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Why do women with early breast cancer in Northern Sri Lanka undergo mastectomy? Decision-making and ways forward

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Abstract

Background Despite robust evidence confirming equivalent survival rates and better cosmetic outcomes with breast-conserving surgery (BCS) and radiotherapy compared to mastectomy, the rates of mastectomy among women with early breast cancer have not declined significantly in Sri Lanka. This study explores views on the surgical treatment of breast cancer among Northern Sri Lankan women who were eligible for BCS but underwent mastectomy.

Methods An exploratory descriptive qualitative study was carried out among 15 women who underwent mastectomy for early breast cancer. Patients who were referred to the Tellippalai Trail Cancer Hospital for adjuvant therapy after mastectomy and matched the study criteria were recruited. Data were collected through in-depth semi-structured interviews, which were transcribed in Tamil, translated into English, coded using QDA Miner Lite software, and analysed thematically.

Results Nine out of 15 participants were either not aware of breast-conserving surgery (BCS) as a treatment option or their eligibility for BCS at the time of mastectomy. According to participant narratives, the treating team had recommended mastectomy to most participants. While many opted for mastectomy believing that it was associated with lower rates of recurrence and spread compared to BCS, these beliefs were frequently reinforced by the treating team. The pros and cons of the two approaches had not been discussed before surgery with most participants. In the absence of information, family and friends weighed in on the decision to opt for mastectomy, ultimately resulting in feelings of loss and regret in most instances.

Conclusion Most participants were not aware that they were eligible for BCS. These information gaps need to be urgently addressed for women to make informed decisions about their health.

Keywords Breast-conserving surgery, Modified radical mastectomy, Shared decision-making, Pre-surgical counselling, Sri Lanka

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Introduction

The incidence of breast cancer has risen over the years [1], including in South Asia [2]. Breast cancer is the most common cancer among women in Sri Lanka; around 3000 cases are diagnosed annually [3]. The management of breast cancer has radically evolved over the decades. The primary treatment for early breast cancer is surgery followed by a combination of adjuvant radiotherapy, chemotherapy, endocrine therapy and targeted therapy as per the indications [4]. Mastectomy and breast-conserving surgery (BCS) are the two main surgical options for the primary tumour [5]. Breast-conserving therapy (BCT) includes BCS and adjuvant radiotherapy and remains the standard of care for early breast cancer [6].

The evidence for equivalent survival outcomes with BCT compared to modified radical mastectomy in women with early breast cancer emerged in the early nineties when BCT became the standard of care [7, 8]. Several longitudinal studies have reported equivalent overall survival, disease-free survival, and distant disease-free survival after both surgical approaches [7–10]. Better survival with BCT has been reported in recent observational studies [11, 12]. A pooled analysis of early clinical trials reported a higher local recurrence rate with BCT than with mastectomy [13], but has since been refuted by studies that report similar local recurrence rates [14]. BCT is also associated with better cosmetic outcomes and quality of life (QoL) [15]. Despite this evidence, studies show an increase in mastectomy rates over the years [16, 17]. Asian countries tend to report lower rates of BCT compared to Europe and the United States [18, 19], including in Sri Lanka where only 3% of patients with localized disease are treated with BCT [17].

Undergoing mastectomy is known to have a huge impact on physical, psychological, and social wellbeing. Pain, fatigue, body-image alteration, shame, anxiety, and depression are known to occur after mastectomy, in turn, disrupting relationships, livelihoods, and mobility for women within their communities [20–23]. The uptake of BCT could potentially prevent or mitigate the adverse consequences of mastectomy.

An extensive corpus of literature has examined decision-making regarding the surgical treatment of breast cancer [24–26]. Fear of disease or recurrence and the desire to avoid further surgery are key reasons women of Asian descent prefer mastectomy. Older age, lower education level, lower socio-economic status, large tumour size, and the surgeon's recommendation are known to influence decision-making [27, 28]. Qualitative research in this area suggests that women hold trust and faith in their surgeon, highly value their opinion, and are likely to choose BCS when it is recommended by a surgeon [25]. However, they also express the need for more information regarding treatment options [23, 29, 30]. Studies highlight the importance of honest pre-surgical discussion to avoid misconceptions regarding recurrence and survival after BCT [24].

