itchiness... a bit swollen that was all... it changed side from right to left... I thought the swelling was milk collection since the other side had disappeared by itself"* (F)

Respondent D who was a schoolteacher, had a fine needle aspiration cytology (FNAC) at an early stage,

which was arranged by her friend, a nurse who worked in a surgical clinic. The result had been reported as atypical cells. She had been satisfied with this finding as there was no mention of cancer in the report and she did not consult a doctor. She did not ask for more information because she was ignorant about the significance of atypical cells.

*"...when she (her nurse friend) told me it was not cancer, I felt relief and forget about the lump because it was not painful."* (D)

Respondent F first noticed the symptoms when she was pregnant. She was diagnosed with breast cancer post-partum after she lost consciousness during delivery. While respondent A, G and H noticed their symptoms during lactation.

*"I did not suspect anything... because I thought it (the symptom) was related to breastfeeding. I thought it was milk collection. I did not think of cancer at all. I didn't know anything about cancer..."* (H)

There was also a serious misinterpretation of risk factors, diagnostic tests and treatment among the respondents.

*"...I was totally ignorant... I heard contraceptive pills might prevent breast cancer..."* (H)

*"...if the tumour is in contact with a needle or knife or sharper objects, the cancer would spread faster."* (I)

*"I felt not confident (of treatment)... scared... people said it was like fire... like oven... hot. My husband also felt scared..."* (J)

#### Fear of cancer consequences

Most of the respondents vocalised a fear of cancer consequences which were described as fear of pain, surgery and death. The recommendation for surgery was perceived as a death sentence to some of the respondents.

*"I was scared... I never had surgery previously. I felt if I had it (surgery), surely I would die especially if surgery was done in the chest, very near to our heart. When I was diagnosed with this disease, I only saw death. I heard when people had this disease they surely would die. I could not accept it. (laugh) Scared of pain... I imagined if they used a knife... they might accidentally cut what ever... when cut... its painful... pain... then after surgery we would still feel the pain."* (C)

*"Scared of dying... if I agreed for surgery, surely I would die. People said our life is here (pointed in chest). When you took them out, you would die within two to three months."* (A)

*"...I would die... I thought this was the end of my life... leaving my husband, children... it felt like a bomb... would not wake up... (after surgery). I was thinking, I would leave... all my children were still young..."* (H)

*"It was fearsome... I was scared... while they did it, unconscious... like we already died, I was afraid..."* (B)

*"I felt it was the end of life."* (K)

Some respondents described a fear of chemotherapy side effects and was a reason for delaying treatment.

*"I knew the effects... so scared of chemo... Morning you had it, night you would be feverish... felt ill... could not get up, would vomit from morning till night... could not take anything in. It was extreme suffering, could not say how much... if possible let it be... I did not want it."* (L)



### Beliefs in alternative medicine

Eleven out of twelve respondents had used alternative treatment. Most of them had drunk water that had been chanted upon by a traditional healer or applied flour to their breast lump. One reason given for taking CAM was the hope of avoiding surgery.

"...I tried village healer first because friend said he could heal... not really believed it but I did not know about treatment at hospitals at all. I had not been to a hospital so I did not know yet...I did not really believe it (CAM) but I wanted to try it first." (I)

"My mother-in-law brought me to a traditional healer just to ask him about the symptoms...he said cancer... He gave applied medication; chanted lime juice to a roll of tissue then applied it to the lump..." (A)

"I took traditional medication because I really wanted it... Believed it could shrink the lump. I just wanted to shrink the lump to avoid surgery. He (the practitioner) massaged and gave some leaves for application..." (J)

"...we wanted to do alternative treatment first... we sought treatment from anyone anywhere... even to East Malaysia. Most used like rice... leaves... they took the disease away with egg... then did special prayers at mosques... took chanted water to drink." (L)

"I did blood ozone many times. I took 2 boiled eggs of village chicken, half boiled then ate without breaking the eggs. I also took blended mangosteen peel." (K)

"...people instructed me to comb the lump... but it did not disappear." (H)

"My mother wanted me to take herbal roots on the operation day. She asked not to have the operation and take the herbal water which is very effective. Many had tried and cured." (H)

### Sanction by others

How other people, especially husbands, feel and think influences the respondents' decision to seek help for their symptoms. The majority would obey their husbands' decision. Respondent L's husband made the decision to try alternative treatment first and thus delayed hospital treatment.

