Challenges and opportunities for breast cancer early detection among rural dwelling women in Segamat District, Malaysia: A qualitative study

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Abstract

Introduction
Breast cancer patients in low- and middle-income countries often present at an advanced stage. This qualitative study elicited views regarding the challenges and opportunities for breast cancer screening and early detection among women in a low-income semi-rural community in Segamat district, Malaysia.

Methods
Individual semi-structured interviews with 22 people (health professionals, cancer survivors, community volunteers and member from a non-governmental organization) and four focus group discussions (n = 22 participants) with women from a local community were conducted. All participants were purposively sampled and female residents registered with the South East Asia Community Observatory aged ≥40 years were eligible to participate in the focus group discussions. Data were transcribed verbatim and analyzed using thematic analysis.

Results
The thematic analysis illuminated barriers, challenges and opportunities across six domains: (i) personal experiences and barriers to help-seeking as well as financial and travel access barriers; (ii) primary care challenges (related to delivering clinical breast examination and teaching breast-self-examination); (iii) secondary care challenges (related to...
mammogram services); (iv) disconnection between secondary and primary care breast cancer screening pathways; and (v) opportunities to improve breast cancer early detection relating to community civil service society activities (i.e. awareness raising, support groups, addressing stigma/embarassment and encouraging husbands to support women) and vi) links between public healthcare personnel and community (i.e. improving breast self-examination education, clinical breast examination provision and subsidised mammograms).

**Conclusion**

The results point to a variety of reasons for low uptake and, therefore, to the complex nature of improving breast cancer screening and early detection. There is a need to adopt a systems approach to address this complexity and to take account of the socio-cultural context of communities in order, in turn, to strengthen cancer control policy and practices in Malaysia.

**Introduction**

Breast Cancer (BC) is the most common cancer amongst females in Malaysia with an age-standardised incidence rate (ASR) of 34.1/100,000 [1]. Late-stage presentation is a major challenge in Malaysia and has increased from 43.2% between 2007–2011 to 47.9% between 2012–2016 [1]. BC screening of asymptomatic women is key to detecting and treating cancer early and improving outcomes for cancer patients. Mammography and clinical breast examination (CBE) are the most common BC screening methods globally. Mammography is an x-ray imaging method used to examine breasts for tumours. BC screening is opportunistic in Malaysia and the Ministry of Health recommends for women in the general population aged 50–74 years to be offered mammography biannually [2]. CBE is a physical exam of the breast by clinical staff to check for lumps or other signs of BC. It is a low-cost screening method that, if performed well, achieves the same effect as mammography in terms of mortality [3]. Opportunistic screening requires health care professionals to prompt women who attend the clinic for other reasons to be screened for BC or for women to notice a change in their breast and seek help. Breast self-examination (BSE) is commonly taught to women to regularly self-check for abnormal signs and symptoms, in particular lumps.

Despite these recommendations and efforts to educate women about BC and BC screening, mammography screening in Malaysia has been a particular challenge in rural communities and remains low despite efforts to implement mobile screening camps [4,5], i.e. it has been reported to range from 6.8% to 8.3% in rural areas and from 8.3% and 15% in urban and suburban areas [6]. Disparities in BC screening between women from rural/urban areas as well as from different socio-economic backgrounds have been observed around the world but with greater differences in low- and middle- income countries (LMICs) [7–10]. An in-depth understanding of the unique challenges that women as well as health care providers from rural areas face in providing BC screening is necessary to address the disparities in BC screening uptake in Malaysia. Previous studies that investigated barriers to BC screening uptake have mainly been of quantitative nature [11–14] and some qualitative studies have explored perceived barriers to screening in breast cancer patients [15]. It has been suggested that stigma associated with BC, fear of diagnosis, lack of knowledge, financial concerns and cultural concerns are common barriers to screening [6,16]. Views of women with no BC history within semi-rural communities have not been explored qualitatively. Similarly, there is a lack of understanding...
of health system challenges and opportunities perceived by health professionals in Malaysia. The scope of this research included several studies about BC screening and its uptake in Segamat District of Malaysia. The results presented in this paper focus on the qualitative exploration of the challenges, barriers and opportunities that women and health care professionals describe regarding BC screening in Malaysia.

