

RESEARCH COMMUNICATION

Recognising Symptoms of Breast Cancer as a Reason for Delayed Presentation in Asian Women - The Psycho-socio-cultural Model for Breast Symptom Appraisal: Opportunities for Intervention

Nur Aishah Taib*, Cheng-Har Yip, Wah-Yun Low

Abstract

Introduction: Advanced presentation of breast cancer and the problem of late diagnosis is well documented. Patient delay beyond three months has been shown to reduce survival. This paper aims to explore the experience of Malaysian women presenting with advanced breast cancer with regards to their interpretation of breast symptoms. **Method:** Purposive sampling of 19 breast cancer patients presenting with delayed treatment and/or advanced cancer diagnosed within two years at the University Malaya Medical Centre, Kuala Lumpur were carried out. In-depth interviews were conducted using a self-devised interview guide. The interview guide covered the journey of the patient from discovering of symptoms to their present state. The audiotaped interviews were transcribed verbatim. NVivo 8 qualitative software was utilised for data management. Grounded theory with thematic analysis was utilised. **Results:** Nine women delayed seeking diagnosis although recognizing the symptom, five did not recognize symptom, three delayed treatment and two did not delay health attention. Themes that emerged with regards to triggering help seeking behavior were: a) poor symptom knowledge and recognition; b) importance of knowledge of the disease and its' outcomes; c) role of coping mechanisms and affect; and lastly d) role of significant others in appraising a breast symptom. **Conclusion:** Symptom recognition remains an important public health issue in Malaysia. Educating women, their significant others and primary health and primary care providers in detecting early staged breast cancer are needed. Supporting and sanctioning women with breast symptoms are important. The psycho-social-cultural model of symptom appraisal may serve as an important addition to the fight against cancer in countries that do not have the resources for population based screening mammogram programmes.

Keywords: Help seeking behaviour - symptom appraisal - oncology - breast health - Malaysia - Asia

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Introduction

The problem with late diagnosis is well documented in advanced presentation of women with breast cancer, in South East Asian countries and emerging economies, such as, in Malaysia (Lim, 2002; Hisham and Yip, 2003; 2004; Yip et al., 2006; Agarwal et al., 2009; Leong et al., 2009; Suthahar et al., 2009). Breast cancer is the commonest cancer in Malaysia, affecting about 4000 women annually (Lim, 2008). In Malaysia, population based screening mammogram is not practiced (Taib et al., 2007). Thus, getting an early diagnosis of cancer depends very much on well informed patients who self refer and health providers that practice opportunistic screening.

Advanced presentation has been shown to affect survival. Patient delay beyond three months have been shown to reduce survival by 10% over a follow-up period of 20 years, and delay was not independent of

stage of disease (Richards et al., 1999). Stage remain an independent prognostic factor in breast cancer (Edge et al., 2010). Delay was defined not only from the patients' aspect, known as total patient delay (Andersen et al., 1995). Total patient delay has been stratified to five stages as illustrated in Figure 1. Appraisal delay is the interpretation of bodily symptom to labeling it as serious symptom. Attention was also given to health provider delays (known as provider delay (Facione, 1993) or system delay (Caplan, 1992). System delays beyond 3 months have also been shown to reduce survival (Caplan et al., 1995). Appraisal delay was found to be the major stage in patient delay, accounting to 60% of the total patient delay (Andersen, 1995).

This paper aims to explore the experience of Malaysian women presenting with advanced cancer with regards to their interpretation or appraisal of breast symptoms to the labeling of being ill. Although not generalisable

Department of Surgery, Faculty of Medicine, University of Malaya Medical Centre, Kuala Lumpur, Malaysia *For correspondence: naisha@um.edu.my, nuraish@gmail.com

