

Evaluation of the delivery of survivorship care plans for South Asian female breast cancer survivors residing in Canada

S. Singh-Carlson PhD APHN-BC,* F. Wong MD,[†] and G. Oshan BA[†]

ABSTRACT

Background This paper focuses on phase III of a study evaluating the development and implementation of a survivorship care plan (SCP) that could ultimately improve post-treatment quality of life for South Asian (SA) breast cancer survivors (BCSS). Evaluating the utility of the SCP was important to understand how sociocultural influences might affect uptake of the SCP by SA BCSS, especially as they transition from treatment to community care.

Methods Post-treatment discharge planning using an individualized SCP at discharge for SA female breast cancer patients with stage I or II disease was offered as a pilot service to oncologists at BC Cancer's Fraser Valley and Abbotsford centres. A longitudinal study using a mixed-methods approach was used to evaluate the utility of that service at 1 year after discharge.

Results Participants ($n=16$) completed a survey about their SCP delivery experience, and a 1-year post implementation survey about the SCP content and its utility. Most participants reported the discharge appointments to be extremely or very helpful with respect to post-treatment care questions. All have visited their family physicians for follow-up as recommended. The three major sources of support were family, faith, and family physician. Qualitative responses from the health care professionals who developed or implemented the SCPs identified two challenges in SCP delivery: engaging patients or family members in relationship, and translating key information through interpreters.

Conclusions It is important to evaluate the utility of SCPs for SA female survivors, who might differ from the general BCS population because of a different understanding of the disease; language barriers; strong influence of family members; societal stigmas; and personal, social, cultural, and religious beliefs and values. A formal nurse-led discharge appointment with discussions about follow-up care and an individualized SCP outlining the short- and long-term effects of treatment are recommended. Particular attention has to be paid to the practical and psychosocial needs of SA BCSS and their supporting family members.

Key Words Survivorship care plans, follow-up care, breast cancer survivors, South Asian women, post-treatment cancer care

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INTRODUCTION

As more treatment options become available and supportive care improves, a larger number of people will become cancer survivors. Evidence indicates that survivorship issues could, for female South Asian (SA) breast cancer survivors (BCSS), be different from those for the general BCS population¹⁻³. The differences could be attributable to different understandings of the disease; language barriers; societal stigmas; and personal, social, cultural, and

religious beliefs and values. Other studies have reported "quiet acceptance," with culture, social milieu, and religion being the foundational lens through which quiet acceptance, karma, or fatalism—coupled with inner strength and familial community support—are viewed as part of the identity of SA women^{4,5}. In those studies, SA women identified the usefulness of socially or culturally specific and individualized SCPs in English or their own language. The present research considered women of SA heritage, because people of SA descent represent the third-largest

population group in British Columbia, with most residing in the various cities of the Lower Mainland⁶. The SA women in this study are identified as those of Indian ethnicity.

The U.S. Centres for Disease Control and Prevention identify the survivorship trajectory as beginning at time of diagnosis and continuing throughout the individual's remaining life, with effects for family members, friends, and caregivers⁷. The U.S. National Cancer Institute emphasizes the importance of follow-up care that addresses ongoing physical and psychosocial effects that can develop from months to years after treatment, together with prevention or early detection of recurring cancers⁸. Survivorship follow-up care that addresses quality of life and health promotion, coordination with primary care providers, supportive services, and fertility preservation for the younger generation is also vitally important⁷⁻⁹. In a 2005 report, the U.S. Institute of Medicine (IOM) recommended that cancer patients be provided with a comprehensive care summary and follow-up plan that is clearly reviewed with them and explained upon discharge^{4,9}. The IOM further concluded that a system of coordinated follow-up care did not exist for most cancer survivors, thereby leaving most patients to self-manage through their cancer trajectory. At 9 years after the IOM recommendation, the Commission on Cancer (COC) of the American College of Surgeons instituted compliance with an implementation of SCPS by 1 January 2015¹⁰. The COC supports the recommendation from the IOM, the U.S. National Coalition for Cancer Survivorship (NCCS), and the U.S. National Cancer Institute and has updated the scope and extended the timing for compliance to 31 December 2018 and beyond for 75% of eligible patients to be provided with an SCP.

