

RESEARCH ARTICLE

Qualitative Assessment of Breast Cancer Early Detection Services Provided through Well Woman Clinics in the District of Gampaha in Sri Lanka

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Abstract

Background: Breast cancer is the most common cancer diagnosed among women in Sri Lanka. Early detection can lead to reduction in morbidity and mortality. The objective here was to identify perceptions of public health midwives (PHMs) on the importance of early detection of breast cancer and deficiencies of and suggestions on improving existing breast cancer early detection services provided through Well Woman Clinics. **Materials and Methods:** A qualitative study using four focus group discussions (FGDs) were conducted among 38 PHMs in the Gampaha district in Sri Lanka and the meetings were audio-recorded, transcribed and analyzed using constant comparison and identifying themes and categories. **Results:** All the PHMs had a firm realization on the need of breast cancer early detection. The four FGDs among PHMs revealed non-availability of guidelines, inadequacy of training, lack of skills and material to provide health education, inability to provide privacy during clinical examination, shortage of stationery, lack of community awareness and motivation. The suggestions for the improvements of the programme identified in FGDs were capacity building of PHMs, making availability of guidelines, rescheduling clinics, improving the supervision, strengthening the monitoring, improving coordination between clinical and preventive sectors, and improving community awareness. **Conclusions:** Results of the FGDs can provide useful information on components to be improved in breast cancer early detection services. Study recommendations were training programmes at basic and post basic levels on a regular basis and supervision for the sustenance of the breast cancer early detection program.

Keywords: Early detection of breast cancer - Well Woman Clinics - qualitative assessment - Sri Lanka

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Introduction

Breast cancer is the most common cancer and is the leading cause of cancer death among women worldwide (Parkin et al., 2005; Benson and Jatoui, 2012; Bray et al., 2013). In the Sri Lankan context, neoplasms were the third leading cause of death of all the hospital admissions in 2008 (Ministry of Health Sri Lanka, 2013) and breast cancer is the commonest cancer among females with an age standardized rate of 20.6 per 100,000 population in 2006, accounting for 27% of female cancers (National Cancer Control Programme Sri Lanka, 2012).

Early detection and intervening at an early stage is the potentially effective way to increase the cure rate or prolonging the survival of breast cancer patients (Fung, 1998; Anderson et al., 2008; Lan et al., 2013). Breast self-examination (BSE), clinical breast examination (CBE) and mammography are the methods used for early detection of breast cancer. Cancer screening with advances in treatment have reduced breast cancer related mortality,

and improved survival (Ries et al., 2003; Hofvind et al., 2013; Mandelblatt et al., 2013). However, different studies give different values for sensitivity and specificity of CBE and BSE (Ratanachaikanont, 2005) which depends on how correctly it is practiced.

The opportunistic early detection of breast cancer was introduced to Sri Lanka through field health services in 1996 through Well Woman Clinics (WWCs). Women over 35 years of age get them screened for hypertension, diabetes mellitus, breast malignancies and cervical cancer in WWCs. CBE and increasing awareness on BSE are conducted for breast cancer early detection. Mammographic facilities are costly and not available at WWCs.

There were 611 functioning WWCs in the entire country at the end of year 2007 (Family Health Bureau Sri Lanka, 2009). WWCs are conducted by Medical Officers of Health (MOH) with his team. Public Health Midwife (PHM) plays a major role in the WWCs by conducting CBE and increasing awareness on BSE.

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Therefore, sensitivity and specificity of CBE and BSE depends on the PHM's ability to perform CBE accurately and conduct effective behavior change communication in relation to BSE.

For the future improvements of the breast cancer early detection in WWCs, it is essential to understand the views of the PHM on the breast cancer early detection programme. Therefore, present study was conducted with the aim to identify PHMs' perceptions on the importance and deficiencies of the existing breast cancer early detection services provided through WWCs and to identify their suggestions on improving the breast cancer early detection services.