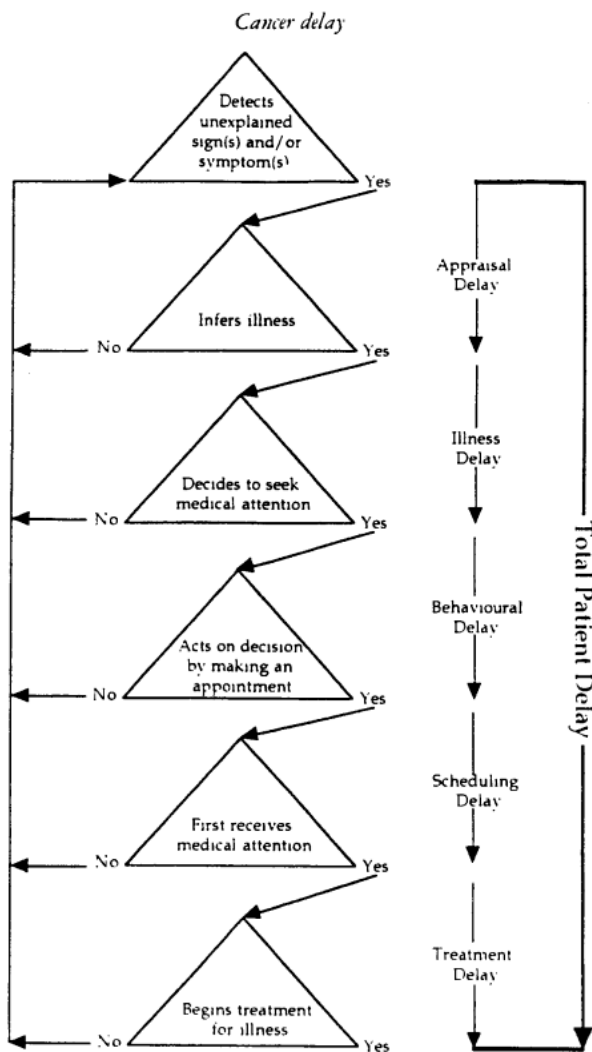


Figure 1. A Model for Total Patient Delay (Andersen & Cacioppo, 1995)

to other populations, the multiethnic and multicultural participants may provide some insight to the issues at hand. It is important to understand the community that one is focusing interventions to improve cancer outcomes. This study is the first study to our knowledge to describe the stories of a multi-ethnic and multi-cultural women who present with advanced breast cancer in Malaysia. This is a unique opportunity to observe reasons for presenting with advanced cancer and tailoring future research and interventions in Malaysia.

Materials and Methods

Sample

Purposive sampling of 19 breast cancer patients presenting with delayed treatment and/or advanced cancer diagnosed within two years at the University Malaya Medical Centre, Kuala Lumpur were carried out. The sample size was determined by saturation of data. These women were chosen from the outpatient clinics, in-patient admissions as well as from institutional database stratified by stage and year of diagnosis. To reduce recall bias, only women who were diagnosed within two years were selected for the study. Women who were stage III or IV

based on the AJCC 5th edition were chosen to participate. Malaysia is a multiethnic society, thus a wide ranging choice of participants from different ethnicities were catered for by using bilingual research nurses to conduct the interviews. Ethics were obtained from the University of Malaya Medical Centre Ethics' Committee. Informed and written consent were obtained from all participants.

The Interview

Each in-depth interview was conducted using a self-devised interview guide. The interview guide covered the journey of the patient from discovery of symptoms to their present state. Each interview was done in the language most comfortable for the participant, 10 were conducted in Malay, 4 in English, 4 in Mandarin and 1 in Tamil. The interviews took about 1 hour to 2 hours and may be done several times, depending on the comfort of the participants. The audio-recordings were transcribed verbatim. The researcher is bilingual thus analysed Malay and English transcripts in its original form. For the Chinese and Tamil, translation was done to English, and corroboration of translation was done with the research nurse and translator and the participant to ensure accuracy of the English translation. These transcripts were analysed in English. The participants were referred to the primary treating team, if psychological or physical distress were detected during the interviews.

Data analysis

NVivo 8 qualitative software was utilised for data management. Grounded theory with thematic analysis was utilised. Transcripts were analysed repeatedly to identify themes. Member check was done with three participants to check for accuracy in the transcriptions. The researcher reflexively is a breast surgeon but was not involved in the medical treatment of the participants.