In resource-poor settings, introducing BCS has been difficult owing to the unavailability of resource-intensive technologies related to pathology, imaging, and radiation therapy, as well as specialized health personnel and surgical proficiency [31]. The Tellippalai Trail Cancer Hospital (TTCH), where the study is set, is a centre of excellence for cancer care. Possessing the only radiotherapy unit in the Northern Province, this non-fee levying public hospital caters to a population of about 1.2 million. Most women diagnosed with breast cancer in the Northern Province seek treatment at this facility. TTCH did not have the infrastructure or equipment to offer precise adjuvant radiotherapy until early 2019 when the facility acquired a linear accelerator. In the same year, digital mammography, which is needed for diagnosis and post-treatment surveillance, became available at the nearest tertiary care centre—Teaching Hospital Jaffna. Despite the availability of these facilities, the rates of mastectomy have not declined significantly since 2019. Hence this study was carried out to explore the views on surgical treatment of breast cancer among women who were eligible for BCT and underwent mastectomy in Northern Sri Lanka.

Methods

This exploratory descriptive qualitative study was conducted at the out-patient department of TTCH, located in the war-affected Northern Province of Sri Lanka.

Women ≥ 18 years who were eligible for BCT but underwent mastectomy for early-stage breast cancer within six months of the data collection period, and presented to the outpatient department of TTCH for adjuvant therapy were included in the study. Eligibility was assessed by the attending consultant oncologist through comprehensive review of the cases upon initial presentation. A total of 35 patients were enrolled for curative intent treatment during the recruitment period. Among them, mastectomy was indicated for 10 due to skin involvement, multicentric disease, or multifocal microcalcification in other quadrants. Of the remaining 25 women, 5 (20%) had BCS. From the 20 patients left, one opted for mastectomy, and another was recommended mastectomy due to poor compliance. The oncologist determined the eligibility of the remaining 18 patients. These women were invited to the study by nurses who were not involved in the project. Fifteen patients agreed to participate and were requested to return to the clinic for an interview on a specified date and compensated for travel.

Data were generated with semi-structured in-depth interviews, carried out by two medical students in the 4th year of training who had no direct contact with the participants before data collection. They were trained in qualitative interview techniques by two experienced qualitative researchers. Practice interviews were conducted with health personnel acting as simulated patients. All interviews took place between January 22 and May 08, 2022, on weekends when clinics were not in session in the out-patient department of TTCH. Both data collectors participated in all interviews, taking turns interviewing and note-taking.

The interviews were held in Tamil and facilitated with an interview guide developed by the research team. The guide was designed to explore what participants knew about the surgical options for breast cancer treatment before they underwent mastectomy, the information given by healthcare providers, and how they selected mastectomy as their treatment option. Informed written consent was obtained. The interviews lasted between 22 and 56 min and were digitally recorded with prior consent. Data saturation was reached after 15 interviews.

The recorded interviews were transcribed in Tamil by SM. DT and GS who are bi-lingual with high proficiency in Tamil and English translated the transcripts into English, which were then meticulously reviewed by CR. The transcripts were then scrutinized by CR and RK and preliminary themes identified. A list of pre-defined codes was developed based on the study objectives and complemented with in vivo codes guided by the preliminary themes. A structured coding tree was developed. The transcripts were then coded using QDA Miner Lite software by DT and GS and reviewed by CR and RK. Deductive thematic analysis was performed. Data were first collated under three broad topic areas (information gaps and information received; decision-making and decision makers; and consequences) before organizing the content under four themes: "What women knew about surgical options before mastectomy", "What they were told and not told by doctors", "Why they opted for mastectomy and who made the decision" and "Consequences of the decision". At least two research team members reached consensus at each stage of the analysis.

