Original Article

Qualitative evaluation of care plans for Canadian breast and head-and-neck cancer survivors

K. Collie PhD, J. McCormick MSc, A. Waller PhD, C. Railton RN MN ACNP CON(C), L. Shirt RN BN CON(C), J. Chobanuk BScN MN CON(C) CHPCN(C), A. Taylor MD, H. Lau MD, D. Hao MD, B. Walley MD, B. Kapusta, A.A. Joy MD, L.E. Carlson PhD, and J. Giese–Davis PhD

ABSTRACT

Background
Survivorship care plans (scps) have been recommended as a way to ease the transition from active cancer treatment to follow-up care, to reduce uncertainty for survivors in the management of their ongoing health, and to improve continuity of care. The objective of the demonstration project reported here was to assess the value of scps for cancer survivors in western Canada.

Methods
The Alberta CancerBridges team developed, implemented, and evaluated scps for 36 breast and 21 head-and-neck cancer survivors. For the evaluation, we interviewed 12 of the survivors, 9 nurses who delivered the scps, and 3 family physicians who received the scps (n = 24 in total). We asked about satisfaction, usefulness, emotional impact, and communication value. We collected written feedback from the three groups about positive aspects of the scps and possible improvements (n = 85). We analyzed the combined data using qualitative thematic analysis.

Results
Survivors, nurses, and family physicians agreed that scps could ease the transition to survivorship partly by enhancing communication between survivors and care providers. Survivors appreciated the individualized attention and the comprehensiveness of the plans. They described positive emotional impacts, but wanted a way to ensure that their physicians received the scps. Nurses and physicians responded positively, but expressed concern about the time required to implement the plans. Suggestions for streamlining the process included providing survivors with scp templates in advance, auto-populating the templates for the nurses, and creating summary pages for physicians.

Conclusions
The results suggest ways in which scps could help to improve the transition to cancer survivorship and provide starting points for larger feasibility studies.

KEY WORDS
Care plans, survivorship, communication, breast cancer, head-and-neck cancer, qualitative analysis

1. INTRODUCTION
People with cancer are living longer because of improved access to effective screening, diagnosis, and treatment. However, some survivors experience ongoing psychosocial and physical symptoms, including fatigue, pain, sleep disturbance, depression, and anxiety. Many express uncertainty about how to manage their health after the transition from treatment to follow-up care and about who will be responsible for particular aspects of their care as they move forward. Some report a lack of information about possible recurrence, psychosocial resources, and late and long-term treatment effects.

Breast cancer survivors report a multitude of post-treatment physical, psychological, sexual, body image, social, occupational, and relationship problems that require attention, including problems with fatigue, sleep, weight gain, memory, and concentration. Some have vasomotor menopausal symptoms or psychosocial concerns including problems with family relationships and problems re-integrating into their lives (or both). They report a range of unmet information, medical communication, and psychological needs 6–24 months after diagnosis and unmet existential needs up to
10 years after diagnosis, especially problems with anxiety or depression\(^1\). Some report clinical depression at 3 months\(^2\), and 6 months\(^3\) post-treatment, and those who experienced chronic distress during the first year after diagnosis typically experience even greater long-term distress (6 years later)\(^4\).

Although less is known about the needs of survivors of head-and-neck cancer, research also shows that the disease and its treatments can have long-lasting and debilitating effects on physical and psychosocial wellbeing\(^5\). Problems with teeth, mouth-opening, mouth dryness, sticky saliva, appetite, and finances can persist or worsen during the first 5 years after treatment\(^6,7\). There can also be increases in pain, fatigue, depression, and anxiety\(^8,9\).

New strategies are needed for survivorship care, which can include patient education, ongoing routine monitoring, and tailored support\(^10,11\). The confusion reported by family physicians and oncologists about their roles and responsibilities in survivorship care\(^12\), the increasing number of cancer survivors, and recommendations from the U.S. Institute of Medicine (IOM)\(^1\) all point to survivorship care plans (SCPs) as a strategy for managing and reducing the ongoing needs of cancer survivors\(^13\).

