

Original Research



Quality of life and delays in breast cancer care in Sri Lanka

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DOI: <https://doi.org/10.4038/jccpsl.v28i2.8523>

Received on 6 April 2022

Accepted on 8 August 2022

Abstract

Introduction: Delay in care adversely affect survival in breast cancer. Delays may lower the quality of life (QoL) too, but no evidence is available for Sri Lanka at present.

Objectives: To determine if the overall delay in breast cancer care affect the QoL of patients in Sri Lanka

Methods: An unmatched case-control study was conducted among 800 consecutively selected female breast cancer patients diagnosed with breast cancer within 12 months and started on definitive treatment. They were interviewed at follow-up clinics and wards at four provincial cancer treatment centres using a validated questionnaire and medical records to collect relevant dates. The QoL was determined by converting the score obtained by the validated Sinhala version of the EQ-5D-3L tool into health state utility values (HSUV). A gap of 10 weeks or more since the day of detection of breast lesion and receiving treatment was defined as the overall delay in care based on literature and local expert consensus. The statistical significance for the QoL difference between delayed and non-delayed patients was determined by 95% uncertainty interval for the mean difference for the HSUV.

Results: The mean (SD) age of our study population was 55.5 (10.7) years. Overall delay in care was common (n=456; 57%). Most patients (69%) reported anxiety/depression related problems, followed by pain/discomfort (59%). A greater reduction in HSUVs between the breast lesion detection and initiation of primary treatment was seen among patients who experienced an overall delay in care (mean=-0.34; SD=0.46) compared to patients without delays (mean=-0.12; SD=0.17). This difference in the mean was statistically significant (95% CI=0.16, 0.27).

Conclusions & Recommendations: Timely provision of medical interventions is likely to improve not only the survival but also the quality of life of breast cancer patients. Psychological issues are common among breast cancer patients in Sri Lanka.

Key words: breast cancer delays, quality of life, EQ-5D-3L, health state utility values, overall delay, Sri Lanka

Introduction

Globally, breast cancer is the commonest cancer as well as the leading cause of cancer deaths among women (1). In 2020, over 2.3 million women were diagnosed with breast cancer and approximately 700 000 women died of it throughout the world (2). All countries generally show an increasing trend in the incidence rate of breast cancer, but the rate of increase in Asian countries is more rapid than that in the western countries (3-4). Similar to the global scenario, breast cancer is the commonest cancer among females in Sri Lanka. In Sri Lanka, 4447 women were diagnosed with breast cancer in 2019, which accounted for 26% of all women with cancer (5). The age-standardized breast cancer incidence rate for Sri Lanka was 12.9 per 100 000, in 2010. This is a 1.4-fold rise since 2001, which is significant ($p < 0.05$ for trend) (6). Unavailability of data for the tumour stage at diagnosis in Sri Lanka prevents any meaningful understanding of the magnitude of delays in breast cancer care. For example, staging data were not available for 97.9% of breast cancer patients in Sri Lanka in 2019 (5). This gap in knowledge act as a barrier in designing preventive interventions to improve the situation and promote early care. Of the available data for tumour staging, 40.7% had advanced stages of III or IV at the diagnosis. Late stages of breast cancer at diagnosis and access barriers for medical care are considered to be the main contributors to the higher mortality rates in less developed countries (7-8).

Breast cancer is one of the few cancers that could be diagnosed at early stages and almost cured if treated timely (2, 9). Therefore, timing indicators such as the proportion of women suspected of breast cancer seen by a specialist within 2 weeks are used to monitor the quality of cancer services in developed countries (10). Our previous work indicated a higher proportion of breast cancer patients (63%) to experience presentation delay in Sri Lanka, but timely referral, diagnosis or management have not yet been adopted as quality indicators (11). Timely diagnosis and treatment are known to improve not only the survival but also the QoL of cancer patients (12). Evidence on the detrimental effect of delays on the survival as well as QoL of cancer patients has directed the

policymakers to opt for interventions to minimize the delays in developed countries. In Sri Lanka, National Strategic Framework for Palliative Care Development (13) discusses ensuring the availability of skilled multidisciplinary teams to deliver palliative care services at the institutional and community level to improve the QoL of patients, but it has not identified avoiding delays as a mean of improving the QoL.

