



Perceptions of survivorship care among South Asian female breast cancer survivors

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ABSTRACT

Background and Objectives

To explore the perceptions of South Asian (SA) breast cancer survivors concerning their follow-up care, and to determine the optimal content and format of a survivorship care plan (SCP) for this population, according to various life stages.

Methods

A survey was mailed to 259 SA women with a diagnosis of nonmetastatic breast cancer who were 18–85 years of age, 3–60 months post-discharge, and not on active treatment. Descriptive statistics and content analysis were applied to the responses. The data were cross-tabulated by age: group A (<44 years), group B (45–54 years), group C (55–64 years), and group D (>64 years).

Results

We received 64 completed surveys. The compliance rate for adjuvant hormonal therapy was high (86.3%). Most of the respondents ($n = 61$, 95.4%) had visited their family doctor within several months (0.5–24 months) after discharge. Their main physical effects concern was fatigue, and anxiety concerning health was the main psychosocial impact. Groups A and B were more concerned about physical appearance, depression, and the impact of cancer on family members. Women in the older groups were concerned about family obligations and work issues. Several women ($n = 9$, 14.1%) described strain on their marriage and on their relationships with family and friends as significant issues. Slightly more than one third ($n = 24$, 37.5%) experienced a deepening of faith, and almost as many ($n = 23$, 35.9%) felt that their illness was something that was meant to happen.

Conclusions

Many of the impacts of breast cancer treatment are shared by women of all ethnic backgrounds. Others—such as high levels of compliance, little reported strain on spousal and family relationships, and the importance of faith—reflect specific cultural variations. These universal and culture-specific themes should all be kept in mind when developing a SCP tailored to SA women. The developmental life stage of a woman affects how she views the cancer diagnosis, especially with respect to family, reproduction, and work issues.

KEY WORDS

Breast cancer survivors, survivorship care plans, follow-up cancer care, South Asian

1. INTRODUCTION

Approximately 825,000 survivors with persistent breast cancer live in Canada, breast cancer being the most prevalent cancer among Canadian women^{1,2}. Indeed, the number of breast cancer survivors (BCSS) has been on the upswing for more than 6 years^{3–6}, underscoring the need for services and guidance in providing comprehensive follow-up survivorship care plans (SCPs) for patients as they are discharged from specialist to community care after completing their cancer-related treatment.

In 2006, the U.S. Institute of Medicine issued a report recommending that “cancer patients completing treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained” and that this care plan “should be reviewed with the patient during a formal discharge process”⁷. The plan should include surveillance for recurrence, management of side effects, necessary screening tests, and instructions for health promotion and lifestyle modification. In response, a number of

centres have developed and evaluated SCPS aimed at ensuring quality of life for survivors⁷⁻¹⁰. The SCP is now being seen as critical to the overall health and well-being of the patient^{6,8,10}. The Canadian Partnership Against Cancer has also formed a National Survivorship Working Group whose current focus is the implementation of care maps and models of care to guide survivors and their caregivers⁷. Evidence indicates that, although there is movement toward providing customized SCPS, little information is available to guide health care providers on how to do so for this heterogeneous population¹⁰⁻¹².

In British Columbia, Canada, BCSS are generally followed by their primary care physician after treatment in cancer centres. However, the transition does not go smoothly for many patients, with communication and information transfer being the major weaknesses^{13,14}. In 2001, the Canadian Breast Cancer Foundation identified this “continuing care” phase in their gap analysis report and noted gaps of recovery and rehabilitation awareness, community supportive care, and consumer empowerment^{4,8}. Primary care physicians also reported that additional information about the common medical and psychological issues of cancer survivors would be useful to them¹³. Those findings highlight the importance of an organized transition from specialist to primary care and reinforce the need for comprehensive care plans aiming to support BCSS in the survivorship phase^{5,6,10,14}.

Studies have shown that BCSS may feel isolated and uninformed after completion of treatment, when they have less interaction with oncology health professionals^{6,8,15,16}. A recent study confirmed evidence that BCSS have persistent difficulties with fatigue, pain, sleep, psychological distress, fear of recurrence, family distress, concerns with employment and finances, and uncertainty over the future¹⁰. In addition, research conducted with various ethnic groups reported disparities in quality of life and support¹⁷⁻²². For instance, African American BCSS experience posttraumatic stress to a greater extent than do their white counterparts¹⁹. Minority patients seem to want more race-specific information when counselled about cancer-related side effects, especially in the context of cultural factors related to beliefs about illness, gender roles, and family obligations (for example, self-sacrifice)²³.

