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Survivors of breast cancer: patient perspectives on survivorship care planning

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Abstract

Introduction Survivors of breast cancer (SBC) constitute the largest population of cancer survivors. Needs for survivorship care may vary according to life stage and urban/rural place of residence. This study was conducted to better understand patient preferences for survivorship care plans (SCP).

Methods Patients were identified through cancer agency electronic records and invited to participate by mail. Sessions were stratified by age and rural/urban place of residence. Participants were asked about preferences for content and format of SCP. Focus groups were conducted using a semi-structured format with interviews being taped, transcribed, cross-checked for accuracy, and analyzed independently, using constant comparative methods.

Results Preferred SCP key elements included treatment summary, information on nutrition/exercise, expected side effects, signs and symptoms of recurrence, recommended follow-up schedule, information sent to primary care physician, and updates on changes. SBC emphasized preference for individualized content depending upon physical and psychosocial effects. No difference was observed between preferred SCP content among patients residing in urban/rural areas. Rural participants preferred electronic formats for ongoing information bulletins and communication with health care providers.

Discussion/conclusions SBC from all age groups identify common preferences for key SCP elements with individualized content reflecting the wide variation observed among physical and psychosocial effects of breast cancer. Patterns of key psychological, social, and physical effects observed at different life stages may help SCP customization.

Implications for cancer survivors Results provide direction for designing key content and format of SCP and also provide information about elements of care planning that should be customized to individual patient needs.

Keywords Breast cancer survivors · Survivorship care · Psychosocial and physical functioning · Life stage

Introduction

Almost 260,000 women in the United States and 23,000 women in Canada are diagnosed with either invasive breast cancer or carcinoma in situ annually [1–3]. Advances in screening and improvements in therapies for breast cancer have led to improved survival [4], such that women with a

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history of breast cancer comprise the largest group of cancer survivors [5]. Long-term survivors of breast cancer (SBC), identified as those women diagnosed with breast cancer who have lived beyond 5 years from diagnosis without recurrence, comprise more than 80% of breast cancer patients [6, 7]. The population of survivors of breast cancer is expected to increase further in the coming years due to an aging population in North America.

Due to the growing number of patients surviving cancer, there is increased interest in survivorship care. The Institute of Medicine (IOM) recommends that upon completion of treatment, cancer patients should be provided with a comprehensive care summary and follow-up plan that is clearly explained and reviewed with them upon discharge [8]. The Canadian Partnership Against Cancer (CPAC) has formed a National Survivorship Working Group, whose current focus is on implementation of care maps and models of care to guide survivors and their caregivers [9]. While there is a movement toward providing customized care plans for SBC, there is little information guiding health care providers on how to do so for this heterogeneous population [10].

The entire study had two main objectives: (a) to explore the experiences of survivors of breast cancer (SBC) from different age groups and from rural and urban locations, in the period following completion of active treatment and (b) to explore preferences for content and format of survivorship care in the same group of women. The current paper summarizes the results obtained from objective (b). This information may help health care providers design and customize survivorship care plans (SCP) based on patient demographics.

Methods

The study was conducted at the British Columbia Cancer Agency (BCCA). The BCCA provides all radiotherapy services and manages the budget for all anti-neoplastic drugs in the province of British Columbia (BC). It consists of five regional cancer centers with a single electronic and paper charting system and a centralized transcription and letter dissemination process. Breast cancer patients are often discharged to the care of their primary care physician within a year following completion of radiation or chemotherapy with guidance on appropriate surveillance and recommended type and duration of adjuvant hormone therapy. The center does not currently provide a comprehensive survivorship program.

English-speaking women between the ages of 18 and 80, who had been assessed at the BCCA for non-metastatic invasive breast cancer, were 3–12 months post-completion of last active treatment, and lived in the catchment area for the BCCA–Vancouver Island Centre (BCCA–VIC), were identified using BCCA electronic records. For purposes of this study, active treatment was defined as surgery, adjuvant radiation therapy, or chemotherapy, including Trastuzumab. To be eligible, patients had to be discharged from the cancer clinic. Ethical approval was obtained in order to identify eligible patients.