Results

The socio-demographics and clinical data of the participants are given in Table 1. Nine women delayed seeking diagnosis, five had poor symptom recognition, three delayed treatment and two did not delay. Themes that emerged with regards to labeling a breast symptom were a) poor symptom knowledge b) poor knowledge of the disease and its' outcomes, c) role of coping mechanisms and lastly d) role of significant others in appraising a breast symptom.

a) Symptom Knowledge

A process of symptom appraisal occurs when a patient detects an abnormal bodily sensation and interprets or labels it as 'serious'.

Of the 19 women, 16 had infiltrating ductal carcinoma, 1 had malignant phylloides, 2 had infiltrating lobular cancer which is well known for producing non-lump symptoms. Pain was only seen in 5 out of 17 patients presenting initially with a breast lump the others had painless lumps, two women presented with axillary lumps, none of the women in this study had vague initial symptoms like nipple inversion or just thickening.

Table 1. Sociodemographics and Clinical Features of the 19 Women in the Study

ID	Age	Ethnicity	Marital status	Occupation	Location	Date of	Status during	Date of diagnosis	Stage Diag	Delayed Treatment	Current Status*	
P1	82	Malay	Married	Housewife	Hospital	March 2009	Fairly ill	June 2008	III B	Yes	No	Died
P2	49	Malay	Married	Housewife	Hospital	March 2009	Fairly ill	Oct 2007	III B	No	Yes	Died
P3	49	Malay	Married	School clerk	Home	March 2009	Well	May 2008	III A	No	Yes	Died
P4	61	Chinese	Single	Tea lady	Home	April 2009	Fairly ill	Nov 2007	IV	Yes	No	Died
P5	56	Malay	Married	Retired teacher	Home	April 2009	Well	Jan 2008	III A	No	No	Well
P6	46	Malay	Married	Staff Nurse	Hospital	April 2009	Well	Jan 2008	III A	Yes	No	Well
P7	53	Chinese	Married	Housewife	Home	April 2009	Fairly ill	Oct 2007	III B	Yes	Yes	Died
P8	35	Chinese	Married	Journalist	Outpatient	April 2009	Well	Nov 2007	III B	Yes	Yes	Recur
P9	48	Malay	Separated	Housewife	Hospital	April 2009	Slightly ill	Dec 2008	III B	Yes	Yes	Died
P10	58	Indian	Married	Private teacher	Outpatient	April 2009	Well	March 2008	IV	Yes	No	Well
P11	35	Malay	Married	Lecturer	Hospital	April 2009	Fairly ill	Augt 2008	IV	Yes	Yes	Died
P12	54	Malay	Married	Housewife	Outpatient	May 2009	Well	April 2009	II A	No	Yes	Well
P13	47	Chinese	Married	Administrator	Outpatient	April 2009	Well	June 2007	IIIA	Yes	No	Well
P14	34	Indian	Married	Housewife	Outpatient	June 2009	Well	June 2009	IV	No	No	Died
P15	24	Malay	Single	Machinist	Outpatient	May 2009	Well	May 2008	IIIB	No	Yes	Well
P16	53	Malay	Married	Housewife	Hospital	July 2009	Well	May 2009	IV	Yes	No	Well
P17	65	Indian	Widowed	Retired teacher	Hospital	July 2009	Well	Nov 2008	IV	Yes	No	Well
P18	55	Chinese	Married	Hawker	Outpatient	Aug 2009	Relapsed	Aug2007	IV	Yes	No	Died
P19	60	Indian	Married	Editor	Outpatient	Aug 2009	Well	Jan 2007	IV	Yes	No	Died

*Dec 2010

In this study, non-recognition of both lump and non-lump symptoms were found. Five women in this study did not recognize the symptom of a breast lump as something potentially dangerous. The women associated painless lumps as being harmless.

I couldn't really feel it, just saw my armpit becoming swollen. When I felt, there was a lump. But I left it, I thought it was nothing. It did not occur to me that it was cancer. It was painless. After checking with the doctor, I cried . (P 16)

Very small one [at first]. Then I keep quiet and nothing [happened]...no pain...no nothing.(P18)

Some women lacked confidence in the breast changes; they had to be sure there was something there, so they waited for some time.