Care plans such as those provided by the American Society of Clinical Oncology were deemed valuable, but overly technical and limited in self-care teachings¹⁶. In Canada, SA women who are BCSS may have experiences with breast cancer diagnosis and treatment that are different from those of their counterparts because of potential concerns arising from prior negative health care experiences, migration and settlement issues, language barriers, and the learning of new approaches in a new country^{19-21,23-25}. Gurm *et al.*²⁰ reported that some SA BCSS appeared distressed, showing signs of depression despite having undergone curative treatment, making it necessary

to provide them with language-specific resources.

The present project was conceived to address the post-treatment cancer care needs of the diverse ethnic populations in the Lower Mainland of British Columbia. We specifically chose women of SA heritage, because they constitute the third largest population group in British Columbia, and our centre is situated in a region with a sizeable SA community²⁶. We identified SA women as those of Indian ethnicity. In the first phase of this project, we used a qualitative approach to explore the experiences and concerns of SA women, with the aim of determining their understanding of follow-up care and better understanding their preferences for the content of a SCP²⁷.

Using focus groups and one-on-one semistructured interviews, data were collected from 24 SA participants who had been discharged from 2 centres of the BC Cancer Agency (BCCA). Thematic and content analysis of the experiential data highlighted universal effects (common to patients described in studies not specific to any cultural group)^{10,17} such as fatigue, cognitive changes, fear of recurrence, and depression after treatment. Themes unique to the SA participants in the context of culture and of social and acculturation factors captured the theme of “quiet acceptance” (believing that one has to suffer through the illness, but not necessarily take a passive role) as the SA woman’s approach to the diagnosis. Other subthemes stemming from “quiet acceptance” included faith and inner strength, karma and fate, and a social network context that further illustrated the major impacts of family and community, *hounsla* (the belief of most that they had the courage and hope to live through cancer), and peer support.

Recurring patterns within the various age groups (<44, 45–54, 55–64, and >65 years) revealed that younger women (<44 and 45–54 years) preferred receiving information on depression and peer support and that older participants (55–64 and >64 years) wanted to know how to support their family and how to help community members understand the cancer diagnosis. Those results echo findings from other studies demonstrating life-stage patterns—for example, younger age groups wanting information on reproduction, early menopause, employment, and financial issues^{5,28}.

To further explore and confirm the foregoing findings with other participants of SA ethnicity residing in the rest of British Columbia who had been discharged from other BCCA cancer centres, we developed a survey questionnaire. Obtaining confirmation was important before setting out to pilot a SCP with diverse populations²⁹. The aims of the present descriptive study were to

- further explore and confirm findings from the qualitative phase by gaining deeper insight into a larger and more diverse group of SA women², and
- better understand the content and format preferences of those women for a SCP.

2. METHODS

2.1 Study Population

The BCCA operates 5 regional cancer centres, delivering oncology-related services with a common electronic charting system called the Cancer Agency Information System and a centralized transcription and discharge letter dissemination process. After active treatment for breast cancer, most patients are discharged to their primary care provider. Usually, a generic discharge letter containing follow-up recommendations is sent to the primary care provider with a dictated clinical note. Currently, no comprehensive, individualized SCP is provided to the discharged patient.

After receiving approval from the Research Ethics Board of the University of British Columbia, we queried the Cancer Agency Information System using the inclusion criteria set for the study: SA women participants, 18–85 years of age, discharged by the BCCA, between 3 and 60 months post treatment (could be on hormonal treatment), and having no active disease at the time of the query. This initial search generated 19,896 names, which were then matched to a list of common Indian surnames and forenames, resulting in 633 potential participants, whose records were then reviewed manually, yielding a list of 259 women who met the inclusion criteria. Two of the potential participants indicated that they did not fit the SA ethnicity criteria, resulting in a total of 257 eligible participants.

The list of common Indian surnames was created using a variety of sources, such as the SA white-pages telephone book and the provincial screening mammography name list. The list was not exhaustive, but was a fairly good indicator of common Indian names of persons residing in British Columbia. This method of creating a comprehensive SA names list for matching will be detailed in a separate article.