Coupled with pre-existing comorbidities, a cancer diagnosis changes a patient's health care needs and heightens the complexity of the individual's practical needs—for example, for returning to work and performing activities of daily living^{4,5,11,12}. The NCCS reports that patients should receive written care plans or treatment summaries that begin at diagnosis so that survivors and their loved ones can better understand treatment and follow-up needs¹³. Such plans or summaries inform survivors about how to be their own advocates, self-managing their care so as to enhance their quality of life¹⁴. To that end, the NCCS (*Journey Forward*) and the American Society of Clinical Oncology have both developed patient and provider tools that facilitate completion of SCPS or treatment summaries that effectively support cancer survivors^{13,15}. However, those survivorship tools have generally been too technical, too limited in self-care teachings, and not easily tailored to meet the diversity in age, ethnicity, language, and education level in populations of breast cancer patients¹⁶.

Studies show that, when BCSS have less interaction with oncology health professionals, they can feel isolated and uninformed, and can experience depression and anxiety that lead to challenges in coping with quality of life after completion of treatment¹⁵⁻¹⁷. An integrative synthesis of the available research suggests that Asian women, like the SA ethnic subgroups, report higher levels of health system and information needs; in contrast, white women generally report greater psychosocial needs¹⁸. Most survivors must deal with the physical, psychosocial, and practical effects

of their breast cancer diagnosis and treatment as they try to regain control over their lives and to return to normalcy. Emphasis should therefore be placed on the importance of continuity of care and of consistent communication with health care providers (HCPs) from completion of treatment to surveillance and at transitions in care^{5,15-16}.

Although there has been movement toward providing customized care plans for BCSS, especially given the COC recommendations, pre-existing challenges to limited health care resources and lack of information to guide HCPs in managing this task for heterogeneous populations is recognized^{5,10,18,19}. Given those pre-existing challenges in SCP development and delivery, coupled with challenges inherent to the heterogeneity and diversity of SA female BCSS, it was deemed important to pursue the development of SCPS to be implemented by oncology nurses for SA women upon discharge from the cancer agency^{4,5}. The purpose of the present study was therefore to evaluate the development and implementation of an SCP and the optimal content and format for that SCP, with the ultimate aim of potentially improving this population's post-treatment quality of life. We also evaluated the utility of the SCP so as to understand how sociocultural influences might affect uptake of the SCP by SA BCSS, especially as they transition from treatment to community care. The present work describes phase III of the study, with these aims:

- To better understand the development of an SCP and its delivery and utility in the population of interest
- To confirm the content and format of the SCP within the population of interest

METHODS

A longitudinal mixed-methods approach using surveys and qualitative inquiry set out to evaluate the benefits (self-reported by patients) of an individualized SCP during a 1-year period²⁰.

SCP Process

Currently, when clinically appropriate, BC Cancer discharges patients to primary care providers (PCPs) without an additional discharge planning session for the patient. Post-treatment discharge planning for female SA breast cancer patients with stage I or II disease was offered as a pilot service to oncologists at BC Cancer's Fraser Valley and Abbotsford centres between March 2012 and November 2013. Suitable patients referred by treating oncologists were approached by breast cancer nurse coordinators, who explained the process and booked 1-hour discharge planning appointments^{4,6}. The brief summary that follows describes the process of SCP development, implementation, and evaluation.

■ Development of SCP Content

The SCPS were developed with a core group of radiation and medical oncologists, oncology nurses, PCPs, and a SA BCS. Four members of the core group were of SA descent (PCP, nurse researcher, research assistant, BCS). Three members of the team translated the SCP into Punjabi, with rigorous checking by the group of each

translated version to validate the translation. The SCP package was reviewed by the SA nurse researcher (SSC) with breast cancer care nurses to ensure adequate and appropriate educational information for BCSS.

■ *Content of the SCP*

The SCP consisted of a treatment summary and culturally appropriate or tailored recommendations relating to physical needs, psychosocial symptoms, sexuality and intimacy concerns, faith complexities, and lifestyle modification resources, as suggested by participants in phase I of the study. Sections on sexuality and faith resources were especially revised and tailored, because participants responded negatively to texts with pictorials about sexuality. Because participants in phase I had shared their dislike of the word “survivor” and preferred more positive wording, the SCP was titled *Hounsla* (“fortitude”)⁵.