"I think my husband was more emotional than me... he could not accept diagnosis... my husband asked for time... two three months to think... wanted to try other alternative ways. Other treatment... If other treatment was not successful, we would accept treatment here. So I wanted to satisfy my husband... so never mind..." (L)

"My husband said you did jogging, aerobic, exercise... did not eat fatty foods, took organic rice...he refused to give consent, he did not believe it, no... no... you did not have it... probably you only worked too hard..." (K)

"What a shame (to have mastectomy) because we are women... my emotion was sad, sad not because of disease but sad for my husband... felt sad when I thought how my husband was coping... scared...my confidence level was really low. I felt a pity to my husband. I accepted having the disease but when thinking about husband related thing (how mastectomy affecting him)...sad..." (D)

Apart from husbands, other family members and neighbours were influential.

"My family was against it...especially my uncle, he

even said he refused to take note of my well being..." (A)

"There was an old neighbour, she said the cut (as surgery) was painful... she said they would cut you... you would be in agony asking for help. Some villagers prohibited me from having surgery..." (B)

Experiences of other people also affected the respondents' decision.

"There was my friend who already passed away. She had surgery but still passed away. I felt a trauma looking at her like that... I felt scared to cut off the whole thing (having mastectomy)." (E)

"There was a friend who had breast cancer while pregnant. She was in a bad stage. After her child was one year old, she passed away. I did not want to be like her, I took example from her, if possible I wanted to avoid it." (L)

"A friend did the operation immediately. Then after many years, the cancer recurred and she had another operation. Then she passed away. ...doctor wanted to cut (mastectomy)... husband refused." (J)

### Other priorities

The respondents described other priorities taking precedence over personal health thus delaying consultations for the symptoms. One respondent delayed her operation because of an examination, another waited till after her child's wedding, while another was too busy with her job commitments. Two of the respondents had financial problems and one had a transportation problem.

"I am the type who work hard (laughed). When working, I would not be aware of anything else... I never thought of reading things like health and medical things..." (C)

### Denial

Some respondents had difficulty in accepting the diagnosis and a few asked for another opinion.

"I could not accept (breast cancer diagnosis) because there was no risk factor. I felt confident I would not get cancer. I was confident it was not cancer. I breastfed all my 6 children. I attended breastfeeding courses... they said those who fully breastfeed were protected from cancer... it was not cancer... because I had no family history, jogged, did aerobic... did not eat fatty food...ate organic rice..." (K, a traditional midwife)

"I asked for another FNAC... wanted to know whether the result was correct or not. Felt confused, sad and could not believe it. Was it true?" (L)

"Could not accept... could not accept having cancer." (G)

"...difficult to accept because I did not have any family like this. There was no reason why I could get it..." (C).

### Attitude of 'wait and see'

Some respondents preferred to monitor the symptom progression before making the decision to seek help or accept treatment. Respondent B and J were intentionally ignoring their symptoms.

"...I just ignored it... Emm...let it be... since there was no pain. I intentionally ignored it." (B)

"I want to wait first...if possible... I heard even if I

*agreed for surgery the tumour might reoccur. So if the tumour was enlarging or I could not cope... or I could not stand the pain... or anything I might get help. I submitted to the will of God..."* (J who still refused any treatment at the time of interview)

#### *Weakness of health care provider and system*

The present health campaign was not accessible to some respondents. Respondent C was a school teacher living in a town area, had not received any information regarding breast cancer. She was young, single, previously healthy and had never been to a government health centre therefore she had not been exposed to any breast cancer information and other health promotion activities available at such centres.