Qualitative methodology seemed to be ideal for assessment of the views of the PHM on breast cancer early detection programme: focus group discussions (FGDs) which are frequently used to obtain perspectives and attitudes of people about issues, seek explanations for behaviour, triangulation of data obtained through quantitative methods and generation of hypotheses (Lakshman et al., 2000) were used in the present study.

Materials and Methods

This qualitative study using four FGDs among PHMs was conducted as a part of developing a community interventional study on improving breast cancer early detection in Sri Lanka in 2008.

Study setting

Study was conducted in the Gampaha district of the Western Province which is the most populous of all provinces. Of the three districts in the province, Gampaha had the second highest population of 2,294,641 as enumerated by the Census 2011, with 91% of Sinhalese, 3.5% of Sri Lankan Tamils, 4.2% of Moors and less than 1.3% of other minority groups (Department of Census and Statistics Sri Lanka, 2013).

The Regional Director of Health Services (RDHS) is responsible for the health care system in the district under whom the Medical Officers of Health (MOHs) function. There were 14 MOH areas and 54 functioning WWCs in the Gampaha district in 2008.

Study participants

Four FGDs representing all 14 MOH areas, with participation of 9-10 PHMs for each discussion, were conducted at four community centers in the district away from other health care officials.

Procedure

Focus group guide developed by principal investigator with the help of experts in qualitative research, included areas on PHMs' perception on availability of guidelines and protocols, training received, adequacy of staff, availability of facilities, time for clinic sessions, support from other sectors, reasons for low participation rates and their recommendations for improving utilization of clinic services and components to be included in the interventions to improve breast cancer early detection.

Principle investigator explained the objectives of

the FGDs and discussed about the session in detail with the facilitator and data recorder beforehand. They were provided with the FGD guide.

Facilitator welcomed the participants and introduced herself and asked participants for a self- introduction to create a friendly environment for an open discussion. This enabled the individual participants to note that all of them belonged to a common group. They were informed of the purpose of the discussion and why PHMs were selected as participants. The rules were read out, and informed verbal consent was taken. The need to respond to key issues was emphasized. They were then requested to complete a brief anonymous questionnaire regarding their basic demographic information. The session was started with one or two simple straight forward questions.

Principle investigator was present at all the FGDs as an observer. In addition to taking down notes all proceedings were recorded on audiotapes with permission obtained at the beginning of the session. Simultaneously, observations were made and noted down with regard to facial expressions and interactions among clients. At the end of the discussion key points were identified and summarized and presented back to the group for further clarifications. Participants were thanked for their valuable contribution. Each discussion lasted about 80-90 minutes. By the fourth FGD, point of saturation was reached and no new information was forthcoming.

Data analysis

Data analysis was conducted manually using the concepts related to "Grounded theory" (Glaser, 1992) by identifying and organizing themes in the text as recommended by Morgan and Kreuger, (1998) with necessary modifications.

Audiotapes of FGDs were transcribed. Transcripts were checked for accuracy with what was written down. Transcripts and written notes were used as primary data. They were translated to English. Coding categories were developed by two independent experts. They read through the transcripts, indexed them and sorted them into dominant themes and categories. Next, the two experts met and came to a consensus on the themes and categories. Results were presented in narrative form. Direct quotes of the participants were used whenever relevant. The findings of all four FGDs were similar and therefore all the findings were compiled in to one for the analysis.

An alpha numeric code was used to identify the FGD session and individual participant. PHMs of a given FGD were identified from A to J and differentiated using the FGDs which were numbered from 1-4. Eg: A1- PHM A in FGD 1; D4- PHM D in FGD 4

Whenever same opinion was expressed by several participants, the code of the PHM whose direct quotation was referred to was underlined, whereas the others codes were not underlined.

Ethical and administrative considerations

Ethical clearance was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Kelaniya, Sri Lanka. Permission of RDHS and respective MOHs were obtained. Informed consent was obtained

from all participants before interviews. The privacy and confidentiality (by using a code for reference as described above) of information was assured.