Most previous studies of SCPs have described their optimal qualities\(^14\), or the views of key stakeholders on their possible use\(^1,2,5,7,8,15,30,38,39\). Studies about the implementation of SCPs are limited\(^40,41\). A pilot study showed a possible positive impact of SCPs for clarifying treatment history, available resources, and timing of follow-up appointments for breast cancer patients and for clarifying the treatment history and health status of patients for primary care physicians\(^16\). A randomized controlled trial revealed no improvement in patient-reported trauma symptoms as a result of SCPs that were implemented, on average, 24 months post-treatment (rather than directly after treatment as recommended by the IOM and others)\(^17\). We identified a need for in-depth research about SCPs created and implemented according to IOM guidelines.

We have a multidisciplinary provincially focused team dedicated to researching and delivering evidence-based survivorship care in Alberta, a large western province in Canada. We conducted the present study as a demonstration project to explore the feasibility and utility of developing and implementing SCPs with breast and head-and-neck cancer survivors. The project included a qualitative component that has already been reported (Giese–Davis J, McCormick J, Zhong L, et al. Care plan development for breast and head and neck cancers: an Alberta Cancer Bridges demonstration project. Presented at the Canadian Association of Psychosocial Oncology conference; Toronto, Ontario; May 4–6, 2011); the qualitative component is reported here. The purpose of the qualitative component was to hear directly from survivors, nurses, and family physicians about their experience with the content and delivery of the SCPs, with the aim of addressing these research questions: What are the strengths and shortcomings of the SCP used in this study and of the process of its delivery? How can we improve content and delivery?

2. METHODS

We delivered SCPs to survivors of breast and head-and-neck cancer and conducted an evaluation that entailed collecting qualitative data from the survivors and from nurses and physicians involved in the SCP process. The participants responded to open-ended questions on a questionnaire, and 20% of them completed telephone interviews. Based on earlier research, we organized the evaluation to cover satisfaction, usefulness, emotional reactions, communication value, and suggestions for improvement.

2.1 SCP Creation

Existing SCP templates designed in the United States are not well suited to the Canadian context, and so we developed SCP templates based on recommendations from the Canadian Partnership Against Cancer and the IOM and on input from health professionals and survivors. We used a collaborative, iterative process that produced more than 20 versions over 6 months. The computerized (spreadsheet) templates were designed for nurses to prepare ahead of time and to complete with survivors during in-person or telephone meetings. The nurses passed each completed SCP to the survivor’s family physician and scanned it into the survivor’s medical record. A completed SCP summarizes a survivor’s oncology treatment and provides a personalized plan for survivorship that can be used by both the survivor and the physician (Table 1).

2.2 Recruitment

All recruitment methods were approved by the Conjoint Health Research Ethics Board of the University of Calgary Faculty of Medicine and the Tom Baker Cancer Centre.

2.2.1 Nurses

The focus was provincial for breast cancer survivors and local for head-and-neck cancer survivors. For breast cancer SCPs, we selected nurses employed in 2 tertiary cancer centres in metropolitan areas, in 2 associate cancer centres in rural settings, and in 1 community-based organization focused on breast cancer survivorship. For the head-and-neck cancer survivors, we selected a nurse specialist for that tumour group at a tertiary treatment centre.

2.2.2 Survivors

Nurses recruited 19 breast cancer survivors and 21 head-and-neck cancer survivors from tertiary treatment centres, 6 breast cancer survivors from rural...
CANCER CENTRES, AND 11 BREAST CANCER SURVIVORS FROM THE COMMUNITY-BASED ORGANIZATION. THE NURSES APPROACHED CONSECUTIVE PATIENTS WHO WERE WITHIN ±2 WEEKS OF LEAVING ACTIVE TREATMENT, EXPLAINED THE PROJECT TO THEM, AND ASKED IF A RESEARCH ASSISTANT COULD CONTACT THEM. THE RESEARCH ASSISTANT CONTACTED THOSE WHO AGREED AND FURTHER EXPLAINED THE STUDY, ANSWERED QUESTIONS, AND OBTAINED INFORMED CONSENT.

THE STUDY INCLUDED WOMEN 18 YEARS OF AGE OR OLDER DIAGNOSED WITH STAGE I, II, OR III BREAST CANCER, AND MEN AND WOMEN 18 YEARS OF AGE OR OLDER DIAGNOSED WITH NONMETASTATIC HEAD-AND-NECK CANCER. WE EXCLUDED ANYONE WHOSE ENGLISH COMPREHENSION WAS NOT SUFFICIENT TO COMPLETE QUESTIONNAIRES AND INTERVIEWS.