Methods

This was a qualitative study based on focus group discussions (FGDs) with women from semi-rural communities in Malaysia and semi-structured interviews with key stakeholders that were conducted between July and September 2017. Purposive sampling was used to select participants. All participants provided written informed consent prior to each interview/FGD. We followed the consolidated criteria for reporting qualitative research guidelines (COREQ) to report the conduct and results of this study [17].

Setting

Malaysia is an upper middle-income country located in South-East Asia. Its multi-ethnic population of 32.4 million people is made up of 70% Malays, 23% Chinese, 7% Indian, and 1% of other ethnicities [18]. This study was conducted at the South East Asia Community Observatory (SEACO), a health and demographic surveillance system located in Segamat district, in the state of Johor in Peninsular Malaysia [19]. SEACO operates in 5 of the 11 sub-districts in Segamat, covering an area of approximately 1250 km$^2$. The ethnic representation of the SEACO population is fairly representative, i.e. 62% Malay, 18% Chinese, 10% Indians, 2% indigenous peoples (Orang Asli), and others (8%) [19]. Participants for this study were selected from semi-rural settings under SEACO and recruited over the phone.

Focus group discussions

The objectives of the FGDs were to explore the community’s understanding and perceptions of BC, BSE, CBE and mammogram screening, as well as perceived challenges to attend BC screening. Women aged ≥40 years from SEACO residents were eligible to participate. Participants were identified through the SEACO community engagement committee [20]. A total of 22 multi-ethnic women participated in four face-to-face, semi-structured FGDs that were held in local community centres. A trained female anthropology student conducted the FGDs together with a trained female SEACO research staff who spoke Malay and Mandarin. Handwritten verbatim notes were produced in addition to the audio recordings. The sessions were recorded, transcribed and translated into English. Each FGD began with an initial round of introductions, an explanation of the topic and research objectives, followed by guided FGDs that lasted up to one hour.

Individual semi-structured interviews

The objectives of these interviews were to explore perceptions about BC services, utilization levels of the services and perceived challenges faced in delivering the services. The interview topic guides were developed based on expert panel discussions and a literature review. Twenty-two people participated in semi-structured interviews, including staff nurses under the Ministry of Women, Family and Community Development (LPPKN), physicians from the breast clinic, nurses, a radiologist and a radiographer from a secondary district hospital, doctors and nurses from community and district health centres, general practitioners (from private clinics), volunteers from the Breast Cancer Support Society Segamat (BCSS), community
volunteers and BC survivors. A trained female anthropology student conducted all interviews in English and a female SEACO research staff produced hand-written verbatim notes in addition to the audio recordings. Interviews were conducted in participant homes/offices and lasted approximately 40 minutes. All interviews were audio-recorded and transcribed.

Data analysis
A thematic analysis was conducted in NVivo vs 12. Three authors (WMKH, DS and MMT) coded the interviews independently, compared the codes and identified sub- and key-themes. Any disagreements were discussed with co-authors until an agreement was reached.

Ethical approval and consent
This study received ethical approval from the Monash University Human Research Ethics Committee (ID 29682) and Malaysian Medical Research and Ethics Committee (NMRR-17-1244-35902). Consent to participate was gained verbally during the telephone recruitment interview.

Results
The separate analysis of the individual interviews and FGDs generated the same themes and, so, they are presented together. Table 1 shows the background of participants who completed the interview and Table 2 demonstrates the socio-demographic background of FGD participants. The data analysis generated six key themes that revolved around challenges (n = 3), barriers (n = 1) and opportunities (n = 2).

• Primary care limitations (in terms of the extent to which it can provide gender sensitive and targeted CBE screening services)
• Challenges in providing mammograms in public sector secondary care hospitals
• A disconnection between primary care-oriented BC screening pathway and secondary care
• Personal experiences and barriers to help-seeking
• Community and civil society activities
• Links and networks between public healthcare personnel and community.

