Problems of Breast Cancer Survivors Living in an Urban Area of Nepal

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ABSTRACT

Objective: The main objective of this study was to identify the problems of Nepalese breast cancer survivors living in an urban area who had completed their treatment for at least 6 months. **Methods:** A cross-sectional descriptive study was conducted to assess the problems of breast cancer survivors who were registered at the Nepal Cancer Support Group. Fifty-one women who were diagnosed with breast cancer (Stage 0 to III) and were currently disease-free were enrolled in the study. They were interviewed using structured interview schedule using the Breast Cancer Prevention Trial Symptom Scale. Statistical analysis was carried out with SPSS (version 16). **Results:** The mean age of the women at the time of enrollment was 47.3 years. The most common modality of treatment they received was the combination of surgery, chemotherapy, and radiotherapy (84%). Top five symptoms experienced by the survivors on the basis of frequency and severity were tiredness (61%), lack of energy (57%), forgetfulness (57%), lack of interest in sex (52%), general body aches (49%), and feeling of worrisome and anxiousness about future (49%). Women with age <45 years at diagnosis had higher mean rank score in psychological (24.7) and social problems (23.9) in comparison to women aged ≥45 years. There was a significant relationship between severe psychological (34.9 vs. 19.6; $P = 0.001$) and social problems (29.1 vs. 21.2; $P = 0.03$), with the time since primary treatment completion of <1 year. **Conclusions:** Nepalese breast cancer survivors were found to have multiple physical, psychological, and social problems and might require special attention during follow-up visits.

Key words: Breast cancer, breast cancer survivors, problems

Introduction

Breast cancer is the most frequently diagnosed cancer in women worldwide with an estimated 1.4 million new cases in the year 2008.[1] In Nepal, there is not a national population-based cancer registry except one hospital-based

registry in the year 2005, which included seven major hospitals in the country. This survey included 4397 cancer patients, of which 2340 (53%) were females. According to this survey, the most common sites of cancer in Nepali men are lung (14.6%), oral cavity (7.8%), and stomach (7.5%), and in women, cervix (21.4%), breast (15.7%), and lungs (10.8%) . Breast cancer is the second most common cancer in Nepalese women and is the topmost among younger women.[2] The incidence of breast cancer in Nepal is high in perimenopausal women with the common age group of 41–50 years with Stage III being the most common stage.[3-5]

Physical examination, mammography, and fine-needle aspiration are the commonly used diagnostic modalities of breast cancer in Nepal, and the choice of management modality varies from center to center.[4] A majority of the cases of breast cancer are managed with either radical or modified total mastectomy. However, the management trend is changing day by day with increasing preference toward breast-conserving surgery rather than total mastectomy, ranging between 6% and 15% in different cancer centers.[3,4] Reconstruction surgery using muscle flaps is rarely performed in Nepal, and adjuvant chemotherapy and radiotherapy have regional variation.After completion of the primary treatment breast cancer patients with estrogen receptor positive cancer is treated with systemic hormonal therapy. In Nepal, tamoxifen is the commonly used hormonal medicines irrespective of the menopausal status. However, post menopausal woman who can afford uses ideal medicines selective estrogen receptor modulator (aromatase inhibitor) as systemic therapy.

Due to advancement and availability of multidisciplinary treatment modalities, there has been substantial improvement in the survival rates of the breast cancer patients. The number of people living with or beyond cancer is increasing day by day, and this number is expected to rise every year by >3.2%.[6]

Various studies have shown that the women with breast cancer who have received treatment successfully with adjuvant therapy (chemotherapy, hormonal therapy, targeted drug therapy, and radiation therapy) might experience multiple physical and psychosocial problems.[7-9] In few studies, women who received adjuvant therapy experienced significantly more severe symptoms, including musculoskeletal pain, vaginal problems, weight gain, nausea, hot flashes, night sweats, vaginal discharge, and genital itching.[10-12] Previously published articles showed that the experienced symptoms might impede the process of

smooth transition from the diagnostic and active treatment phase to the phase of rehabilitation and survivorship.[13] Detailed knowledge about the problems faced by the breast cancer survivors is critical to provide posttreatment care that would address the most frequent and severe symptoms in more effective way. In Nepal, there has been a significant advancement in the treatment of breast cancer, and there are many hospitals and cancer centers where different modalities of treatment are available. As a result of these advances, the number of patients surviving after breast cancer must have been increased.

