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Original Research Article

Assess the prevalence for needs of breast cancer survivors' in the oncology ward at a selected tertiary care hospital

**Abstract:** The unmet needs of breast cancer survivors are not being addressed as the number of survivors continues to climb.

**Aim and Objective:** A descriptive research study was conducted in a tertiary care hospital's oncology outpatient clinic and wards.

**Material and Method:** Data was gathered in two sections: I – baseline data, and section II – Modified needs assessment questionnaire. 35 needs were categorized as physical, emotional, family, spiritual, practical routine, and sexual relationship needs, with 'Yes' scored as '1' and 'No' scored as '0'. Data was collected for one month. Data tabulation and analysis was done. **Result:** The majority of BCS had a monthly income of Rs.3000-10000/- (50.8%) and menopause had occurred in 54 (45%) of the women under the age of 45. Majority 65 (78%) did not have health insurance, whereas 42 (35%) had it. Majority 108 (90.33%) breast cancer survivors had high level of needs, whereas 12 (10%) had moderate level of needs. High physical needs reported by 87 (72.50 %) and 32 (26.67%) moderate physical needs. All 100% BCS reported high emotional need. Whereas 2(1.67%) less need, 14(11.67%) moderate, 56 (46.67%) high needs and 48 (40%) very high reported family and spiritual need and 39 (32.5 %) BCS reported moderate level of practical needs. Participants 14(11.67%) less needs, 39 (32.50%) moderate, 22(18.33%) high and very high 8(6.67%) reported practical needs. 100% of breast cancer survivors (BCS) reported physical includes Hot flashes, a change in appetite or eating pattern. Practical demands including education, occupation, income, age at menopause and stage of cancer were found to have significant associations with the overall and physical needs of BCS.

**Conclusion:** Breast cancer survivors' needs are more prevalent and have an impact on quality of life, prognosis, and recovery of clients. Hence, counselling sessions, information display boards, and health care providers should address the needs appropriately for better recovery.

**(Key Words: Breast cancer survivors, Prevalence, Needs and Tertiary Care Hospital)**

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## 1. INTRODUCTION

Breast cancer survival has improved as diagnosis and therapy have progressed. Following primary treatment for breast cancer, women are left with a variety of demands that affect their quality of life. In India, there is a lack of literature to determine the needs of breast cancer survivors. A community-based approach will help in identifying unmet needs. Breast cancer survivors in India have relatively little awareness of the disease, management, and other needs. The work should be focused on meeting the unmet requirements of patients.

As breast cancer becomes more prevalent as a chronic disease, a rising number approximately half of patients between the ages of 25 and 40 are diagnosed,<sup>1</sup> which is an alarming trend with the increased life expectancy of up to ten years. According to research, quality of life declines once the breast cancer treatment is completed. After breast cancer therapy, there is no clear guideline for breast cancer survivors. There was a strong desire to explore the unmet needs of breast cancer survivors and redesign their life.

Breast cancer is the World's most prevalent cancer, in 2020 there were 2.3 million women diagnosed with breast cancer and 685 000 deaths occurs globally. At the end of 2020 there were 7.8 million women's alive, which were diagnosed with breast cancer in the last 5 years.<sup>1</sup>

The research looked into lifestyle changes that are mostly affected by BMI, nutrition, and exercise. According to one survey, there are around 2.5 million breast cancer survivors in the United States.<sup>2</sup> Study confirmed that breast cancer survivors have many unmet needs that are not covered by written documents at the time of discharge its suggests that the unmet needs of every third of breast cancer survivors questions would be addressed by materials currently provided to them.<sup>3</sup>

In Indian women the needs were, financial informational, breast reconstruction surgery, help in household activities, family support, counselling and emotional support needs.<sup>4</sup> The health system and information domains had the highest mean score (2.48; 95% CI: 2.32–2.64) among respondents. Unmet needs were reported by 14.9 % to 34.7% of respondents with a "moderate to high" level of need. Survivors who were younger (less than 60 years old), had better educational attainment, were unemployed, had a survival period of up to 5 years, and were having active treatment had a significantly higher level of unmet needs. The current trend in this study suggests that there is still a much of work needs to be done in satisfying the informational needs of breast cancer survivors. The researchers suggested that community-based breast cancer support groups be developed.<sup>5</sup>