### 2.2.3 Physicians
We invited each survivor’s family physician to participate.

### 2.3 Participants
Of the 57 cancer survivors who collaborated with nurses to create SCPS [98% of those invited (Giese–Davis J, McCormick J, Zhong L, et al. Care plan implementation for breast and head and neck cancers: an Alberta CancerBridges demonstration project. Presented at the Canadian Association of Psychosocial Oncology conference; Toronto, Ontario; May 4–6, 2011)], all but 3 provided written responses to open-ended questions.

<table>
<thead>
<tr>
<th>Elements of care plan</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Basic diagnostic and treatment information summary</td>
<td>Diagnosis and treatment details</td>
</tr>
<tr>
<td></td>
<td>Brief medical history, including chronic diseases and allergies</td>
</tr>
<tr>
<td></td>
<td>List of current prescribed and over-the-counter medications, vitamins, and other therapies</td>
</tr>
<tr>
<td>2. Follow-up surveillance plan</td>
<td>Guidelines for follow-up care of survivors, with list of next follow-up appointments and who within the health system will provide surveillance</td>
</tr>
<tr>
<td></td>
<td>Possible signs of recurrence and cancer spread</td>
</tr>
<tr>
<td></td>
<td>Management of treatment-related side effects (physical and psychosocial)</td>
</tr>
<tr>
<td></td>
<td>List of side effects and treatment plan for survivors</td>
</tr>
<tr>
<td>3. Care-team contact information</td>
<td>Locations and telephone numbers for (among others) the family physician, surgeon, medical and radiation oncologist, nurses, social workers, psychologists, and dieticians caring for survivors</td>
</tr>
<tr>
<td>4. Coping and adjustment recommendations or guidelines, goals, and action plans, or both</td>
<td>An interactive section on coping and adjustment that survivors can use to indicate levels of distress and problems so that nurses can make appropriate referrals</td>
</tr>
<tr>
<td></td>
<td>List of personal coping strategies, strengths, and resources used by survivors</td>
</tr>
<tr>
<td></td>
<td>An interactive section on managing transition after treatment, including priorities, goals, and action plans for relationships and support, intimacy and sexuality, spirituality, finances, employment, and retirement</td>
</tr>
<tr>
<td></td>
<td>Section highlighting other strengths and needs</td>
</tr>
<tr>
<td>5. Healthy living recommendations or guidelines, goals, and action plans, or both</td>
<td>An interactive section on managing health after treatment, so that survivors can prioritize goals and action plans for physical activity, diet, weight, alcohol, and smoking</td>
</tr>
<tr>
<td>6. Resources and activities for survivors</td>
<td>Packet of booklets and brochures</td>
</tr>
<tr>
<td></td>
<td>List of important and relevant local resources and Web sites</td>
</tr>
</tbody>
</table>
on questionnaires. We purposively sampled 20% of the survivors for 12 semi-structured interviews (4 head-and-neck, 8 breast). We sampled for diversity in age, treatment, disease experience, lifestyle factors, location, and additional challenges such as homelessness and alcoholism. Every survivor invited for an interview agreed to be interviewed.

The 9 nurses who delivered the SCPS provided written responses to open-ended questions on questionnaires and also completed interviews. Of the 57 family physicians, 22 provided written responses; we invited 12 to be interviewed, and 3 agreed. Nurse and physician interviews were tied to the 12 survivors interviewed. Thus, we collected written data from 54 survivors, 9 nurses, and 22 physicians (n = 85), and we interviewed 12 survivors, 9 nurses, and 3 physicians (n = 24).

The two groups of survivors demonstrated several demographic differences. The average age of the breast cancer survivors was 53.6 ± 9.29 years, and most were white (91.4%), had higher household incomes (42.9% exceeding $100,000), were married (80.0%), and were employed full time (51.4%). The head-and-neck cancer survivors were predominantly male (80.0%), with a mean age of 55.5 ± 11.90 years. A smaller percentage were white (70.0%), and they had lower household incomes (55.0% less than $60,000). A smaller percentage were married (70.0%), and about half had partial or no employment (55.0%).