In cancer care, both the QoL and length of life are reflected as important outcomes due to the chronic debilitating nature of the disease itself and its management. Quality-Adjusted Life Years (QALY) is a single measure that represents the arithmetic product of both these factors, making it a more suitable index to measure QoL in cancer care. The fundamental idea of QALY assumes that one year of life lived in full health is worth one QALY (14). The quality aspect of the patient's life is incorporated into QALYs in the form of health state utility values. The length is added as the duration spent on that particular health state. Therefore, QALY calculation essentially captures information on both the health state of the patient and the duration spent on that particular health state. Of the many tools available to measure health state utility values, the quality of life instrument developed by the EuroQol Group with 5 dimensions and 3 levels (EQ-5D-3L) is one of the most commonly used instrument worldwide (15). Despite the availability of Sri Lanka-specific utility values estimated by EQ-5D-3L (16), no research has yet attempted to assess the effect of delays on QALYs of breast cancer patients in the local setting. In this backdrop, the present study was conducted to describe the effect of delays on the QoL among breast cancer patients attending state cancer treatment centres in Sri Lanka.

Methods

A hospital-based cross-sectional study was conducted in 2017-18 at four out of nine provincial cancer treatment centres in Sri Lanka. These centres cater for the highest number of breast cancer patients in the country. Our study unit was a female breast cancer patient with pathological confirmation of breast cancer within the past 12 months, who had undergone

any mode of primary treatment (neoadjuvant therapy, definitive surgery or palliative radiotherapy and systemic therapy) for breast cancer and attending state cancer treatment centres for further care. Those who were critically ill to respond, not conversant in Sinhala and recurrence of breast cancer following remissions were excluded from the study. A sample of 800 patients was recruited consecutively from both follow-up care clinics and oncology wards. It was scattered across the four treatment centres, based on the probability proportionate to the number of registered new breast cancer cases in the respective centre.

Data were collected by trained female pre-intern medical officers. A questionnaire developed by the research team to suit the local context and assessed for judgmental validity among 20 breast cancer patients was used to determine the overall delay in breast cancer care. For a patient who has self-detected a suspicious breast lesion, the overall delay in breast cancer care was determined by an interval exceeding 10 weeks from the time of detecting the lesion until the first day of receipt of the primary treatment. For a patient whose suspicious breast lesion was detected by a healthcare provider, this delay was determined by an interval exceeding eight weeks. The cut-off timings were based on the consensus achieved through a panel of relevant experts after reviewing international guidelines (17-18) published literature and local setting such as service availability.

In addition, EQ-5D-3L tool was administered to assess the level of disability of the respondent at the time of the interview under five domains, namely mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Responses for each dimension has three levels: no problem, some problem or extreme problems (19). This instrument has been translated to Sinhala language and certified by the EuroQol group to be valid and accurate for use in Sri Lanka (16). Permission was obtained from the EuroQol group to use it for this study.

Once the data had been collected, the analysis was undertaken as an unmatched case-control study. For this purpose, a case was defined as any study unit (as

described in the cross-sectional study) who had experienced an overall delay in breast cancer care. A control was a similar study unit who had not experienced such a delay. According to the formula used to calculate samples for unmatched case-control studies (20), the minimum number required was 120 per group, based on a probability of type I error of 0.05; power to detect type II error of 80%; an effect size of 0.1 with standard deviation for the Sri Lankan health state utility value of 0.26 (16); and non-response rate of 10%. The total participants of 800 were considered for this analysis, as it exceeded the required minimum sample size.

Data analysis

Demographic and clinic characteristics of the study sample are presented in frequency distributions.