Recently, in Nepal, one of the specialized cancer centers has launched the concept of running a special outpatient department (OPD) services in the name of "Cancer Survivorship Clinic" since 2015.[14] As the new concept is in existence, the researcher realized that it is the right time to assess problems/symptoms of breast cancer survivor to acquire knowledge on the posttreatment problems faced by the survivors. Thus, it is important for the patients, researchers, and clinicians and nurses to assess accurately the occurrence of different symptoms so as to plan optimal survivorship program to make transition of survivorship easier. Assessment of problems can give a basis for the modification of the follow-up care and, thus, optimize healthcare during and after completion of the treatment. There has not been a single study to explore the problems faced by this group of population in Nepal. Hence, this study was conducted to assess the different problems seen in breast cancer survivors who have completed the treatment at least 6 months ago.

Methods

Study design
This was a cross-sectional study done among breast cancer survivors aged 25 years or above who had completed primary cancer treatment 6 months before and had not experienced relapse.

Research setting
The participants who were registered at the Nepal Cancer Support Group were included in the study. The Nepal Cancer Support Group is a not-for-profit nongovernment organization established in 2010. The list of women registered to the group was obtained, and they were interviewed from July to December 2014. All of the women were living in urban area of the country.

Sample size
A total of 196 women registered at the Nepal Cancer

Support Group were identified. Of them, 51 women who met the inclusion criteria and who were approachable and who gave consent to participate were included in the study.

Inclusion criteria

The eligibility criteria were women of age 25 years or above and who had completed the treatment at least 6 months before the study.

Exclusion criteria

Women who were pregnant, had a history of recurrent diseases at the time of the survey, had a history of hospitalization within the last 1 month before data collection, with metastatic disease, had severe cognitive or psychiatric difficulties, and severely ill women unable to give interview were excluded from the study.

Instruments

The research instrument consisted of the demographic and treatment-related variables. The problem was assessed with the Breast Cancer Prevention Trial Symptoms Scale (BCPT) and the Cancer Rehabilitation Evaluation System (CARES). CARES was used to address those problems (such as marital, social, and psychological) which were not addressed by the BCPT scale.

Breast cancer prevention trial scales

BCPT is the standard scale that contains 25 questions with ten domains, which addresses everyday symptoms/problems. The domains in BCPT include hot flashes, nausea, bladder control, vaginal problems, musculoskeletal pain, cognitive problems, weight problems, arm problems, fatigue, and sexual interest. With this scale, the respondents were asked how much they were bothered by each symptom during the past 4 weeks. The responses ranged from not at all = 0, slightly = 1, moderately = 2, and quite a bit = 3 to extremely = 4 in a 5-point Likert scale. The higher the score, the more severe is the problem. This scale exceeds the reliability value of 0.7 on most of the symptoms scale.[15] This tool was used in several previous studies to assess the majority of physical, menopausal, and cognitive symptoms in breast cancer survivor.[10,16]

Cancer rehabilitation evaluation system

This is a multidimensional instrument with different subscale. This instrument has a well-documented reliability, validity, and internal consistency. In this study, only three subscales with thirteen items related with marital (5 items), social (3 items), and psychosocial (5 items) problems, which were not addressed by the BCPT scale, were used. Survivors were asked to rate how much they were bothered by each

symptom/problem during the last 4 weeks on a 5-point rating scales from 0 - not at all/no problem, 1 - a little, 2 - fair, 3 - much, and 4 - very much/severe problem. The higher the score in each item, the more severe is the problem.[17]

The final tool consisted of altogether 38 items (25 from BCPT and 13 from CARES). The tool which is available in English version was first translated into Nepali language, which is the national language of Nepal by a unanimous translator. Back translation of tool from Nepali to English was done to ensure that it gave the same meaning. Pretesting of the final tool was done in five breast cancer survivors. The reliability coefficient was checked with Cronbach's alpha, which was 0.84 for the translated tool in Nepali that signified no requirement of any change in the tool.

