

# Understanding How Malaysian Women Appraise their Breast Cancer Symptoms: A Narrative Approach

Wan Mamat WH<sup>a</sup>, Lund S<sup>b</sup>, Jarrett N<sup>c</sup>, Mohd Taib NA<sup>d</sup>, Duke S<sup>b</sup>

<sup>a</sup>Kulliyah of Nursing, International Islamic University Malaysia, Malaysia

<sup>b</sup>School of Health Sciences, University of Southampton, United Kingdom

<sup>c</sup>School of Health & Care Professions, University of Portsmouth, United Kingdom

<sup>d</sup>Faculty of Medicine, Universiti Malaya, Malaysia

## ABSTRACT

**INTRODUCTION:** Awareness of breast cancer symptoms has made a positive impact on recognition and screening, however there is little research describing how women interpret their bodily changes. This study was conducted to explore how Malaysian women with breast cancer appraise their symptoms and how their interpretation of the symptoms had been shaped by the social norms, knowledge and previous experiences. **MATERIALS AND METHODS:** 14 women with breast cancer were recruited using purposeful sampling. The participants took part in in-depth, one-time, face-to-face, and audio-recorded interviews. All the interviews were subsequently transcribed verbatim and analysed using structure and content of a narrative approach. **RESULTS:** Women interpreted their symptoms based on the physical presentation of the symptoms, previous experiences, and societal norms and beliefs. Some women immediately understood the potential meaning of their breast changes and sought medical opinion, while others waited from one week up to until one year to observe symptoms or normalised them in terms of previous and current experiences. The use of narrative enabled these women to recapitulate particular experiences that had special meaning in order to make sense of their action. **CONCLUSIONS:** The way women interpreted their symptoms reflected their understanding on the significant meaning of the symptoms. Acknowledging this symptom appraisal information may assist healthcare professionals in providing appropriate information that can challenge misconceptions, myths, and negative beliefs about breast cancer to improve breast cancer awareness and early detection among the community.

## Keywords

breast cancer, Malaysia, narrative, women

## Corresponding Author

Dr. Wan Hasliza Wan Mamat  
Kulliyah of Nursing,  
International Islamic University Malaysia,  
Indera Mahkota Campus,  
Jalan Sultan Ahmad Shah,  
25200 Kuantan, Pahang, Malaysia.  
No Tel: +6095707286  
E-mail: whasliza@iiu.edu.my

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## INTRODUCTION

Breast cancer is perceived as a devastating and life-threatening illness associated with suffering, pain and psychological problems,<sup>1,2</sup> in addition to being seen as a long-term illness.<sup>3</sup> Breast cancer is the most prevalent cancer among women globally with an estimated 2.09 million new cases being diagnosed in 2018.<sup>4</sup> In Malaysia, the most recent figures issued by the National Cancer Registry revealed that breast cancer is the most common cancer among women from all three major ethnic groups, accounting for a total of 34.1% of all cancers in the 2012–2016 period<sup>5</sup>. The lifetime risk of developing breast cancer at some stage for a woman in Malaysia is 1 in 27<sup>5</sup> compared to 1 in 7 in the UK<sup>6</sup> and 1 in 8 in the USA.<sup>7</sup> Although Malaysian women face a lower

lifetime risk, they tend to present at a later stage in disease progression, with more than half of newly diagnosed women already having advanced stage breast cancer.<sup>8</sup>

Previous studies reported that some Malaysian women lacked the knowledge and awareness during symptom appraisal. Women may misinterpret their presenting symptoms as being a benign disease, a sign of menses, a milk clot<sup>9</sup> or a blood clot.<sup>10</sup> However, there is still a lack of explanation on of why they make such interpretations regarding the symptoms. Besides pathophysiological changes, symptom interpretation is also formed by individual and socio-cultural factors<sup>11</sup> and this influences how women decide to act. A study in Ghana revealed that

Ghanaian women believed the causes of their breast cancer symptoms are associated with evil spirits, immoral lifestyle choices, and a bite onof the breast.<sup>12</sup> This is a matter of concern sinceis that their decisions this may have a potentially significant impact on their mortality and survival depending on how they interpret their symptoms and how quickly they seek medical opinion. Therefore, in order for healthcare professionals to provide appropriate information and raise awareness, this study aims to increase the understanding of how women appraise early symptoms of breast cancer and how their interpretation of the symptoms had been shaped by the social norms, knowledge and previous experiences.