Ethics approval was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Jaffna, Sri Lanka (Ref. No. J/ERC/21/128/NDR/0260).

Results

Fifteen participants (P) who were eligible for BCS and underwent mastectomy were recruited to the study. All participants identified as Tamils. They were 45–72 years in age with most in their 50s ($n=6$) and married ($n=13$). All participants had been to school, although a third ($n=5$) had not progressed beyond primary level (Table 1).

What women knew about surgical options for breast cancer before mastectomy

Nine participants were either not aware of BCS as a treatment option for early breast cancer or did not know they were eligible for BCS at the time of mastectomy. Among them, three participants learned about BCS only after they presented for adjuvant therapy. The rest had either gleaned this information before mastectomy from healthcare providers or acquired second- or third-hand information about BCS from family and friends. Only one participant spoke of accessing information about treatment options on the internet (Table 2).

What women were told and not told by doctors

There were significant information gaps in pre-surgical counselling. Only one participant reported being encouraged to select BCS by the treating team.

> *The doctor (oncologist) advised me to get only the lump removed. The surgeon also said the [oncologist] had suggested getting only the lump removed and asked my preference. I asked him to remove the whole breast and told him that I would sign and give my consent – P09, 45years.*

All other participants either received information that was heavily biased towards mastectomy or were not given a choice at all. For those who were given a choice, the information was accompanied by warnings about the possibility of recurrence and the need for radiotherapy. Some were informed that the tumour was too large or

Table 1 Demographic details of participants ($n=15$)

Characteristic	No. (%)
Age (years)	
< 50	4 (27)
50–59	6 (40)
60 and over	5 (33)
Marital status	
Married	13 (86)
Widowed	01 (07)
Separated/divorced	01 (07)
Educational level	
≤ Grade 5	05 (33)
Lower secondary education	04 (27)
Upper secondary education	05 (33)
Diploma[a]	01 (07)
Total	15 (100)

[a] There were no degree holders

Table 2 What women knew about the surgical options before mastectomy

Participant	Illustrative quotes
P04	I was aware that we could either remove the lump or the whole breast, even before I met the doctor. I don't have knowledge about the outcomes of mastectomy. But I know that in some people they may remove tissue from the arm and this may result in hand swelling.
P07	I have heard of people having the lump removed while conserving the breast. My aunt also had her whole breast removed due to cancer.
P09	As soon as I found out that the lump I had was cancer, I talked to friends. Through them, I got to know that it was possible to remove only the lump.
P13	… I knew about BCS[a] through the internet even before the doctors spoke to me regarding the surgical options…
P03	I thought removing the whole breast was the standard treatment.
P05	I know of [BCS] only after I came here and met others who have done it.

[a] In all tables, the terms 'BCS', 'mastectomy', 'radiotherapy', 'chemotherapy' are used instead of the lengthier direct translations of Tamil terminology used by participants

had spread to the lymph nodes. That mastectomy was associated with superior survival rates was conveyed to others (Table 3).

While many women were presented with a choice, the pros and cons of the two surgical options, including their survival rates and side effects were not explained. The majority were not aware of the need radiotherapy after BCS at the time of surgery (Table 4).

Why women chose mastectomy over BCS and who made the decision

When given a choice, most women chose mastectomy over BCS based on the limited information provided. Many believed that removing the entire breast reduced the risk of recurrence/spread, while a few spoke of the size of the lump and extent of axillary node involvement as being decisive for treatment—beliefs that were reinforced by doctors. Some worried that undergoing BCS would necessitate a second surgery, while others were concerned about the closer follow up that they believed would be needed after BCS (Table 5). Notably, none alluded to opting for mastectomy to avoid radiotherapy.