A total of 120 patients who fit the inclusion criteria were selected to ensure representation of different age groups and SBC residing in both urban and rural (>2 h drive to BCCA–VIC) locations. Six focus group dates were pre-arranged, and letters of invitation were sent. To facilitate participation of rural patients, one session was pre-arranged at a rural location. To improve response rates, a second mail-out was sent to non-responders 2 to 3 weeks later. Once responses were received, only five focus group sessions were conducted as there was minimal interest in one of the preselected dates. Of 66 responses, 28 expressed interest in attending and there were two cancelations, resulting in 26 participants. Four focus group sessions comprising 21 participants were conducted at BCCA–VIC and one session consisting of five women at a rural location. This number of participants was deemed appropriate when similar themes began emerging from the data. It was determined that the distribution of participants across all the age groups was appropriate when similar stories were being heard from women belonging to similar age groups.

Participants were provided a written consent form as well as a verbal explanation about the study before signing ethics approved informed consent. Qualitative interview methods of five focus groups with five to eight participants in each group followed a semi-structured format. The initial guiding question posed to participants for this objective of the study was: “After you finished active treatment, if a care plan or discharge plan was developed to help you with this transition, what information should it include? What would be, or would have been, helpful to you?” Facilitators posed direct questions as needed, in order for women to elaborate what they valued about the various elements of the SCP. This ensured a deeper understanding of women’s needs and concerns, giving them a voice for both content and format aspects of care planning. Directed questions were used to determine the optimal timing to introduce the concept of a SCP, which health professional would best manage various aspects of survivorship care, and which medium (i.e., written/electronic) would be preferred for information on survivorship issues. In addition, questions were posed regarding preferred format of ongoing follow-up care and communication with health care professionals or support staff. The interviews were audio-recorded. A second researcher took field notes to record observations regarding non-verbal communication.

Data collection, transcription, and cross-checking were conducted to ensure accuracy of the data. Data addressing preferred content and format of SCP were identified, coded, and analyzed using constant comparatives methods to identify components of the SCP that SBC experienced as significant. This constant comparative form of data collection and analysis is true to qualitative methodology which helps to identify recurring categories and converging themes. The analyst was blinded to age and rural/urban place of residence. Once recurring patterns were identified, the age and rural/urban status of the participant providing the data was revealed and the detailed results were extracted according to life stage group, ages 45–54, 55–64, and 65 or over, and according to whether the participant resides in a rural or urban locale.

Results

Participants

The 26 participants ranged in age from 45 to 80 years with a mean age of 59.2 and median age of 58.0. Eight women (30.8%) were 45 to 54 years of age, 10 (38.5%) were 55 to 64 years of age, and 8 (30.8%) were 65 to 80 years of age. This age stratification was done in order to provide an even distribution of participants' age groups. It was thought that this categorization provided meaningful insight as it appeared to correspond to perimenopause and post-menopausal groups and to social groups that were still employed and/or raising children (45–54 years), considering retirement (55–64 years), or retired (≥65 years). Twenty-one participants resided in urban areas and five in rural areas.

Survivorship care plan content

While participants clearly expressed a desire for individualized or customized SCP content, several essential core SCP elements emerged from the analysis. Desire to have these core elements included in a SCP was expressed consistently across all age groups and in both urban and rural participants. Preferred core SCP components for all participants are as follows:

1. Diagnostic and treatment summary: Participants indicated that it would be useful to have a summary of breast cancer characteristics (stage, grade, estrogen receptor status, etc.) and treatments received. Some participants wanted a one-page summary as a reference to provide future health care providers, while others preferred detailed information, with copies of all reports. A quotation from the focus group data illustrates:

> I think [the diagnosis and treatment summary] is something very valuable to every woman; something they can turn around and plug in as to the type of cancer, what type of signs, your age and your prognosis, so that you're aware of things. (Age 57)

2. Information on lifestyle/nutrition/exercise: A desire for information about lifestyle choices to minimize risk of cancer recurrence and to promote health was a common finding, shared by all age groups. Participants wanted information about diet, exercise, and supplements and access to resources such as dieticians and physiotherapists with special knowledge/training in breast cancer care.

> Nutrition information is good, especially for those who are estrogen positive, because there are a lot of foods out there that you're not supposed to be eating. To have that information… is good. (Age 45)

> Should I be taking more vitamins? Something in print as to what vitamins and supplements would be helpful. (Age 49)

> Information on physiotherapists who are knowledgeable… and specialize in after breast cancer care. (Age 51)

> I had to find my own… massage therapist. The exercises I was doing weren't capturing all the little muscles. I had no knowledge of things like that (Age 57)

> For me, it would be good to have an update on nutrition… for a positive lifestyle now that I am finished [treatment], and can return to a more active lifestyle. (Age 68)

3. Information about expected side effects and recovery: Many women expressed uncertainty about expected "normal" recovery post-treatment, which caused anxiety. It follows that information about expected recovery was a desired core element of an SCP.