We analysed the variables of EQ-5D-3L under five domains, using the methods mentioned in the guide of EuroQol group (19). Study participants selected one response for each domain based on their current health status. No response was marked as 1, some problems as 2 and extreme problems as 3. Accordingly, every respondent's health status was created represented by numbers. For example, 12133 would mean no problem in mobility, some problem in self-care, no problem in usual care, extreme problems in pain/discomfort and in anxiety/depression. Different combinations of the responses allow the creation of 532 health states in the EQ-5D-3L tool. Each of these health statuses has a utility value, which is often population-specific and ranging from 0 to 1, 0 being equal to a dead health state and 1 being equal to a full health state. For example, the health state 12133 is assigned a utility value of 0.23. According to this method, the health status of each participant was assigned a Sri Lankan utility value to create their current utility. The baseline utility value before the breast lesion was detected was assumed to be 1. Thereafter, using the formula given below, we estimated the QALYs for each study participant.

$$QALY = \frac{(\text{current utility value}) - (\text{baseline utility value})}{\text{Time duration from the detection of the suspicious breast lesion until the day of the interview}}$$

Finally, the mean QALYs of those who experienced an overall delay in breast cancer care were compared with those who did not, using independent t-test.

Statistical significance was determined at p-value less than 0.05.

Results

The mean age (SD) of the study sample at the diagnosis of breast cancer was 55.5 years (SD=10.7). Gross monthly family income showed a skewed distribution with a median (IQR) of LKR 25 000 (IQR=12 000-35 000) (Table 1). A vast majority of women detected the breast lesion by themselves. Only 5 women (0.6%) had their lesion detected through well-woman clinics operated by the state sector. Only one in three patients (n=274; 34.2%) underwent a mammogram before the definitive treatment for the cancer (Table 2).

Table 3 depicts the distribution of EQ-5D-3L responses (amalgamated into two levels: having and not having problems) across the five domains. The proportion of survivors 'with problems' clearly overrode the proportion "without any problem" in the domains of pain/discomfort (58.8% versus 41.3%) and anxiety/depression (69.1% versus 30.9%).

Table 4 displays the distribution of QALY among the cases and the controls. Negative values imply a loss in QALY over the time. The mean QALY loss for cases (-0.34) was more than the same for the controls (-0.12), indicating a greater loss in QALY among those who experienced an overall delay in breast cancer care compared to those who did not. The mean QALY difference among cases and controls was 0.22 (95% CI=0.16, 0.27). This was statistically significant (p<0.001), indicating the relationship of overall delay with low QoL in breast cancer survivors.

Discussion

Our study findings implied that the QoL of patients who had experienced overall delay in care for their breast cancer is lower compared to those who had not (95% CI=0.16, 0.27). This finding is consistent with the conclusions of previous systematic reviews that delays in care are associated with poorer QoL of breast cancer patients (21-22). Poorer QoL among

delayed patients could be multifactorial, among which the advanced spread of the disease leading to more morbidities and the necessity to administer more toxic drugs could be prominent reasons. Our previous work indicated the presentation delay, spending more than two weeks from the self-detection of a suspicious breast lesion to seek health care, to be the most prominent type of delay among breast cancer patients in Sri Lanka than diagnosis or treatment delays (23). Therefore, the potential substantial improvement in the QoL if presented early could be used in promoting the health-seeking behaviour of women when a suspicious breast lesion is detected. Service implementation without monitoring and evaluation is fruitless, and the service providers will not be able to see the effectiveness of the services. It is the responsibility of relevant authorities to introduce quality indicators including the delays in care to their service monitoring and evaluation systems, as an understanding of the magnitude of the problem is essential in designing effective preventive measures.

Another interesting finding of our study was that anxiety/ depression is the most affected domain (69.1%) among patients. Previous literature supports our finding of higher prevalence of psychological issues among cancer patients in Sri Lanka. Mudduwa & Punchihewa reported 48.6% of breast cancer patients diagnosed within the previous two years experienced psychological distress at any point following the diagnosis (24). Local evidence indicates severe depression to be as high as 40% among inpatient patients and 16% among out-patients (25). Similarly, another local survey found out 57% of breast cancer interviewed patients to suffer from severe distress (26).