It was a very small lump when I felt it [for the first time]. Felt like there was something [there], but cannot be certain...sometimes [the lump] felt like it could move about. Then at the end, it slowly became bigger, for over half of a year. (P 13)

At times they did not notice the lump until it was very large, it is not something a women keeps looking out for. Accidental discovery was mentioned by some participants

I didn't notice it because of the stress. I don't really do breast self-examination, when I was washing clothes I felt it, I told myself it couldn't have grown so big? (P 3)

There was a strong belief that family history should be present for someone to be at risk for cancer.

I noticed when it was already large. It didn't occur to us. I had no family history. (P 1)

I have been having pain for 2 years on my left side I thought, "Oh, I don't have cancer... there is no cancer in my family. (P 19)

Two participants were pregnant when the lump was

discovered. Many were misled by breast changes due to pregnancy. Including their significant others and more importantly this included doctors and nurses who examined these women. Women who had experienced pregnancy and childbirth were elected to be significant reference persons by these women.

I bought a pump from the pharmacy and tried to pump out the milk. But no milk came out. My husband has also never seen cancer before, he also doesn't know anything about cancer. Both of us thought the swelling was because of the milk. (P 14)

I told many people about it. When I went for check-up, I did tell them that I had something like a milk abscess and I felt pain. But no one said anything about cancer. Everyone [doctors during checkups] said that it might be a milk abscess because I was pregnant. If any one of them said that it might be cancer, I definitely would have come in early.(P 14)

I did tell my husband. My husband also doesn't know what it was. Then I asked my elder sister. She is much older, besides she has children. I asked her, then she said it was "bloated with milk". I let her feel the lump, she said it was 'milk'. (P 8)

A 24 year old woman in this study had presented early to a private clinic for a breast lump, but was erroneously told to be normal breast changes.

He [the general practitioner] told me there is nothing. It was a private clinic. He said it was normal. (P 15)

b) Breast Cancer Knowledge on Disease and Outcomes

Information on what causes breast cancer did not reach these women. Some attributed it to stagnant milk or blood clots. Many were ignorant of the causes. In the interviews, it was noted that women wanted to know what caused the cancer.

Maybe its milk that causes the cancer. It was painful when I breastfed my child who is now 11 years old. I

thought it was just a normal swelling. Maybe after that, a long time after that, the pain went away and just recently it came back again. It was just a lump. I don't know anyone with cancer, no friends, or family members with cancer. Initially I didn't feel anything but sometimes it smarts, then one day I felt a lump. My daughter said to go get it checked at the hospital. Don't go when it's too late... I told her to wait awhile. It wasn't painful. I was also scared. If I knew it, I would have gone much earlier [11 years ago]. But who would take care of my baby if I went to the hospital. I think it all began at that time. I didn't feel any lump, the doctor also told me I might have had it since 12 years ago. I have no regrets. (P 16)

Due to the misconception of the disease progression which many thought would be immediate death. Not realizing the slow protracted course of the disease and impact on their quality of life, when they experienced the severity of the disease, many regretted not attending to it earlier

I was scared to face the reality At the same time I was thinking of the family and thinking what it would mean that I may go 'off' [die] suddenly. (P 17)

I just wanted to say..that I didn't want treatment ...let it [breast cancer] progress naturally. When the time comes to die, just let it [die] be. I didn't care, that's how I was thinking.(P 4)

Some were not aware of cancer and the seriousness of the diagnosis in relation to the metastatic potential.

I didn't know the cancer can run. I think only the breast is involved. A little bit. I think, that was how cancer behaves. I thought it's very easy. Operation was enough. I don't know the cancer can go to other places. (P 18)

Some believed that cancer is a hard discrete breast lump portrayed by the media. Thus, vague lumps or breast changes were not attended to.

I did not have much understanding [about cancer]. Sometimes, the newspapers mentioned that if there is a hard lump, we must immediately go for a check-up. Knowing this, it may mean that it is not good. But sometimes I cannot feel [the lump], but most of the times I can feel, but at times, it is as if I cannot feel the lump. When the lump became big...I could feel it. (P 13)

Women get information from people around them, they do not read newspapers. If they did, the information was not detailed to include pictures.