> I think information about what we might expect and what is normal would be good. (Age 66)

> I would like some guidelines on the actual healing of the breast after radiation, because I found that I had these little twinges in it. (Age 70)

> Information on how long [cognitive changes] lasts would be good. (Age 48)
>
> I wish that somebody had told me how tired I was going to be. (Age 59)

4. Information about signs and symptoms of recurrence: SBC from all age groups felt that information about signs and symptoms of breast cancer recurrence are an essential component of a SCP:

> I would like a list of symptoms to watch out for… certain things to be on the lookout for. (Age 59)

5. Recommended follow-up schedule: SBC wanted information on appropriate follow-up so they could guide their own follow-up surveillance:

> I would love to see it really set out, like how often you should see your family doctor, what you should be asking, what kind of tests you should be getting, just to have that a little bit more laid out. (Age 49)
> I need written instructions, with the final report, about when I'm supposed to have mammograms and six month exams. (Age 61)

6. Knowledge of available resources on support groups, nutrition, and counseling: SBC wanted information about resources for ongoing support and counseling:

> I don't know whether I'm eligible to phone [Patient and Family Counselling] or not. If there was something in the package, [about] resources to call—the nutritionist, or a social worker… up to two years after… that will give us a place to go to if we are really feeling bad. (Age 55)
>
> Family members can also be impacted and have some of the same psychological kind of symptoms or problems. So if you're having a problem, there might be a suggestion of who you can go to… not just every therapist is going to be able to help you deal with [cancer]. (Age 54)

7. Knowledge of information sent to primary care physician: Participants explicitly stated that they would like to know what information was communicated to their primary care physician. There seemed to be concern that the family physician did not receive sufficient information to manage their ongoing care appropriately. Patients seemed to want this information so they could advocate for their own health.

> I would like to know what my GP is given and what might he not be given. (Age 51)
>
> My GP is capable and we get along well. I feel I can talk with him, but how soon do I need to see him and how much information is he going to have about my case? (Age 67)
>
> What kinds of things do I need to make sure that I take some responsibility for, if [my GP] doesn't pick up on it? (Age 62)

8. Updates on research findings, especially those that result in changes to recommended care: Several patients expressed a desire for ongoing updates about breast cancer research in the months and years following completion of their treatment.

> I want to know if there is anything new or any change in the current protocols, anything that changes is important for me. (Age 49)
>
> Anything that gives me more hope about things that are happening, that there are new discoveries. (Age 47)

Despite consistency in preferred core elements of an ideal breast cancer SCP, participants emphasized the importance of customized care plans. Beyond the core elements above, preferred SCP content echoed the wide variation in impacts of breast cancer observed in the first objective of this study (not yet published). While the core elements above appeared to be important elements to participants from all age groups, the individualized portion of SCP content appeared to shift with patient age group, but not with rural/urban place of residence. For example, we observed that younger women (aged 45–54 years) experienced intense emotional impacts and concern for spouse and children, participants from the mid-age group (55–64 years) experienced concerns about retirement and finances, and older SBC described more of an "interruption" of their usual activities.

> Cancer is not a one size fits all disease and it is not possible to treat it as a one size fits all. Everyone is different. The journey is different. (Age 48)
>
> An individualized post treatment plan is ideal…. (Age 67)
>
> They would have to set up for estrogen positive people and for the different types of cancer, and [customize] for that specific type [of cancer]. (Age 61)

Survivorship care plan format

Most elements of preferred format for an SCP were consistent. There did not appear to be differences between age groups or those living in rural or urban places, with the exception of electronic communication, which was suggested only by rural participants.

1. When to provide information about survivorship:

   Participants consistently stated that the optimal time to introduce the concept of survivorship care was near the end of the last component of their intensive treatment (surgery/chemotherapy/radiation). They asserted that prior to and/or during treatment, their focus was on learning about breast cancer and managing side effects of treatment and that survivorship information at that time would be overwhelming.