Although a higher proportion of patients with breast cancer is known to suffer from depression (27), the need for healthcare services is largely unmet even in developed countries (28). The situation could be worse in developing countries with scarce resources. For example, a previous local study indicated that 90% of cancer patients requested additional support from treatment centres to cope with their psychological problems (25). Although this service gap is long-standing in the country (29), equitable

Table 1: Socio-demographic characteristics of study participants (N=800)

Characteristic	No.	%
Age category at symptom detection (years)		
< 30	2	0.1
30 - 39	59	7.4
40 – 49	164	20.5
50 – 59	279	34.8
60 – 69	217	27.1
≥ 70	79	9.9
Ethnicity		
Sinhala	711	88.9
Tamil	50	6.3
Moor	35	4.4
Other	4	0.5
Having children		
Yes	696	87.0
No	104	13.0
Sector of residence		
Urban	190	23.8
Rural	610	76.3
Highest level of education		
No formal schooling	35	4.4
Primary education	88	11.0
Grade 6-11	209	26.1
Ordinary level completed	218	27.3
Advanced level completed	216	27.0
Undergraduate	32	4.0
Post-graduate	2	0.3
Employment status		
Never been employed	425	53.1
Currently not employed	100	12.5
Currently employed	275	34.4
Average monthly family income (LKR)		
< 24,999.00	377	47.1
25,000.00 – 49, 999.00	292	36.5
50,000.00 – 74,999.00	97	12.1
75,000.00 – 99,999.00	18	2.3
> 100,000.00	16	2.0
Possession of a health insurance at the time of symptom detection		
Yes	79	9.9
No	721	90.1

Table 2: Clinical characteristics among the study participants

Characteristic	No.	%
Mode of detection of the suspicious lesion		
Self-detected	787	98.4
By a Healthcare Provider at a screening service at Well-woman clinic	5	0.6
By a Healthcare Provider at a screening service at private sector	8	1.0
Utilization of state breast cancer services among self-detected participants		
Utilized	128	16.3
Not utilized	659	83.7
Initial suspicious breast lesion experienced/ detected		
Breast lump	642	80.3
Hard area in the breast	38	4.8
Skin changes over the breast	25	3.1
Breast pain	24	3.0
Nipple changes	20	2.5
Axillary lump	16	2.0
Nipple discharge	11	1.4
Other	24	3.0
Having mammography before primary treatment		
Yes	274	34.2
No	526	65.7
Mode of confirmatory diagnosis		
Fine needle aspiration cytology	536	67.0
Biopsy	264	33.0
Histological type of the tumour according to ICD-10		
Invasive ductal carcinoma	643	80.3
Lobular carcinoma	15	1.9
Other	142	17.7
Stage of the tumour at diagnosis		
I	83	10.5
II	352	44.0
III	214	27.1
IV	96	12.1
Not available	55	6.8
Mode of primary treatment		
Definitive surgery	563	70.4
Neoadjuvant therapy	141	17.6
Palliative radiotherapy and systemic therapy	96	12.0

Table 3: Distribution of the study participants by their responses to five domains of EQ-5D-3L

Response level	Mobility	Self-care	Usual activities	Pain/discomfort	Anxiety/depression
No problem	583 (72.9)	714 (89.3)	578 (72.3)	330 (41.3)	247 (30.9)
Some problem	190 (23.8)	66 (8.3)	211 (26.4)	386 (48.3)	468 (58.5)
Extreme problem	27 (3.4)	20 (2.5)	11 (1.4)	84 (10.5)	85 (10.6)

Table 4: Comparison of descriptive statistics of QALYs among cases and controls

Statistics	Cases	Controls
Minimum	-3.47	- 1.36
Maximum	0.04	0.06
Mean (SD)	-0.34 (0.46)	-0.12 (0.17)
95% confidence interval for the mean	(-0.38) – (-0.30)	(-0.14) – (-0.10)

services are yet to materialise. Regular assessment of psychological needs of cancer patients is not happening at the ground level (personal communication with care providers).