Surgery patients who survived less than a year after surgery had substantially higher unmet needs in all need domains except for the sexuality domain. Patients who survived for 1-3 years had much higher psychological and information needs. Unmet needs were linked to depression (p 0.001) and quality of life (p0.001).<sup>6</sup>

Kim Soo Haun, et.al. (2020), A focus group interview study found that participant's needs were categories under the five themes of symptoms and emotional management needs, information need,

needs of relationship with health care professional, adaptation needs. Self-management skill was required to relieve symptoms (eg. peripheral neuropathy, insomnia ) emotional problem (eg. fear of recurrence , anxiety ,depression) and adapt to changes due to cancer treatment , constructive relationship needs with health care professional or providers were expressed by participants specially respecting them and communication. Whereas patient self-confidence is highly valued by participants for successful self-management skill.<sup>7</sup>

A study by the American Society of Clinical Oncology (ASCO) and the American Cancer Society (ACC) the patient perspective on reducing economic burden after breast cancer. The authors made nine specific recommendations for changes to insurance, supportive services, financial assistance, and protective policies.<sup>8</sup>

The study was nurses should impart routine self-care education to breast cancer patient . Study has recommended that, plan individualized education program in formulating their own education program, focusing and emphasizing on unique needs of each patient.<sup>9</sup>

The current study looked into information needs, breast reconstruction surgery, housekeeping assistance, family support, counselling, emotional support, and financial needs during and after diagnosis. People with breast cancer in India pray to God to relieve them from curses and evil spirits, believing that disease is caused by God's curse on the elderly and evil spirits.<sup>4</sup> Maximum with cancer believed that spirituality help them to strengthen their hope.<sup>10</sup> Breast cancer survivors needs for information on signs and symptoms of cancer recurrence.<sup>11</sup>

Edib et.al.(2016 ) found that , highest supportive care needs were reported in the psychological; domain followed by physical domain. Most prevent unmet supportive care need were incertained about the future, fear about the spreads of cancer, feeling of sadness, death and dying , concern about family depressed. Psychological needs had poor association with QOL.<sup>12</sup>

## **2 Objectives**

To determine the prevalence of post-treatment unmet needs of breast cancer survivors: To find out the association between unmet needs of breast cancer survivors and selected demographic variables.

### **3 Methodology**

Descriptive research study design was chosen. The research was carried out in oncology wards and tertiary care hospitals' outpatient departments. The study used a non-probability sampling method.

#### **3.1 Participants**

The research included a breast cancer survivor who met inclusion criteria and was willing to participate in the study. The study included 120 breast cancer survivors (with first, second, or third stage breast cancer) who were above the age of 18 and were completed primary treatment in the form of radiation, chemotherapy, or surgery. They also had to be able to read and understand Marathi, Hindi, and English. The study excluded breast cancer survivors with psychological illnesses or cognitive deficiencies, as well as survivors with hearing or visual impairments.

#### **3.2 Data Collection Period**

The data collected for one month period (1 October 2019 to 30 November 2019).

#### **3.3 Ethical Permission**

The research proposal was approved by the Research Review Committee (RRC) and the Institutional Ethical Committee (IEC), and ethical permission was obtained. The permission of the competent hospital authority was acquired in order to conduct the study. The participant's written informed consent was obtained and were reassured about the data's confidentiality.

#### **3.4 Tools and Technique**

A literature review was used to create the breast cancer survivor needs assessment questionnaire, which was then validated by experts in the field. The research was conducted using a paper pencil technique. The tool is divided into two sections: Section I – baseline data – was prepared, as were Sections II and I – two-point modified needs assessment questionnaire. Thirty-five unmet needs were divided into five domains: physical, emotional, family, spiritual, practical, routine, and sexual relationship needs, each with its own questionnaire. The participant's response, which was either "Yes" or "No," determined the item's score. If BCS responds "Yes," you will receive a one (1), and if BCS responds "No," you will receive a zero (0). Unmet needs were categorised together because the overall score

was 35. For unmet needs, the score was added up and converted into a percentage. If the score was (0-9) "0-25 % less needs" were identified, (10-18) 26-50 % of "moderate needs" were identified, (19-27) 51-75 % of "high needs" were identified, and "very high prevalence needs" were identified if the score was (28-35) 76-100%. The tool was prepared in the regional language of Marathi. To determine the tool's validity, experts were consulted. The tool's reliability was tested, and it was found to be  $r=89$ .