Data collection procedure

Women registered at Nepal Cancer Support Groups were screened for the eligibility criteria, who were then followed up through phone calls. Final screening was again done, and details of the study were explained. Only those women who were well motivated and interested were called at the hospital of their follow-up visit. All women were interviewed by the principal investigator in a separate room of the OPD maintaining the privacy and confidentiality using the purposive sampling technique. The information related to the demographic data and clinical symptoms was collected from the interview whereas the clinical data related to stage and treatment modalities of cancer were taken from the records brought by the respondents. After the completion of interview, the participants were allowed to ventilate their feelings and share their experiences with other women of the list. The participants discussed the complaints and about the prosthesis they are using currently.

Ethics

The respondents were explained about the purpose/objective and other details (risk and benefits) of the study through phone call by the staff of National Cancer Support Group. Those who wished to participate were called to nearby cancer treating hospital of their follow-up visit of their convenience. The women who came for interview were those who were well motivated and interested. Therefore, only informed verbal consent was obtained. Information was collected on the separate room maintaining the privacy of each respondent.

Statistical analysis

The statistical analysis was done with the Statistical Package for Social Sciences, version 16.0 (SPSS Inc., Chicago, IL, USA). All categorical variables are expressed as frequency

and percentage. To assess common problems, frequency and percentage were used. The severity of each symptom was assessed with the mean ± standard deviation. For the assessment of the relationship between selected demographic and clinical variables with problems, the data were checked first for normality test using Kolmogorov–Smirnov test. For the variables which were not normally distributed, nonparametric test (Man–Whitney U-test) was used to find the relationship of the clinical and demographic variables with different problems.

Results

Recruitment result

One hundred ninety-six breast cancer survivors registered at the Nepal Cancer Support Group were approached, and records were reviewed and screened manually for eligibility criteria. Only 150 survivors met the inclusion criteria. The contact number of the potential women was searched, of which details of thirty women were not found. Of 120 women, 35 could not be approached as they were far from the research setting. Of the remaining 85 women who responded the phone call, 3 were hospitalized in the previous 1 month and 5 were too ill to participate. Twenty-three of the screened women rejected for the interview. Fifty-four women who expressed interest in the participation were interviewed. Among 54 responders, three had incomplete information and were excluded from the study and final analysis was done in 51 survivors [Figure 1].

Demographic and clinical characteristics

The mean age of the women at the time of the diagnosis and survey was 43.5 and 47.3 years, respectively [Table 1]. A majority (90%) of them were married. Fifty-five percent of the women had education level up to secondary level and rest (45%) had above this level. Sixty-five percent of the women were not employed at the time of diagnosis. Sixty-seven percent of them were diagnosed with Stages II-III breast cancer. The most common treatment modality of breast cancer was the combination of surgery, chemotherapy, and radiotherapy (84%), followed by surgery and chemotherapy (8%), surgery and radiotherapy (6%), and only surgery (2%). Thirty-three percent of the women were currently receiving hormonal therapy. Time from the completion of cancer treatment was 2 to 5 years in 60% of women.

Menopausal status by age group at the time of diagnosis and at the time of enrollment is shown in Table 2. Almost all women (95.8%) below 45 years were premenopausal at the time of diagnosis; however, this value was 35% (35.7%)

at the time of enrollment. Similarly, near about 43% of the women above 45 years were also at premenopausal status; however, this was reduced to 6% at the time of the enrollment.

The studied women had varying degree of symptoms and none of them were free from any symptom.
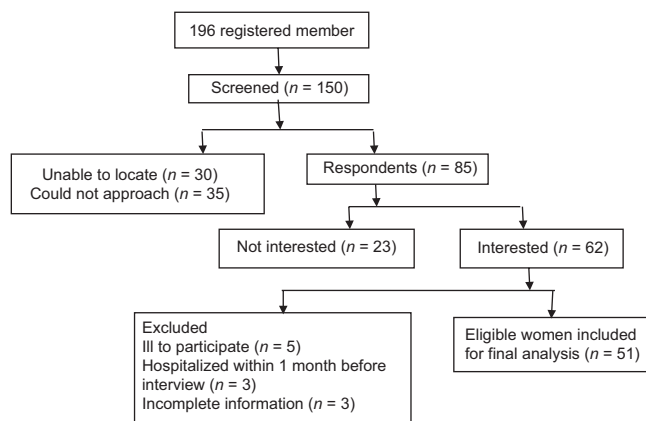