Each theme is discussed here and relevant quotes are presented in Table 3.

| Interviews                                           | Participants (n) |
|-----------------------------------------------------|------------------|
| Breast cancer survivors                            | 4                |
| Community volunteers                                | 4                |
| General practitioners                               | 3                |
| District hospital (doctors, radiographer, nurses)   | 4                |
| District health clinics (doctors & nurses)          | 3                |
| Breast cancer support society (BCSS) members        | 2                |
| Staff nurses from the National Population and Family Development Board Malaysia under the Ministry of Women, Family and Community Development (LPPKN) | 2 |
| **Total**                                           | **22**           |

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1 Challenges

1.1 Primary care limitations (in terms of the extent to which it can provide gender sensitive and targeted CBE screening services). The primary health care service (i.e. general practice clinics and family planning clinics in Malaysia) is the first call of contact for patients with acute or chronic illnesses as well as for preventative medicine. Its role in BC early detection is to facilitate biannual CBEs to eligible women and to teach women BSE. A major challenge reported by nurses and doctors to facilitating CBE and BSE was the high workload of staff and, hence, a lack of time to discuss preventative screening with asymptomatic patients. Some doctors also commented on the variable skills of nurses to detect abnormalities during a CBE, particularly amongst junior staff. Long waiting times in clinics and the limited number of female staff for CBE screening in clinics were challenges reported by FGD participants since women reported to feel uncomfortable to have their breasts checked by male staff.

Nurses described that BSE was often taught to women of child-bearing age (aged ≤40 years) during antenatal or postnatal check-ups and mother-child visits. BSE is commonly

| Table 2. Socio-demographic information from FGD participants (n = 22). |
|------------------|---|---|
| **Age**          | n | %  |
| 30–39            | 1 | 4.5 |
| 40–49            | 9 | 40.9|
| 50–59            | 7 | 31.8|
| 60–69            | 4 | 18.2|
| ≥70              | 1 | 4.5 |
| **Ethnicity**    |   |    |
| Malay            | 5 | 22.7|
| Chinese          | 5 | 22.7|
| Indian           | 6 | 27.3|
| Orang Asli       | 6 | 27.3|
| **Education**    |   |    |
| No formal education | 3 | 13.6|
| Primary          | 8 | 36.4|
| Secondary        | 7 | 31.8|
| Tertiary         | 1 | 4.5 |
| Missing          | 3 | 13.6|
| **Household income** |   |    |
| < RM 1,000       | 8 | 36.4|
| RM 1,000 –RM 4,000 | 11 | 50.0|
| Missing          | 3 | 13.6|
| **Sub-district** |   |    |
| Sungai Segamat   | 4 | 18.2|
| Gemereh          | 5 | 22.7|
| Bekok            | 6 | 27.3|
| Chaah            | 6 | 27.3|
| Pogho            | 1 | 4.5 |
| **Distance to nearest clinic (km)** |   |    |
| <5km             | 16| 72.7|
| 5-10km           | 0 | 0  |
| ≥10km            | 6 | 27.3|

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## Table 3. Key- and sub-themes identified in the focus group discussions and interviews.