*"I never received any printed materials about it... I did not have time to go into electronic media. If given, surely I would read them."* (C)

Some respondents received information from health care givers that was misleading but appeared to satisfy the needs of the respondents such that the respondents did not pursue the matter further. Many respondents were told that the lumps were not cancer even though a tissue biopsy had not been performed. Some did not give any information or refer for further investigations.

*"Initially they said it was not cancer. Then they said probably I worked very hard... they said winds, muscles or knots..."* (L)

*"Private doctor examined and said it was not tumour, probably normal growth..."* (G)

*"I went to a hospital. The doctor said it was only vein... then went again to a private clinic, he gave medication and said probably a milk collection..."* (A)

*"The nurse examined... but did not tell anything..."* (H)

There were problems with hospital appointments. Respondent H and E were given appointments at the government hospital several months after the first consultation. Respondent K was told to come back in 3 months but no appointment was given. After 3 months, she felt no changes and did not bother to return. She also had problems while waiting for her surgery. The operation was postponed many times due to her concurrent medical health problems, difficulty getting onto the waiting list and priority for emergency cases. Respondent L had a problem with FNAC whereby the results were either inconclusive or benign.

## **Discussion**

We conducted this qualitative study among Malay women in the East Coast of peninsular Malaysia, which is more rural and less developed than the West Coast. Some respondents in this study could not associate their symptoms with breast cancer and this could be one reason for delay in seeking help. Knowledge about the variation in breast cancer symptoms has been found to be an important factor so that patients could correctly suspect cancer and immediately consult a general practitioner (Bish et al., 2005). Lack of knowledge has been shown to influence patients' decision in seeking medical help (Burgess et

al., 2001). Women in Nigeria had poor awareness about breast cancer that many presented in the advanced stage of disease (Adesunkanmi et al., 2006). An Iranian study reported 16.2% patients who delayed 3 months or longer had lack of knowledge regarding breast cancer symptoms compared to only 1.5% among those who delayed less than that (Harirchi et al., 2005). Another study also reported women who were more likely to delay were those who had limited knowledge regarding their own risk for breast cancer, risk factors and variation of symptoms (Grunfeld et al., 2002). A lack of knowledge combined with the fact that their breast cancer symptoms were minor and non-specific, led to confusion for most respondents. They had no perception of the seriousness of their symptoms. Knowledge can also influence patients' assessment of the severity of the symptoms (Burgess et al., 2001). One study has suggested that an intervention informing women of the diversity of breast cancer symptoms, advice on how to obtain help after recognition of symptoms and advances in breast cancer management might reduce delay in help-seeking behaviour (Grunfeld et al., 2003).

If patients connect their symptoms to diseases like cancer, they would consult a general practitioner earlier. In our study many of the respondents initially attributed their symptoms to benign diseases. Most respondents did not interpret their symptoms as cancer because there was no pain; an atypical presentation like itchiness was not recognised and small mobile lumps were considered to be benign. A number of respondents had presentation of symptoms during pregnancy or lactation. This was unfortunate as breast symptoms during pregnancy or lactation are frequently not taken seriously by either patients or health care providers. Most will explain the symptoms as the effects of hormonal changes on breast tissues. Furthermore, such patients are young and young people more commonly get benign breast diseases rather than cancer.

This study highlighted the incorrect perceptions about the aetiology, risk factors and treatment of breast cancer which has also been found in other studies (Johnson et al., 1999; Malik and Gopalan 2003; Remennick, 2006). Some respondents believed that metal instruments coming in contact with the tumour might spread cancer cells quicker, another described having radiotherapy was like being fried in a hot oven. Many respondents also believed that mastectomy would lead to death because the breast is situated on the chest, near the heart.