2.2 Survey Questionnaire

The study questionnaire was based largely on a survey developed and validated with white breast cancer survivors at the BCCA Vancouver Island Cancer Centre (unpublished data), excluding the SF-36 quality-of-life questionnaire component. Because the content of the surveys was created using qualitative data, changes for the present study questionnaire were made to reflect participant experiences observed during the phase one qualitative study: for example, the needs of participants to focus on communication and their relationship with the family physician, and the availability of language-specific resources and patient support at the BCCA. Other survey content (the parts focusing on physical and psychosocial aspects and on preferences for the content and format of a SCP) remained the same as that in the original survey. Our survey was also translated into Punjabi

by professional interpreters at the BCCA and was then verified by 3 SA research team members to ensure the translation's accuracy and transferability. Additional input was obtained from the Breast Research Team members at the BCCA Fraser Valley Cancer Centre, including radiation and medical oncologists, an oncology nurse researcher, two clinical oncology nurses, and a statistician. The final version of the questionnaire consisted of 27 questions divided into 4 sections: impact of breast cancer treatment, overall patient satisfaction with follow-up care, information needs at discharge and completion of treatment, and demographic information. The questions included some that were close-ended, with multiple choices, and some that were open-ended, with and without a Likert-type scale. Where used, the Likert scale was a four-point scale: "Not at all," "A little," "Quite a bit," "Very much." The questionnaire is available from the corresponding author upon request.

2.3 Validation of the Survey Questionnaire

The English and Punjabi surveys were initially validated with 12 participants who had been part of the individual or focus group interviews in the first (qualitative) phase of the project. The 12 participants were chosen purposively by the researcher to represent women of various age groups while testing the survey for readability in English and Punjabi, evaluating the amount of time required to complete the survey, and allowing participants to confirm their experiences. The survey questionnaire was mailed together with an explanatory letter and a stamped, addressed return envelope. If the recipients opted to participate, they were interviewed a week later by the researcher by telephone.

The validation process ensured that the questions were clear, verified that responses reflected the intent of the questions, determined the time needed to complete the survey, and assured the comprehensiveness of the English-to-Punjabi translation. To test for reliability, participants were also asked to complete the survey again 2 weeks after initial completion³⁰. Of the 12 participants, 10 returned the survey.

After the validation process, data collection was conducted by mailing the questionnaire, a letter explaining the study in both English and Punjabi, and an anonymous stamped, addressed return envelope to the 257 possible participants. Completion of the survey was considered to be consent to the study, but the researcher's contact information was provided on the letter of introduction for any questions about the study. Anonymity was ensured throughout. The Access software application (Office 2003; Microsoft Corporation, Redmond, WA, U.S.A.) was used to store the data and to record returned completed surveys by their consecutively numbered self-addressed envelopes. Reminder letters were sent a month later to those addressees who did not return the initial surveys.

2.4 Statistical Analysis

The analysis includes descriptive statistics reported as frequencies calculated using the SPSS software application (version 14.0: SPSS, Chicago, IL, U.S.A.) for Windows. Frequencies were calculated based on the total number of respondents, rather than the total number of responses to each question. Missing data represented responses not completed, because not all respondents answered every question. The thematic and content analysis used for the qualitative survey questions was similar to that used in the qualitative phase of the project. This methodology was useful when confirming the women's personal experiential data; it highlighted their voices because they were given a choice to elaborate on things that they felt were important. The researchers analyzed the data through team discussion after reading the data individually²⁹.

The descriptive data were cross tabulated by age: group A, less than 44 years; group B, 45–54 years; group C, 55–64 years; and group D, more than 64 years. These groupings provided meaningful life-stage stratification, because they corresponded to the perimenopausal and postmenopausal groups, and to women of childbearing age or raising children (group A), those who were still employed (group B), those considering retirement (group C), and those who were retired (group D).

3. RESULTS

3.1 Characteristics of Respondents

The collective response rate was 24.9% (64 survey respondents). As part of treatment for their breast cancer, 31 (48.4%) had received chemotherapy, 45 (70.3%) had undergone radiation, and 48 (75%) had been prescribed hormonal therapy. Table 1 summarizes the demographic characteristics of the respondents.