2.4 SCP Implementation

Each nurse received a full day of education about survivorship, the research project, the purpose and content of the SCP, cancer follow-up guidelines, and use of the SCP template. A research assistant provided ongoing support to the nurses throughout the study. The nurses completed their SCP tasks during paid work time with permission from their managers. The tasks included co-creating the SCP with the survivor, passing the SCP to the survivor’s family physician, and scanning the SCP into the survivor’s oncology record.

The goal was to deliver an SCP within 2 weeks of the end of active treatment, but because of scheduling and illness complications, the median time post-treatment was 33 days (range: 6–63 days) for breast cancer survivors and 2 days (range: –32 to 100 days) for head-and-neck cancer survivors. There were delays in rural settings because of travel complications and the workload of nurse navigators.

There were 4 kinds of nurses and 4 delivery methods:

- A chronic disease nurse in an urban community-based organization delivered SCPs in one-on-one meetings with survivors who were her patients.
- A nurse practitioner delivered SCPs through a survivorship class located at a tertiary treatment centre, having prepared the plans in advance.
- A clinical nurse specialist made individualized SCPs for head-and-neck cancer survivors and discussed them with the survivors in one-on-one meetings.
- Nurse navigators delivered most of the SCPs by telephone in 1 urban and 2 rural sites, having previously mailed paper copies to the survivors.

2.5 Data Collection

2.5.1 Questionnaires

Survivors, nurses, and physicians answered open-ended questions posed using questionnaires at the time of SCP delivery. The Likert-type questionnaires had questions for survivors and medical professionals about their interactions during the SCP process and included open-ended questions about positive aspects of the experience and possible improvements (Table 1). The answers to the open-ended questions were included in the analysis.

2.5.2 Interviews

The research assistant conducted individual telephone interviews with participants a median of 38.5 days after SCP delivery (range: 1–162 days). The interviews included specific questions about satisfaction, usefulness, emotional reaction, and communication value, and general questions about the experience of participants in delivering or receiving the SCP and suggestions for improvement (Table 1). The interviews averaged 32.76 minutes (range: 13.06–61.30 minutes) for survivors, 23.67 minutes (range: 14.49–42.27 minutes) for nurses, and 11.38 minutes (range: 9.08–15.09 minutes) for physicians. We audiotaped the interviews, and a trained transcriptionist transcribed them verbatim.

2.6 Data Analysis

We combined the data from survivors, nurses, and physicians because we were interested in their collective perspective on the collaborative process of implementing SCPs. JM and AW conducted the analysis in consultation with KC. They began with a question analysis and identified data from the interviews and open-ended questions that pertained to satisfaction, usefulness, emotional reaction, communication value, and suggestions for improvement. They coded data within each of those topics for themes, and as themes emerged across questions and participant groups, they completed the analysis as a thematic analysis guided by the two research questions44. JM and AW coded the data individually and met regularly to refine the coding scheme and to discuss emerging themes. When they disagreed, they coded together until a consensus was built. In this way, they identified dominant themes (those that were given special emphasis by participants, that were shared across the groups of participants, or that were mentioned frequently). They made note of alternative views. They used the
HyperRESEARCH software application (version 3.0: ResearchWare, Randolph, MA, U.S.A.) to help manage and analyze the data.

3. RESULTS

The themes that emerged from the analysis mirrored the interview questions and reflected our interest in satisfaction, usefulness, emotional reactions, communication value, and suggestions for improvement. The themes and subthemes are described in the subsections that follow and are listed in Table III.

3.1 Satisfaction and Usefulness

Survivors, nurses, and physicians all said that they found the scp’s useful for reducing uncertainty, easing the transition from active cancer treatment to survivorship, and enhancing follow-up care.

3.1.1 Comprehensiveness

Survivors said that they liked having information about their cancer, treatment, and ongoing care written down in one place so that they would not have to rely on memory or materials collected over the course of treatment. They were satisfied that the scp’s covered their most important medical, informational, emotional, financial, and social concerns, including issues that they had not previously considered.

One survivor said, “This is certainly useful because you don’t necessarily focus on that kind of stuff unless someone sits down with you and makes you pay attention to it.”