Results

Altogether 38 PHMs with a mean age of 44.7 years (SD=7.7: range=27-56 years) participated in the four FGDs. All were Sinhalese. Thirty six (94.7%) were Buddhists and 2 (5.3%) were Christians. Thirty five (92.1%) were currently married and three (7.9%) were single.

Analysis yielded three major themes: 1) the need for early detection of breast cancer; 2) the gaps in the early detection services provided in the field; 3) suggestions to eliminate/ minimize those gaps. Categories were created under each theme to describe the diverse aspects of PHMs' perception on early detection of breast cancer (Table 1).

Theme 01 – The need for early detection of breast cancer (Table 1)

(A). Increase curability: Participants unanimously expressed the importance of early detection for increasing curability.

Implications of late detections were also emphasized:

“Whatever, you may do, cure is impossible if detected at a late stage” (A₁).

“I know a person with breast cancer who was detected at a late stage, who died despite all possible treatment as it had already spread to rest of the body at the time of detection” (A₁).

(B). Prolong life: They believed that early detection will prolong life:

“If we detect breast cancer early, and institute early intervention, it will definitely prolong life” (A₃).

“During early stage cancer is confined only to breasts; treatment is easy and hence a cure rate would be 100%” (D₄).

(C). Avoid invasive treatment: They knew that early detection would avoid invasive treatment.

“Late detection will lead to more invasive treatment options such as total removal of breasts, which is definitely

Theme 02 and 03 - Gaps in the existing breast cancer early detection services provided in the field and suggestions to improve services (Both themes are presented together):

(A). Lack of guidelines: Lack of awareness on guidelines and protocols issued by the Ministry of Health on breast cancer early detection was identified as a big issue.

“We have never seen any guidelines” (A₁).

All expressed their strong agreement through non-verbal gestures.

All the participants accepted the need for having specific guidelines and protocols.

“If we have guidelines we will know how to practice correctly,” (E₄) “When the women attend to the clinic, we just examine the breasts without even knowing the frequency of conducting such examinations” (B₃).

Provision of guidelines: All participants suggested developing guidelines and making same freely available for their use.

“Guidelines should be in Sinhalese language to be understood by most of us” (C₃).

“Guidelines have to be written in simple language and be user friendly” (D₃).

(B). Lack of training: Lack of the training on breast cancer early detection was identified as a major issue.

“We did not have any training” (C₁, E₂ and C₄).

“Breast cancer early detection was not covered even during our basic training” (A₁, H₁, B₂, and E₄).

“In our basic training we were taught about cancers in general but not on individual cancers” (J₁).

“We have not received any in-service training on breast cancer early detection” (G₁, I₂, A₃, and J₃).

“We had not received any special training” (E₁, I₃ and A₄).

“We have not received any training other than by Public Health Nursing Sisters who provided instructions on performing CBE and health education on BSE” (B₁, C₂ and G₃).

“When we first started, we learnt from PHMs who had experience with WWC work” (E₁, J₂, E₃ and H₄).

Table 1. Summary of Themes Identified Through the Focus Group Discussions

No. Themes 1 & 2/ Categories	Suggestions (Theme 03)
1. Theme - Need for early detection services	
Increases curability	-
Prolongs life	-
Avoid invasive procedures	-
2. Theme – Gaps in existing services	
Lack of guidelines	Provision of guidelines
Lack of training	Training during basic course and post basic
	Subject areas to cover
	Special reference on IEC* techniques
	Supervision
Inadequate facilities	Make available adequate quantities
	Make available modern techniques-Video tapes on BSE**
	Provision of separate rooms
Short supply of stationery	Uniform distribution in the district
	Keeping additional stocks
Coverage	Use of mass media
	Organization of street dramas
	Increase in the number of clinics
	Holding clinics on Saturdays to attract more women
	Conduct of separate clinics(dissociate from polyclinics)
	Organization of health camps
Referrals	Improve coordination between field and hospital services
Monitoring of compliance of clients	Introduction of a tool

*Information, education and communication; **Breast self-examination

"We practice CBE, and educate clients on BSE with no proper guidelines or training" (G₁, I₂ and A₄).