### **3.5 Data collection Process**

The concerned authorities granted permission for the data acquisition. Participants were chosen, the environment was made comfortable for participants, and the researchers explained the study's goal. Informed written consent was obtained. A tool was provided, and the participant was instructed to fill in the relevant information. The Structure questionnaire was provided to measure unmet needs, and participants were asked to check the boxes next to the statements that applied to them. The form was given enough time to complete (40–50 minutes), and forms were collected by the researcher after they were completed. Participants were greeted for their contribution and valuable information and were assured of its anonymity and confidentiality. Data was collected for one month. Data tabulation and analysis was done.

## **4 Result**

**4.1 Baseline data:** According to the study's findings, 50 (41.66 %) of breast cancer survivors were under 45 years old, while 70 (58.33%) were over 45. The participants' average age was 52 years old. In total, 58 (48.33 %) of the BCS had graduated from high school. The maximum number of home makers was 52(43.33 %). Then comes a daily wage of 33(27.5 %). The majority of BCS had a monthly income ranging from Rs.3000 to Rs.10000/- (50.8 %).

**4.2 Reproductive history:** According to our findings, more than half of BCS started menstruating before the age of 13 . 15% of 13-year-olds began menstruating before the age of 13, while the other half began after the age of 13. Menopause had affected 54 (%) of women under the age of 45. The BCS has 98 married people (81.66 %), 43 (40.19%) of women between the ages of 23 and 30 had their first child. She was 44 years old (41.12%) and had two children.

**4.3 Medical history:** Our study reported that 90% of participants had no history of breast cancer in their family, 95% never had a personal tumor before. The diagnosis period for all BCS was 1 to 2 years. The bulk of them had stage I cancer (72.50%), while 33 (27.50%) had stage II cancer. Chemotherapy (99.17%), Radiation Therapy (96.67%), Surgical Treatment (63.33%), and (44.7%) of breast cancer survivors received hormone therapy. A modified mastectomy was performed on 42.10 % of the BCS.

**4.4 Personal History:** Although none of the BCS smoked, drank alcohol, or chewed Gutka, 39 (32.5%) admitted to putting mishri and 29 (24.16%) admitted to chewing betel. A total of 65.83% of them do not take calcium and vitamin D supplements on a daily basis. Sources of information on lifestyle changes in the past Newspapers and magazines account for 25%, while television accounts for 25% (25.83%). The majority of BCS (78%) did not have health insurance, while 42 (35 percent) did. The majority of BCS participants, 85 (70.83 %), stated that they did not engage in any special physical activity while 35 confirmed that they did. Only 18 of the 35 participants (51.43 %) walked for 20 minutes every day. Sedentary activity was preferred by 52.50 % of breast cancer survivors.

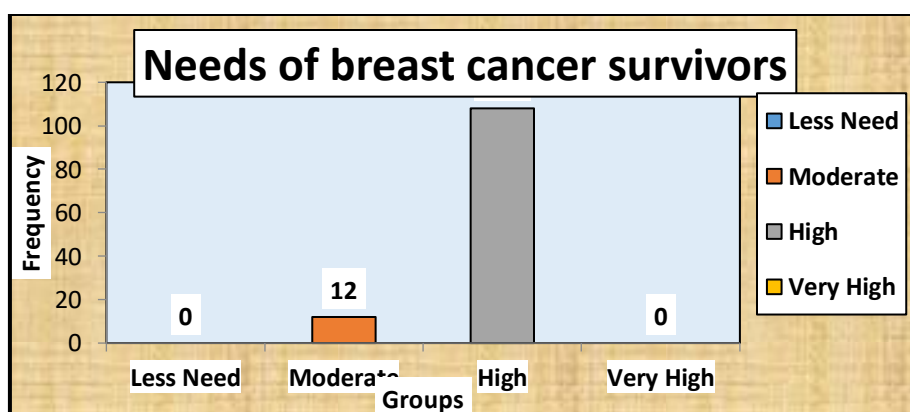
Table 1. Demographic profile of the respondents

