

Understanding the Psychosocial Needs of Women who Present with Advanced Breast Cancer

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Abstract

Introduction: Advanced breast cancer (ABC) remains common in Singapore. In 2019, 22.1% of breast cancer patients presented with ABC in our institution. Despite increasing affluence and the advent of national mammographic screening, the incidence of ABC has not changed significantly. This suggests inherent differences in women who present late. We aim to explore the socio-economic background, knowledge and attitudes of women who present with ABC.

Methods: Between December 2013 and July 2015, 100 patients who presented consecutively with ABC in a tertiary institution in Singapore were recruited to participate in an interviewer-led questionnaire exploring psychosocial and economic issues.

Results: Among the 100 patients, 63 and 37 presented with stages 3 and 4 breast cancer respectively. Median age was 57 (27–86), 52% had at least secondary education, 53% had no formal employment and 71% were married; 88% were aware of breast cancer symptoms, 82% were aware that mammography can help detect cancer, 82% believed that current treatment modality for breast cancer is effective, 96% had never undergone a mammography and 52.9% felt mammograms were unnecessary. A total of 64% presented symptomatic from the breast tumour, with a median duration of 3 months. Many of the patients were aware of breast cancer symptoms and the utility of mammography. However, a group of patients did not comply with screening. This may be due to poor understanding about breast screening and detection in its asymptomatic phase.

Conclusion: Further public education to improve understanding of breast cancer and screening mammography may help to improve rates for earlier detection of breast cancer.

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Introduction

Breast cancer is the most common cancer in women worldwide, accounting for 25.1% of all cancers.¹ In 2012, it was estimated that the global incidence of breast cancer was close to 1.7 million, with 521,907 deaths attributed to the cancer.¹ Breast cancer is also the most common cancer in Singaporean women, accounting for 29.3% of all cancers in women between 2007 and 2011.² In 2018, it was the third most common stage 4 cancer in Singapore.³ The 5-year survival rate for early-stage breast cancer exceeds 80%, and ranges from 10–40%

for advanced breast cancer (ABC).⁴ This difference underlies the rationale for breast screening to facilitate early detection and treatment, while taking into consideration that the disease and treatment process can lead to a range of physical and emotional effects on patients.⁵

A nationwide screening mammography programme was set up in 2002. Despite this, ABC remains common in Singapore. In 2012, 28.8% of women diagnosed with breast cancer in Singapore presented with ABC;^{5,6} for comparison, a study by Anttila et al. tabulated 9.2%

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of women in Finland aged 55–59 and 60–64 respectively, who were observed with incidence of non-localised breast cancer upon screening.⁷ Helvie et al. reported a 37% reduction in late-stage breast cancer in the US following the introduction of a screening programme.⁸ Women with large tumours and clinically palpable nodes comprise the majority of cases presenting with advanced disease. These women generally present to symptomatic clinics and many do not attend routine screening. A Singapore national health survey conducted in 2015 found that only 38.9% of women between the ages of 50 and 69 years attended the national mammographic screening.⁹ Wong et al. reported that 32.9% of women in Singapore eligible for the national mammographic screening attended at least once every 2 years, with 66% of the women surveyed reported to have attended a screening mammogram at least once.¹⁰ This is lower than international attendance rates.^{11–13} Despite increasing affluence and the advent of national mammographic screening, many countries have observed little change in the incidence of ABC,^{14–17} implying that a proportion of women do not attend screening and continue to present late.¹⁸

In this study, we sought to understand the psyche of women who present with ABC. We conducted a questionnaire-based survey to gain insight into the socio-economic background, knowledge and attitudes of women who present late, and identify factors to better promote awareness of early detection and treatment.