"But we do not know whether we are examining breasts correctly or incorrectly" (E₄).

The gravity of conducting CBE incorrectly was expressed by stating:

"If we do it incorrectly, we will miss the cancer. Woman will be reassured. But cancer will spread and will be detected at a very late stage" (C₁, E₃ and H₄).

"We do not know the shortcomings of our techniques" (B₂).

The above statement reflects the need for knowing the accurate procedure in performing CBE. PHMs were well aware of the deficiencies they experienced and the resultant adverse consequences. The above statements reflected on lack of confidence and thus the need for proper training. However, the awareness regarding their deficiencies was encouraging in that, they would exercise caution when confronted with ambiguous situations.

Provision of training: All accepted that there was a need for training.

"Training should be included in our basic course" (B₄) and E₄ added "It should cover all the aspects".

"Inclusion in basic training alone is not enough as the techniques and guidelines keep changing and we need to be updated" (A₄, G₁, E₂ and D₃).

Topics to cover in training: PHMs identified the topics and methods to be covered in training. The topics identified included:

"If we know those at risk, we can pay more attention on them and detect breast cancer early in them" (A₄).

"We are not aware of the diagnostic methods used in the hospitals" (C₃).

"If we have correct knowledge on the methods of diagnosis, we can confidently educate the woman about the need for further management," (B₂) "It is very important to allay their fears in going to the hospital" (D₂).

"If we know the treatment options available we can educate the community on those" (E₁).

"We visit women after detection of abnormalities and request them to go to the hospital, but we are not familiar with the follow up action that should be adopted" (A₁, C₂ and E₃).

"We need to have proper training on health education on breast cancer early detection" (J₁, I₂ and H₃).

Hands on training: All the participants felt the need for having hands on practice on breast cancer patients.

"Even though we conducted CBE, we do not know the feel of breasts in a patient with breast cancer" (B₁ and E₂).

"This experience will make us more confident in conducting CBE" (C₁).

"Then we will detect more cancers" (E₄).

Use of modern teaching techniques: They expressed the necessity for the use of modern techniques of teaching and the use of Information, Education and Communication (IEC) materials.

"If we can observe correct methods of CBE on video tapes, it will also help us to learn" (B₁, E₂ and E₃).

Supervision: They also expressed the need for frequent supervision.

"Supervision will enable us to correct our techniques which will make us confident on the tasks performed" (J₂).

"We want our supervisors to correct us" (C₁, E₂ and G₄).

"For that they should have the knowledge and skills" (A₁)

(C). Inadequate facilities: They perceived the gaps related to facilities at the clinic setting and they pointed out the inadequacies related to facilities in the WWCs and lack of privacy.

"We do not have a proper place to conduct breast examination" (I₁, H₂ and A₄).

"Sometimes we examine two or three women in the same room. Even though everybody will prefer to have privacy, we are not in a position to provide it always" (B₂).

Provision of facilities: They pointed out the need to have a separate room to conduct CBE.

Lack IEC materials: They identified several gaps related to WWC process. They emphasized on the inadequacy of health education materials including flash cards, leaflets and video tapes.

"We teach BSE but for the entire MOH area only one set of flash cards was available" (B₁, C₂, A₃ and G₄).

Provision of IEC materials: They suggested providing one set of flash cards set per PHM and having facilities to demonstrate BSE through video display.

Short supply of stationery: Need of a timely supply of records and returns was highlighted.

"Although we are supposed to provide a card for each client, last year the cards were not available nearly over a period of three months and we had to make an extra effort to collect money to photocopy the cards" (A₁, H₂ and C₃).

However, there was controversy with regard to availability of stationary as some said:

"We always managed to have an adequate stock" (D₁, B₂ and A₄).

Finally, this was attributed to lack of uniform distribution of cards in the district.