### Table II

<table>
<thead>
<tr>
<th>Category</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>What was it like for you to participate in making the care plan?</td>
</tr>
<tr>
<td></td>
<td>What do you think about the timing of when the plan was given to you?</td>
</tr>
<tr>
<td></td>
<td>What do you think about the content of the care plan?</td>
</tr>
<tr>
<td></td>
<td>Is anything missing you would have liked to have seen included?</td>
</tr>
<tr>
<td></td>
<td>Are there things included that you are confused by?</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>In what ways are you satisfied with this plan overall?</td>
</tr>
<tr>
<td></td>
<td>What do you think about the process of creating the care plan?</td>
</tr>
<tr>
<td></td>
<td>How could it be improved?</td>
</tr>
<tr>
<td>Usefulness</td>
<td>In what ways will this plan be useful be for you over the next 6 months to a year?</td>
</tr>
<tr>
<td></td>
<td>In what ways does this plan give you some concrete direction now that you are finished with treatment?</td>
</tr>
<tr>
<td>Emotional reaction</td>
<td>In what ways does this care plan affect your feelings about leaving the cancer centre now that your treatment is done?</td>
</tr>
<tr>
<td>Communication value</td>
<td>Do you think having this care plan will make a difference in your follow-up care? If so, in what ways might it make a difference?</td>
</tr>
<tr>
<td></td>
<td>In what ways do you think this care plan might impact the communication between yourself and your care providers?</td>
</tr>
<tr>
<td>End of interview</td>
<td>Finally, we would like to give you a chance to make any further comments you’d like to share with us, and any suggestions you have for improving the care plans themselves or the process of creating and delivering the plan.</td>
</tr>
<tr>
<td>Open-ended</td>
<td>What was particularly positive about this experience for you?</td>
</tr>
<tr>
<td></td>
<td>What would you change to improve this experience?</td>
</tr>
<tr>
<td></td>
<td>Is there anything we have not given you a chance to say?</td>
</tr>
</tbody>
</table>

* Interviews were conducted with the nurses who delivered care plans, the survivors who collaborated in plan creation and received plans, and the family physicians who received plans. Questions were formulated to stimulate discussion for the survivors. Questions for the nurses and family physicians followed the same format, but were worded appropriately. For example, survivors were asked “In what ways is this useful for you?”; nurses and physicians were asked “In what ways do you think this will be useful for you and the survivor?”
Nurses said that the comprehensiveness of the \textsc{scp}s would help to ensure that all aspects of care were addressed in a timely manner. Some said that the process of creating \textsc{scp}s improved their understanding of the care that would be needed.

Physicians said that the \textsc{scp}s provided useful guidelines for follow-up care, especially in the case of an uncommon cancer or a physician with less experience with cancer. They said that it was useful to have information outlining expectations for patients and physicians in one document.

### 3.1.2 Future Reference
Survivors valued the \textsc{scp}s as a reference for the future. One survivor said, “At this point in time there’s information in there that I don’t need, but who knows what will happen down the road?” Psychosocial issues might arise that could require specialized care or resources beyond what the family physician can offer. Survivors wanted their \textsc{scp}s to be living documents that they could use to record details of their disease, psychosocial concerns, and lifestyle factors, and to monitor their progress over time.

### 3.2 Emotional Reactions
Survivors reported positive emotional reactions to the \textsc{scp}s in three areas:

- Reassurance, comfort, and stress reduction
- Uncertainty reduction, empowerment, and increased sense of control
- Support

No negative emotional reactions were reported.

#### 3.2.1 Reassurance, Comfort, and Stress Reduction
Survivors appreciated having additional time with “experienced” nurses and said that the interactions afforded them important opportunities to clarify their concerns, thus reducing anxiety and stress:

> Having a face-to-face interview with [the nurse] was invaluable as far as notching down the stress level.... To have someone that is so experienced and has seen a million things and had this conversation so many times with so many women just made me feel far more comfortable.