> I think that mentally you are open to a lot more information at (the end of treatment) than you are when you're first diagnosed because everything is so new and so overwhelming… I digest [information] a lot easier than I did the (first) day. (Age 54)
>
> It would be nice… when you are done with the treatments. (Age 47)
>
> Immediately after your last appointment. (Age 57)
>
> For me it would have been the last visit with the oncologist because at that time I could think more clearly and formulate any other questions that I might have in that regard. (Age 55)

2. Who to provide information about survivorship

   Many participants thought an oncology nurse with experience working with breast cancer patients would be most appropriate:

> I think it should be the nurse. (Age 57)
>
> I don't think it has to be the oncologist. Certainly there are a lot of nurses in the treatment centres who are excellent communicators. (Age 70)
>
> I don't think it necessarily has to be the oncologist. … somebody who is trained in [breast cancer survivorship issues] that can talk to you on an individual basis. (Age 47)

Fewer numbers of participants suggested their general practitioner (GP), a general practitioner of oncology (GPO), or the oncologist would be the most appropriate person to provide survivorship information.

> I think the GP; the oncologist is too busy… but the GP could be taking care of that kind of stuff. (Age 49)
>
> A GP with oncology [focus]; the GPOs that we have here. (Age 74)

3. How to provide information about survivorship

   Participants indicated that a summary consultation reviewed in person with a health professional would be best. For adjunct information, they preferred written point-form material, in lay language. This would include the content summarized above (personalized summary, expected toxicities, signs/symptoms to watch for, and knowledge of information forwarded to their GP).

> It's very helpful to have things written down. (Age 47)
>
> I would like it written in laymen's terms. (Age 67)
>
> I want something short… maybe in point form. (Age 68)
>
> I think I would want my GP to have it… so that when I went back for a check-up he had some reference; you had this and this. (Age 45)

Following the initial "survivorship consultation", ongoing contact with an oncology resource person was desired. The preferred medium for this connection was telephone for most, but some suggested email would be better for them. Although the number of rural participants was small, relatively more participants from the rural group preferred email communication.

> Even a phone call for ten minutes would probably answer the questions I have. (Ages 49 and 62) (The 62 year old participant did not use these exact words, but expressed her agreement with the above comment during the session.)
>
> I would love it if there was a system where I could just email somebody and then whoever could answer it. (Age 62) (Rural)
>
> A year post treatment we should get an email—an email would be really good because that would give you a chance to think about it and respond…you could sit down and think about it and then if you did have any issues, you could email back (Age 62) (Rural)

For ongoing communication, in addition to the telephone connection with a resource person, information updates were desired in either in "bulletin" format, either mailed or sent electronically.

4. Organized transition from specialist to primary care

   Emphasis was placed on the importance of continuity of care and consistent communication between health care providers during the time of transition from active treatment to surveillance.

> I want to keep my family doctor as part of the team, so there's a sense of continuity of care. (Age 68)

> If he [family doctor] has been a part of the team all along then the transition should be seamless and we would not feel like we have been abandoned. (Age 55)

> For example when the cancer centre is discharging you and your next treatment is within the next three months, this information should be sent to your private physician. (Age 57)

Discussion/background

The IOM recognizes cancer survivorship as a distinct phase of cancer care and recommends implementation of a comprehensive survivorship care plan. [8] In Canada, CPAC has identified cancer survivorship as a high priority in order to ensure patients and their families are better served through a coordinated approach to improve quality of life [1, 9]. The patient view is critical when developing and implementing survivorship care models [11, 12]. SCP are viewed positively by patients [10, 13–15], but some find the information provided in SCP to be too technical with inadequate information on side effects and self-care approaches [14, 15]. Patients express satisfaction with the receipt of an SCP, but report that communication and information transfer is a major weakness and suggest that clear communication between health professionals would benefit the patient's health and well-being [16, 17]. Patients and their care providers agree that SCP would be useful [8–10, 13], and there is increased interest in providing effective survivorship care planning [7–9]. The present study provides further insight about patient preferences for content and format of SCP.

Implementing a coordinated approach to survivorship care can be challenging due to diverse practice settings, need for multiple health care providers, and complexity of cancer care. In British Columbia, it is common to discharge patients to be followed exclusively by their primary care physician soon after treatment is completed [18]. It is recognized, however, that other models of practice such as oncologist follow-up or shared care are used elsewhere [11, 12]. When considering which survivorship care model to develop, it is important to focus on the essential components of care that should be addressed regardless of whether the patient is being followed by the primary care physician or the treating oncologist [12]. Patients in the present study emphasized the importance of communication, even requesting a desire to know which information was provided to other health care providers, to facilitate coordinated care. This finding supports the idea that a central goal of the SCP is to optimize continuity and coordination of care [19–21].