| Key themes | Sub-themes | Quotes |
|------------|------------|--------|
| 1. Challenges | Insufficient staff resources and high workload | "I ask myself, how can I, without crying, see so many people come here? Last time I only had 2 staff, with my assistant, I didn't have anyone. Last year I was very, very bad (sad). Even for social media, I didn't take any photo. My children will say, if you don’t work over the weekend, ah, and at the end of the month when we have written mail, I stay up, even one day, full week. I didn’t work from 6AM in the morning until 6PM. I stayed here from 6AM and 6PM. Last time, I cried (laugh), it was so hard."
| | Long waiting times | "Other people. They prefer home visits. In the clinic, the wait is long, they don’t want to waste their time." | 657-118 GMD Malay |
| | Unavailability of female staff for CBE | "... Many people, if they work only in boxing doctors, they will feel embarrassed." | 657-118 GMD Malay |
| | Insufficient patient information about mammogram screening | "... Some patients, when they do not understand, they will not come for mammogram screening."
| | Variable CBE clinical skills | "... They prefer home visits, the wait is long.
| | Poor mammogram screening for women of child-bearing age | "... They prefer home visits, the wait is long."
| | Poor maintenance of facilities (not just the equipment) | "... Poor maintenance of facilities (not just the equipment)"
| 1.2 Challenges in providing mammograms in public sector secondary care hospitals | Unavailability of female radiograph in breast cancer care | "... We have 40 only if we are female radiographers, it is also difficult to train, so sometimes female radiographers when work night, she will be working in the afternoon, so we lack of staff."
| | Lack of funding to subsidise mammograms | "... They lack of funding to subsidise mammograms..."
| | Poor patient information about mammogram screening | "... Poor patient information about mammogram screening..."
| | Poor information given to patients about mammogram screening | "... Poor information given to patients about mammogram screening..." |
| 1.3 A disconnection between primary care-oriented BC screening pathway and secondary care | Gaps in existing Mabanggo’s budget for mammogram screening | "... Gaps in existing Mabanggo’s budget for mammogram screening..."
| 2. Barriers | Insufficient staff resources and high workload | "... Insufficient staff resources and high workload..."
| | Long waiting times | "... Long waiting times..."
| | Unavailability of female staff for CBE | "... Unavailability of female staff for CBE..."
| | Variable CBE clinical skills | "... Variable CBE clinical skills..."
| | Poor mammogram screening for women of child-bearing age | "... Poor mammogram screening for women of child-bearing age..."
| | Poor information given to patients about mammogram screening | "... Poor information given to patients about mammogram screening..." |
| 2. Barriers | Insufficient patient information about mammogram screening | "... Insufficient patient information about mammogram screening..."

(Continued)
Table 3. (Continued)