■ *Implementation of the SCP*

Oncology nurses implemented the SCP as part of the post-treatment discharge appointment, explaining the main elements in a 1-hour meeting. Specific sociocultural nuances about communication style and ethics of relations with SA BCSS were shared with oncology nurses to ensure respectful delivery of the information. The oncology nurses confirmed each participant’s understanding of the aspects of follow-up care and focused on areas needing clarification. The PHQ-9 Depression Test was conducted at the end of the appointment to screen for major or minor symptoms of depression. BC Cancer’s Patient and Family Counselling services were offered to women with a high PHQ-9 score (>9) or to those manifesting psychosocial or emotional needs. To ensure the reliability and credibility of the oncology nurse’s intent during the translator’s interpretation to the patient, SA members of the team developed cue cards to facilitate communication about counselling.

■ *Evaluation of the SCP*

The SCP content, utility, and implementation were evaluated using surveys of participants and PCPs. Qualitative data about individual perceptions of the discharge planning process were obtained in one-to-one interviews with participants. The HCPs (radiation oncologists, oncology nurses) who took part in the SCP implementation were interviewed as a group. Evaluation of HCP perceptions of the receipt by BCSS of their SCPs during the implementation process was key for clinical practice improvement.

Surveys

Post-SCP Implementation Patient Survey

Surveys were designed to elicit data about the participant’s perceptions of the approach and communication by the oncology nurse during implementation of the individualized SCP. Questions aimed to elicit the benefit of post-treatment-related information, the responses of the oncology nurses to participant questions, the appointment format, and the

participant’s understanding of the SCP content and its utility. The questions required yes or no responses, or a choice of grading (scales of 3–5). Descriptive responses were invited to illustrate personal experiences during post-treatment discharge to the community.

One-Year Post-Implementation Patient Survey

The 1-year post-implementation patient survey was validated and used in phase II of our study⁶. To evaluate the utility of the SCP, questions were added to assess each participant’s perceptions of SCP usefulness during the post-discharge year. Questions focused on the participant’s perceptions of the resources and their experiences of sharing the SCP content with their PCP. Space was provided to suggest additions to or deletions from the SCP. A demographic question about the religion practiced by the participant, if any, was added to provide broader baseline data. Other questions remained the same as in phase II. The survey used closed-ended questions with multiple-choice responses, some Likert-type scale responses, and open-ended qualitative responses. To ensure accuracy and transferability, the 28 questions in the final version were translated into Punjabi by 3 SA team members.

Family Physician Survey

The family physician (FP) survey was strategically designed on 1 page for easy response. The aim was to elicit the FP’s perceptions about the benefit of the individualized patient SCP. The survey was mailed 1 year after patient discharge, and again 1 month later as a reminder. Alerts about the surveys were telephoned to each FP’s receptionist. It is important to note that FPs also received the BC Cancer discharge report or letter from the patient’s oncologists according to current standard practice.

Data Collection

At the beginning of their appointment, participants were asked for informed consent in their preferred language. They were also told that the post-SCP implementation survey had to be completed and mailed back within 1 week in the envelope provided. The compliance rate of those participants for survey return was, however, extremely low. The procedure was then changed to invite participants to complete the survey in a private room immediately after SCP delivery. Participants were given an envelope in which to seal the survey for privacy and confidentiality. To ensure random sequencing, the research assistant did not open the envelopes until several envelopes had been returned. The new strategy proved to be effective.

Participants were also told at the same visit to complete and return the 1-year post-implementation patient survey that they would receive in the mail with a return envelope, 1 year after SCP delivery. They were also invited to participate in focus-group discussions at the 1-year mark.

When necessary, communication with patients was facilitated with the help of professional interpreters. Most participants spoke Punjabi. A few spoke Hindi, and others spoke both English and Punjabi. Because of the sensitive nature of the term “counselling” and its stigma within the general SA community (shared by participants in phase I), a cue card inquiring about a participant’s need

for counselling was prepared in the Punjabi and Hindi languages for the interpreters⁴. That strategy promoted the accuracy and consistency of language and format in the translation of this important question. Interpreters read directly from the cue cards and translated individual responses for the oncology nurses.