3.2 Follow-Up Care

Of the survey respondents, 51 (79.7%) were asked to continue their medications after discharge as part of their breast cancer treatment (any medications, including adjuvant hormonal treatment), and 44 of the 51 (86.3%) indicated that they took their medication more than 80% of the time or always.

Only 24 respondents (37.5%) understood “follow-up” to be regular check-ups with their doctor and mammograms. Follow-up was being provided by the family doctor to 34 respondents (53.1%), by a cancer specialist in the community to 8 (12.5%), and by both types of practitioners to 17 (26.6%). Another 4 respondents (6.3%) were unsure about who was responsible for follow-up, and 1 (1.6%) felt that no one was responsible for her follow-up care.

TABLE 1 Characteristics of the survey respondents

<i>Characteristic</i>	<i>Value</i>	
	(n)	(%)
Patients	64	
Age at diagnosis		
<44 Years	6	9.4
45–54 Years	19	29.7
55–64 Years	21	32.8
>65 Years	18	28.1
Primary spoken language		
English	24	37.5
Punjabi	31	48.4
Hindi	4	6.3
Other	3	4.7
Not specified	2	3.1
Time in Canada		
Born in Canada	2	3.1
≤10 Years	5	7.8
11–20 Years	17	26.6
>20 Years	38	59.4
Not specified	2	3.1
Marital status		
Married	42	65.6
Never married	4	6.3
Widowed	12	18.8
Divorced/separated	3	4.7
Not specified	3	4.7
Living situation		
With spouse	20	31.3
With children	6	9.4
With adult family	14	21.9
Combination	19	29.7
Alone	2	3.1
Not specified	3	4.7
Work status		
Employed	16	25.0
Self-employed	6	9.4
Homemaker	8	12.5
Unemployed	4	6.3
Retired	20	31.3
Unable to work	8	12.5
Not specified	2	3.1
Education		
<High school	13	20.3
High school	24	37.5
Certificate/diploma	10	15.6
Bachelor degree	9	14.1
>Bachelor degree	8	12.5
Not specified	3	4.7

After discharge from the cancer centre, 61 respondents (95.3%) had visited their family doctor (within 0.5–24 months). When asked about whether the family doctor had discussed follow-up cancer care, 21 respondents (32.8%) answered “a little,” and 38 (59.4%), “quite a bit” or “very much.” Table II illustrates patient perception of how well the family doctor managed care related to follow-up. “Very well” or “adequately” were the most common answers. When analyzed by age group, 3 respondents in group A (50.0%) felt that the family doctor did not manage family counselling very well, and 4 in the same group (66.7%) felt that the family doctor did not manage counselling on sex and body image very well. In group B, 5 respondents (26.3%) felt that the family doctor did not manage anxiety and fear of recurrence very well, which compares with 0 respondents in group A (0.0%), 1 respondent in group C (4.8%), and 1 respondent in group D (5.6%).

With respect to the physical or medical issues related to breast cancer, 34 respondents (53.1%) felt that their cancer centre (where they received their cancer treatments) knew “quite a bit” or “very much”; 36 respondents (56.3%) gave the same ratings to their community (for example, the family doctor, community support groups, and so on). When the same question was asked about emotional or social issues, 27 respondents (42.2%) felt that their cancer centre, and 28 (43.8%) felt that their community, knew “quite a bit” or “very much.” More than half of all respondents ($n = 37$, 57.8%) felt that they had received “quite a bit” or “very much” reliable resources for information about breast cancer; however, 2 respondents in group A (33.3%) answered “not at all” to the same question.

3.3 Impact of Breast Cancer Treatment

Since completing treatment, 12 respondents (18.8%) had accessed patient and family counselling services available at the cancer centre. Those who had not

accessed such resources most commonly indicated either that such services were not needed and that they had enough support, or that they did not know that such resources were available. The top 3 support resources for emotional and social issues were: family, the family doctor, and faith.

Table III shows physical side effects that lasted for more than 6 months after treatment completion. The physical effect with the most adverse impact on quality of life was fatigue, mentioned by 14 respondents (21.9%). When faced with such effects, 29 respondents (45.3%) indicated that they were “not at all” or “a little” prepared to manage, and 45 (70.3%) visited the family doctor. The most common reason given for not visiting the family doctor was that the symptoms were tolerable.