Fear of cancer consequences was a psychological barrier identified for the delay in help-seeking behaviour among breast cancer patients in this study. This has also been identified in other studies (Caplan et al., 1996; Andrews and Bates, 2000; Burgess et al., 2001; Smith et al., 2005). The emotion of fear is needed to ignite action. Without fear, patients would not give attention to and neglect the symptoms. Feeling fear was related to clinical features, belief that the symptom was dangerous and required consultation (Burgess et al., 1998). Fear detected among breast cancer patients included fear of diagnostic test (Weinmann et al., 2005), cancer consequences (Nosarti et al., 2000), pain, suffering and disfigurement after mastectomy (Mohamed et al., 2005, Burgess et al.,

2006), embarrassment during breast examination and change of body image after surgery (Smith et al., 2005), mastectomy itself (Ajekigbe 1991; Malik and Gopalan, 2003) and being left by spouse or partner (Facione and Giancarlo, 1998). Mastectomy had an effect on the wife-husband relationship since it can affect the sexuality and body image of a woman.

Usually patients would choose CAM if they perceived modern medicine would not cure the disease or when prognosis was poor or there was chronic suffering or when surgery was needed (Ariff and Beng, 2006). Many respondents described using CAM as a way to avoid surgery, which was perceived as a death penalty to some respondents. Some also believed that breast cancer did not have effective treatment or traditional medication was more effective than modern medicine. Many patients would experiment with traditional alternative treatment and when they found it was not effective then they would accept hospital treatment. By that time, most symptoms would have worsened and most patients would eventually come in advanced stage of disease (Taib et al., 2007). This finding has been supported by a study conducted in East Malaysia among the poor, non-educated rural patients in which 20.4% defaulted treatment and opted traditional alternatives (Leong et al., 2007).

A systematic review on reasons for CAM use reported that people practiced CAM because of its benefits, wanted to be in control of their treatment, had a strong belief and as the last hope (Molassiotis et al., 2005). Patients also practiced CAM to increase their physical and emotional health to fight cancer. Some might have had bad experiences at hospitals or felt the system was not friendly compared to traditional healers or shaman. CAM is also easily available and known to most people, the practitioners share similar socio-cultural background to the patients and the cost is usually not set and frequently affordable.

CAM may facilitate conventional treatment as supportive treatment. On the other hand, it has the potential to interact with conventional medicine. Most of the therapies have no scientific evidence of its effectiveness and safety. The use may cause harm if patients choose alternative treatment totally and delay conventional treatment. The scope of CAM is very wide and has been defined as comprising all health and medical care using methods and products that is not included under conventional modern medicine (CAMBASICS, 2007). Therefore CAM includes traditional medicine, which is practiced in this part of Malaysia usually encompassing the use of herbs and manipulative methods and is given by traditional healers or shaman. In our study most respondents had ingested 'chanted' water or had applied some flour-based paste to the breast lump. Studies in 14 European countries reported the rate of CAM use among breast cancer patients was 14.8-73.1% (Molassiotis et al., 2005). The rate in Pakistan was 34% (Malik and Gopalan, 2003), in United States was 95% (Yates et al., 2005) and in Malaysia was between 15.5-45.3% (Taib et al., 2007). Among the more popular therapies were herbal, homeopathy, vitamin, mineral, tea, dietary supplement, spiritual therapy and relaxation technique

(DiGianni et al., 2002). In Nigeria many breast cancer patients delayed consultation because they were trying religious and spiritual therapy (Ajekigbe, 1991), while Chinese American chose Chinese alternative medication (Facione et al., 2000).

The Malay society in this part of Malaysia is influenced by a traditional patriarchy system whereby most women's decision and actions are controlled by a male in the family especially the husbands. Most women would seek their husbands' permission and be chaperoned for any examination or procedure involving the breast (Ednin, 2007). In this study some husbands refused permission for the respondents to seek medical treatment.

Modern women have many important roles in the family and having a disease might disrupt and burden their family. When women can no longer carry on their roles and need others to care for her, the husbands usually have difficulty in taking over the roles and some marriages or relationships end in divorce or separation or men taking another wife [polygamy is legal for Muslims in Malaysia]. The treatment of breast cancer is not without some bothersome side-effects and consequences; it is possible that some women would delay seeking help to avoid disrupting the well-being of their family but they may be sacrificing their own lives by doing so.