| Key themes | Sub-themes | Quotes |
|------------|------------|--------|
| Personal experience and barriers to help-seeking | Poor awareness and understanding of BC screening | "Because, another thing is that many don't understand what mammogram is, they don't understand and don't want to know about it, the people from long time ago, women, because this refer the above 40 years old, like the elder women with grand babies, age of more than 60, they do not want to do it, because they didn't study much, so they do 'what's that thing, don't need it, don't want'--LPPKN nurse. "Some said if they have the song, it will kill the cells, so they are afraid of getting this, they are like negative. Difficult too."--LPPKN nurse. "I am very sad, many people still don't know about breast cancer"--Cancer survivor. |
| Law perceived susceptibility | Preference for traditional treatment due to fear or lack of knowledge about medical procedures | Sometimes, they are afraid of the diagnosis. They would rather resort to a traditional healer. --FGD Malay. "I'm very sad is the doctor's advice,"--Private clinic doctor. "I won't have breast cancer so they don't have to check or do anything."--Government clinic doctor. "I'm very sad is the doctor's advice,"--Private clinic doctor. "So if you are told by a traditional healer, they are afraid of the diagnosis. They would rather resort to a traditional healer."--FGD Malay. |
| Financial concerns | Access barriers (transportation, multiple visits) | Last time we use to come from KL as we do have van, we can take up 30 people, serve the public, and then they pay RM30 for mammogram, and we all can patient free (laugh), transportation RM30, because we have a van, we have a driver, but now, we heard that we have a mammogram there, all expenses, because they are not going to subsidise, because last time storing they give us 500 people every year, after that they reduce to 800, last year.--Cancer survivor. "But for us--we are a bit troublesome. Quite difficult."--LPPKN nurse. "...not everyone will come, some are easy to come by the clinic and collect medicine, the other half is rather difficult for them to visit the clinic."--Government clinic doctor. "Because some of them, most of them, have their own transport. Some of them have to rest at 1AM, RM50 per travel, RM100 just for them to come to the centre."--Government hospital doctor. "Sometimes they cannot come because of the vehicles, sometimes 1 or 2 get them. They poor and have a transportation problem."--Community Volunteer. |
| Ethical differences (awareness, interest in screening, preference for doctor, willingness to pay) | Language/ literacy and health literacy barriers (materials are not tailored to address) | Poor support from husband who is often the main decision maker "Ah, they don't come..." we have our organizations, so the earlier about the health education to the husbands... we do all the husbands, they say no, no, no, I'm not interested."--Community Volunteer. Embarrassed and afraid. They are afraid of the diagnosis, that they may have to remove a breast. Then, their husband will find another woman. But for us--we are a bit troublesome. Quite difficult."--LPPKN nurse. "They are afraid that this machine will cause pain..."--Government hospital doctor. "They are afraid that this machine will cause pain..."--Government clinic doctor. "Sometimes, the husbands do not allow us to show bodies to another man, even outsider. Sometimes if we mentioned we are not feeling well, the husband would say it is a little thing only."--FGD Malay. "I think the Malay and Indian, mostly the Malay they will follow the husband, sometimes, they won't get permission from the husband, the family knew."--BCS member. |
| Competing priorities (child care) | Breast of health checks (i.e. faced in pain and costs) | "Malay take care of grandchildren, so they have to come. They come out, sometimes they say okay, if you do it Monday, today, not today. The mother can take the child, they say to me. So sometimes we do like that, Friday--Community Volunteer. Ever on two or back out because they couldn't get somebody to take their children. So they said they cannot."--Community Volunteer. "I always said that, for Orang Asli, sometimes they fill embarrassed to talk about this."--Government clinic doctor. "If the clinic is only male doctors, we would feel embarrassed. It is really a feeling of embarrassment."--FGD with the Malay community member."--FGD Malay. "Even if a woman has breast cancer, sometimes they are shy to see the doctor. There are a lot of male doctors. The women are afraid to expose their bodies."--FGD Indian. "Sometimes, the husbands do not allow us to show our bodies to another man, even a doctor."--FGD Malay. |
| Embarrassment (to talk about BC and to show body to male doctors), used husband's permission | Fear of health checks (i.e. fear of pain and results) | "But you know all people, even if they are free health checks, they don't really want to attend. They are scare, when they found out that that they are sick, they get scared."--FGD Malay. "First, the Orang Asli are afraid, indeed, second, they are embarrassed. They always said, I'm so scared, you know, definitely will say so."--Government clinic doctor. "You asked me, is it very painful? I said no, it is okay. Actually, it is only a little piece, I asked for them, you know your hands is painful? I said no, just a bit, doesn't matter."--Cancer survivor. "Yeah, many said they are afraid, afraid of the pain, and also the result, fear of having the bad results."--LPPKN nurse. "They are afraid that this machine will cause pain."--LPPKN nurse. "But one thing that I promiss, maybe in one other thing that we should promote is not only, that ugly picture of breast cancer, we should show them the breast reconstruction also. Because normally the women are very panting [shocked] below the breast because if you don't have a breast anymore then you are not a woman anymore. So they are afraid to show their breasts."--Government clinic doctor. "This is important or you? They see a few you know, my hair drop, then don't want me, then they have to explain to them, why you need chemo. So many people don't go for chemo, I have to explain to them, why you need chemo. And then some of them, I knew it's very frightening, I want to go to, but I am sure you know how many, how they operate."--Cancer survivor. "Sometimes I have to shave my breast. Take it off, you see just on only mark and no stitches, so they said, there was few in the Bare them, I showed them, oh that only OK, then I didn't mind too."--Cancer survivor. |
| Breast of treatment (fear of losing hair and losing breast) | (Continued)
We do all talk and awareness campaign whereby we teach them how to do BSE. It is very important for finding the initial stage, early detection. In this way we would teach them the way. So we would be organizing awareness campaign in schools or in anywhere. Community Volunteer

We normally do the health talks in a place. We ask the woman to assemble in a particular house. The number is not many, maybe five. They came and we gave a demonstration and taught them on breast self-examination. Community Volunteer

We always have talks and bring the pamphlets and show everybody, and sometimes we ask those who did mammogram to spread the word with their neighbours. FRPSN nurse

Sometimes the BSE hits us target talks. Other than that, we also collaborate with political parties such as UMNO, and with the club for wives of policemen. Government hospital doctor

When patients handed to us, straight away we teach them breast self-examination, they have to do it in front of mirror. A government hospital doctor

Yeah, I will demonstrate and teach them breast self-examination in the female patients who are around the age where they should be practicing that. Private clinic doctor