Table IV presents psychosocial impacts that lasted for more than 6 months after discharge. The most common impact was fear, worry, and concern about health issues. In group A, 3 respondents (50.0%) had “quite a bit” or “very much” distress about their physical appearance, and 4 (66.7%) reported the same levels for feelings of depression. In this group, 4 respondents (66.7%) also had “quite a bit” or “very much” concern about the impact of breast cancer on spouse and children. With respect to those impacts, 28 respondents (43.8%) were “not at all” or “a little” prepared to manage, and 33 (51.6%) visited the family doctor. The most frequent explanations for choosing not to visit the doctor included the notion that doctors tend only to physical ailments and a feeling on the part of the respondent that she already had a good support system in place.

3.4 Satisfaction with Follow-Up Care

With respect to follow-up care received since completion of treatment, 38 respondents (59.4%) indicated that they were either “extremely satisfied” or “very satisfied.” Concerning physical or medical issues, 34 respondents (53.1%) felt that they had received “quite

TABLE II Patient perception of how well the family doctor managed follow-up care

<i>Aspect of follow-up</i>	<i>Rating of doctor's management by 64 respondents [n (%)]</i>				
	<i>Very well</i>	<i>Adequately</i>	<i>Not very well</i>	<i>Not applicable^a</i>	<i>Not specified</i>
Checking for recurrence	31 (48.4)	27 (42.2)	4 (6.3)	0 (0.0)	2 (3.1)
Treatment-related osteoporosis	21 (32.8)	26 (40.6)	6 (9.4)	0 (0.0)	11 (17.2)
Lymphedema	24 (37.5)	20 (31.3)	8 (12.5)	0 (0.0)	12 (18.8)
Treatment-induced menopause	18 (28.1)	22 (34.4)	3 (4.7)	4 (6.3)	17 (26.6)
Managing hormone therapy	17 (26.6)	24 (37.5)	8 (12.5)	0 (0.0)	15 (23.4)
Advice on nutrition and exercise	25 (39.1)	29 (45.3)	4 (6.3)	0 (0.0)	6 (9.4)
Anxiety and fear of recurrence	26 (40.6)	21 (32.8)	7 (10.9)	0 (0.0)	10 (15.6)
Family counselling	19 (29.7)	19 (29.7)	12 (18.8)	0 (0.0)	14 (21.9)
Counselling on sex and body image	14 (21.9)	20 (31.3)	14 (21.9)	2 (3.1)	14 (21.9)

^a A “not applicable” option was not provided, but some respondents wrote “N/A” in response to the question.

TABLE III Physical side effects that lasted for more than 6 months after discharge from the cancer centre

<i>Side effect</i>	<i>Rating at 6 months by 64 respondents [n (%)]</i>			
	<i>Not at all/a little</i>	<i>Quite a bit/very much</i>	<i>Not applicable</i>	<i>Not specified</i>
Fatigue or tiredness	25 (39.1)	37 (57.8)	0 (0.0)	2 (3.1)
Hot flushes	30 (46.9)	33 (51.6)	0 (0.0)	1 (1.6)
Breast or chest wall pain	42 (65.6)	21 (32.8)	0 (0.0)	1 (1.6)
Muscle or joint pain	25 (39.1)	34 (53.1)	0 (0.0)	5 (7.8)
Swelling in arm	39 (60.9)	21 (32.8)	0 (0.0)	4 (6.3)
Difficulty lifting arm	36 (56.3)	27 (42.2)	0 (0.0)	1 (1.6)
Tingling or numbness	41 (64.1)	20 (31.3)	0 (0.0)	3 (4.7)
Muscle weakness	32 (50.0)	30 (46.9)	0 (0.0)	2 (3.1)
Unwanted weight gain	40 (62.5)	21 (32.8)	0 (0.0)	3 (4.7)
Lower interest in sex	20 (31.3)	22 (34.4)	18 (28.1)	4 (6.3)
Concerns about fertility	24 (37.5)	6 (9.4)	29 (45.3)	5 (7.8)

TABLE IV Psychosocial impacts that lasted for more than 6 months after discharge from the cancer centre