Previous observations of other breast cancer patients had also left behind negative perceptions of the disease course and treatment. The respondents have described scary stories regarding mastectomy, ineffective treatment and death after suffering. Some believed that even with treatment, patients would still suffer and die of breast cancer, therefore they refused diagnostic tests and treatment.

Many barriers to the respondents seeking medical help have been identified in this study which includes financial constraint, commitment at home or work and opposition of husband or relatives. A similar study in United States showed that some women delayed consultation because they were away from the area, on vacation, had competing physical or emotional problems or too busy with other things (Caplan et al., 1996; Facione et al., 2000; Burgess et al., 2001), the different reasons reported emphasizes the importance that each country should undertake their own studies into the reasons for delay so that effective health promotion programs can be formulated that was suitable for that particular society.

Denial is a psychological defence mechanism to cope with an extremely stressful situation (Remennick, 2006). Denial at the beginning of diagnosis may help reduce anxiety in patients, but prolonged denial may prevent patients from getting appropriate management by defaulting appointments, non-compliance, delaying and refusing treatment (Andrews and Bates, 2000). Denial also results in disruption of the assimilation process with reality. The usage of denial as a coping mechanism depends upon the severity of the situation, individual personalities and family and cultural background (Kreitler, 1999). Some of the respondents in this study did not believe that they had breast cancer and needed time to accept diagnosis and treatment.

One respondent in this study refused any treatment



because she wanted to monitor her symptoms and wanted to submit to God's will. A study conducted in the United States reported that religious beliefs about God's role in curing cancer influenced women's intentions to watch the lump for changes (Altpeter et al., 2005). There were patients who believed that they had breast cancer because of predestiny and people have no control on disease, life or death, thus some 'conceded to God's will' and refused treatment. These findings were also supported by studies conducted among the Punjabi and Tamil women in Canada (Meena et al., 2001; Gurm et al., 2008). Studies have also reported that some women believed they had breast cancer as a punishment for previous sins and was a way of 'lessons from God' (Facione and Giancarlo, 1998; Meena et al., 2001; Altpeter et al., 2005; Gurm et al., 2008).

Accessibility to medical care is not a problem in Malaysia since the nearest health centre in rural areas has been reported to be within 5.3 km of households (IPH, 2008). In developed countries, most delay was related to a lack of availability of medical care due to not having medical insurance (Ferrante et al., 2007). This problem is not serious in Malaysia since most medical care at the government hospitals are subsidized and provided free of charge or for a small fee. If patients are not able to afford the charges, the welfare department or non-governmental organisations might assist. There is a disparity in the quality of health care in Malaysia (Yip, 2007). Most patients have to queue for appointments, diagnostic tests or treatment at the government hospitals because there was an excess of demand for service. In most government hospitals, emergency operation is given priority and elective cases like mastectomy or lumpectomy may be cancelled if there was no empty operating theatre. Only those who could pay have the option for private services to avoid delay.

In conclusions, this qualitative study was conducted only among Malay ethnic respondents since most of the population in this area are Malays. This ethnic group has been reported to frequently present at advanced stages of disease, had poor compliance and a high refusal rate for treatment (Hisham and Yip, 2003). The findings of this study can not be inferred to the population of Malaysia and future studies should include other ethnicities since they may have different factors that influence their help-seeking behaviour.

This study explored identified the factors that influence help-seeking behaviour among Malay breast cancer patients. Help-seeking behaviour was influenced by a complex interaction of cognitive, environmental, beliefs, culture and psycho-social factors. There was an inadequacy of breast cancer awareness and knowledge and a lot of misconceptions regarding aetiology, risk factors and treatment of breast cancer. Regular breast cancer awareness campaigns should be conducted in East Coast Malaysia emphasizing the early symptoms and signs of breast cancer. Fear of treatment, denial and negative attitude could be avoided through counselling. Support groups comprising of breast cancer survivors may assist in reassuring newly diagnosed patients about the efficacy of conventional treatment. Respondents needed role models from breast cancer survivors who could give testimonials

that breast cancer is not necessarily fatal. Those who believe in CAM should be given sufficient education regarding the benefits and adverse effects of it. Women also need encouragement to make decisions about their health by themselves without relying on others. Barriers such as finance or transportation could be assisted by non-government organisation or the welfare department. Healthcare providers need to be sensitive and alert of their patients' needs and fears.

