A narrative study of Malaysian women with breast cancer sharing their experiences

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Introduction

Worldwide, breast cancer is the most prevalent cancer among women and impacting 2.3 million new cases (WHO, 2021).

In Malaysia, breast cancer affects 34.1% while 1 in 27 women likely to develop breast cancer in their lifetime (Azizah et al., 2019).

Referring to Clinical Practice Guideline for management of breast cancer in Malaysia, patients presenting with the breast symptoms should be evaluated with a full clinical examination, mammography and/or ultrasound followed by biopsy, either fine needle and/or core biopsy (Malaysia Ministry of Health, 2010).

There is still lack of research in Malaysia pertaining to the experiences of women with breast cancer specifically during the diagnostic interval.

Objective

To understand what are the experience of Malaysian women during the diagnostic interval of their breast cancer

Methods

Design	Qualitative, narrative approach
Sampling	Purposive sampling
Inclusion criteria	1) women 2) diagnosed with primary breast cancer 3) 18 years old and above 4) able to speak Malay or English.
Sample size	14
Data collection	• Face-to-face, informal and unstructured interview using a piloted narrative script. • Twelve interviews took place in the participants' homes and 2 interviews at workplace. • Each interview lasted between 20 and 90 minutes (average 32 minutes).

Methods cont...

Data analysis	• A narrative analysis by Riessman (1990
Ethical consideration	• Study participation was voluntary, and right to withdraw at any point of the study with no consequences. • Written consent was obtained from each participant prior to data collection. • The interviews were recorded with participant's permission • Guaranteed confidentiality and anonymity of their data.
Ethical approval	1) Faculty of Health Sciences, University of Southampton (Ethics no: 22983) 2) Research Ethics Committee, Malaysia Ministry of Health Research and Ethics Committee (NMRR-16-1319-31877).

Result

Age	28 – 62 (mean: 46.1)	
Marital status	Single Married Widow	2 11 1
Ethnicity	Malay Chinese Indian	9 3 2
Occupation	Government worker Private worker Self-employment Housewife/retired	6 2 2 4
Stage of breast cancer	Stage I Stage II Stage III Stage IV	2 4 7 1
Treatment	Surgery Chemotherapy Radiotherapy	7 6 1
Duration noticing symptom to first medical contact	< 1 week 1 week to < 1 month 1 month to <3 months 3 months to <6 months 6 months to ≤1 year	8 3 1 0 2
Duration first medical contact to diagnosis	1 month 2 months 3 months	6 7 1

Theme 1: Women who suspected having breast cancer

Participant 6 said:

> *After that, I went to a government clinic. The doctor referred me to the hospital. I went to hospital X, checked with Dr. A. Then, on the same day, he immediately asked me to have a mammogram and ultrasound. The next week, he asked me to do MRI. The following week, I did biopsis [biopsy] ... From the start, I could see that the doctor seemed like he was rushing to do the test. I felt like, like something was wrong. As usual practice, we tend to have late appointments, right, usually two to three weeks, but at that time, starting from the first day I met with the doctor, that doctor seemed to want to do many things. So, I expected something serious, like cancer.*

Theme 2: Women who experienced false reassurance

Participant 10 said:

> *The doctor said, “It’s nothing. Lymph nodes only.” S/he gave me medicine. S/he gave an antibiotic. I thought it was fine.*

As consequences ...

Participant 10 said:

> *Four to five months later, I realised that the thing had got bigger. I had already told the doctor. I was mad at that doctor. It was already quite big, 8cm.*

Theme 3: Women who experienced delayed referral

Participant 8 said:

> *So, I went to the ordinary clinic taking a medication. It seemed okay. Then it [pain] happened again. Three times it happened. So, after it happened for a third time, the doctor asked me to go to a hospital, referred me to the hospital ... during my first visit, the doctor gave Panadol. Second time, different painkiller.*

Theme 4: Women who experienced inconclusive investigations result

Participant 1 said:

> *Two, three days after that, I went to the hospital again. Checked, checked, checked. The doctor took, what is that called (p), took our meat (tissue) inside. Biopsy. Huh, biopsy. Two times she did it. At first, with the small needle. Cannot, unable to identify. The doctor did it again, on the following week. S/he did again.*

Discussion

Even some women sought early medical consultation, it still took 1 to 3 months of undergoing diagnostic procedures before the diagnosis of breast cancer was confirmed.

This interval was shorter compared to countries such as Libya (Ermiah et al., 2012) and Brazil (Soares et al., 2012), but it was longer when compared to Thailand (Poem et al., 2014).

In Malaysia, this situation occurred possibly due to lack of facilities and doctors, overcrowding and long waiting lists (Rasiah et al., 2010).

Some of the women had experienced premature reassurance from the first medical doctor that they consulted.

During diagnostic interval, the HCP appraisal process can be subjected to error and biases that may lead to misdiagnosis, dismissal of symptoms or no diagnosis (Scott et al., 2013).

As a consequence of premature reassurance, these women in this study took about 4 months to 1 year before they went back to see the doctor for the second time.

This duration was almost the same as in a previous study, in which it was reported that false reassurance can persist for months and even years in relation to seeking help for subsequent cancer symptoms (Renzi et al., 2015).

Discussion cont …

In this study, one woman sought a medical consultation three times at the clinic, and it took more than a month before she was referred to the hospital for further investigation.

The number of consultations is associated with an increased time from presentation to referral for cancer treatment (Lyratzopoulos et al., 2014).

Some women had experienced unconfirmed diagnostic result.

Detection issues may relate to inherent features of the tumour or surrounding tissue, technical problems, or human error (Giess et al., 2012).

Gandhi et al. (2006) found that 59% of diagnostic errors had three or more contributing process breakdowns, delaying diagnosis by more than 1 year on average.

Conclusion

This study found that doctors' action tended to result in both positive and negative consequences.

Effort is required to minimise the potential risk of falsely reassuring patients. This can be accomplished by informing the patients about any uncertainty in the findings, explaining the symptom changes that need special attention, advising immediate help seeking behaviour if necessary and explaining the potential progress of the illness over time (Renzi et al., 2015).

Simplicity in the diagnostic process is critical in limited-resource settings and they suggested that a combination of the many diagnostic tests available allows for the establishment of pathology diagnosis in one visit (Shyyan et al., 2006).

Limitation & recommendation

This study provides a basis for future research to gain healthcare provider's perspectives that are directly involved during diagnostic interval. Their information could be then used to improve the early diagnosis of women with breast cancer.

Even though the participants displayed a breadth of characteristics, including a variety in their stages of breast cancer, ethnicity, and age, this study focuses on patients that were engaged with medical services, but did not include the women who did not seek medical intervention and are continuing to ignore the symptoms. This study also focuses on specific setting that may not generalise to other population.

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