The English and Punjabi versions of the 1-year post-implementation patient survey were sent to each participant at 1 year, with reminders after 1 month. Because of a lack of response, the SA researcher contacted participants directly by telephone and asked the same structured questions after positively identifying the participants. That strategy ensured 100% participation. Anonymity was ensured by giving the survey responses to the research assistant without numbering them. Because of the logistics involved in inviting participants to focus-group interviews and the preference of participants for one-on-one contact, semi-structured interviews were conducted individually to obtain the perceptions of participants about the SCP content and utility, and the resources provided. All participants received the SCP, but only those who consented for the evaluation component were included in the study.

Despite several attempts at contact by mail and telephone, only 2 FPs responded to the surveys. The resulting data were therefore deemed inadequate and are not included.

A focus group was also conducted with the HCPS (radiation oncologist, oncology nurses) who took part in the SCP development and implementation.

Data Analysis

Analysis took two forms: content analysis and descriptive statistics. Content analysis was used to systematically identify the perceptions of SA BCSS about the utility of the SCPS and the experiences of HCPS with SCP implementation²¹. For that analysis, the qualitative data were explicitly coded into categories after an initial line-by-line reading, classifying the data into broad categories and characterizing the perceptions of both groups of participants. Audiotaped data responses were translated and transcribed. Detailed recordkeeping of survey responses ensured auditability, and critical writing and reflection were used to avoid assumptions or stereotyping by research team members. Descriptive statistics (reported as frequencies) were calculated using the SPSS software application (version 14.0: SPSS, Chicago, IL, U.S.A.) for Windows (Microsoft Corporation, Redmond, WA, U.S.A.). Frequencies were calculated based on the number of responses to the particular question.

RESULTS

Characteristics of the Participants

Of 20 patients who were referred, one was not discharged, and a second could not be interviewed because an interpreter was not available. The remaining 18 patients received individualized SCPS delivered by the oncology nurse upon discharge, with an offer to participate in the study. Inability to read and write in either English or their own language led 2 patients to decline participation. They felt that they could not recruit help from family members to complete the surveys. The remaining 16 agreed to be part of the study, accepting to complete the surveys after SCP

delivery and at 1 year afterward. Participant ages ranged from 27 years to 63 years at diagnosis and from 32 years to 66 years at the time of participation in this study (average age: 55 years). Table I summarizes the age distribution for the participants.

Post-Implementation Evaluation of the SCP

Table II summarizes participant responses about the SCP after its delivery. Only 15 responses were received; 1 participant did not return the survey. All SCPS were delivered in written English and another preferred language. Using interpreters as necessary, 6 SCPS were delivered in English, 9 in Punjabi, and 1 in Hindi. Most participants found their appointment to be extremely or very helpful. They felt that all their questions about the post-treatment protocol were answered by the oncology nurse. Family members were present for more than 50% of appointments. Participants expressed no preference for other family members when asked "Is there another family member you would like to include?"

Most participants felt that the format was just long enough and that the presentation used an effective communication style. The *Hounsla* SCP developed for SA BCSS was found to be extremely beneficial, with 100% of participants finding the information about resources and physical effects after treatment to be useful. More than 75% of participants felt that the PCP information, treatment summary, and resources for the follow-up program and healthy living were beneficial and useful. Participants did not believe that anything else had to be covered in the *Hounsla* SCP, and they were generally comfortable with its format. Most participants shared their experiences of feeling comfortable in their relationship with the oncology nurse during the discharge meeting. The following verbatim quotes highlight the environment that was created through clear communication by the oncology nurses: "Happy with you [HCPS]." "[It] was a great session." "[The oncology nurse] was informative and supportive." "I appreciate knowing I can contact her any time." Although the foregoing quotes present a congenial environment, some participants expressed a wish for more choices with respect to the resources available for them, as highlighted by this example: "[I] would have liked better selection of wigs, Indian-style with long black hair."

One-Year Post-Implementation Patient Survey

The 1-year post implementation survey, which evaluated participant perceptions of the content, resources, and utility of SCPS, attracted responses from 16 participants. Most of the surveys were answered in English, with Punjabi-language surveys being second. That result indicates that participants received help from family members, because Punjabi was the primary language for the participants.