I also read about it in the papers.[I am not so aware] as people around me, my relatives and friends do not have this cancer. I only hear about it, but not seen it. Newspapers also did not print pictures of breast cancer. (P 8)

I never heard anything about it. I don't read newspapers. I am busy. (P 18)

The participants used prior experience to interpret the symptoms; optimistic bias towards a less serious condition was seen. Knowledge of cancer was limited, even a registered nurse interpreted her signs to be benign, and

expecting cancer to present as a rapidly enlarging mass with skin and nipple changes. Her previous exposure at work and nursing school had been with women with advanced disease.

Every month I checked after my periods. But the thing became bigger and bigger. At that time I thought it was a fibroadenoma. Dead set it was a fibroadenoma, because it was mobile. There were no skin changes on the skin, no nipple discharge or retraction. So I was confident. But when I asked the doctor, she said you better check. Only a biopsy will tell if it is cancer. I thought to myself: if this is cancer, it will be fast growing, there will be skin changes, the nipple will not be symmetrical, it would be pulled in and there would be nipple discharge. One breast would be smaller than the other. I have seen breast cancer myself, but they were all late presentations. All were quite bad, ulcerating, cauliflower types, with nipple retraction. During my nursing course, that was what was shown to us. All were late staged. Not the early ones. The early type is just a lump right? Maybe a fibro or a cancer. Could this be cancer? but the lump was mobile, cancer would be fixed, strongly fixed and not movable. That was my thinking at that time.(P 6)

Heck it's just a lump. You see I'm prone to blood clots. Ever since I was young I will get blood clots here, blood clots there. Even in my breast this was actually the third blood clot. First two I went and checked they said its benign So I assume this was also benign.(P 19)

There was an omnipresent misconception of outcomes of breast cancer in the participants and their social contacts. Fatalistic views of cancer were pervasive in the community. In turn, they felt it was not worth the effort and poor quality of life was related to treatment. This pervasiveness was from the contact they have with breast cancer patients, usually within their neighbourhood. This was substantiated by their significant others who felt the same way.

I knew, so I would do as I please, because I know I don't have much time to live anymore. So don't force me [to do chemotherapy]. Allow me to satisfy myself [with what I want to do] but I'm not sure how it will be when I die. (P 11 when she first discovered a breast lump)

Many of my neighbours were affected, had so many types of chemo but continued to die. Two in my neighbourhood died. So I tried homeopathy. But I don't know what stage they were in, they don't talk about it. They had operated, but still died. But if they came in earlier stages may be it would have been different? But I found quite a large lump.... (P 12)

I would have just left it like that, because you know when you hear you have cancer, you just feel well, that's it. You just wait for time to come. Because everybody tells you that "ooo....cancer, that's it. Sorry. Then pray hard that you'll go in peace". (P 19)

c) Coping Mechanisms

Denial was seen in many women, who readily admitted that they were not ready to accept an expectant diagnosis of cancer. Because cancer was perceived by the patients as being fatal, it was easier to deny the truth, than to be

faced by a life-threatening disease. Fear is an emotion described by many women, the fear was on outcomes of treatment related to the cancer and about the fatal outcome of cancer itself.

It took a while, to make sure it really was cancer. About two to three months, I didn't really want to accept the truth. (P 2)

It was a small lump but sometime it was mobile and it just goes off. It disappears and then when I rubbed it, it subsides so I didn't take it that seriously at the beginning. But I was a bit scared, I mean in my sub-conscious mind I was maybe thinking that I may have cancer but I didn't want to face the reality. I didn't want to know about it, afraid to know the truth. I was not scared of the treatment or anything. Scared to know the reality I should say... (P 18)

When they first discovered breast cancer on the right, I was fifty seven. And when I was given this news I was shattered. I didn't know what to do. So, one of my friends suggested I go and see the professor herself and get her opinion, but I was very reluctant because you know fears sets in. When fear sets in, denial also sets in. It cannot be me. That kind of thought. I was just putting it off, until I looked at the mirror one day and said what the heck am I doing. I better face the consequences. There was a fear, I was in denial. I said, it cannot be. I went on a pilgrimage to India. I just had this feeling that it was cancer and nothing else. Even in India it was oozing.. I knew it was cancer....and I better attend to it, it was like a sign to me. If you don't attend to it now then.. We cannot help you. (P 19)

d) Role of significant others in symptom appraisal

The role of significant others in symptom appraisal are two fold, as a source of information as well as to validate the presence of a serious symptom (sanctioning). Denial in accepting the possibility of cancer in significant others also perpetuated delay in presentation. Furthermore, thinking of the impact of diagnosis on their loved ones also perpetuated delay.