We must increase our budget to perform mammogram because it's always high demand, so if we have the budget, we should increase the subsidy quota for mammograms screening. FRPSN nurse

| Key themes | Sub-themes | Quotes |
|------------|------------|--------|
| 3. Challenges | Community civil society activities | Community education to raise awareness about BC and screening | We do all talk and awareness campaign whereby we teach them how to do BSE. It is very important for finding the initial stage, early detection. In this way we would teach them the way. So we would be organizing awareness campaign in schools or in anywhere. Community Volunteer |
|             | Support groups | | At times has gone by, we did all caring and sharing that, it was different. Caring and Sharing is done in other ways. Sewing, whereby they sit down together and talk, as they sew they will talk. Community Volunteer |
|             | School awareness programmes | | Secondary school would be the best, because once secondary school they are exposed to science subjects. I think it is better. Government hospital doctor |
|             | Address stigma and embarrassment about breast cancer | | I think less for breast cancer or even cervical cancer its like the talk they make it very very open, like public, everybody wouldn't feel shy anymore you know, like breast, don't know, feel shy and embarrassed to grindask, but once we open, public, then they will not feel any shy, they can ask anybody, they can discuss among themselves and also openly. Private clinic doctor |
|             | Target husbands to support women in seeking breast health care | | It would be a wise action to involve men in how to offer breast cancer support. But they don't know whether the men would attend or not. At least they would be more aware. FRPSN Chinese |
|             | Improve currently sporadic BSE education at primary and secondary care level | | We always have talks and bring the pamphlets and show everybody, and sometimes we ask those who did mammogram to spread the word with their neighbours. FRPSN nurse |
|             | Provide financial support, i.e. subsidised mammograms | | Sometimes the BSE hits us target talks. Other than that, we also collaborate with political parties such as UMNO, and with the club for wives of policemen. Government hospital doctor |

BCare – Breast Cancer unit in Hospital Segamat; MOH – Ministry of Health, IIMU – International Islamic University of Malaysia (IIUM has a Specialised Breast Centre)

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taught by showing women pictures of the technique without any physical contact due to the conservative nature of the country and the lack of private facilities during community outreach programmes.

1.2 Challenges in providing mammograms in public sector secondary care hospitals. This sub-theme relates to challenges experienced by hospital staff regarding mammogram screening. Similarly to staffing challenges in the primary care sector, there was a lack of staff specialised in BC care, particularly female radiographers that are mandatory for providing mammogram services. Interviewees reported that only about 30% of hospital radiographers were women. Furthermore, the subsidised District Hospital could only offer a limited number of mammograms each month and the number of mammograms has been reduced over the years. This leaves many women, who don’t want to pay or are not able to pay for a mammogram, waiting. Due to budget constraints, the mammogram equipment and other facilities such as air-conditioners necessary for its operation were old or not always well maintained and could breakdown easily. FGD participants and nurses also reported that women often lacked knowledge about the importance of mammograms and the health care staff in the public sector did not have the time to provide detailed explanations due to a high patient volume and work load.

1.3 A disconnection between primary care-oriented BC screening pathway and secondary care. Hospital physicians described that community clinics had to meet monthly appointment/screening key performance indicators (KPIs) for CBE that were set by the government. Therefore, BC screening services offered to patients directly from the hospital were not supported by the primary care providers, thus reducing referrals and extending waiting times for patients.

2 Barriers

2.1 Personal experiences and barriers to help-seeking. Personal barriers were most discussed by women participating in the FGDs and also recognised by a number of health care professionals. Participants reported that many women from rural areas in Malaysia have very limited knowledge and awareness about BC, did not want to know about it (denial), were misinformed about cancer or cancer treatment or did not think that they were susceptible to getting BC and therefore were not interested in screening. Some women believed in treating cancer with traditional medicine, either alone or in combination with Western medicine, particularly women from the Orang Asli community. Other ethnic differences in terms of breast health seeking were also reported—mainly that Malay women must see a female nurse or doctor for BC screening, whilst Indian and Chinese women can see male doctors. Chinese Malaysian women were also reported by health care staff to be most interested in preventative health testing compared to other Malaysian women.