<i>Side effect</i>	<i>Rating at 6 months by 64 respondents [n (%)]</i>			
	<i>Not at all/a little</i>	<i>Quite a bit/very much</i>	<i>Not applicable</i>	<i>Not specified</i>
Distress about physical appearance	34 (53.1)	28 (43.8)	0 (0.0)	2 (3.1)
Depression	40 (62.5)	21 (32.8)	0 (0.0)	3 (4.7)
Fear or worry or concern about health	24 (37.5)	39 (60.9)	0 (0.0)	1 (1.6)
Concern about impact on spouse	25 (39.1)	21 (32.8)	15 (23.4)	3 (4.7)
Concern about impact on children	25 (39.1)	26 (40.6)	9 (14.1)	4 (6.3)
Concern about ability to do usual job	31 (48.4)	26 (40.6)	5 (7.8)	2 (3.1)
Strain on marriage or primary relationship	34 (53.1)	9 (14.1)	16 (25.0)	5 (7.8)
Negative impact on sexual or intimate relationships	27 (42.2)	18 (28.1)	15 (23.4)	4 (6.3)
Strain on relationship with other family or friends	54 (84.4)	9 (14.1)	0 (0.0)	1 (1.6)
Financial difficulties	46 (71.9)	14 (21.9)	0 (0.0)	4 (6.3)
Limitations on usual work or employment	30 (46.9)	16 (25.0)	11 (17.2)	7 (10.9)
Deepening of faith	23 (35.9)	24 (37.5)	10 (15.6)	7 (10.9)
Feeling that this illness is something that was meant to happen	29 (45.3)	23 (35.9)	7 (10.9)	5 (7.8)

a bit” or “very much” information from the cancer centre; but only 27 respondents (42.2%) felt the same about emotional or social issues, and 27 (42.2%), about people they could contact with concerns or questions.

3.5 Preferred SCP Content and Format

Table v summarizes the content preferred by respondents if a written information package were to be given to them upon completion of treatment. The most common “very useful” elements were a summary of diagnosis and treatment, and nutrition and supplement information. Information on managing sexual changes and menopausal symptoms were

deemed “very useful” to 3 respondents (50.0%) in group A and to 12 (63.2%) in group B.

As to the format of the information, 14 respondents (21.9%) would prefer a one-on-one meeting with a health professional, 14 (21.9%) would prefer written information in booklet form, and 16 (25.0%) would like to have both. To deliver the written information package to them, 34 respondents (53.1%) would opt for the cancer specialist or doctor from the cancer centre. Within the first year after completion of treatment, 32 (50.0%) would want scheduled contact with a breast cancer resource person every 6 months, and 31 (48.4%) would want that contact to occur in person.

TABLE V Preferences for the potential content of a written information package to be given to patients after completion of breast cancer treatment

Item	Rating by 64 respondents			
	Very useful	Somewhat useful	Not useful	No response
Summary of diagnosis	47 (73.4)	7 (10.9)	1 (1.6)	9 (14.1)
Summary of treatment	46 (71.9)	7 (10.9)	1 (1.6)	10 (15.6)
Nutrition and supplement information	43 (67.2)	9 (14.1)	3 (4.7)	9 (14.1)
Side effects of medication	42 (65.6)	11 (17.2)	2 (3.1)	9 (14.1)
Information on managing fatigue	42 (65.6)	11 (17.2)	1 (1.6)	10 (15.6)
Recommended exercise program	41 (64.1)	13 (20.3)	0 (0.0)	10 (15.6)
Prognosis	41 (64.1)	9 (14.1)	2 (3.1)	12 (18.8)
Information on signs and symptoms of recurrence	41 (64.1)	10 (15.6)	2 (3.1)	11 (17.2)
Statement of who is now responsible for care	39 (60.9)	14 (21.9)	0 (0.0)	11 (17.2)
Expected or normal symptoms	39 (60.9)	9 (14.1)	2 (3.1)	14 (21.9)
Recommended follow-up care	38 (59.4)	10 (15.6)	1 (1.6)	15 (23.4)
Information on prevention or treatment of osteoporosis	38 (59.4)	12 (18.8)	2 (3.1)	12 (18.8)
Contact information for BCCA resource person	36 (56.3)	12 (18.8)	2 (3.1)	14 (21.9)
Lymphedema or swelling prevention and treatment	34 (53.1)	16 (25.0)	1 (1.6)	13 (20.3)
Breast reconstruction information	26 (40.6)	17 (26.6)	6 (9.4)	15 (23.4)
Information on managing menopausal symptoms	25 (39.1)	15 (23.4)	8 (12.5)	16 (25.0)
Information on managing sexual changes	24 (37.5)	18 (28.1)	8 (12.5)	14 (21.9)
Patient and family counselling resources	22 (34.4)	23 (35.9)	5 (7.8)	14 (21.9)
Information on peer support groups, community resources	20 (31.3)	24 (37.5)	7 (10.9)	13 (20.3)

BCCA = BC Cancer Agency.