Figure 1: Recruitment process

Table 1: Demographic and clinical characteristics		
Characteristic	***n* (51)**	**%**
Age at enrollment (years)		
<40	7	14
40-50	23	45
≥50	21	41
Mean age in years (SD)		
Diagnosis	43.5 (7.5)	
Treatment completion	44.4 (7.8)	
Enrollment	47.3 (8.6)	
Marital status		
Married	46	90
Single	5	10
Education level		
Secondary level	28	55
Higher secondary and above	23	45
Employment status		
Employed	18	35
Unemployed	33	65
Stage at diagnosis		
0-I	17	33
II-III	34	67
Treatment		
Surgery only	1	2
Surgery plus chemotherapy	4	8
Surgery plus radiotherapy	3	6
Surgery plus chemotherapy plus radiotherapy	43	84
Time since completion of treatment		
6 months to 1 year	11	22
1-5 year	31	61
≥5 years	9	18
SD: Standard deviation		

Forty-seven percent of the women had more than ten symptoms and the mean number of symptoms per woman was 9.94 ± 5.33. The top most prevalent symptoms reported were tiredness (61%), lack of energy (57%), forgetfulness (57%), lack of interest in sex (52%), general aches and pain (49%), feeling of worrisome and anxiousness about future (49%), and night sweats (43%) [Table 3]. One of the noted findings of the study is that almost all of the top ten symptoms yielded high score in the severity index, which were lack of interest in sex (1.04 ± 1.24), tiredness (0.88 ± 0.88), forgetfulness (0.78 ± 0.85), night sweats (0.76 ± 1.01), lack of energy (0.75 ± 0.79), hot flashes (0.73 ± 1.00), feeling of worrisome and anxiousness about future (0.73 ± 0.94), general aches and pain (0.69 ± 0.88), decreased range of motion of affected arm 0.67 ± 0.81, low sexual enjoyment (0.53 ± 0.89), and arm swelling (0.51 ± 0.78).

For the analysis of the relationship of demographic- and treatment-related variables [Table 4], the women who had undergone hysterectomy were excluded from the study. There was no difference in mean rank score between age and different problems such as fatigue, hot flashes, bladder control, sexual problems, and psychological and social problems. Women with age <45 years at diagnosis had higher mean rank score in psychological (24.7) and social problems (23.9) in comparison to women aged ≥45 years. In contrast, physical symptoms were more pronounced in elderly survivors (>45 years) in comparison to younger survivors (<45 years). Bladder control (24.9 vs. 18.6), hot flashes (24.82 vs. 18.9), and easy fatigability (24.3 vs. 20.0) ranked higher scores in survivors in the age group >45 years.

Women who were diagnosed with Stages II-III had significantly higher mean score in arm problems in comparison to women diagnosed with Stages 0-I (25.6 vs. 17.7; *P* = 0.005). Women who had completed cancer treatment 6 months to 1 year had significantly higher mean rank score in psychological (34.9 vs. 19.6; *P* = 0.001) and social domain (29.1 vs. 21.2; *P* = 0.03) in comparison to those who had completed the treatment for >1 year. The mean rank score for problems such as fatigability, bladder control, and hot flashes was higher in women who were at 6 months to 1 year of their treatment completion. The women who were on hormonal therapy at the time of interview had higher mean rank score in hot flashes, night sweats, and fatigue; however, this could not elicit significant relationship.

Discussion

This study was done to explore the physical and psychosocial problems faced by the breast cancer survivors.