## **MATERIALS AND METHODS**

### **DESIGN AND SAMPLE**

This study used a qualitative, narrative approach. Narrative is more appropriate for this research because of its focus on how the participant constructs and understands their symptoms in relation to their social context. A narrative is created within a broader socio-cultural context,<sup>13</sup> and the resulting socio-cultural template provides a store of meaning for people to live by and to explain their experience.<sup>14</sup> Purposive sampling was used to recruit patients from two government hospitals which provide comprehensive services in the field of cancer care. The inclusion criteria for the participants are: 1) women; 2) diagnosed with primary breast cancer; 3) have undergone their first conventional medical treatment within a year; 4) 18 years old and above; and 5) able to speak Malay or English.

### **ETHICAL CONSIDERATIONS**

Study participation was voluntary, and written consent was obtained from each participant prior to data collection. All the participants were guaranteed confidentiality as well as anonymity throughout during the publication of aspects of the study. Ethics approval was obtained from the study was approved by the Faculty of Health Sciences, University of Southampton and Research Ethics Committee (Ethics no: 22983) and the

Malaysia Ministry of Health Research and Ethics Committee (NMRR-16-1319-31877).

### **PROCEDURES**

Before starting the interview, the researchers took time to build rapport with the participants. Later, interviews were conducted to gain the participants' stories using a piloted narrative script. The interviews were conducted in an informal, unstructured, face-to-face and conversational style. Most of the interviews took place in the participants' homes through their own choice. Each interview lasted between 20 and 90 minutes. Narrative interviews can vary considerably in length since they depend on the storytelling style of each the participant.<sup>15</sup>

Data processing comprised three stages. The first stage was verbatim transcription. All of the interviews were transcribed verbatim in the language used by the participants during the interviews. After completing the transcription process, the transcripts were read and re-read several times for the purpose of familiarisation and gaining a basic understanding of the participants' stories. The second stage was data analysis using the narrative analysis process described by Riessman.<sup>16</sup> Data analysis began with the structure of each narrative in order to examine the sequence of the events that had taken place. This process continues with analysis of the content of the narrative. Finally, the stage of interpretation, in which the narrative devices such as language, causality, temporality and contextual aspects were examined.<sup>16</sup> After the individual analysis was completed, a search for commonalities across narratives was undertaken to look for patterns across the experiences of participants regarding symptom appraisal.

### **TRUSTWORTHINESS OF DATA**

Dependability and confirmability can be achieved via an audit trail.<sup>17,18</sup> An audit trail was kept in this study in order to maintain a track of the steps and/or changes throughout the processes of data collection, analysis, interpretation and writing up of the findings. This audit trail was primarily recorded in the research diary together

with the researcher’s reflections on the research process, meeting with the participants, challenges, thoughts, feelings, assumptions and interpretations. Riessman<sup>19</sup> suggested that describing how the interpretations were produced enables the reader to determine the rigor in narrative research. In this study, the interpretations of the findings were based on the participants’ interview transcripts, audio recordings, reflective diary, field notes, frequent discussions with three experts in qualitative research, and knowledge of the literature. Moreover, this study also included interviews with a family member as chosen by the woman – this data helped inform the narrative and enabled triangulation, but this paper only reports on the interviews with the women.

## RESULTS

Throughout the period of data collection, 14 women agreed to participate in both hospital. Background of the participants are summarised in Table 1.

Table 1: Demographic characteristics of the participants (n=14)

	Participants (n)	
Age	28 – 62 (mean: 46.1)	
Marital status	Single	2
	Married	11
	Widow	1
Ethnicity	Malay	9
	Chinese	3
	Indian	2
Occupation	Government	6
	Private	2
	Self-employment	2
	Not working	4
Stage of breast cancer	Stage I	2
	Stage II	4
	Stage III	7
	Stage IV	1
Treatment	Surgery	7
	Chemotherapy	6
	Radiotherapy	1
The number of participant for 6 months to 1 year which is 2 participants should be in-line	<1 week	8
	1 week to <1 month	3
	1 month to <3 months	1
	3 months to <6 months	0
	6 months to ≤1 year	2

Through narrative analysis, three themes were identified regarding the appraisal of the symptoms: 1) women who appraise the symptoms based on its physical presentation; 2) women who appraise the symptoms based on previous experiences; and 3) women who appraise the symptoms based on societal norms and beliefs.

## WOMEN WHO APPRAISE THE SYMPTOMS BASED ON ITS PHYSICAL PRESENTATION

Some of the women in this study decided to seek immediate medical opinion after they found the lump. Telling their husband was one of their first decisions. This is illustrated in the following quotes:

While taking a shower, I felt the lump. It was small. This size [shows half of her little finger’s nail]. There were two lumps. Immediately, I told my husband. We went straightaway to see a doctor in a clinic. (PT11).