Methods

This was a prospective study carried out in a single tertiary institution between December 2013 and July 2015. One hundred consecutive women presenting with ABC to our unit were recruited. This study was approved by the institutional ethics committee (DSRB2010/00031). We included women presenting with breast tumours >5cm in size and clinically involved nodes, women with regional lymphadenopathy, tumours directly involving the overlying skin or chest wall, women with extensive nodal disease regardless of tumour size, and women who presented with de novo metastasis.

The questionnaire was designed based on an existing questionnaire that was used for the Singapore Breast Cancer Cohort Study, a multi-institutional cohort study established in 2009. Additional questions related specifically to breast cancer screening were derived from frequently asked questions and feedback obtained from patients and women who attend our breast cancer awareness outreach.

The questionnaire survey was divided into sections, which included questions regarding the functional and

general health status; socio-economic status; personal breast cancer risk factors; knowledge about breast cancer and screening mammography; attitude towards screening and breast cancer diagnosis and treatment; as well as personal presentation and diagnosis of breast cancer. A single research assistant conducted the interviewer-led questionnaire.

Results

We recruited 100 women who presented with ABC for our study; 63% had presented with stage 3 disease and 37% had presented with stage 4 disease. The median age at presentation was 57 years (ranging from 27–86 years). We also approached 149 patients who were newly diagnosed with ABC for participation. The response rate was 67.1%, with 49 patients declining participation.

The ethnic breakdown within this group showed a population comprising 76% Chinese, 13% Malay, 6% Indian, and 5% of other races. This is similar to the general population make up make-up Singapore.

Majority were married. Fifty-four percent of the women lived with their children, while 9% stayed alone. More than half of these women had at least secondary schooleducation, with 6% having a bachelor's degree or higher qualification. Only 14% had no formal education. About half of the women had no formal employment, while 24% were professionals or in managerial or skilled jobs (Table 1). A third (37 of 100) of the patients knew of family or friends who had been diagnosed and treated for breast cancer. The large majority (88 patients) claimed to be aware of the symptoms of breast cancer, with nipple discharge and palpable breast lumps known to most of them.

The majority of women were also aware of the national screening mammography programme and 82% agreed that screening mammography could help to detect breast cancer. However, 96% of the women who presented with ABC had never undergone a mammogram assessment. Only 70 women were willing to answer why they did not attend screening mammography. When asked, 52.9% (37 of 70) of the women replied that they felt it was unnecessary to undergo screening if they were asymptomatic. A third of women (31.4%) stated that they were not aware of how to get a screening mammogram done, even though they were aware of such a programme. Eight of 70 women (11.4%) did not attend screening because of the perceived pain from the mammogram compression (See Table 2).

Fifteen of 100 women believed that screening mammography would lead to unnecessary investigations and treatment, and 11 women believed that frequent

Table 1. Demographic data of patients with advanced breast cancer (total n=100)

Demographics	n (%)	
Median Age (years)	57	(27–86)
Race		
Chinese	76	(76)
Malay	13	(13)
Indian	6	(6)
Others	5	(5)
Social support		
Marital status		
Never married	29	(29)
Previously/currently married	71	(71)
Who patient lives with:		
Children (with or without spouse)	54	(54)
Spouse only	9	(9)
Other relatives	26	(26)
Unrelated persons	2	(2)
Lives alone	9	(9)
Highest academic qualification		
None	14	(14)
Primary school	34	(34)
Secondary school	37	(37)
Diploma / Vocational institute	9	(9)
University	6	(6)
Occupation		
Professional	4	(4)
Managerial / Skilled	20	(20)
Partly skilled / Unskilled	23	(23)
Unemployed	53	(53)

Table 2. Knowledge and attitude towards breast cancer and mammogram (MMG) screening

Questions and responses	Responses, n (%)
Knowledge and attitude towards breast cancer and mammogram (MMG) screening:	Total n=100
Aware of breast cancer risk factors	85 (85)
Aware of screening MMG	73 (73)
Aware that MMG can detect breast cancer	82 (82)
Feel that MMG is an unnecessary investigation	15 (15)