---

**TABLE III** Themes, subthemes, and exemplar quotes

<table>
<thead>
<tr>
<th>Themes and subthemes</th>
<th>Exemplar quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Satisfaction and usefulness</td>
<td>This is certainly useful because you don’t necessarily focus on that kind of stuff unless someone sits down with you and makes you pay attention to it.</td>
</tr>
<tr>
<td>Comprehensiveness</td>
<td>At this point in time there’s information in there that I don’t need. But who knows what will happen down the road?</td>
</tr>
<tr>
<td>Future reference</td>
<td></td>
</tr>
<tr>
<td>2. Emotional reactions</td>
<td>Having a face-to-face interview with [the nurse] was invaluable as far as notching down the stress level.</td>
</tr>
<tr>
<td>Reassurance, comfort, and stress reduction</td>
<td>They can keep moving forward instead of stalling.</td>
</tr>
<tr>
<td>Uncertainty reduction, increased sense of control and empowerment</td>
<td>I think the concept of a care plan or some sort of supportive transfer of care is really vital for these people.</td>
</tr>
<tr>
<td>Support</td>
<td></td>
</tr>
<tr>
<td>3. Communication value</td>
<td>[Everybody could be] on the same page.</td>
</tr>
<tr>
<td>4. Concerns and alternate views</td>
<td>It’s fine for me to hand her the care plan; it’s fine for us to send it to the physician; but I don’t know who her physician is. I don’t know what he or she would be willing to do or not do.</td>
</tr>
<tr>
<td>5. Suggestions for improvement</td>
<td>[By providing a copy in advance] not only would you be able to see it ahead of time and kind of prepare yourself for what was going to be presented, but it also might aid in filling in gaps.</td>
</tr>
</tbody>
</table>
Survivors said that they found it reassuring to have comprehensive information. One said, “It’s been an overwhelming couple of years for me, and so to have this laid out—what needs to be done, when, and the contact names and phone number—I really appreciate that.” Another said that the SCP “reduces the anxiety about [cancer] significantly because you know who to call if you have questions.”

3.2.2 Uncertainty Reduction, Increased Sense of Control, and Empowerment
Survivors, nurses, and physicians all emphasized the value of uncertainty reduction. A nurse explained that it is important for some survivors to know that things “aren’t going to go easily” because of side effects and unforeseen changes, and that they need to know “what will be cause for concern, as opposed to normal, expected events.” Survivors said that their SCPs gave them a sense of control that empowered them to advocate for themselves and to take care of their own health. A nurse said that, when survivors know what is normal and what to expect, “they can keep moving forward instead of stalling.”

3.2.3 Support
Survivors expressed the view that it was valuable to know they were not “disconnected” as they entered survivorship and that assistance would be available if problems arose. That idea was echoed by the nurses and physicians. A nurse said:

I think the concept of a care plan or some sort of supportive transfer of care is really vital for these people, because many people will say that transition from being released from the cancer center and their final treatment to them just being out there on their own is a tremendously difficult transition.

A survivor put it this way:

“That this isn’t the end. That things continue on. And here is a plan, and we care about you, and this is what we put together. This is what we think—and go through it all together.”

3.3 Communication Value
The process of creating SCPs provided an enriched form of interaction between survivors, nurses, and physicians that all parties appreciated. Survivors expressed this appreciation whether the care plans had been delivered one-on-one or in classes. Nurses and physicians said they found the SCPs to be an excellent prompt for discussions, as well as a vehicle for gaining a fuller understanding of survivors in their care. Similarly, survivors said that the SCPs prompted discussions with physicians that neither side might have initiated. A physician for a head-and-neck cancer survivor said:

Certainly his particular cancer is one that I’m not as familiar with, so even for me knowing what are the expected effects and healing times and all that. And especially that I can be reassuring to him.

The SCPs demonstrated to survivors that there was communication between the cancer centre and their family physician and that everybody was “on the same page.”

3.4 Concerns and Alternate Views
Some nurses were concerned that an SCP process that took between 0.5 and 2 hours would be too time-consuming to fit into a nurse’s schedule and would be “a tough sell” from a sustainability perspective—even if it became faster with familiarity. Most survivors were not concerned about the amount of time. One said, “If you want a decent care plan you have to take the time to do it right,” but a few said that it took too long because they were too tired or sick to take in all the information. Some survivors wanted to ensure that their physicians received the SCP with instructions about its purpose.