I started to feel a lump while taking a shower. It was in my right breast. I said, “*What is this?*” Then I told my husband. My husband said, “Go to the doctor, go to the doctor.” So, we went to a clinic. (PT9).

Although some of the women recognised the presence of a lump, they decided to ignore the symptom because of its abnormal shape, and it was causing them no pain or bodily disruption. This is evident in the following quotes:

I started to feel, when I wore the bra. It felt like a lump, *but it was not a round lump*, but it was like, like slightly flattened, nail size, two thousand, two thousand fifteen, in January, and in my left breast. It was also painless, so, I just ignored it ... I never thought that thing [lump] could be cancer. (PT14).

When I took a shower, I felt a hard lump. I felt it. Sometimes, I felt like a throbbing pain. *But, the pain was rare*. On this side [pointing to her breast]. Left side. It felt like a hard lump. It happened almost two months ago. I just observed to see how it would progress. (PT3).

In contrast, not every woman had a breast lump. In the instance of PT6, she noticed changes in her breast, she decided to observe the symptoms because she considered breast firmness was “normal” possibly due to menstrual processes.

In July, I felt like, like my breast was firm. It was just firm, but no lump. It was not painful. I thought it was normal, yeah maybe due to a menstrual cycle. After that, I observed, and it was still swollen....during menstruation, our hormones are productive, right. I thought it was just normal swelling. (PT6)

The situations above demonstrate how some women immediately understood the potential meaning of their breast changes and sought medical opinion, while others were waiting to monitor their symptom because it was painless.

### **WOMEN WHO APPRAISE THE SYMPTOMS BASED ON PREVIOUS EXPERIENCES**

Some of the women normalised the symptom in terms of their previous or contemporaneous experience. For example, PT8 normalised her breast lump due to her previous experience of fibroadenoma disease. Moreover, she believed that breast cancer was hereditary.

I had a lump. But that lump was normal. Because, before this, I had already had lumps removed many times. Because it kept on growing, or I removed that lump, not because it was cancer, but because it had an infection, or it was painful. So, I removed it. It was just an ordinary lump, ordinary fibroadenoma ... Because I had no family history. (PT8)

Another woman, PT5 also shared same experience with recurrent breast lumps, but she immediately went for a medical check-up.

It happened again in two thousand sixteen. I felt the lump again. I felt it, but it was not as big as before, about 5cm, rather than 7cm. Huh, I had the lump. I went to see the doctor near to our house. (PT5)

For another woman, symptoms were immediately recognised due to experience with close family member

with breast cancer that led to immediate medical check-up.

At that time, I was having a shower. I felt a small lump, but no pain at all. Left breast. At that time, I only thought about breast cancer because my mother had it. But she had already died a few years ago. After that, I quickly told my husband, and he said, "Let's go to the clinic, see the doctor." So, we went to a private clinic. (PT7)

However, not every woman was concerned about the symptoms even if they had previous experience dealing with family members who had breast cancer. This is evident in the quote of PT1.

I took a shower again that night, I felt it again ... Eh, this size [shows her little finger]. I felt this size, in the middle of my breast [points with her finger]. After that, I just left the lump alone. I decided to observe it ... because there was no pain, nothing. I just felt the lump ... There is breast cancer in my family too. My late sister, also in her left breast. But when she found out, it was already in stage four. She had cancer outside the breast, like meat. (PT1)

The scenarios above demonstrated how some women interpreted their symptoms based on previous diagnosis, recurrent symptom, and experiences with family members.

### **WOMEN WHO APPRAISE THE SYMPTOMS BASED ON SOCIETAL NORMS AND BELIEFS.**

Some women were concerned with what other people within the community had said about the symptoms. This is evident in the quote of PT2.

I felt the lump, but it did not burst, not watery [discharge]. People said that breast cancer was painful and had watery discharge ... It felt lumpy, but there was no pain. So, I just ignored it. I did not know it was cancer. I thought there was nothing wrong with it because there was no pain (PT2)

Another woman, PT4 described how her postpartum situation reshaped her ideas about why she had a breast lump.

I started to feel sick after I gave birth to, gave birth to my baby. At first, I noticed a lump under my nipple. At first, I thought that it was milk. I thought that it was a milk clot because I was breastfeeding ... That's why I felt odd during my confinement, something was not right with my right breast. Although it was engorged, but I did not feel any pain. But my left breast was hurting. I did wonder why, but I did not expect anything bad since it was not hurting. I decided to ignore it since I did not feel any pain. I thought it was normal hardening of the breast. I thought it was overfilled with milk. It was a normal thing. (PT4)

Both excerpts above reveal that the participants were normalising the symptom based on their understanding of a sociocultural template which suggests breast feeding and breast cancer are associated with pain.