With centralized cancer care, letter transcription, and dissemination process, the BCCA is in a unique position to provide a core SCP document to address the need for a coordinated approach. Using the information from this study, a core SCP document should include the content considered essential by patients, namely a diagnosis and treatment summary, information on lifestyle, nutrition, exercise, expected side effects, usual recovery, signs and symptoms of recurrence, a recommended follow-up schedule, knowledge of available support resources, and knowledge of information sent to primary care physician. It is encouraging that the essential SCP content identified by patients in our study, from varying age groups and rural/urban places of residence, largely concur with the IOM recommendations [8, 11, 14–16, 22–24]. This consistency suggests that these elements are a useful starting point in developing SCP content [2, 8–10, 13, 25].

While a written document addressing core content could be implemented, the task of providing effective survivorship care is still challenging due to heterogeneous patient populations, complexity of cancer care, and the wide range of physical and psychosocial impacts that survivors encounter [1, 8, 25–29]. Cancer specialists recognize that each patient is unique in clinical presentation, prognosis, treatment tolerance, supportive care needs, and outcomes, especially in light of distinct biology, ethnicity, and other illnesses [23]. Data from the current study confirms the finding by others researchers that survivorship care needs to be tailored and patient-centered to the individual's clinical situation and their preferences [19, 20]. Content should be personalized to reflect the issues faced by an individual survivor [8–10, 14, 20]. While individualization is desired, limited health care resources and large population of SBC necessitate efficient means of assessing individual needs and preferences. In this study, we looked at the physical and psychosocial impacts of breast cancer and preferences for content and format of SCP according to age group and rural/urban place of residence. These factors did not appear to affect the preference for core elements of content, which were consistent among all groups, but patterns in the impacts of breast cancer experienced by SBC from different age groups were observed. This information could be utilized to guide health care providers as an initial step in customizing SCP. We recognize that age grouping is a very basic way to stratify SBC and that patients are much more complex than simply their age; we are not suggesting that this simple means is adequate to individualize SCP. Place of residence did not appear to affect the impacts of breast cancer experienced by SBC and thus did not influence preferred content.

With respect to preferred format, a desire for a one-on-one consultation, with written information package containing core elements with customized details were consistant in all groups. The preferred media used for ongoing communication with health care professionals was usually telephone; however, some rural patients preferred email communication. These findings suggest a need for flexibility in the format of SCP. Efficacy of multimedia approaches is supported by studies which show patients feel supported through the use of audio conferences and internet-based cancer support groups that provide informational, emotional, and psychosocial support [25]. Customization of SCP format to address needs for patients living in remote areas [25] and to provide service to patients with language barriers or disabilities pose additional challenges, but again illustrate the importance of flexibility as a key component of any effective SCP program [1–3, 25].

One limitation of this study is that the sample size of 26 women was smaller than expected and may not be representative of the entire population of SBC. That said, there was even representation of the age groups analyzed and the data obtained were abundant. The sample did not include women over 80 years or under 45 years, so results from this study may not be generalizeable to women in these age groups, particularly because of the age-specific findings of the study. Participants were purposely chosen who had been discharged from active follow-up at the cancer clinic to help identify needs of patients in the community. As a consequence of this methodology, our data may not accurately depict preferences of patients receiving shared follow-up or oncologist follow-up. Since only qualitative data were obtained, we cannot make definite conclusions about similarities or differences between the age groups. This is seen as a minor limitation, as survivorship care will need to be customized at an individual level, and the purpose of this research is not to create a "one size fits all" approach to survivorship care but merely to serve as a guide to health care providers about key survivorship issues for women at different life stages. It is not possible to identify the relative importance of various components of SCP to patients based on the methodology used in this study. This is a consideration for further research.

Implications for cancer survivors

Our findings reinforce the need for comprehensive care plans for survivors of breast cancer and provide information about patients' preferred content and format of survivorship care. The importance of organized transition from specialist to primary care is highlighted. Essential core elements of a survivorship care plan for patients include a treatment summary, lifestyle/nutrition/exercise information, expected side effects, signs/symptoms of recurrence, follow-up schedule, knowledge of what information is sent to primary care physician, and updates on changes to recommended care. Further content should be customized to address individual needs. Common physical and psychosocial effects of breast cancer observed in survivors from specific age groups may assist health care providers in customizing care plans. Preferred format for SCP is an in-person consultation at completion of treatment with an oncology professional such as a nurse. Preferred media for other SCP components include written materials for patient reference, telephone, or email follow-up with a resource person and electronic or written bulletins for communicating updates.

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