Age of Respondents

Compared with the phase II participants, the SA BCSS participating in this phase III study were younger at diagnosis and at the time of participation. Although the phase III sample was small, noncompliance with medication (not at all or <50%) was reported by 4 of 14 BCSS (29%) compared with 7 of 51 phase II participants (14%). Again, that finding could be a result of the difference in age range.

TABLE I Characteristics of the survey respondents

Characteristic	Value	
	(n)	(%)
Participants (n)	16	
Age group		
At time of study		
<35 Years	1	6.3
35–44 Years	3	18.8
45–54 Years	5	31.3
55–64 Years	6	37.5
≥65 Years	3	18.8
At diagnosis		
<35 Years	1	6.25
35–44 Years	2	12.5
45–54 Years	7	43.8
55–64 Years	6	37.5
Language		
Primary		
English	2	12.5
Punjabi	13	81.3
Hindi	1	6.3
Secondary		
English	8	50.0
Hindi	1	6.3
Gujrati	1	6.3
None	6	37.5
Residency in Canada		
<10 Years	5	31.3
11–20 Years	6	37.5
>20 Years	5	31.3
Education		
Less than high school	8	50.0
High school graduate	5	31.3
Certificate or diploma	1	6.3
Bachelor degree	2	12.5
Employment		
Employed for wages	6	37.5
Self-employed	2	12.5
Homemaker	4	25.0
Unemployed	1	6.3
Unable to work	1	6.3
Retired	2	12.5
Marital status		
Married	12	75.0
Separated or divorced	2	12.5
Widowed	2	12.5
Religion		
Sikhism	13	81.3
Hinduism	2	12.5
Islam	1	6.3

Perceptions of Post-Discharge Follow-Up Care Received

Despite 100% of participants affirming being told by the oncology nurse at the discharge appointment that their FP was responsible for their breast cancer follow-up care, only 13 of 16 (81.3%) reported 1 year later that the FP was responsible for their follow-up care. All participants had visited their FP for follow-up visits between 1 and 8 months after discharge from BC Cancer as recommended. However, only 12 of the 16 (75%) felt that the FP knew the details of their cancer diagnosis or treatment. Only 10 of the 16 (63%) reported that the FP had talked with them about follow-up care. Those findings are consistent with our phase II⁶ results.

Participants did not appear to have confidence in their FP's ability to manage their psychosocial symptoms, especially sex and body image, family counselling, or anxiety and fear of recurrence. Others (4 of 16, 25%) did not think that their FP could manage the hormonal therapy well. Although 4 of 16 participants (25%) felt little support from BC Cancer for physical needs or emotional support, they reported receiving better support from the community in connection with physical symptoms, but worse support from community in connection with emotional issues.

Perceptions of Post-Discharge Effects of Treatment

Of 15 participants, 11 (73%) reported fears or concerns about their health being the most common psychosocial side effect, with 75% visiting their FP in connection with psychosocial effects. However, the same 75% felt that they were not able to manage the effects even after the FP visit.

The top 3 supportive resources identified—family, faith, and FP—were the same as those identified in the phase II responses⁶. Participants identified fatigue as the most common physical side effect, with 15 of 16 participants (94%) visiting their FP in connection with physical side effects; however, most participants (14 of 16, 87%) felt that the FP was generally not able to manage those side effects.

Evaluation of the Usefulness of SCP Content

Overall, the level of satisfaction with the information provided for follow-up cancer care was better for the phase III participants (15 of 16, 94%) than for the phase II participants (59%)⁶. Most participants (94%) felt that they would recommend SCP delivery at discharge and could not add anything new to the SCP. Table III summarizes patient responses evaluating the content of the SCP.

Health Care Professionals

Two oncology nurses and one radiation oncologist who took part in SCP development and implementation for SA BCs were interviewed about their perceptions of the process. They identified 2 challenges and facilitators to providing health care to diverse populations, such as the complexity seen in the sociocultural and linguistic contexts of SA breast cancer patients. Challenges in engaging patients and family members in health care relationships and challenges in translating key information through interpreters resonated throughout the experiences of the HCPS.