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## References

- Adesunkanmi ARK, Lawal OO, Adelusola KA, Durosimi MA (2006). The severity, outcome and challenges of breast cancer in Nigeria. *Breast*, **15**, 399-409.
- Ajekigbe AT (1991). Fear of mastectomy: the most common factor responsible for late presentation of carcinoma of the breast in Nigeria. *Clin Oncol*, **3**, 78-80.
- Altpeter M, Mitchell J, Pennell J (2005). Advancing social workers' responsiveness to health disparities: the case of breast cancer screening. *Health Soc Work*, **30**, 221-33.
- Andrews BT, Bates T (2000). Delay in the diagnosis of breast cancer: medico-legal implications. *Breast*, **9**, 223-37.
- Ariff MK, Beng KS (2006). Cultural health beliefs in a rural family practice: A Malaysian perspective. *Aus J Rural Health*, **14**, 2-8.
- Arndt V, Stürmer T, Stegmaier C, et al (2003). Provider delay among patients with breast cancer in Germany: a population-based study. *J Clin Oncol*, **21**, 1440-6.
- Bish A, Ramirez A, Burgess C, Hunter M (2005). Understanding why women delay in seeking help for breast cancer symptoms. *J Psychosom Res*, **58**, 321-6.
- Burgess C, Hunter MS, Ramirez AJ (2001). A qualitative study of delay among women reporting symptoms of breast cancer. *Br J Gen Pract*, **51**, 967-71.
- Burgess CC, Potts HW, Hamed H, et al (2006). Why do older women delay presentation with breast cancer symptoms? *Psychol Oncol*, **15**, 962-8.
- Burgess CC, Ramirez AJ, Richards M, Love SB (1998). Who and what influences delayed presentation in breast cancer? *Br J Cancer*, **77**, 1343-8.
- CAMBASICS (2007). National Center For Complementary And Alternative Medicine. National Institutes of Health. <http://nccam.nih.gov/health/whatiscam/pdf/D347.pdf> [1 Mac 2011].
- Caplan LS, Helzlsouer KJ, Shapiro S, et al (1996). Reasons for delay in breast cancer diagnosis. *Prev Med*, **25**, 218-24.
- DiGianni LM, Garber JE, Winer EP (2002). Complementary and alternative medicine use among women with breast cancer. *J Clin Oncol*, **20**, 34-8.
- Ednin H (2007). The socio-cultural aspects of supportive care. Proceeding International Conference on Survivorship and Supportive Care in Cancer. 10-12th August. *Kuala Lumpur: Breast Cancer Welfare Association*, 32-4.