Some nurses expressed concern about confidentiality in class settings and about discussions that did not apply to everyone. All the physicians mentioned the short amount of time they have with patients and said that it would be difficult to address all the issues covered in the SCPs. Some were uncertain about the role they were to play in the process of delivering, maintaining, or using the SCP. One nurse said that not having an opportunity to discuss the SCP directly with the family physician was problematic:

It’s fine for me to hand her the care plan. It’s fine for us to send it to the physician. But I don’t know who her physician is. I don’t know what he or she would be willing to do or not do.

There was disagreement about the best time to deliver the SCP for head-and-neck cancer survivors. Some survivors said that during the last treatment session or immediately after treatment would be best. Others said a few weeks after treatment would be better because they would be less troubled by side effects and more able to focus on other issues.

3.5 Suggestions for Improvement
All the nurses suggested auto-populating the SCPs from electronic medical records to save time (which was not technologically feasible at the time of the study), and some suggested that clerical staff complete the form and nurses check it for accuracy before...
delivering it. Nurses and survivors suggested providing survivors with a copy of the SCP ahead of time to speed the process and help survivors to be prepared. A survivor said, “not only would you be able to see it ahead of time and kind of prepare yourself for what was going to be presented, but it also might aid in filling in gaps.”

Physicians asked for a summary that they could “flip to,” rather than having to read the whole document. The head-and-neck nurse suggested having one version to deliver immediately after treatment and a second to deliver at the 6-week follow-up. Survivors, nurses, and family physicians all said that removing information not relevant to the particular survivor would make the document more user-friendly. Nurses and survivors both discussed the need for a balance between personalization and sustainability.

There were suggestions for things to add to the SCPs, such as information about rural resources and about family issues, body image, and breast self-examination. Head-and-neck cancer survivors wanted more practical, day-to-day information, especially about eating. Family physicians requested more information about less common side effects.

4. DISCUSSION

In this demonstration project, we evaluated SCPs delivered to 57 breast and head-and-neck cancer survivors in Alberta, Canada. We conducted a thematic analysis of 24 interviews with survivors, nurses, and physicians involved in the SCP process and of 85 written responses from the three groups. By combining data from survivors, nurses, and physicians, we generated an overall perspective that emphasized the collaborative nature of SCPs. A dominant theme that crossed all three groups of participants was that SCPs can significantly enhance communication between survivors, their nurses, and their family physicians at an important time.

This study, with its quantitative counterpart, was one of the first to deliver SCPs close to the end of active treatment. The positive results contrast with a previous study of SCPs delivered an average of 24 months post-treatment. Further research is needed to clarify the optimum time for delivering an SCP and to assess the feasibility of delivering it within 2 weeks of the end of active treatment, particularly for survivors in rural areas. The important issue of the best time to deliver an SCP, per IOM guidelines, remains to be tested against the reality of delivering them when nurses are available and survivors are emotionally ready.

A surprising result of the study was the emphasis that survivors placed on the usefulness of the process of creating the SCP, in particular the extra time spent with knowledgeable nurses. Although nurses echoed that view, nurses and physicians were both concerned about the time needed to implement an SCP. We believe that the time required could be an important investment in the health and well-being of survivors, but future research is needed to investigate the feasibility of taking the time and the value of that time in relation to the long-term benefits of SCPs.

We see the practical suggestions offered by participants to address the crucial issue of sustainability as an important result of the study. We were pleased to hear survivors say that the SCP creation process worked as well in a class format as it did one-on-one. For the class format to be useful, confidentiality issues would have to be addressed. Nurses indicated that the SCP process might require better communication between nurses and physicians to work well. We focused the present evaluation on practical, emotional, and systemic dimensions of SCPs. The results shed light on the potential value of SCPs in the context of whole-person care and provided useful information for improving the content and delivery of SCPs.

Reduction of stress and anxiety stood out as the dominant positive emotional reaction reported by survivors. A contributing factor was uncertainty reduction, which survivors said increased their sense of control and led to feelings of empowerment to be proactive in their care. Stress reduction is valuable in its own right and as a means of improving not only quality of life and psychological function, but also the immune, endocrine, and physiologic function important to cancer progression. The elements of the SCP process that contributed to stress reduction could be accentuated as SCP development continues, as could factors that led survivors to feel empowered.