TABLE II Post-delivery responses by 15 women to the survivorship care plan

Question	Response [n (%)]
Was this meeting helpful in giving you information on breast cancer after treatment?	
Extremely helpful	9 (60)
Very helpful	4 (26.7)
Somewhat helpful	2 (13.3)
Was the nurse helpful in answering any questions you may have after discharge?	
All my questions were answered	14 (93.3)
Many questions were answered	1 (6.7)
Is there another family member or friend you would include in this meeting?	
No	7 (46.7)
Yes	8 (53.3)
Was the format of discharge meeting helpful?	
No response	3 (20)
Just enough	11 (73.3)
Too long	1 (6.7)
Was the interaction or communication effective?	
No response	3 (20)
Yes	12 (80)
How useful were the sections or pamphlets of the "Hounsla Care Plan" developed for South Asian women	
(a) Provider and contact information	
Very useful	12 (80)
Somewhat useful	3 (20)
(b) Breast cancer treatment summary	
Very useful	11 (73.3)
Somewhat useful	4 (26.7)
(c) Follow-up program after breast cancer treatment	
Very useful	3 (20)
Somewhat useful	12 (80)
(d) Physical impacts of treatment	
Very useful	15 (100)
Somewhat useful	0 (0)
(e) Psychosocial impacts of treatment	
Very useful	13 (86.7)
Somewhat useful	2 (13.3)
(f) Healthy living after treatment	
Very useful	13 (86.7)
Somewhat useful	2 (13.3)
(g) Other resources	
Very useful	15 (100)
Somewhat useful	0 (0)
Are there topics you feel the "Hounsla care plan" does not cover?	
No	14 (93.3)
Yes	1 (6.7)
Please provide any other comments to help us give better breast cancer care after treatment.	
<ul style="list-style-type: none"> ■ Would have liked better selection of wigs, more Indian styles ■ They did a good job; nurse was informative and supportive ■ Appreciate knowing I can contact the nurse anytime ■ I am very happy with all you ■ It was a great session 	

TABLE III Post-discharge evaluation by 16 women of survivorship care plan usefulness

Question	Response [n (%)]			
	Very useful	Somewhat useful	Not useful	Not applicable
<i>Your personalised treatment summary and care plan (9 pages)</i>				
Contact information of providers (FP, oncologists)	12 (75)	4 (25)	—	—
Summary of your breast cancer diagnosis	11 (68.8)	3 (18.8)	1 (6.3)	1 (6.3)
Summary of treatment you received	7 (43.8)	7 (43.8)	2 (12.5)	—
Summary of who is now responsible for your care	14 (87.5)	2 (12.5)	—	—
Information on signs/symptoms of recurrence	15 (93.8)	1 (6.3)	—	—
Follow-up program after breast cancer treatments	14 (87.5)	1 (6.3)	—	1 (6.3)
Physical impacts of treatment: General information	15 (93.8)	1 (6.3)	—	—
Psychosocial side effects of treatment	15 (93.8)	1 (6.3)	—	—
<i>Healthy living</i>				
General information	15 (93.8)	1 (6.3)	—	—
<i>Your resource package (83 pages)</i>				
<i>Physical symptoms</i>				
Lymphedema or swelling prevention and treatment	4 (25)	1 (6.3)	—	11 (68.8)
<i>Exercising</i>				
Message from your oncologist	6 (37.5)	8 (50)	1 (6.3)	1 (6.3)
<i>Canadian Physical Activity Guidelines</i>	5 (31.3)	2 (12.5)	1 (6.3)	8 (50)
Physical activity line	5 (31.3)	2 (12.5)	1 (6.3)	8 (50)
WalkBC.ca Web site	4 (25)	3 (18.8)	1 (6.3)	8 (50)
Sexuality	3 (18.8)	4 (25)	1 (6.3)	8 (50)
Information on natural health products	3 (18.8)	11 (68.8)	1 (6.3)	1 (6.3)
Faith	7 (43.8)	8 (50)	1 (6.3)	—
<i>Psychosocial</i>				
Cancer Chat Canada	1 (6.3)	1 (6.3)	1 (6.3)	13 (81.3)

FP = family practitioner.