Sr.No	Variable	Groups	Frequency	Percentage
1	Age	18-22	1	0.83
		23-26	3	2.50
		27-31	10	8.33
		32-36	8	6.67
		37-45	28	23.33
		45-50	32	26.67
		above 50	38	31.67
2	Education	Post-Graduation	16	13.33
		Graduation	26	21.67
		Secondary	58	48.33
		Primary	20	16.67
3	Occupation	Business	15	12.50
		Service	20	16.67
		Home maker	52	43.33
4	Monthly Income (In Rupees	Daily Wages	33	27.50
		Rs.3000/- - Rs. 10000/-	61	50.83
		Rs.11000/- - Rs. 20000/-	22	18.33
		Rs.21000/- - Rs. 30000/-	14	11.67
		Rs.31000/- & Above	23	19.17

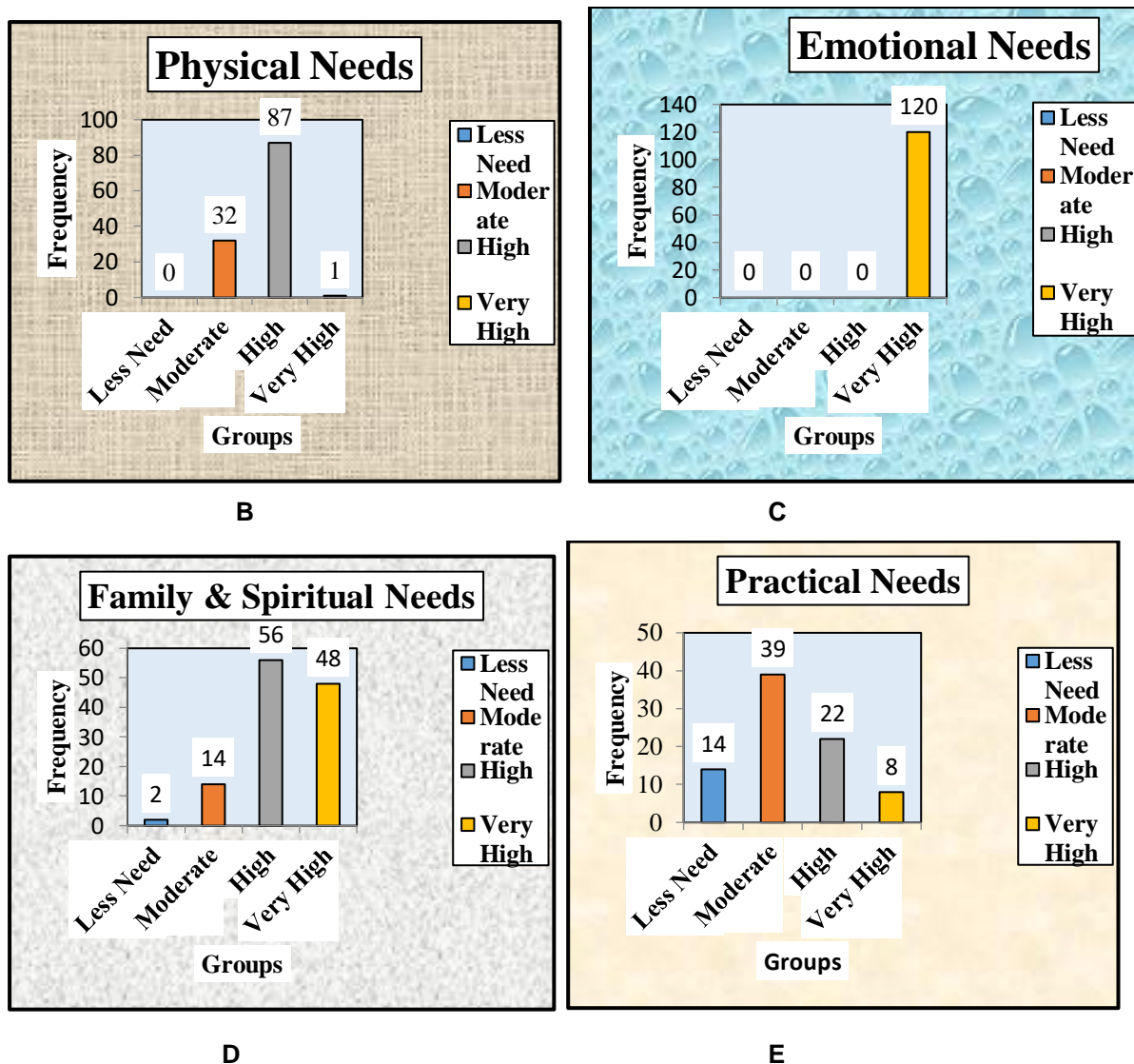
<b>Reproductive History</b>				
5	Age at Menarche	Below 13	60	50.00
		Above 13	60	50.00
6	Age at menopause	Below 45	54	45.00
		Above 45	39	32.50
		Not yet achieved	27	22.50
7	Marital Status	Single	12	10.00
		Married	98	81.67
		Widow	10	8.33
8	Age at pregnancy	18 - 22 Years	39	36.45
		23-30 Years	43	40.19
		Above 31 Year	24	24.48
9	History of Abortion	Yes	15	14.02
		No	92	85.98
		None	21	19.63
10	No of Children	One	15	14.02
		Two	44	41.12
		Three	40	37.38
<b>Medical History</b>				
11	Family History of Breast Cancer	Yes	12	10.00
		No	108	90.00
12	Past personal Tumor History	Yes	6	5.00
		No	114	95.00
13	Stage of cancer	Stage I	87	72.50
		Stage II	33	27.50
14	Treatment received	Chemotherapy	119	99.17
		Radiation Therapy	116	96.67
		Surgical Treatment	76	62.50
		Hormonal Therapy	53	44.17
15	Surgical Treatment	Mastectomy	23	30.26
		Modified Mastectomy	32	42.10
		Axillary lymph node dissection	21	27.63
16	Duration of treatment	6mon -1Year	4	3.33
		1-2Years	116	96.67
17	Medical Comorbidity	Diabetes Mellitus	0	0.00
		HTN	0	0.00
		Myocardial Infarction	0	0.00
		Renal Diseases	0	0.00
		Anaemia	0	0.00
		Liver disorder,	0	0.00
		Musculoskeletal disorder	0	0.00
None	120	100.00		
18	Personal Habits	Smoking	0	0.00