Table 2. Knowledge and attitude towards breast cancer and mammogram (MMG) screening (Cont'd)

Questions and responses	Responses, n (%)
Feel that frequent MMGs can cause cancer	11 (11)
Awareness of breast cancer symptoms known to group:	Total n=100
Nipple discharge	88 (88)
Change in nipple position	55 (55)
Nipple retraction	51 (51)
Nipple rash	36 (36)
Recent breast lump	86 (86)
Painful breast lump	73 (73)
Painless breast lump	66 (66)
Sudden onset of breast lump	64 (64)
Axillary lump	62 (62)
Asymmetry of the breast	59 (59)
Skin changes	52 (52)
Mastalgia	46 (46)
Aware that women are still at risk of breast cancer if:	Total n=100
They have no medical problems	85 (85)
They have no previous breast problems	82 (82)
Patients are parous	80 (80)
There is no family history of breast cancer	79 (79)
There are breast implants	77 (77)
Women give birth before the age of 30 years	76 (76)
There is no use of exogenous hormones	74 (74)
Women breastfed	71 (71)
Women had previous breast imaging	47 (47)
Reasons for not going for mammography:	Total n=70
Unnecessary as patient was asymptomatic	37/70 (52.9%)
Unsure where mammography can be done	22/70 (31.4%)
Cost	3/70 (4.3%)
Fear of perceived pain from mammogram	8/70 (11.4%)
View on breast cancer treatment:	Total n=100
The treatments are effective and can cure cancer	82 (82)
The treatments can only stop the cancer for a while but the cancer will surely return	12 (12)
The treatments are not effective and make no difference	4 (4)
Refused to answer	2 (2)

mammograms could cause cancer. Most women believed the current breast cancer treatments are effective, while 12 women felt that relapse was inevitable and that current treatments provided only temporary control.

Sixty-four women presented to the clinic with symptomatic disease. A breast lump was the most common presenting complaint, occurring in 34 of the 100 women (Table 3). The median interval from the time of detection to clinic attendance was 3 months. Twenty-two women claimed that they were unaware of any symptoms until it was brought to their attention by other doctors, their family or friends.

Table 3. Primary reason for investigating breast lump (total n=100)

Primary reason for investigating breast lump	n (%)
Enlarging breast lump	34 (34)
Painful breast lump	23 (23)
Incidental clinician-detected lump during health checks for other reasons	20 (20)
Did not specify	9 (9)
Blood / discharge from lump	7 (7)
Family / friend noticed the problem	2 (2)
Refused to answer	2 (2)
Nipple discharge	1 (1)
Nipple changes	1 (1)
Metastatic symptoms	1 (1)

Discussion

Many women continue to present with ABC at our institute. A review of our data found an incidence of 28.8% in the 6 years after the start of the national breast cancer screening programme, BreastScreen Singapore (BSS). By 2019, 18 years since the start of BSS, ABC still accounted for 22.1% of all new cancer cases diagnosed at our unit. ABC accounted for 21–26% of all new breast cancer cases annually between 2016 and 2019.

In our previous work, we found Malay women to present late more often, compared to Chinese women.¹⁹ However, within this group of women with ABC, there was no ethnic bias and the ethnic breakdown of patients who presented with ABC was similar to that of the ethnic breakdown of the population in Singapore (74% Chinese, 13% Malay, 9% Indian and 3% other races).²⁰ Wong et al. reported that Malay women were least likely to seek mammographic screening; this could also be true for our participants, though it would not

be possible to infer this from our study given that we have focused only on women presenting with ABC.¹⁰ In 2014, the majority of patients were diagnosed with breast cancer between the ages of 45 and 64.²¹ The median age of presentation of women with ABC in our unit was 57, which falls within the usual age range for breast cancer presentation, and not an older age group, as suggested previously.²²

Poor socio-economic support and lack of education have often been cited as reasons for why women do not present in a timely manner.¹⁰ In our study, the large majority of the patients had at least primary school education, implying that they were able to read and understand most of the materials used in the awareness outreach programmes. Education levels did not always affect patients’ decision to seek medical attention early or attend screening mammography.^{14,18} Social support appeared adequate, with two thirds of the patients staying with their children or spouses. Furthermore, screening mammogram and specialist consults are subsidised by the government, and co-payment schemes ensure that screening and healthcare remain affordable and accessible regardless of the patient’s financial status.