Challenges in Engaging Patients and Family Members in Relationships

Language was the foremost communication barrier when working with some SA women from different SA subgroups, especially those who were older and who did not speak English. In comparison, some were very “enthusiastic about getting the information.... The two most enthusiastic ones... both spoke English and were well educated.” Oncology nurses shared how their “experiences were varied and ranged from providing fairly short responses during the scp to very enthusiastic responses by some of the participants.” Oncology nurses observed that, when they took time to introduce the process of the scp delivery appointment while making the initial telephone contact or attending the discharge appointment between the participant and the oncologist, participants and family members felt more comfortable and engaged in the conversation during scp delivery. Oncology nurses felt that participants were more prepared if an explanation of the time commitment of 1 hour had been provided beforehand. The challenge at times was engaging the family member or members in the conversation, especially when they seemed very anxious

because of the length of the appointment. Oncology nurses reported family member behaviours as including either pacing, talking on the telephone, or constantly looking at a watch. Oncology nurses felt that developing rapport with the participant and family members through the discharge process led to engaging relationships that allowed for the development of trust. The other component of developing a relationship was the environment—for example, the “quiet room is set with couches, ambient lighting. It’s not harsh. It’s away from the clinics, a non-clinical type of environment.” Oncology nurses felt that SA BCSS did not ask too many questions and had a “quiet acceptance” of the cancer diagnosis or treatment, while accepting the information provided during the scp implementation as “something they had to do as part of the cancer journey.”

Challenges of Translating Key Information Through Interpreters

Oncology nurses felt challenged when some interpreters appeared to translate a minimal version of the information being imparted, especially when the interpreters would “literally say a few words after I had just spoken a few

sentences.” Nurses felt that such minimal interpretation might “influence the quality of the session and dampen the desire for more information and engagement.” Nurses reported that, in most instances, the sex and age of the interpreter made a difference in their fervour to engage with participants. For example, “the enthusiastic one was probably maybe mid- to late thirties, and the other was in her late fifties or early sixties.” At other times, oncology nurses experienced older aged interpreters as seeming “kind of flaccid, not really wanting to open up at first. But you can see the bonding happening over the period of the appointment, and the enthusiasm was infusing into the patient as well.” The HCPs felt that, although a preference for interpreters of female sex is expressed for SA BCs appointments, the agency is not always able to fulfil the request, making it difficult to communicate with non-English-speaking patients.

DISCUSSION

The coc instituted by the American College of Surgeons supports the NCCS and the IOM’s recommendation that each cancer patient should receive a comprehensive post-treatment SCP as part of follow-up care^{5,8–10}. Those endorsements accord with the focus of the Canadian Partnership Against Cancer’s National Survivorship Working Group on care maps and models of SCPS for patients after treatment²². For the present phase III study, we developed, implemented, and evaluated SCPS, obtaining qualitative data that were confirmed by other SA BCSS from British Columbia^{4,5}. Most participants (93%) recommended SCP delivery at the post-treatment discharge appointment. The overall level of satisfaction with the follow-up cancer care was better for phase III participants (15 of 16, 93%) than for the participants in phase II (59%), who did not receive discharge planning discussions. Participants more often reported receiving information relating to both physical needs and psychosocial issues, reaching 59.4% in phase III compared with 42.2% in phase II. Reliability of information and resources for follow-up care was also rated higher in phase III (81% vs. 56.3%). Those differences in the responses by phase could have been influenced by several factors, such as the oncology nurse delivering the SCP at discharge, the SCP resources provided, or participant empowerment through the knowledge that the FP follow-up visit is part of post-treatment care²³. Studies report that clear follow-up recommendations and guidelines will lessen role confusion for FPs and will increase a patient’s understanding of what to expect from their FP during follow-up appointments²⁴.

Visits to the FP for psychosocial effects were made more often by participants in phase III (75%) than by those in phase II (51.6%). However, more participants in phase III (75%) than in phase II (44%) felt that they were not able to manage those effects. That result accords with a provincial survey of cancer patients that showed a lack of emotional support in the community²⁵. Continuing education and additional training for FPs in cancer screening, genetic testing, survivorship care, and innovative and new cancer treatments and protocols with their effects on cancer survivors appears to be an important factor to consider, because FPs are, owing to

time constraints, more frequently relying on Web sites for self-education about post-treatment protocols^{23,26}. Studies suggest that, given a general lack of knowledge and discordance relating to patient care management among FPs, FPs have to be better integrated into the health care system²⁷. It would be interesting to conduct future research that examines the relationship of SA women with their FPs, especially in light of gender issues, sociocultural biases, and community connectedness.