- Facione NC, Giancarlo CA (1998). Narratives of breast symptom discovery: implications for early detection. *Cancer Nurs*, **21**, 430-40.
- Facione NC, Giancarlo C, Chan L (2000). Perceived risk and help-seeking behavior for breast cancer: A Chinese-American perspective. *Cancer Nurs*, **23**, 258-67.
- Ferrante JM, Rovi S, Das K, Kim S (2007). Family physicians expedite diagnosis of breast disease in urban minority women. *J Am Board Fam Med*, **20**, 52-9.
- GLOBOCAN (2002). Cancer incidence, mortality and prevalence worldwide. IARC Cancer Base No. 5. Lyon, IARC Press. <http://www-dep.iarc.fr/> [10 Februari 2010].
- Grunfeld EA, Hunter MS, Ramirez AJ, Richards MA (2003). Perceptions of breast cancer across the lifespan. *J Psychosom Res*, **54**, 141-6.
- Grunfeld EA, Ramirez AJ, Hunter MS, Richards MA (2002). Women's knowledge and beliefs regarding breast cancer. *Br J Cancer*, **86**, 1373-8.
- Gurm BK, Stephen J, MacKenzie G, et al (2008). Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: a qualitative study. *Int J Nurs Stud*, **45**, 266-76.
- Harirchi I, Ghaemmaghami F, Karbakhsh M, et al (2005). Patient delay in women presenting with advanced breast cancer: an Iranian study. *Public Health*, **119**, 885-91.
- Hisham AN, Yip CH (2003). Spectrum of breast cancer in Malaysian women: overview. *World J Surg*, **27**, 921-3.
- Institute for Public Health (IPH) (2008). The Third National Health and Morbidity Survey (NHMS III) 2006. Kuala Lumpur: Ministry of Health Malaysia.
- Johnson JL, Bottorff JL, Balneaves LG, et al (1999). South Asian women's views on the causes of breast cancer: images and explanations. *Patient Educ Couns*, **37**, 243-54.
- Kreitler, S. (1999). Denial in cancer patients. *Cancer Invest*, **17**, 514-34.
- Leong BDK, Chuah JA, Kumar VM, Yip CH (2007). Breast cancer in Sabah, Malaysia: a two year prospective study. *Asian Pacific J Cancer Prev*, **8**, 525-9.
- Malik IA, Gopalan S (2003). Use of CAM results in delay in seeking medical advice for breast cancer. *Eur J Epidemiol*, **18**, 817-22.
- Meana M, Bunston T, George U, et al (2001). Older immigrant Tamil women and their doctors: attitudes towards breast cancer screening. *J Immigr Health*, **3**, 5-13.
- Mohamed IE, Williams KS, Tamburrino MB, et al (2005). Understanding locally advanced breast cancer: What influences a woman's decision to delay treatment? *Prev Med*, **41**, 399-405.
- Molassiotis A, Fernandez-Ortega P, Pud D, et al (2005). Use of complementary and alternative medicine in cancer patients: a European survey. *Ann Oncol*, **16**, 655-63.
- Nosarti C, Crayford T, Roberts JV, et al (2000). Delay in presentation of symptomatic referrals to a breast clinic: Patient and system factors. *Br J Cancer*, **82**, 742-8.
- Remennick L (2006). The challenge of early breast cancer detection among immigrant and minority women in multicultural societies. *Breast J*, **12**, 103-10.
- Richards MA, Westcombe AM, Love SB, et al (1999). Influence of delay on survival in patients with breast cancer: A systematic review. *Lancet*, **353**, 1119-26.
- Smith LK, Pope C, Botha JL (2005). Patients' help-seeking experiences and delay in cancer presentation: A qualitative synthesis. *Lancet*, **366**, 825-31.
- Taib NA, Yip CH, Ibrahim M, et al (2007). Breast cancer in Malaysia: are our women getting the right message? 10-year experience in a single institution in Malaysia. *Asian Pac J Cancer Prev*, **8**, 141-5.
- Thongsuksai P, Chongsuvivatwong V, Sriplung H (2000). Delay in breast cancer care: A study in Thai women. *Med Care*, **38**, 108-14.
- Weinmann S, Taplin SH, Gilbert J, et al (2005). Characteristics of women refusing follow-up for tests or symptoms suggestive of breast cancer. *J Natl Cancer Inst Monogr*, **35**, 33-8.
- Yates JS, Mustian KM, Morrow GR, et al (2005). Prevalence of complementary and alternative medicine use in cancer patients during treatment. *Sup Care Cancer*, **13**, 806-11.
- Yip CH, Taib NA, Ibrahim M (2006). epidemiology of breast cancer in Malaysia. *Asian Pac J Cancer Prev*, **7**, 369-74.
- Yip CH (2007). Equity to access to cancer treatment. Proceeding International Conference on Survivorship and Supportive Care in Cancer. 10-12th August. Breast Cancer Welfare Association: Kuala Lumpur, 67-8.
- Zainal Ariffin O, Nor Saleha IT (2011). National Cancer Registry Report 2007. Malaysia Cancer Statistics- Data and Figure. Kuala Lumpur: National Cancer Registry, Ministry of Health Malaysia.