Somewhere in June, I just felt, there was a lump there and the same thoughts came back. "No. We are not going to be affected. Everything is fine with you. It's just a normal cyst or something like that." I went to a GP and she told me to go "Oh. You must go and check." So, my husband, we believe in God. We are Christians you know. So, my husband was in sort of a denial. "God won't allow this thing to happen to us." His brother is a pharmacist and he said, "There is alternative medicine you know." And he put me on homeopathy. (P 10)

It was a shock. I asked around my family members. They said forget it. Nobody in the family has it, how can you have it. . I said but you see the papers are saying the number one killer is breast cancer you know. Don't even think about it, they said. think positive. I said ok, think positive that's what I'll do. (P 19)

The need for being sanctioned sick or ill was an important trigger to labeling symptoms as serious. Therefore when significant other individuals were not informed of signs of cancer, the symptoms were left

unattended.

He [my husband] only knew there was a boil with pus. He asked me what it was. I said it was a boil. We just left it like that. It didn't occurred to him that it could be cancer. Nothing, because I was a normal person. I had no symptom, nothing. (P 19)

Lack of disclosure was seen to impair this need for sanctioning. Many had symptoms discovered when they were truly symptomatic with a bleeding tumour. Reasons for not disclosing symptoms include lack of social support, and the impact on significant others. Some had opportunities to confide, but didn't. Some had good social support, but because they did not tell, they were not able to utilize the support.

No one knew about the lump, my husband did not know, we slept apart. When our relationship was good in the past, the breast was normal. When we separated, this thing grew little by little. But when the pressure came on, it begun. You know what my husband did to me. I believe in hospital treatment, but I didn't come early because no one could send me. No one, my children are married and stay on their own. I am staying with my son, just the two of us. But I didn't ask him. I was scared to go to hospital, I don't know how to say it but I was scared. Now that it has progressed, I just give in. At that time I didn't go because I had no one to count on. (P9)

The lump can be seen on my breast on this side. I didn't tell my grandchildren. They forced me to come to hospital. I didn't think it was cancer. My granddaughter accidentally brushed against it, she asked why is your breast hard? It cannot be left like that. (P 1)

Even though we are educated and sometimes we make the biggest mistake in life for not telling.. earlier. So.. one day when I was watching TV and it happened. My blood suddenly felt sticking to my skin so I looked down and I saw, blood on my breast and I slowly went in and did my own dressing. For about a week, I just kept quiet and then, my daughter discovered me out of breath, she cornered me and asked me, what is actually wrong with you? I said nothing then she said you tell me the truth. She started screaming [when she saw the tumour]. They all took it very badly. They immediately took me to a hospital nearby to do a test. The main reason for not telling them is because I wanted them to settle down [get married] I don't want to trouble them, to be a burden to anybody. I was hoping for some miracle that I'll be cured or something will happen that... it won't be known to others . Just like that I will go off [die] or if it burst, it will just slowly dry up. I mean I just didn't know, that it'll be later [slowly progressing]... I'm fortunate that I was caught by my [daughter] if she didn't catch me at that period of time, I wouldn't have told her. I would have just carried on I think. (P 17)

Discussion

It is very important to note that women in this study had overlapping reasons for presenting with locally advanced breast cancer. Two of the women had biologically aggressive cancers which progressed within weeks. Many delayed seeking a diagnosis; five did not know the symptom was that of cancer, nine knew there was

a breast lump but due to worry that it was cancer, delayed seeking a diagnosis. Four did not disclose their symptoms to anyone and three presented as an “emergency because of massive bleeding from the breast”.