In medical communication, patients usually make informed decisions based on their comprehension of the information provided by the treating team. Regardless of their level of education, the participants plainly conveyed what had been communicated to them before surgery. Many highlighted the crucial influence of the surgeon in their decisions, with a few indicating that their requests for BCS were rejected. Women's narratives also suggest that family and friends weighed in on decision-making, which is no surprise in tightly knit northern Tamil communities (Table 6).

Consequences of the decision

Having undergone mastectomy, the participants expressed different emotions and experiences related to their decisions. While some conveyed regret, others

Table 3 What women were told by their doctors

Participant	Illustrative quotes
P05	The doctors told me that I have a lump and that they are going to remove the whole breast. …. they did not say anything about removing just the lump.
P13	…the [surgeon] told me that I needed to get my breast fully excised and removed and that it would be good to do so.
P01	…the surgeon told that if I had come earlier, they would've been able to do BCS and that I may have recovered after completing the drug therapy. But when we showed up, it was too late, and the lump had already become large.
P02	I asked [the surgeon] if I could go for BCS, as I thought that it would be difficult for me to go out as usual, if I did mastectomy. But [the surgeon] said that since it has already spread to the axillary region, and since my child is still very young, it would be good to remove the whole breast …that I could live longer.
P04	The [surgeon] told me that if I underwent BCS the cancer may recur or spread to other sites and that I may have to have another surgery if it does
P08	When I asked the [surgeon] if the lump can be removed, he said that was an option too, but I will have to undergo radiotherapy…I repeatedly asked if I could get the lump removed instead of the whole breast, but the [surgeon] was insistent that the latter was the better option.
P12	Initially the surgeon said they would remove the lump, and since there was nipple discharge, they would also remove tissue from the areolar area. Later, after doing the MRI, they told me that they would remove the whole breast.
P15	[The doctors] said that it had spread to the lymph nodes so the whole breast needed to be removed, and if not, other areas may also become affected.

Table 4 What women were not told by their doctors

Participant	Illustrative quotes
P01	…I didn't know that BCS is a better option when compared to mastectomy, for patients having breast cancer of early stage… Recently I've met a few people who underwent BCS and are on radiotherapy, but I didn't realize that it could also be done on me, and that the outcome would be more favorable.
P08	I was not told about the advantages and disadvantages or about survival of the two options.
P09	They did not tell me anything regarding the advantages and disadvantages of the two options… I was not told about the complications of surgery or the need for chemo/radiotherapy… I got to know that I had to undergo chemotherapy only after coming to Tellipalai Hospital.
P11	…I wasn't given a clue regarding BCS… They also didn't comment on the outcome, what would happen if the breast was not removed, or the possible complications and follow up plan if I underwent BCS.
P13	I was not told regarding the need for radiotherapy or chemotherapy post-surgery or that I would have to follow radiotherapy if I underwent BCS.

Table 5 Why women chose mastectomy over BCS

Participant	Illustrative quotes
P01	Some people said not to remove the breast. But because my older sibling too had the same illness, I was afraid. So, I told the surgeon to remove it completely so that the disease won't spread and I won't have any fears.
P02	If we undergo [mastectomy] and do further treatment, then we can live healthily for very long and we don't need to be afraid. If we remove only the tumor, there's a risk that it might spread later, which is a bit frightening.
P03	I opted for total mastectomy mainly because I was afraid that it would spread. I am not aware of radiotherapy, so I did not make my decision because of fear regarding radiotherapy. If BCS is done, I will have to constantly keep checking for tumors, so I thought it was less of a hassle to remove the whole breast.
P04	I was also told that if I undergo BCS, the cancer might recur or spread to other sites, and that I may need another surgery if it does.
P06	People will have lumps of different sizes. If they are very small, they can talk about removing just the lump. If the lump is large, there is no other way.
P12	Since this is a spreading disease, even if there's a small part remaining, it could spread to other sites. That's why I wanted a mastectomy to be done, despite being given a choice