The effects of fatigue and other physical problems in the present study are consistent with the literature and with the phase II data²⁸. However, SA participants in phase III reported that FPs were generally not able to manage the side effects, which might be a reflection of an inability on the part of HCPs to improve fatigue adequately for SA BCSS to manage demanding daily activities or duties. Furthermore, a gap in communication is evident, given that 25%–30% of participants felt that they generally could not obtain reliable information about the effects of treatment from BC Cancer or the community. Perhaps resources can be made more readily available at BC Cancer centres for BCSS after their discharge appointments. The current literature on engaging cancer patients in self-care management strategies from diagnosis throughout treatment suggests that survivors be their own advocates by taking an active role in their own care¹⁸. That engagement includes obtaining feedback on what to expect after each treatment, especially in light of sociocultural diversity and their understanding of their disease. Also illustrated is the key role that navigators can play in being accessible during and after discharge to support cancer patients. Having consistent nurses or navigators during the treatment process could also help to build the trust level, especially SA nurses with SA BCSS.

In contrast to phase II, phase III showed a higher level of noncompliance by participants with medication (29%) for adjuvant treatment. That finding is consistent with compliance at large; however, it might also reflect the younger age of the phase III cohort with respect to concerns about fertility and menopause (as voiced by the younger-age participants in phase II⁵). The importance of reproduction for SA women is sometimes deemed to be a part of societal or cultural expectations of the role that women play as wives. However, those expectations could be evolving because of the Western influence on most women⁵. Other literature indicates that BCSS should be educated about the importance of continuing their adjuvant treatment even after post-treatment discharge because it is a holistic part of their treatment²⁹. Contextual factors such as age, education, the patient’s partner, the type of treatment received with counselling, and the number of consultations with the breast specialist and clinical oncologist have been reported to affect adherence to hormonal therapy in women with breast cancer³⁰. Adherence rates can also vary when some medical oncologists continue to provide follow-up care because they feel a sense of responsibility toward the survivor’s compliance with adjuvant therapies³¹. The currently observed noncompliance could also be a consequence of the language barrier and raises the question of how effectively interpreters are engaging with patients and how much information the patient is receiving after translation.

RECOMMENDATIONS FOR CANCER CARE PROVIDERS

A formal nurse-led discharge appointment with a discussion about follow-up care based on an individualized SCP that outlines the short- and long-term effects of treatments is recommended. Such an appointment provides an opportunity to interact in a humanistic manner that leads to an understanding of the FP's role in the community. The provision of interpreters to serve patients with diverse backgrounds is also a key institutional responsibility—especially the need to pay attention to the sex and age of the interpreters in light of sociocultural contexts that include pre-existing biases and stigma concerning breast cancer. Being attentive to the needs of SA BCSS will include being supportive of this population's known and unknown health care needs and fears of recurrence in a culturally sensitive fashion.

Some crucial recommendations from the HCP focus group indicate that although resource needs will be increased for BCSS, it is important to schedule adequate time for SCP delivery at discharge. Because a language barrier is common in most Canadian clinical settings, a stable group of interpreters pre-screened for cultural appropriateness would be ideal. Providing consistent nursing personnel during the cancer treatment journey could be helpful in building trust and rapport. The result could be better uptake of SCP information and better compliance with adjuvant hormonal therapy. Knowledge of self-care management strategies will lead to empowerment and engagement in health promotion and disease prevention.

Our findings from the implementation and evaluation of SCPs for SA BCSS illustrates the importance of understanding the need for resources for this population. Because sociocultural lenses will influence quality of life for survivors after treatment, our study emphasizes that HCPs must be cognizant of the patient's sociocultural context as they provide cancer care.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

AUTHOR AFFILIATIONS

*School of Nursing, San Diego State University, San Diego, CA, U.S.A.; †BC Cancer–Fraser Valley Centre, Surrey, BC.

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