4. DISCUSSION

Breast cancer survivors endure many hardships, including the physical, emotional, and psychosocial impacts of treatment, which may persist over the long term^{5,9,10,15}. In the present study, we set out to describe those impacts and to identify for the first time the perceptions and preferences of SA women with breast cancer concerning survivorship care post treatment. The surveyed women reported an acceptable level of satisfaction with their current follow-up care, but also described ongoing social, emotional, and informational support needs.

Respondents to our survey reported various physical side effects after breast cancer treatment that mirror those found in all women, independent of ethnicity^{17,20,30}. Fatigue was especially prevalent, being the physical symptom that negatively affected them the most. That finding is consistent with the identification in previous studies of fatigue as the most frequent symptom in BCSS and a predictive factor for poorer quality of life^{10,31,32}. Other elements universal in women of all ethnic backgrounds included psychosocial issues such as fear of recurrence and depression. Indeed, fear of recurrence has often

been identified in studies as a common response and a prevalent unmet need^{5,30–34}. Depression was documented as the issue causing greatest negative effect on quality of life for the women participating in the present study. Depression has been well documented in up to a quarter of BCSS^{32,35,36}.

In the present study, 66.7% of group A experienced “quite a bit” or “very much” distress when it came to feeling sad or depressed. Bailey *et al.*³⁶ suggested that an assessment of depressive stage should include the culture of the patients and their perceptions about the diagnosis and treatment of cancer, and of their own illness. Those suggestions are significant because Raguram *et al.*³⁷ reported a positive relationship between the severity of depressive symptoms and scores on the stigma scale, resulting in somatization of symptoms that affected the ability to work and function socially for women in South India. The women in our group A not only demonstrated more interest in receiving information about depression, but also sexuality and body image, family counselling, breast reconstruction, and menopausal symptoms. Those findings represent the unique needs of young BCSS for the preparation of a SCP.

In the present study, participants felt that their cancer centres gave them less information about emotional and social issues than about physical or medical issues. Other authors have also described the need to address the psychosocial needs of survivors in addition to the physical aspects of their care and follow-up schedule, especially according to age group^{5,15,32}. Younger age has been reported to be associated with greater care needs after treatment^{9,38}. In the present study, younger participants reported high levels of concern for their spouse and children. They might have relatively younger children and might feel more overwhelmed by the everyday demands of life.

Very few participants described strain or negative impacts on family relationships. That finding may imply a tendency of the illness to strengthen spousal support rather than to create marital tension in SA participants. In contrast, in a study focusing on older, predominantly white BCSS, being married was associated with a greater decline in mental health scores, perhaps because of the burden of spousal care or the added strain to the relationship¹⁵. South Asian women take pride in their strong bond with and devotion to their family and community^{24,39} and have also been found to trust their family members for support during their illness^{21,25}. Beliefs known to play a large role in the lives of SA women are their duties and responsibilities toward family (as evidenced by the concerns of younger respondents with the well-being of their spouse and children). However, although these women might identify family and friends as a good support network, they might also hide their emotions to avoid burdening their families and to retain a sense of normalcy^{24,39}. This suppression of feeling could lead to isolation, because women might not always have someone in whom to confide their fears. Therefore, although family is indeed important, it should not be assumed that all SA women are distress-free or feel well supported after treatment.

In the present study, counselling and peer support—although still viewed as important—were not considered as useful by a number of the participants. It has been shown that women from diverse ethnicities may benefit from counselling interventions, and yet they are less likely to use such services²⁰. Peer support groups entail disclosure of personal experiences, and SA women may feel more comfortable sharing in their own language²⁰. Other barriers such as lack of transportation, the duty to put others first, multiple life demands such as caring for dependents, catering to the household, and engaging in paid work can hamper the perceived importance of counselling. Furthermore, stigma associated with seeking counselling, because it implies a psychological disorder, has been reported in the SA population in South India⁴⁰. The importance of preserving an image of coping well and maintaining cultural roles was evidenced in studies with SA women who identified coping strategies while experiencing depression^{24,39,40}.