Table 6 Who ultimately made the decision

Influence	Participant	Illustrative quotes
Self	P12	Though I was initially informed regarding BCS and I was given a choice, I preferred to undergo a mastectomy.
	P13	Though I knew about BCS through the internet even before the doctors spoke to me about the surgical options, I myself wanted to get the whole of my affected breast removed.
Surgeon	P08	I repeatedly asked if I could get the lump removed instead of the whole breast, but the doctor was insistent that mastectomy was the better option.
	P11	Initially I thought that they would remove only the lump but they insisted that it would be better to remove the whole breast.
Family and friends	P06	My husband wanted the whole breast removed.
	P07	I spoke to my siblings, husband, his siblings, relatives from abroad, and friends. They also said that it was better to remove the whole breast.
	P03	…a cousin who is an attendant (support staff at hospital) suggested that removing the whole breast is better…. After listening to her and the doctor I opted for mastectomy.
	P02	A teacher friend who has had cancer underwent mastectomy seven years ago. She suggested that mastectomy is a better option.

felt a sense of relief. Some women spoke of a sense of loss and others shared stigmatizing experiences (Table 7).

It should be noted however that some women did express optimism: *"Stepping outside is not a big problem for me because I've been given an artificial breast,"* P04 said. Most participants denied that the mastectomy had impacted their sense of femininity or sexuality.

Table 7 Consequences of the decision

Influence	Participant	Illustrative quotes
Regret	P05	The lump was small and I wish they had removed just the lump. I am still affected by the mastectomy.
	P08	I was not happy with the final decision. It was made only because the doctor said so. There was no one to advise me to think carefully and discuss more clearly with the doctors.
	P12	The only thing I worry about is that I've lost an organ in my body.
Relief	P04	Before the surgery I was crying, but then I realized that if I hadn't removed the breast fully, I might have been anxious and would be checking frequently if the tumor has spread.
	P10	I am happy now after removing the entire breast. If only a part of it is removed, we will have to suffer….
	P11	I'm not worried about surgically removing my breast, because now I'm free of illness
Shame and stigma	P02	I feel embarrassed …I don't look forward to going out as I did before.
	P08	It was a huge shock …I am saddened. One side feels odd.
	P03	I get hurt when people talk about me having my breast removed, so I don't go out. My children are also very concerned about this and even physically assaulted a woman who spoke ill of my condition. …The surgery per se does not affect me. What gets to me is when people talk about this behind my back.
	P07	I hesitate to out and my children are even more hesitant to send me out.
	P14	I am unable to step outside the house. I am stuck inside the house. Other people talk about me, and I feel hurt.

Discussion

The advantage of BCT is that it provides equivalent survival compared to mastectomy, with good cosmetic outcomes and improvements in QoL [7–10, 15]. Despite overwhelming evidence in favour of BCT, women diagnosed with early breast cancer in northern Sri Lanka receive mastectomy. While many factors appear to influence the decision in favour of mastectomy, as in other settings, misconceptions regarding survival rates and the risk of recurrence and spread as well as the surgeon's recommendation seem pivotal [25].

Our findings suggest that worries about stringent monitoring and the necessity of a second operation due to a mistaken understanding of the increased risk of local recurrence following BCS affected decision-making. Participants rejected BCS believing the anxiety associated with having an intact breast and the risk of recurrence would be too much to bear. However, the follow-up of breast cancer warrants regular clinical assessment and annual mammography for 5 years and thereafter every 2–3 years [32], irrespective of the surgical approach [33]. Further, participants justified having a mastectomy at an early stage believing that recurrence following BCT would warrant a mastectomy in future. While local recurrence rates have been proven to be similar following mastectomy and BCT [14], in the event of recurrence following BCT, a mastectomy is not always necessary. A prospective trial by the North American Research Group reported that a second lumpectomy with adjuvant partial breast irradiation following local recurrence in a conserved breast was achievable in 90% of patients with very low rates of re-recurrence [34].