This study also highlights the importance of symptom appraisal as seen in other studies (Nosarti et al., 2000; Burgess et al., 2001; Rauscher et al., 2010). The analysis indicates that symptom interpretation was weak, with not only non-lump symptoms as seen in other studies (Burgess et al., 2001; Bish et al., 2005) but unique in this study is that those with symptom of a lump also delayed, especially if it was painless. In contrast, for some women, expecting classical breast cancer symptoms such as a hard discrete lump and signs of advanced disease also led to missing the diagnosis at an early stage as seen in other studies (Burgess, 2001). In this study, three women, one Malay, one Chinese and one Indian participant presented as an emergency when they had massively bleeding tumours. These strong sensory signals such as pain and bleeding also lead to shorter appraisal delay in other studies (Safer, 1979). Studies show that misconception of symptoms were more in ethnic minorities and women of lower socioeconomic status (Rauscher, 2010). This study saw a mixture of participants from a housewife grandmother to a young university lecturer. Also there were three distinct ethnic groups who presented with advanced cancer. A larger study will be needed to identify who are at risk of presenting with advanced disease.

Other factors that contribute to symptom recognition delay were perceived less personal risk (Bish et al., 2005) as seen in this study where participants erroneously expect a strong family history to be associated with breast cancer. Negative beliefs about breast cancer and its treatment was also seen to play a role in this study and others (Bish et al., 2005). Poorer knowledge of symptoms and risks among older women may help to explain the strong association between older age and delay in help-seeking (Grunfeld et al., 2002). In this study most women were younger in their 40s and 50s. They were not knowledgeable in breast cancer symptoms. An elderly lady of 82 years also did not know that the hardening of her breast was due to cancer. It appears poor breast literacy was seen across all age groups. Larger quantitative studies will be needed to confirm this.

Symptom appraisal by the patient may not be the only source of delay, misdiagnosis by health providers is also well known. Attributing a malignant lump to a benign lump was seen where a constant annual false negative rate of 4-5% was seen in the assessment of breast lumps in a referral centre (Goodson et al., 2002). Thus symptom appraisal by physicians and other health professionals are important to diagnose symptomatic women early in the course of the disease especially in young “low risk” women (Eberts, 1934; Greenough, 1935; McCarthy, 1948). Education and academic detailing of breast cancer symptoms have not reached the public and more urgently health care providers who missed the diagnosis in the young and pregnant women in this study.

Psychology literature from the 1950s have consistently placed past experience as a central theme in appraising symptoms (Andersen et al., 1995). Past experience of others and the individual will form ideas on the causes of

the breast symptom. As seen in this study previous history of benign lumps brought about a false sense of security.

Interpreting the symptom would lead women to label whether they think the symptom is benign or malignant. What that means to them would influence their behaviour to seek or to avoid confirmation of diagnosis. Avoiding would be due to maladapted coping mechanisms to reduce anxiety. In this study, it was seen that many women could not verbalise why they didn't seek a diagnosis. It could mean the other factor was coping with the thought of having cancer. Avoiding could also mean that they feel that outcomes of treatment of breast cancer is fatal and therefore choose alternative treatment pathways that they have not seen before. There is a relatively low incidence of cancer in Malaysia, which is half the incidence seen in the developed world (Yip et al., 2006) that would make a personal encounter with breast cancer quite rare within the community. Due to the poor outcomes of breast cancer which are stage related and ethnic specific where women of Malay ethnicity survive poorly compared to the Chinese and Indian women (Pathy et al., 2011; Taib et al., 2011), this brings about a social norm of doom. Hence, many women with advanced breast cancer around them, would have had similar therapies to those undergoing treatment for early cancer. The poor outcome of women with advanced disease is a clear reminder to women with a new breast symptom that it is futile to treat by conventional means. Fatalism has been studied and exists in many communities and ethnicities. Studies show that fatalistic belief was different in Asians where it meant that cancer was pre-ordained or fated (Straughan et al., 1998), while in African Americans, it was a sign of helplessness and hopelessness (Powe et al., 2003). In this study, fatalism emerged strongly, and was not seen just as a preordained fatal condition, in some it did not trigger powerlessness, as the women chose to have less “toxic” alternative treatment to cure themselves. But in others, it did give a sense of hopelessness, where they did not seek any treatment.

More importantly, the breast symptom triggered fear and the response to that was ineffective coping like avoidance of getting a diagnosis. In some women, it triggered the use of alternative treatment as they perceived that conventional treatment was not effective or not compatible with their needs.