Regular supply of stationery: Suggested solutions were: to have uniform distribution and to make available adequate stocks in the MOH areas.

(D). Poor coverage: They have identified several gaps related to the outcome of programme. All of them agreed that breast cancer early detection coverage was poor. Under-served groups identified were:

"Mainly married women are coming to our clinics. Unmarried women attend rarely and even those with breast problems attend only after making repeated requests" (B₁, I₁, E₂ and E₃).

"Elderly women are more prone to cancer than younger women. But, we do not cover this group" (H₁).

They attributed the above drawback to lack of awareness on the need for regular health check-ups. They emphasized on the difficulties in changing the behaviour of women in the community.

"Women are not concerned about their health. They are more occupied with household work" (A₁, C₁, B₂ and B₄).

"They look after their children and husbands and they give less importance to their own health" (B₂).

Another reason for lack of motivation identified by them was women not feeling overtly ill:

"They are free of features of illnesses" (C₁).

"But if we have detected an abnormality, all in the neighbourhood would attend the clinic" (E₁, D₂ and E₄).

Having only few clinic centers, and low frequency of clinics conducted were identified as the reasons for poor coverage.

"We conduct only few clinics at few places and therefore, the number covered is less" (A₁).

They complained that irrespective of above, the attendance would anyway be poor. The reasons they have pointed out for this, were: lack of awareness of the importance of the services provided by WWCs, being less concerned about their own health and poor accessibility.

Suggestions to improve coverage: The solution the participants have identified was to have different sources of information to raise public awareness such as mass media, street dramas and the support of medical officers at the hospital/private sector.

They suggested increasing number and frequency of WWCs. They emphasized the need for holding WWCs on Saturdays.

"Saturday is not a working day. Women are not busy taking children to schools or nurseries" (C₂ and E₄).

Almost all expressed that WWC should be held as a separate clinic rather than as a poly clinic.

"WWC is meant to provide services for women who are apparently well. Therefore, if combined with other clinics, WWC activities will get neglected" (E₄)

A1 suggested conducting health camps to attract people:

"Whenever we conduct mobile clinics participation is more" "For those clinics we give more propaganda beforehand" (E₁).

"As these offer a variety of services, which will be available for all the family members, it is more convenient for them to cover the needs of all in one go" (B₄).

Further, they expressed the need for referring the client to the clinic where area PHM is available.

"The clients would prefer to attend the clinic where their area PHM serves, rather than a clinic placed in close proximity with easier access" (J₁, E₂ and E₃).

(E). Referrals: They expressed concern on not receiving back referrals /acknowledgements from the hospital staff.

"When we send clients to hospital, the attention paid by hospital staff is poor at times. The remarks they make reduce the confidence the clients have on us" (C₁, A₂ and E₄).

They emphasized the need for strengthening the coordination between clinical and preventive sectors.

"Hospital staff lack an understanding of what is done in the field" (G₁).

(F). Monitoring of the BSE: Monitoring of BSE was identified as a need by the participants.

"If we have something to monitor practice of breast cancer early detection among women at field level it will be useful" (A₁, D₂, H₃ and A₄).

"Then both service providers and clients will be more motivated" (A₁, B₂ and I₂).

PHMs agreed that they had a major role in providing knowledge on breast cancer early detection to the community.

"Paying home visits and inviting them to attend the clinic is useful" (C₁, E₂ and D₄).

Their views indicated their desire to keep their authority on breast cancer early detection to themselves, but seek much wider propaganda through mass media. Their views were thus directed on the need for social marketing.

Discussion

This component of the study looked in-depth over the breast cancer early detection programme implemented through the WWCs in the Gampaha district in Sri Lanka. The important revelations of the FGD were: lack of health education, lack of proper training on method of breast cancer early detection, for which emphasis was laid on both basic training as well as regular conduct of in service training, non- availability of proper guidelines and follow-up and interventions targeted towards the community to improve coverage.