Family physicians can play an important shared role in caring for people with cancer during active treatment. That role is even more relevant once a patient transitions to survivorship. Many people have long-standing relationships with their family physicians, who often have considerable background knowledge of their patients’ medical and lifestyle history and thus are in an ideal position to provide care once a cancer patient moves into the survivorship phase. Our study revealed multiple ways in which SCPs could enhance communication between survivors and their care providers, and between cancer facilities and family physicians. The results suggest that well-designed and carefully implemented SCPs can enhance medical interactions, smooth the transition back to primary care, and improve the follow-up care that survivors receive from their family physicians.
5. CONCLUSIONS

The results of our study are limited by the mixture of participants, disease sites, and methods of delivery, and by the small number of physicians who were interviewed. Our simple thematic analysis of the mixed data generated an overall impression of the potential value of SCPS. Studies that are more focused and that include more in-depth analyses are needed to fully understand the usefulness, communication value, emotional impact, and sustainability of SCPS. The present study shed light on how SCPS might ease the transition to survivorship by coalescing information needed for follow-up care, enhancing communication between survivors and medical professionals, and providing important emotional benefits to survivors. The results suggest that SCPS could produce long-term benefits; however, further research is needed to determine the extent to which SCPS might improve follow-up care over the long term.

6. ACKNOWLEDGMENTS

We thank the Canadian Partnership Against Cancer for funding this study (CCR-28). Salary funding for JGD came from Alberta Cancer Research Institute Recruitment and Retention Grants 4739 and 24397, the Alberta Cancer Foundation, and the Enbridge Research Chair. LEC holds the Enbridge Research Chair in Psychosocial Oncology Research, co-funded by the Alberta Cancer Foundation and the Canadian Cancer Society, Alberta–Northwest Territories division. She also holds an Alberta Heritage Foundation for Medical Research Health Scholar Award. Thanks also to other contributors, including Louise Smith, Shelley Cloutier, Loring Gimbel, Teresa Skarlicki, Anne Marie Stacey, Kate Rancourt, Shannon Gil, Debbie Blais, Sylvia Huber, Lue Petruk, Audrey Smith, Linda Tkachuk, Lisa Lamont, and Guy Pelletier.

The results reported here have not been published elsewhere, although portions have been presented at the Canadian Association of Psychosocial Oncology conference; Toronto, Ontario; May 4–6, 2011; the Alberta Cancer Foundation Research Conference; Banff, Alberta; November 8–10, 2010; the Care About Cancer Conference, Edmonton, Alberta; June 16–18, 2011; the Canadian Cancer Research Conference; Toronto, Ontario; November 27–30, 2011; and the American Society of Clinical Oncology/American Society for Radiation Oncology Multidisciplinary Head and Neck Cancer Symposium; Phoenix, Arizona; January 26–28, 2012; and at a number of local continuing education forums.

7. CONFLICT OF INTEREST DISCLOSURES

The authors report that they have no financial conflicts of interest.

8. REFERENCES


16. Lam WW, Shing YT, Bonanno GA, Mancini AD, Fielding R. Distress trajectories at the first year diagnosis of breast


**Correspondence to:** Janine Giese–Davis, Department of Psychosocial Resources, Richmond Road Diagnostic and Treatment Centre, 1820 Richmond Road SW, Calgary, Alberta T2T 5C7

**E-mail:** jgieseda@ucalgary.ca

* Department of Psychosocial and Spiritual Resources, Cross Cancer Institute, Edmonton, AB.
† Department of Oncology, Palliative Care Division, University of Alberta, Edmonton, AB.
‡ Department of Oncology, Division of Psychosocial Oncology, University of Calgary, Calgary, AB.
§ Psychosocial Resources, Tom Baker Cancer Centre, Calgary, AB.
‖ Department of Oncology, Calgary Region Breast Health Program, Tom Baker Cancer Centre, Calgary, AB.
# Department of Radiation Oncology, Head-and-Neck Tumour Group, Tom Baker Cancer Centre, Calgary, AB.
** Comprehensive Breast Care Program, Community Oncology, Alberta Health Services-Cancer Care, Edmonton, AB.
†† Breast Cancer Supportive Care Foundation, Calgary, AB.
‡‡ Cancer survivor and writer.
§§ Division of Medical Oncology, Department of Oncology, University of Alberta, Cross Cancer Institute, Edmonton, AB.