		Drinking Alcohol	0	0.00
		Mishri	39	32.50
		Bettel	29	24.17
		Gutka	0	0.00
		None	52	43.33
		Friends	28	23.33
		Health care workers	21	17.50
19	Previous Source of information regarding life style modification.	Newspaper/ magazines	30	25.00
		Television	31	25.83
		Internet /social networking site	10	8.33
20	Do you regularly take either of the following Calcium & Vitamin D supplements	Yes	41	34.17
		No	79	65.83
21	Do you have health insurance	Yes	42	35.00
		No	78	65.00
22	Do you had breast Cancer Recurrence	Yes	0	0.00
		No	120	100.00
<b>Physical Activity</b>				
23	Do you perform exercise regularly	Yes	35	29.17
		No	85	70.83
24	If Yes What is the duration	20 Minute	18	51.43
		30 Min	13	37.14
		1 Hr	4	11.43
		More than 1 Hr	0	0.00
25	Which type of exercise do you prefer	Brisk Walking	25	83.33
		Dancing	5	16.67
		Any other	0	0.00
26	Activity	Sedentary	63	52.50
		Lightly	15	12.50
		Heavy	42	35.00

**4.5 Needs of breast cancer survivors**



**A) Overall needs of BCS**



**Fig. No.1. Categories of Needs for Breast cancer survivors (A) Overall Needs pf BCS, (B) Physical Needs ,(C) emotional needs,(D) Family and spiritual needs and (E) Practical Needs.**

Needs of breast cancer survivors Present study majority 108 (90.33%) breast cancer survivors had high level of needs, where as 12 (10%) had moderate level of needs. High physical needs reported by 87 (72.50 %) and 32 (26.67%) moderate physical needs. All 100% BCS reported high emotional need. Whereas 2(1.67%) less need, 14(11.67%) moderate, 56 (46.67%) high needs and 48 (40%) very high reported family and spiritual need and 39 (32.5 %) BCS reported moderate level of practical needs. Participants 14(11.67%) less needs, 39 (32.50%) moderate, 22(18.33%) high and very high 8(6.67%) reported practical needs.