## DISCUSSION AND CONCLUSION

This study has confirmed that recognising the significance of common symptoms associated with breast cancer is not straightforward. Majority of the participants were aware of the presence of the breast lump, but their interpretation about the lump was influenced by their knowledge, personal beliefs, recurrence of symptoms, previous experiences of illness either personally or of family members and social norms.

Some of the women in this study recognised their risk of developing breast cancer due to family history when they discovered the breast lump. Haber, Ahmad, & Pekovic<sup>20</sup> reported that women with a family history of cancer have higher risk perception levels compared to those without. This finding is also consistent with another study in Netherland, in which the decision was made to seek health care due to the presence of family history of breast cancer.<sup>21</sup>

In our study, some of the women did not perceive their symptoms as abnormal due to a lack of knowledge about breast cancer. In line with other study findings in Malaysia<sup>9,10</sup> and the UK,<sup>22,23</sup> some women with no family history of breast cancer did not expect their symptoms to be cancer because they did not consider themselves to be at risk. This means that these women did not expect to get breast cancer, which led them to live with a false sense of security that directly influenced how they defined themselves, even when they realised the presence of a lump in their breast.

Several narrative accounts have suggested that the breast cancer symptoms were seen by some of the women in the wider community as being “normal” and interpreting their narratives to rationalise such an opinion based on a number of factors. These findings are congruent with another local study in Malaysia.<sup>9</sup> Some women in this present study associated related their breast symptoms to a previous history of having had a benign lump, clotted milk due to breastfeeding or menses symptom due to hormonal changes. According to Lam et al.<sup>24</sup> women interpret their breast cancer symptoms based on a comparison of the nature of the symptoms with their pre-existing knowledge and experiences. This might reflect show that the people generally in the society still have poor knowledge of breast cancer symptoms.

This study also highlighted the narrators' account of their community's view regarding the symptoms of breast cancer. Some of the women in this study had difficulty appraising their symptoms, particularly when they differed from what other people had reported or experienced concerning breast cancer. This was noted by White & Epston<sup>25</sup> as a lack of fit between the cultural narrative and the actual lived experience of the people. The socio-cultural template regarding the symptoms, including that “breast cancer was painful and had watery discharge” and viewing the lump as “clotted milk”, made these women believe that they did not have breast cancer because they experienced only a painless lump. According to Donkor et al.<sup>26</sup> symptoms may be considered serious depending on the individual's preconceived ideas about the nature of breast cancer, which should cause pain in theirs that the



presence of cancer in the breast should cause pain. Therefore, this study showed an interconnection between societal beliefs and symptom interpretation related to breast cancer.

The new findings that can be highlighted in this paper is the role of husband even if it is not the focus of this paper. Previous research has suggested that some Malaysian women reported that their husbands refused to allow permission for the respondents to seek medical treatment<sup>9</sup> and that they decided that the women should try alternative treatment.<sup>10</sup> Consequently, there is almost a sense of “blaming” the husbands for any worsening of the women’s situation because of the husbands’ decision. This study however demonstrates a contrasting view of the negative images about the husbands role in general with many at the time. Some women reporting stated that their husbands encouraged them to check their symptoms immediately with a doctor the moment that they knew about it.

Even though the participants displayed a breadth of characteristics, including a variety in their stages of breast cancer, ethnicity, treatment, and age, the small number of Chinese and Indian participants might limit the knowledge with regards to socio-cultural beliefs within these ethnic groups. This study focuses on patients that were engaged with medical services, but missed women who did not seek medical intervention and are continuing to ignore the symptoms.

As a conclusion, the findings in this study suggested that better targeting of information especially about the breast lumps should be conducted to improve awareness and knowledge within the society to ensure that the societal narrative is correct. Improved information can challenge misconceptions, myths and negative beliefs and feelings by providing guidance and education to the communities regarding the symptoms, risk factors and treatment, which affect them in terms of early detection, diagnosis and treatment. This can be achieved by increasing awareness among the patients and public regarding breast cancer through health promotion. Healthcare professionals working with women from different communities and cultures should be sensitive to their interpretation of

breast cancer. They should be informed about the available government-provided screening subsidises and facilities for detecting breast cancer, in addition to the available non-governmental funding incentives available. This study also acknowledging that a women may be aware of what the lump may mean but choose not to recognise or act on this awareness. Additionally, healthcare professionals can learn from this finding in that husbands were often initiators in seeking help and they should be targeted and engaged in health promotion activities regarding breast cancer.

## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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