Malay women reported that some husbands did not permit their wives to show their body to another man and feared that their husband may leave them after a breast removal surgery. Women from all ethnicities expressed embarrassment to show their body to a male doctor or to talk about breast health issues. Child care was a competing priority for some women who said they would not have time for breast checks. FGD and interview participants described that some women were scared of being diagnosed with cancer or that the screening was painful. General practitioners and BC survivors also reported that patients are afraid of breast removal surgery and of losing hair due to BC treatment.

Community volunteers described that some rural women are illiterate and therefore not able to engage with written information (e.g. brochures etc). Language barriers were an issue if health care provider did not speak the primary language of the patients.
Community access barriers, such as having to pay for mammograms was another barrier to participate in screening, as well as difficulties in travelling to the clinic or hospital for CBEs/ mammograms and multiple visits needed were reported by nurses, volunteers, doctors and cancer survivors.

3 Opportunities

3.1 Community civil society activities. Non-Governmental Organisations (NGOs), community volunteers and nurses from the Ministry of Women, Family and Community Development ran community outreach events and awareness campaigns to educate on BC and demonstrate BSE in the past, however, participants felt that more could be done to increase awareness, particular in rural areas and amongst the elderly. Clinicians suggested that the stigma around BC needs to be addressed so that women feel comfortable talking openly about their breast health. FGD participants and community volunteers advocated for male relatives to be included in BC screening and early detection campaigns, in particular husbands who often act as the decision maker for their wives. NGO representatives and physicians recommended breast health education to be taught in secondary schools for girls to be educated early. NGO programmes that provided moral support for women were thought of as very beneficial to support women who are worried about BC as well as BC patients.

3.2 links and networks between public healthcare personnel and community. Hospital and clinic staff reported teaching BSE to women who visited government clinics and hospitals, and nurses described health awareness talks that took place in the clinics regularly. Most clinics provide educational brochures with information on BC as part of the awareness talks. Clinicians also and community volunteer collaborated with political parties to receive additional support financial or logistical support (e.g. venue hire). Nurses strongly advocated for an increased number of subsidised mammograms as an incentive to participate in screening.

Overall, awareness raising efforts were depending on the individual clinics, health care staff and clinic budgets and it was suggested to improve the sporadic BSE education within primary and secondary health care settings.

Discussion

The main finding of our study highlights the challenges faced by health systems and community members in sustaining BC early detection. This is one of the few studies that explored the context of BC screening and early diagnosis in a semi-rural area in Malaysia.

Themes spanned across different levels of the health care system and a number of individual barriers were also identified. A major challenge that was reflected across the themes was that screening was opportunistic and partly targeted at age groups not at-risk of developing BC, and therefore women were not routinely educated and prompted to participate in screening and screening services were not adequately resourced to accommodate large numbers of CBEs and mammograms. This was previously recognised as a barrier to cervical screening by healthcare providers practicing in urban areas in Malaysia [21]. Some individual-level barriers also overlapped with those associated with cervical screening, i.e. lack of awareness, low perceived risk, embarrassment, fear of a cancer diagnosis, competing responsibilities and lack of family support [21]. Fear of a cancer diagnosis was also the most commonly reported barrier to screening in Malaysian women previously (75%) [14]. This suggests that women in Malaysia, regardless of location, face similar barriers to access female cancer screening.

A challenge amongst women from rural areas (including women who were interviewed for this study), where general health literacy is commonly lower, particularly in developing countries [22], is the use of traditional medicine [23], especially amongst the Aborigine community.
The use of complementary and alternative medicine has previously been linked to a delay in BC diagnosis and treatment [24]. Previous research also highlighted racial discrimination in hospitals (i.e. non-Orang Asli staff were employed in a government-run Orang Asli hospital), which may have led to distrusting Western Medicine amongst the Orang Asli [25] and may be a major barrier to help-seeking for BC screening. It is therefore important to recognise and address women’s preference for medical treatment and find a compromise in working with traditional and Western medicine practitioners. Lower health literacy amongst rural women may also explain low BC awareness and low perceived susceptibility to getting BC in this study population [26]. Similarly, longer travel distances to a health clinic was a common access barrier amongst rural population groups as reported in this study. Higher education and shorter travel distances to health services were previously linked to better awareness and screening uptake amongst women in Indonesia [27]. Perceived difficulties to access medical support was previously associated with an anticipated delay to seeking medical help for cancer symptoms of over 2 weeks in Malaysia [28].