The only national policy discussing psychological care provision to cancer patients in Sri Lanka is the National Strategic Framework for Palliative Care Development. This framework discusses ensuring the availability of skilled multidisciplinary teams, including psychiatric services, to deliver palliative care services at the institutional and community level (13). While the efforts to ensure services to patients receiving palliative care is commendable, it is merely not adequate to close the service gap. Global evidence suggests the effectiveness of psychosocial interventions and follow-up strategies in improving the QoL of breast cancer patients (30-31). In the light of such a background, limiting the psychological services to a certain group of patients raises the issue of equity in healthcare service provision. Furthermore, our study findings that patients having psychological issues to be similarly distributed among early (49.2%) and late (50.8%) tumour stages strongly imply the necessity to make available the services to all patients in need.

Even though the provision of individual psychological interventions to each breast cancer patient is beyond feasibility due to the overcrowded hospitals and clinics, policymakers should investigate realistic

strategies to overcome this service gap. For example, counselling and making patients aware about the course of breast cancer care could be provided to groups of patients at the first contact point with the cancer care providers by a trained nursing officer. Such novel strategies could address the service gap which is very important from the patient perspective.

Conclusions & Recommendations

Our findings show that spending more than 10 weeks to receive the first definitive treatment for breast cancer since its self-detection is likely to impair the QoL of patients. Improving the situation related to delays in breast cancer care will possibly contribute to improving patients' quality of life. Improving care delays involve monitoring and evaluating care services that address delays. Therefore, we believe the implementation of a strategic framework in liaison with clinicians to monitor and evaluate the care services qualitatively and quantitatively should be the first step towards improving delays in breast cancer care. Another important finding of our study was that a higher proportion of study participants (69.1%) had problems in the anxiety/ depression domain. This finding when considered together with previous evidence of service gaps in addressing psychological issues among cancer patients, highlights the necessity for such interventions. Exploration of feasible novel interventions to fulfil

this service gap must be a prioritised exercise for relevant authorities.

Public Health Implications

- Our study signifies the importance of re-orienting health care services to support the needs of breast cancer patients. Compared to developed countries, we failed to identify any national policies or strategic framework providing indicators or policy directives to monitor delays in breast cancer care in Sri Lanka.
- Our findings support the global body of evidence that delays probably lower the QoL of breast cancer patients, which is an indication to improve the current situation related to breast cancer care in Sri Lanka.

Author Declarations

Competing interests: All authors declare no competing interest.

Ethics approval and consent to participate: Ethical clearance for the study was obtained from the Faculty of Medicine, University of Kelaniya (Registration number P/015/2017). In addition, administrative permission was sought from the institutional directors of each hospital and clinicians who were in charge of caring for patients. Informed verbal consent was obtained from all participants prior to data collection.

Funding: This work was supported by the National Cancer Control Program, Sri Lanka (Project grant number 111-02-14-21-2509 (11), 2018).

Acknowledgement: The authors wish to acknowledge Professor Rajitha Wickramasinghe for his technical inputs to improve the quality of the study and Dr Nirmala Seneviratne at the National Cancer Control Programme for her support in providing resources during the study implementation. Doctors Malshani Herath, Sanchana, Nirmani Herath, Rehana Cader, Kalpani Ovitigala, Jayamini Atapattu, and Malika Kumari are acknowledged for their involvement in data collection.

Author contributions: SH conceptualized the study, involved in designing the method and data collection, acquired funding, performed the primary analysis and drafted the first manuscript and then involved in revising it.

NG conceptualized the study, involved in designing the methods and supervised the overall project administration, data analysis and reviewing and editing the manuscript. SS conceptualized the study, involved in designing the methods, supervised the overall project and data analysis, acquired funding for the project, and reviewed and edited the draft manuscript. NJ participated in supervision of data collection, supervision of the project administration and reviewing and editing the draft manuscript. SK conceptualized the study, involved in designing the methods, supervised the overall project including data analysis and reviewed and edited the draft manuscript.

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