The suggestion of counselling for depression as a part of a SCP for SA survivors would have to be approached in a culturally sensitive manner.

Some survivorship issues may be unique to SA women treated for breast cancer. First, adherence to adjuvant hormonal therapy was high in our study, with 86.3% of SA women reporting taking their medication more than 80% of the time, compared with 50% in other BCSS⁴¹. Likewise, a high percentage of our respondents (95.3%) visited their family doctor as planned after discharge from the cancer centre. Indeed, it has been shown that most SA women hold physicians in high regard and believe that to “do what the doctor says” is best^{21,23,25}, possibly explaining the high compliance levels we observed. However, some younger participants (50% of group A) expressed concern about the ability of the family physician to provide counselling on family, sexual, and self-image issues.

Although the small sample size and resultant possible selection bias limits our analysis by age group, our results confirmed the qualitative findings from the first phase of the project. It also provided further insight into how to adapt and individualize future care plans according to the experiences of SA women and their post-treatment needs. Even so, certain limitations need to be addressed. The response rate was low (24.9%) and participants did not always answer every question in the survey, as evidenced by the rate of missing data. Inherent to any survey-based study is recall bias, with results being based only on self-account by the patients. Moreover, fewer than 10% of our respondents were less than 44 years of age, and so that particular age group was underrepresented (a not unexpected result, given that breast cancer is more prevalent in older age groups). Lastly, the results of our study may not be generalizable to all SA women with breast cancer: SA women in British Columbia with breast cancer may have viewpoints and experiences that are different from those of other women of Indian descent in other regions²³.

Related studies with SA and other migrant women from diverse backgrounds and countries of origin have reported that the experience of a cancer illness might be coloured by difficulties related to the immigration experience and living in an altered culture^{17,25,27,40}. Such challenges include a wide range of stressors, such as financial burdens, uprooting and resettlement experiences, difficulties in providing adequate health care for members of the extended family, the struggle to keep their beliefs and values related to the upbringing of children, and maintaining activities of daily living²⁵. It is also important to remember that the acculturation experiences of SA women with breast cancer will vary according to their number of years of residency in Canada and other individual factors. Suggesting that the health practices of immigrant women are attributable to culture or social factors alone can lead to essentializing and further stereotyping the

particular immigrant group^{35,39}. Consequently, whenever clinical practice change is deemed necessary, it is important to analyze not only individual contextual factors, but also the breadth of the larger social and institutional context.

In view of the prevalence of breast cancer and the important population of SA women in western Canada, it is important to provide culturally appropriate SCPS. High medication compliance rates perhaps suggest that less emphasis can be put on the importance of tests and follow-up visits. And because SA women experience many post-treatment effects similar to those seen in other BCSS of different ethnicity, general interventions developed to address the social and emotional impacts of the disease are applicable to all survivors.

Opinions from the participants of the present study about the format and delivery of a SCP will help to shape the last phase of our project, which is to develop, implement, and evaluate a SCP tailored to the SA population. An important aspect is to develop methods to screen for distress in SA women with breast cancer before the end of treatment so as to offer support and counseling in a context that will be socially acceptable—for example, suggesting counselling as a medical service appointment, or as informational sessions directed toward the patient and the family.

5. CONCLUSIONS

Our findings suggest that many of the physical and psychosocial impacts of breast cancer diagnosis and treatment are shared by women of all ethnic backgrounds, and that emotional needs persist over the survivorship trajectory. There is a need for support resources, especially counselling concerning sexuality, body image, and depression in younger patients. Several cultural insights of SA women, such as the importance of family, also influence survivorship care, highlighting the need to adapt future SCPS to the reality of SA women so as to prevent barriers that would discourage active participation in follow-up care.

It is important that health care providers—including oncologists, oncology nurses, and patient and family counsellors—who provide cancer care for various ethnic groups with varying types of cancers assess the impact that the cancer diagnosis and its treatment has on the entire family and the individual.

It is imperative for health care providers to understand that, although cancer survivorship care has many universal facets, each individual's culture and perception of their illness might demand different support approaches.

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7. CONFLICT OF INTEREST DISCLOSURES

The authors have no relationships with pharmaceutical companies and declare that no financial conflicts of interest exist.

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