Due to the ethnic profile of the Malaysian population, health care providers face unique challenges. Findings from the FGDs suggested that the religious, linguistic and ethnic differences affect women’s health seeking needs. Written information is not always provided in all three main languages and Chinese and Indian women who are not fluent in Malay may be disadvantaged when seeking medical help from health care facilities with prominently Malay speaking health care providers. Despite that, Chinese Malaysians are known for engaging better in preventative health care measures compared to other ethnic groups. Malay women in this study reported cultural barriers to BC screening related to the conservative culture. The need to seek permission from their husbands to expose their body to a doctor and the fear of their husbands leaving them if their breasts had to be surgically removed was a barrier for mainly Malay women. Muslim men from conservative cultures often influence women’s decisions and behaviours, which is a major sociocultural obstacle to BC screening and good knowledge about BC amongst husbands was previously associated to their wife’s mammography screening history in Saudi Arabia [29]. This strongly suggests that men also need to be targeted in BC education and screening programmes to improve uptake amongst Muslim communities. Furthermore, training lay health workers form the local community in breast health care may be a low-cost solution to support the varied cultural needs of women in Malaysia and support women to attend BC screening. As such, community health workers have filled in roles to educate women and navigate them to BC screening and conduct CBEs [30].

Women from all ethnic groups reported that they were more comfortable with female health care staff conducting the BC screening and health care providers reported a lack of particularly female support staff to conduct screening (i.e. nurses and radiographers). This was similar to quantitative findings reported previously where 50% women from Segamat reported that male doctors pose a barrier to BC screening attendance [14]. Since BC screening has to be conducted by female radiographers in Malaysia, this likely leads to underuse of mammogram facilities. The Malaysian government should train more female radiographers and nurses specialised in BC screening and early detection. There was also a discrepancy between the need for demonstrating BSE and conducting CBE and the lack of privacy during community screening programmes. Furthermore, women’s financial concerns also opposed the reduction in subsidised mammogram available each month. This is in line with previous research suggesting 70% of women see cost as a barrier to screening [14]. These issues highlight the conflicting reality between women’s personal barriers that are exacerbated by the shortcomings in the healthcare system that have been highlighted in this study [31].

Efforts have been made in the past to increase BC education and screening in rural Malaysia by NGOs, commercial businesses and researchers but awareness campaigns were usually of
short duration, and hence, not sustainable [32]. A 5-week mass media campaign has previously been demonstrated to increase BC awareness in urban and semi-urban areas in Malaysia but it seemed to have no impact on BC screening [33]. This study suggested that one-to-one education about BSE was mostly taught to women of childbearing age, which is not the age group most at risk for BC. More sustainable solutions need to be identified and implemented to improve education, BC screening and diagnosis for women who are at average risk for BC.

The rich data collected from a range of different health professionals and women from different ethnic backgrounds in Malaysia is a strength of this study. A limitation of this study is that and women who agreed to participate in this study maybe be more health conscious than other women. However, the sampling of women from the community rather than a health care setting in our study is likely to provide a more representative sample [23].

Conclusion
Findings from this study highlight a number of health-system and personal barriers that help explain the low BC screening rate amongst Malaysian women. Access to BC screening and early detection services is a major concern for women in semi-rural Malaysia, due to travel, financial and socio-cultural barriers. Opportunities lie in aligning priorities of the different levels of healthcare services and prioritising access to screening through offering culturally appropriate support for women to address embarrassment, fear and BC awareness amongst women and spouses. Opportunities to provide low-cost screening e.g. CBE or other evidence-based screening methods are needed to improve access for semi-rural women in Malaysia. This study is part of a collaborative programme of research about the early detection of BC in Malaysia that comprises several studies including reviews, surveys and the evaluation of efforts to improve the uptake of BC screening. The results of this qualitative study will be triangulated with the results from other studies in the programme including the quantitative analysis of survey data incorporating validated scales.

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