Overall, the mean was  $21.31 \pm 2.38$ , with bodily requirements being  $10.46 \pm 1.76$ , emotional needs was  $4.81 \pm 0.40$ , family and spiritual needs becoming  $3.26 \pm 0.78$ , and practical needs was  $2.78 \pm 1.11$ , respectively. Among physical needs hot flashes were experienced by 68% of the participants. 81

%of BCS stated that strenuous activity causes them to become fatigued. During exertion, 53 % reported feeling out of breath. 53% pain on strenuous activity. 78% of those BCS said their sleep had been disturbed. 55% had dry, itchy or sore skin. 32% find change in your body weight which was increase. Tingling in the hands and feet were experienced by 33 % of BCS. No one reported that they suffered from any other health problem. 99% reported a change in appetite or eating pattern, whereas 59% had issues from indigestion. Diarrhea or constipation impacted 86 % of the subjects. A cough was mentioned by 18 % of those assessed. 45 reported breathlessness on activity. 81% experienced a change in their personal appearance.70% sore or dry mouth. 50% reported they occasionally experience nausea or vomiting. 56% noticed the difference in taste. 65% have trouble communicating with others. 32 %t of people noticed an upsurge in their body weight. 18% of those respondents admitted having sexual dysfunctions and had not yet sought counselling. Majority 100 % BCS reported emotional needs which included worry anxiety, feeling sad or depression , anger ,frustration, or guilt problem, lowliness and isolated needs were at the top. Whereas 81% reported sexual concern’s needs.

Family and spiritual needs the majority BCS had positive family relations with 93% of children and 92 % of partners. In contrast, 85 % said they had positive relationships with others. A loss of hope or other spiritual concern was expressed by 50% of BCS respondents. 5.8% of respondents think they have lost their sense of meaning or purpose in life. Whenever it comes to cooking preparations or cooking, 53% of participants stated they have trouble remembering things Practical needs Majority BCS females reported 32% problems at work or education. 33% said they have problems for making activity plans. Less than half of BCS reported that have get adequate information. 19% replied that sometimes they have problems with bathing and dressing. All the BCS reported problem with housing or finance. 53% replied get trouble while preparing food.

**Table No.2. Mean and SD of Needs of Breast Cancer Survivors (N=120)**

	<b>Physical</b>	<b>Emotional</b>	<b>Family &amp; Spiritual</b>	<b>Practical</b>	<b>Over all Need</b>
<b>Mean</b>	10.46	4.81	3.26	2.78	21.31
<b>SD</b>	1.76	0.40	0.78	1.11	2.38

#### 4.5 Association with Demographic Variables

Age, education, occupation, income, age at menopause, marital status, number of children, breast feeding given, stage of cancer, surgical treatment received, personal habits, previous source of information, and exercise are all associated with the overall and physical needs of breast cancer survivors ( $p > 0.05$ ). Education  $P 0.00$ , occupation  $P 0.014$ , income  $P 0.014$ , and cancer stage  $P 0.041$  were discovered to have significant associations. The physical and spiritual requirements of BCS were found to be strongly related to previous information  $P 0.09$ . A chi - squared test was not possible since all of the samples had such strong emotional needs.