The recommendations that arose from the FGDs were directed towards the policy makers which included: capacity building of PHMs, provision of guidelines, rescheduling clinics, strengthening supervision. FGDs are considered as a useful qualitative tool to assess opinions/ information generated through interaction as opposed to in-depth interviews, which provides only a reflection of individual opinions. For organization of healthcare services, what is more useful is thus the former tool which provides an overview of collective ideas (McLafferty, 2004)

Basic training of the PHM is mainly targeted towards maternal and child health currently. They get exposed to WWC programme only at their clinical training at National Institute of Health Sciences which according to the PHMs is inadequate. As they are directly involved in early detection, it is imperative that they are given the knowledge on basics related to anatomy, and physiology with emphasis on the relevance of the cyclical changes as well as correct techniques of CBE and BSE. Having this knowledge will help them understand the correct timing and technique of palpation and identification of pathological lesions, which is the key to early detection. This will help to reduce the medical officers work load in confirming the cases detected by PHMs, thus making it a very efficient service. Hence, there is an urgent need to introduce details in the basic training course of the PHMS as well as in-service training. Current study recommends a curriculum revision with the intention of expanding the knowledge and skills required to provide an efficient early breast cancer detection service at the field level.

Need for developing guidelines on breast cancer early detection and follow up in simple user friendly language and making them accessible to all WWC staff was raised. The availability of such referral material is likely to enhance the confidence, as they are ensured of a means of clarifying doubts when faced with problems.

Rescheduling WWCs to provide better service to cater for more clients was suggested. Options identified for this are; increasing the frequency of clinics, increasing the number of clients catered to in one clinic, having WWC as a separate clinic rather than as poly- clinics, conducting clinics on Saturdays and having health camps. Follow up of women with abnormalities before and after confirmation of diagnosis, which lacks the emphasis it deserves currently, should be an essential aspect that needs to be addressed in improving quality. However, adoption of these options should be based on the need in that particular MOH area.

It became evident from this study that most PHMs gained knowledge and development of skills through informal sources such as peers and fellow PHMs. Thus, it is important that the initial training should be provided through surgeons. At the same time supervisory officers should be provided with capacity building on supervision of breast cancer early detection programme and on improving the capacity of the PHMs. They should be knowledgeable and competent on practicing correct procedures including CEB, BSE and provision of quality care. Anyhow, supervision alone will not be effective if remedial action is not forthcoming. The need to reward good quality work is another aspect that needs exploration as a measure of improving quality of services. Some of the defective components found in the WWCs could be improved with good managerial functions. Therefore, capacity building of front line and middle level managers should also be conducted periodically in order to improve their managerial functions.

Need for having a good coordination between the curative and preventive sectors in order to provide quality care on management of breast abnormalities, was highlighted. Referral center staff should be updated on the preliminary activities that take place at the field level. It is important for them to realize that this is the first contact point of the same health care system. This knowledge is likely to enhance the respect and the attention paid to the referrals. Lack of such regard is likely to weaken the link between the client/ patient and the PHM and thus the follow up care for the needy persons. Active participation of the surgeons in training the PHMs as mentioned above is one way through which the coordination between the two sectors could be enhanced.

Adoption of measures to improve community awareness such as regular health education talks through mass media and organization of street plays in addition to health education conducted by PHMs at field level have proven to be essential from FGDs. For that, the MOH should focus on the best measures suited to his/her area on improving the awareness related to breast cancer early detection. Supervision of WWC clinics and formative assessments and evaluation of coverage should be regular events done at divisional, district and national levels.

As PHMs from all the MOH areas of Gampaha district participated in the FGDs, the findings reflected the need of the entire district, which is a strength of this study. The same findings were the basis for the intervention planned subsequently, which was tested and found to have favourable results (Vithana, 2010). As the study was confined to the Gampaha district, some of the findings would be applicable only to this district. However, the valuable comments made regarding aspects such as training and the need for guidelines were common to the entire national program and application of appropriate remedial measures will certainly make a positive impact on improving breast cancer early detection programme implemented by WWCs in the whole of Sri Lanka.

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