A significant factor that affected the decision-making process was the treatment team's recommendation. Many participants reported that mastectomy was recommended by the surgeon. Women's narratives suggest that misconceptions on the part of patients may be perpetuated by treating teams even when breast conservation is a viable option. Some participants were denied BCS due to large primary tumours or the involvement of axillary nodes. Cytoreductive chemotherapy followed by BCS is an option for larger tumours [35] and axillary nodal involvement does not necessarily determine the treatment of the primary tumour [36]. While studies conducted in other settings report that shared-decision making between patient and treating teams is associated with selecting BCT over mastectomy [37], a systematic review found that patients who were attended by female surgeons and those who had performed > 10 breast conservation procedures were more likely to select BCT [25].

Radiotherapy is known as "current" and has a bad public image in Sri Lanka [38]. Before this study, there was consensus based on anecdotal evidence among treating teams that mandatory adjuvant radiotherapy following BCS crucially factored into women's decisions. However, many participants said that their fear of radiation was not the intimidating mammoth.

In the close-knit Tamil community in northern Sri Lanka, the impact of family and community on decision-making is inescapable [38], a fact also observed in the treatment of breast cancer. In the absence of comprehensive information from healthcare providers, women relied on second- and third-hand accounts of experiences with BCT, often attributing recurrence and spread to the type of surgical option.

Losing a breast can be incredibly distressing. However, prior research suggests that women in northern Sri Lanka prioritize survival over cosmetic outcomes

in emotionally disabling moments [23]. Furthermore, breast asymmetry may not be as noticeable to others due to modest clothing codes. While mastectomy is known to alter body image and perceptions of femininity and sexuality, the literature in ambivalent regarding the difference in QoL [39–41]. Participants in the present study denied having any problems related to femininity and sexuality. While accepting the loss of a breast may be easier in northern Sri Lanka compared with other settings, some participants expressed regret and struggled with emotional trauma and social stigma. Anxiety among women undergoing treatment for breast cancer is well established and is reported to be more with mastectomy compared to BCT [15, 39, 42]. However, none of the participants indicated that treatment teams discussed cosmesis and the psychological anguish a mastectomy would cause.

It is crucial to have open discussions with patients providing sufficient information and time before embarking on treatment. In a resource-limited setting, such discussions are challenging owing heavy caseloads and a grossly disproportionate doctor-patient ratio [43].

This study has some limitations. We explored women's views on surgical options, leaving out the perspective of treating teams. A second study is underway exploring this topic and will soon complement this research. The study findings are specific to northern Sri Lanka and cannot be generalized, but point to interesting avenues for research in low-resource settings.

Conclusion

Women with early breast cancer undergo mastectomy in northern Sri Lanka despite evidence for equivalent survival outcomes, local recurrence and better cosmetic outcomes with BCT. Our findings suggest that most women opt for mastectomy in the face of significant information gaps. The recommendation of the treating team and the influence of family and friends on decision-making also contribute to women opting for mastectomy. Presenting evidence-based information in honest and open pre-surgical discussions between patients and multi-professional treatment teams covering outcomes, prognosis and post-surgical adjuvant therapy may support women with breast cancer to make informed decisions on their health.

Abbreviations

BCS	Breast Conserving Surgery
BCT	Breast Conserving Therapy
P	Participant
QoL	Quality of Life

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Authors' contributions

Chrishanthi I Rajasooriyar: Conceptualization, funding acquisition, methodology, data curation, analysis, writing original draft, review & editing.Ramya Kumar: Methodology, analysis, reviewing and editing.Dhivya S Thuseetharan: Methodology, data collection, analysis, reviewing.Gopikha Sivakumar: Methodology, data collection, analysis, reviewing. Suman Muthulingam: Methodology, transcribing, reviewing.Sutharshan Vengadasalam: Methodology, reviewing and feedback.

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Availability of data and materials

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Jaffna, Sri Lanka (Ref. No. J/ERC/21/128/NDR/0260). This study was conducted in accordance with the Declaration of Helsinki. All patients understood and signed an inform consent form.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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