**Table No.3. Association of Needs of Breast cancer survivors with selected demographic variables (N=120)**

Variables	Age	Education	Occupation	Income	Stage of Cancer	Personal Habits	Previous Information	Health Insurance	Physical Habits
<b>Over all Needs of Breast cancer Survivors</b>									
Chi Square	6.99	2.85	3.33	5.12	0.78	1.84	2.21	0.016	3.19
d.f	6	3	3	3	1	2	4	1	2
p value	0.32	0.41	0.34	0.16	0.37	0.39	0.69	0.89	0.2
S/NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
<b>Physical Needs of Breast Cancer Survivors</b>									
Chi Square	16.32	1.21	7.05	5.61	1.35	2.58	4.07	1.09	5.52
d.f	12	6	6	6	2	4	8	2	2
p value	0.18	0.98	0.32	0.47	0.57	0.58	0.85	0.58	0.24
S/NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
<b>Emotional Needs of Breast cancer survivors</b>	<b>All sample had very high emotional need , hence cannot conduct chi square test</b>								
<b>Family and spiritual Needs of Breast Cancer Survivors</b>									
Chi Square	30.14	6.16	11.79	9.42	7.73	6.81	23.39	6.55	2.61
d.f	18	9	9	9	3	6	3	3	6
p value	0.036	0.72	0.23	0.4	0.052	0.34	0.09	0.09	0.86

S/NS	NS	NS	NS	NS	NS	NS	<b>S</b>	NS	NS
<b>Practical Needs of Breast Cancer Survivors</b>									
Chi Square	15.24	29.72	20.68	20.68	8.28	6.47	5.77	5.38	6.95
d.f	18	9	9	9	3	6	12	3	6
p value	0.65	0.00	0.014	0.014	0.041	0.37	0.93	0.15	0.33
S/NS	NS	<b>S</b>	<b>S</b>	<b>S</b>	<b>S</b>	NS	NS	NS	NS

## 6. Discussion

According to Napoles AM et al. (2020 Jul), 80% had less than a high school education. <sup>13</sup> According to the Nitin Gangane et al. 2017 study, 62% were the wife's. <sup>14</sup> According to Neelam Sharma's findings, 75% of the respondents had a low socioeconomic status study findings corresponds to present stud<sup>15</sup>. Half of BCS started menstruating before the age of 13 findings were higher than Sofi NY et al. (Jul-Sep 2019) study <sup>16</sup>. According to Suhani S. et al. (2020), 50 % of post - menopausal women 39 (32.5%) of those who participated were over the age of 45 current findings corresponds with the study<sup>17</sup>. Present study found 81.66% women were married findings were congruent with Nitin Gangane et al. A 2017 study the majority of participants, or 83.6%, were married <sup>14</sup>. Current study found that 90% of participants had no family history of breast cancer, similar findings were reported by Suhani S. et al. (2020) 15% of the participants had a family history of BC <sup>17</sup>. Yan B et al. 2016 reported that approximately 89 percent of participants had mastectomy and surgical treatment, which corresponds with the current study. Participants had some form of health insurance with a low co-payment<sup>18</sup>.

The current study findings, which are similar to those of Zubaida Edib et al. (2016), reveal that physical domain had the highest unmet supportive care needs and the psychological domain had the lowest 78.6 % were uncertain about the future, 76.1 % were afraid of cancer, 69.2 % were sad, 68.4 % were afraid of death, and % were depressed. <sup>12</sup> Health care professional must pay attention towards Physical, psychological and practical unmet needs of the breast cancer survivors to improve quality of life.

## **6. Conclusion**

Breast cancer survivors' needs are more prevalent and have an impact on quality of life, prognosis, and recovery of clients. Hence, counselling sessions, information display boards, and health care providers should address the needs appropriately for better recovery.

## **7. Significance of the Study**

It will aid in the planning of need-based interventions and the provision of comprehensive care to breast cancer survivors beyond treatment completion. This will aid in a better prognosis and recovery. The findings will contribute to a better understanding of the needs of breast cancer survivors.

## **9. Limitation of the Study**

Samples were from one Tertiary care hospital with a specific geographical area hence generalization to whole country is not possible, smaller sample size with purposive sampling technique. Self-reported data might have influence the result through participants' bias. Needs were limited other needs should be studied for making health policies. Such type of study can be undertaken at large scale at country level to overcome the limitation.

## 15. Consent

Written informed consent were taken regarding their willingness for participation in the study and they were told that their participation in the study is voluntary and informed that they can withdraw from the study at any point of time. Detail explanations regarding study and its objectives, were given to study subjects. Subjects were assured anonymity and confidentiality of data given by them at the time of outcome dissemination.

## 16. Ethical Approval

All authors hereby declare that study is approved by Institutional Ethical and have the therefore been performed in accordance with the ethical standards.

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