Appraisal is a decision making process; studies that have looked at the process of appraisal by Andersen in 2009 theorised that bodily sensations are also governed by the social and cultural situation experienced by the individual. The cultural situation of Indian women not able to marry off daughters due to the stigma of cancer was seen in this study and was a pertinent reason why the Indian woman in this study did not disclose her symptoms although she suspected it was cancer.

At times, symptoms were too mild to be important enough to disclose. Importance of having significant others to provide validation to label their breast symptom as serious were evident in this study. This is called sanctioning and was seen in another study (Smith et al., 2005). At times non-disclosure was due to social isolation or a personal choice. Seeking help was seen to be dependent on social support with daughters or sons

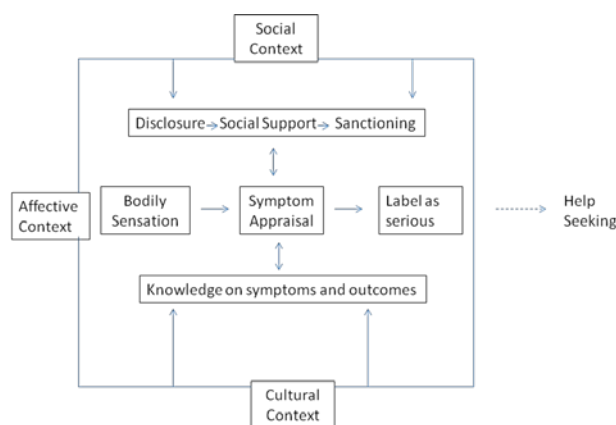


Figure 2. The Psycho-Socio-Cultural Model of Symptom Appraisal. A modified model of understanding symptom appraisal in women with breast symptoms

rushing mothers off to emergency departments for a bleeding breast tumour.

From the evidence gathered here, a theoretical approach to explain symptom appraisal of bodily sensation as told by these women resulted in a symptom recognition model, based on other models such as the Model For Understanding Delayed Presentation in breast cancer by Bish in 2005 and the Model Of Socio-Cultural Interpretation Of Symptoms by Andersen in 2010. This model that we propose differs in the addition of the affective context and other important constructs, converging them all into the same model. Figure 2 shows the psycho-socio-cultural model of symptom appraisal that explains from bodily sensation to symptom appraisal and to labeling a serious condition. This process is governed by knowledge of disease and the outcomes as well as needing to disclose, obtain social support and sanctioning or validating the presence of a breast symptom. These factors are governed by the social, cultural and affective contexts. The affective context for the woman is how she copes with the discovery of the bodily sensation and the coping after she labels the symptom as threatening or not.

This model (Figure 2) would serve as a theoretical model for designing confirmatory studies or designing interventions. This study challenges views on Malaysian community breast health literacy with the evidence of ignorance not only towards non-lump but towards breast lump symptoms. This study informs the need for urgent interventions in the primary health care and primary care settings where general practitioners, obstetricians, midwives or other health providers, providing for women who seek help for breast changes. Education on breast changes and signs must be detailed and taught to women, their significant others and to doctors and other health care providers.

This study has limitations inherent to its' inductive and exploratory nature. Confirmatory studies would need to be done to confirm these findings to generalize it to the population. Recall of past events with a foresight of experience may unwittingly make the stories of these women biased and inaccurate in explaining their journey. Especially so, because they had personally experienced

progressive disease. More cultural differences may exist but was not studied specifically in this study thus a sampling of more Chinese and Indian women may help unearth some important cultural issues to aid designing culturally appropriate educational programmes to the public. The limitation of not being able to interview all women due to the language barrier by the researcher and losing the nuances not provided by translated transcripts also reduced accuracy of the findings in those participants.

However, qualitative studies prove superior in obtaining more detailed information from women as displayed in this study. This study is the first and important study in Malaysia to provide in-depth evidence to health care providers and policy makers on what issues exists in women with delayed or advanced presentation.

In conclusion, symptom recognition remains an important public health issue in Malaysia. Supporting and sanctioning women with breast symptoms are important. The psycho-social-cultural model of symptom appraisal may serve as an important addition to the fight against cancer in countries that do not have the resources for early detection such as population based screening mammogram programmes.

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