Almost all the women (96%) had never undergone a previous mammography. This was despite more than 80% being aware of breast cancer symptoms, knowing that mammography could detect breast cancer, and being confident that current modalities were effective in treating breast cancer. More than half of the women had not thought it necessary to attend screening since they had no symptoms. Such is the prevailing attitude among many women, and only 30–40% of women above 50 years of age adhere to the recommended mammography screening interval of every 2 years.^{9,10} About 11% of women cited pain from mammography as the main reason why they avoided it. Currently, public forums on breast cancer are regularly organised, with many falling in the Breast Cancer Awareness Month in October. Screening mammography is subsidised by the government under the BSS programme. Greater engagement with the public has been initiated through public forums, engagement with primary healthcare physicians to encourage screening mammography during clinic encounters with patients, advertisements on the need for screening mammography, and pamphlets sent out to women between the ages of 50 and 69 to invite them to attend BSS screening. Unexpectedly, despite the publicity, a third of the women surveyed claimed to not know where to go to have a screening mammogram.

The incidence of ABC would be expected to decline with the implementation of national screening programmes. Reports from the US and Germany

demonstrated consistent decline in the incidence of ABC with the introduction of mammographic screening.^{8,23} However, it would seem that within our surveyed group, there remains a group of women who fail to respond to efforts to promote routine screening. Autier et al. had also described no significant reduction in ABC incidences in countries (Australia, Italy, the Netherlands, Norway, Switzerland and the US) with widespread sustained mammographic screening, with an uptake rate of $\geq 60\%$ in the recommended national screening frequency over at least 7 years.^{15,16}

The rationale for screening mammography arises from data supporting survival benefits of early detection and treatment. The US Preventive Services Taskforce reported a 15% reduction in breast cancer mortality following mammographic screening for women aged 39–49 (relative risk 0.85).²⁴ The inverse correlation between survival and disease stage would imply that earlier presentation and treatment would improve outcomes.⁴ An earlier stage of cancer diagnosed would likely reduce the need for systemic treatments like chemotherapy. We should therefore continue to push for more active uptake of screening mammography among Singaporean women. Our study demonstrates that there is a percentage of women who continue to not attend screening despite established outreach. Socio-economic and education levels do not seem to be the main issues. Rather, many of the women surveyed were not convinced of the need for screening mammography in the absence of any breast symptoms. The results indicating majority of the women as being aware of the symptoms of breast cancer likely reflects the success of outreach programmes that tend to emphasise the warning signs and symptoms of breast cancer. Steering outreach programmes to educate women on the rationale and benefits of screening when there are no symptoms of breast cancer can help improve awareness on the need to attend screenings.

One of the limitations of this study is response bias, as the group of women who were willing to be interviewed may potentially have a slightly different outlook of breast cancer screening and treatment. However, this is inevitable, especially when approaching this group of women who may be emotionally sensitive about their advanced breast cancer and treatment, and may be less willing to answer. This was also noted during the course of the study when 2 women had declined to give their views on breast cancer treatment as they were upset about their health condition. The

research team sought to decrease the risk of response bias through the larger study group of 100 participants.

Conclusion

Advanced breast cancer is still a pertinent problem in Singapore. While most women have faith in the utility of screening mammography and the effectiveness of breast cancer treatment, they tend to feel that breast cancer will not affect them. Increased public education on the incidence of breast cancer and the importance of screening mammography will help to decrease the incidence of advanced breast cancer in the long run.

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