Table 2: Menopausal status before and after treatment

Menopausal status	Before treatment (*n*=45)		After treatment (*n*=45)	
	<45 years (*n*=24), *n* (%)	≥45 years (*n*=21), *n* (%)	<45 years (*n*=14), *n* (%)	≥45 years (*n*=31), *n* (%)
Premenopausal	23 (95.8)	9 (42.9)	5 (35.7)	2 (6.5)
Perimenopausal	1 (4.2)	2 (9.5)	5 (35.7)	4 (12.9)
Postmenopausal	0	10 (47.6)	4 (28.6)	25 (80.6)

Table 3: Symptoms prevalence and score (*n*=51)

Symptoms	*n* (%)	Symptoms score, mean (SD)
Hot flash		
Hot flashes	23 (45)	0.73 (1.00)
Night sweats	22 (43)	0.76 (1.01)
Bladder control		
Loss of bladder control (laughter)	13 (26)	0.49 (0.98)
Vaginal problems		
Vaginal dryness	14 (28)	0.35 (0.62)
Musculoskeletal problems		
General aches and pain	25 (49)	0.69 (0.88)
Joint pain	18 (35)	0.47 (0.73)
Muscle stiffness	16 (31)	0.45 (0.80)
Weight problems		
Unhappy with appearance of owns body	17 (33)	0.51 (0.90)
Weight gain	16 (31)	0.51 (0.90)
Cognitive problems		
Forgetfulness	29 (57)	0.78 (0.85)
Difficulty concentrating	14 (28)	0.31 (0.54)
Easily distracted	13 (26)	0.27 (0.49)
Arm problems		
Decreased range of motion of affected arm	24 (47)	0.67 (0.81)
Arm swelling	18 (35)	0.51 (0.78)
Fatigue		
Tiredness	31 (61)	0.88 (0.88)
Lack of energy	29 (57)	0.75 (0.79)
Sexual interest		
Lack of interest in sex (*n*=46)	24 (52)	1.04 (1.24)
Low sexual enjoyment (*n*=45)	14 (31)	0.53 (0.89)
Psychological problems		
Felt worried and anxious about future	25 (49)	0.73 (0.94)
Felt despair about health	20 (39)	0.47 (0.67)
Felt sad depressed and lost interest	14 (28)	0.35 (0.65)
Felt angry and irritable	14 (28)	0.37 (0.72)

Prevalence >20% is presented

We have found that the women who have survived successful breast cancer treatment would face at least one of those problems. About half of the women (47%) reported the presence of >10 symptoms, which is a bit higher than the studies done in other countries.[18,19] In a study done among 150 breast cancer survivors, Cheng *et al*. reported that 17% of women experienced >10 symptoms. The mean number of symptoms per survivor in our study was 9.94 ± 5.5, which was higher than the published report.[18]

Table 4: Relationship of different variables and the problems (*n*=45)							
Characteristics	**Mean rank**						
	Fatigue	**Arm problems**	**Hot flashes**	**Bladder control**	**Sexual interests**	**Psychological problem**	**Social problem**
Age (years)							
<45 (*n*=14)	20.0	26.9	18.9	18.6	18.4	24.7	23.9
≥45 (*n*=31)	24.3	21.2	24.82	24.9	21.6	22.1	22.5
P	0.05	0.15	0.14	0.05	0.39	0.52	0.67
Stage							
0-I (*n*=15)	20.8	17.7	21.97	20.9	17.4	19	20.7
Stage II-III (*n*=30)	24	25.6	23.52	24	22.3	24.9	24.1
P	0.42	0.04	0.69	0.32	0.17	0.14	0.31
Completion of treatment							
<1 (*n*=10)	25.1	22.8	25.4	25.6	20.4	34.9	29.1
≥9 (*n*=35)	22.4	23	22.3	22.2	20.5	19.6	21.2
P	0.55	0.96	0.49	0.36	0.97	0.001	0.03
Menopausal status							
Premenopausal (*n*=16)	22.4	24.5	18.6	19.9	15	22.3	20.8
Postmenopausal (*n*=29)	23.3	22.1	25.3	24.6	24.1	23.3	24.1
P	0.82	0.52	0.08	0.13	0.004	0.8	0.3
Current hormonal medicines							
Yes (*n*=17)	25.6	25.8	24.3	23.7	23.8	23.5	25.2
No (*n*=28)	21.3	21.2	22.1	22.5	18.5	22.6	21.6
P	0.27	0.24	0.57	0.71	0.14	0.82	0.26
P<0.05 was considered statistically significant							

The most commonly reported symptoms were fatigue (tiredness - 61% and lack of energy - 57%), forgetfulness, lack of interest in sex, and general body aches, which were seen in >50% of women. This is in congruent with previously published studies.[18-20] Holzner *et al.* found that the common symptoms encountered by the cancer survivors were lack of energy, numbness, and pain.[20] Another study also reported that many women complained of general body aches, joint pain, and muscle stiffness.[21] The symptoms that were seen in 35–50% were feeling of worrisome and anxiousness about future, hot flashes, night sweats, decreased range of motion of affected arm, and arm swelling. Similar findings were also reported in previously published study, in which 46% survivors experienced hot flashes and night sweats.[22]

In this study, 95% of women below 45 years of age were premenopausal at the time of diagnosis and 35.7% at the time of enrollment. This was in support with the findings by Ganz *et al.*, where there were substantial shift in menstrual status before diagnosis and at the time of enrollment.[21]

As similar to the previous study,[21] we have found that majority of more frequent problems faced by the cancer survivors are more severe. Attending nurses need to pay more attention and quality of care to such survivors to help them get rid of their problems. Although statistically insignificant, women with < 45 years of age had higher scores in psychological and social problem, which could be due to the worrisome of these survivors about their future in terms of possibility of financial burden and recurrence of the disease. Our finding is similar to those mentioned by Ganz e*t al.*,[21] which showed poor mental health in younger survivors.

Women who were diagnosed with breast cancer Stages II-III had significantly higher mean rank score in arm problems compared to Stages 0-I. This might be due to the most extensive surgery performed in Stages II-III along with the removal of axillary lymph nodes. In one of the studies done in Nepal, majority of surgery for breast cancer had undergone total mastectomy with axillary lymph nodes dissection.[3] This corresponds to the findings of the study done by Ugur *et al.*, in which lymphedema was significantly more common (*P* = 0.018) in women with advanced cancer as compared to early stage breast cancer.[23] On the basis of these findings, we can now suggest that the higher possibility of lymphedema after breast cancer surgery needs to be well explained to the clients before surgery and the operating surgeons need to pay attention to prevent the occurrence of these complications.

The women who were at 6 months to 1 year of treatment completion had statistically significant higher scores in psychological and social problems in comparison to > 1 year of treatment completion. This finding is comparable to

other studies,[24] in which breast cancer survivor had marked improvement in social and role functioning by 1 year post diagnosis as well as overall improvement of quality of life. In early years of posttreatment, women might be having fear due to uncertainty about the effects of treatment modalities aggravating psychological symptoms. As time passes, confidence level increases with amelioration of previously felt problems. The postmenopausal women had more sex-related problems in comparison to premenopausal women.

One of the limitations of this study is the study design, which is a cross-sectional study. The second potential limitation is the representativeness of the sample. The participants are women who are the member of the Nepal Cancer Support Group and are motivated for participation in the study. Although we tried to involve all women, all of them were not accessible because either the phone number recorded was wrong or was changed. The Nepal Cancer Support Group had prepared their own registries of the cancer patients who come to visit some of the renowned hospital (government, public) with the help of which the group of researchers were able to conduct this research. Moreover, informed verbal consent was taken instead of written consent. In addition, this is a direct face to face interview, in which women might not feel comfortable to explore and rate their problems, especially sex-related problems.

Conclusion

Although there are several limitations, this study provides some insight on the problems of breast cancer survivor of developing countries like Nepal. This is the first study on breast cancer survivor in Nepal. The findings of this study can be useful to the clinicians and nurses so that they can concentrate on these symptoms and include it while assessing clients on their follow-up visit. It may be useful for nurses for planning continued psychological support to the survivors even after completion of the treatment. The nurse can also organize and coordinate the meeting with counselors and psychologists, and the survivors could be engaged themselves in lifestyle modifications such as physical exercise, yoga, and meditation. Many women in the underdeveloped countries like Nepal might not feel comfortable to raise the issue of sexual problems unless they are encouraged, which can be ameliorated by continuous counseling and discussion with sharing ideas on alternative remedies.

Conflicts of interest

There are no conflicts of interest.

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