

Perspectives of Survivorship Care Plans Among Older Breast Cancer Survivors: A Pilot Study

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Abstract

The Commission on Cancer's standard 3.3 represents a paradigm shift in the care of cancer survivors, recommending that survivors receive a treatment summary and survivorship care plan (SCPs). A focus on older breast cancer survivors is needed, as they are the majority of the breast cancer population and their experiences and perspectives of SCPs is limited in the literature. This pilot study utilized a mixed methods approach (focus groups and self-report questionnaire data) to gather information on older (≥ 65 years) breast cancer survivors' perspectives of their SCPs, cancer survivorship, and communication with their health-care providers. The questionnaire was completed individually by the participants prior to the focus group and contained items on basic demographics and their health status following cancer treatment. The focus groups indicated that only a minority of women actually developed a SCP. Those who developed a SCP in collaboration with their providers valued the personal care and attention received. However, some participants reported poor communication with their providers and within their health-care team, resulting in frustration and confusion. Participants' suggestions for ideal SCPs included better education and personalization, particularly in appropriate nutrition and exercise, and managing side effects and comorbidities. Lastly, the women believed that additional long-term care resources, such as health coaches, were important in improving their survivorship. These findings provide insight into enhancing the content, communication, and application of SCPs to improve the survivorship experience of older breast cancer survivors.

Keywords

breast cancer, geriatric oncology, survivorship, survivorship care plans, focus groups

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Introduction

Advancements in prevention, screening, and treatment, coupled with the aging of the population, have resulted in women aged 65 years and older accounting for more than half of the 3.1 million US breast cancer survivors.¹ Older breast cancer survivors are a unique population, because they often have age-related declines in functioning and reserve, increasing incidence and severity of comorbid illness, and diminished social and economic resources.^{2,3} Addressing survivorship among this population requires a comprehensive approach considering recommended follow-up care, managing

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multimorbidities and medications, and coordinating care from multiple physicians.^{2,4} Breast cancer survivorship can also be further complicated if older patients are confused about survivorship care recommendations, have to prioritize/juggle one chronic disease over another, as well as symptoms.

The Commission on Cancer's (CoC) standard 3.3 recommends that survivors receive a treatment summary and survivorship care plan (SCPs).⁵ Survivorship care plan breast cancer recommendations came shortly after the American Cancer Society and American Society of Clinical Oncology's (ASCO's) 2015 breast cancer survivorship care guidelines.⁶ These guidelines encourage the following: regular surveillance for breast cancer recurrence, screening for second primary cancers, assessment and management of physical and psychosocial long-term and late effects of breast cancer and treatment, health promotion (eg, nutrition, diet, exercise), and care coordination.⁶ Although SCPs and guidelines are comprehensive, the CoC recommendation for SCPs is lacking due to limited evidence that SCPs impact survivorship outcomes. For example, Faul and colleagues² found that only 35% of women in their sample received SCPs and the receipt decreased 5% for each 1-year increase in age. They also found that physical and emotional functioning among women with SCPs was not different from those women without SCPs. Thus, more research into how SCPs can be improved upon for breast cancer survivors is needed.

In this study, we examine whether SCPs can be improved for breast cancer survivors by including the perspectives of older (≥ 65 years), community-dwelling breast cancer survivors regarding their SCPs. A focus on older breast cancer survivors is needed, as they are the majority of the breast cancer survivor population^{7,8} and their experiences with SCPs are limited in the literature. A review of qualitative studies by Keesing et al found no studies specifically examined older breast cancer survivors' experience of using SCPs.⁹ Furthermore, a 2018 systematic review¹⁰ found that only 2 studies^{11,12} of SCPs have focused exclusively on the outcomes of older adults, however, these studies did not conducted among breast cancer survivors. Coinciding with the Cancer and Aging Research group's suggestion, there is also a need for the incorporation of geriatric principles (eg, managing comorbidity, maintaining functional independence) into these SCPs.³

Current evidence on the utility and robustness of SCPs, barriers to following SCPs, and patient perspectives of cancer survivorship and care coordination among older breast cancer survivors is lacking.^{2,3} Given the CoC's recommendation for SCPs, it is critical to understand the patient perspectives of those plans while accounting for their unique needs in order to develop future interventions to improve SCP design and delivery.^{3,13,14} The growing older breast cancer survivor population, recent updates to policy standards and guidelines, and limited research focusing on the perspectives of SCPs among older breast cancer survivors warrants this timely study. Thus, this pilot study sought to gather information on older breast cancer survivors' perspectives of SCP utility and adherence,

communication about SCPs, as well as areas of improvement for these plans.

Materials and Methods

Participants and Recruitment

Two focus groups were conducted. Eligibility criteria were community dwelling women, at least 1 year out from adjuvant therapy, aged 65 years or older, who had a survivorship clinic visit and received a SCP. All breast cancer subtypes and stages, as well as women receiving adjuvant hormone therapy were eligible to participate.

The SCPs distributed during the survivorship clinic visit utilized the ASCO's SCP template which includes a treatment summary, follow-ups, surveillance, late/long-term effects, and healthy behaviors.¹⁵ At the survivorship clinic visit, SCPs were provided in person and reviewed with nurse practitioners at the multidisciplinary survivorship clinic.

Women who met the eligibility criteria were recruited through 2 primary methods. The first method was during follow-up visits to The Stephanie Spielman Geriatric Oncology Clinic. When prospective patients were identified, a physician study member provided the participant with a recruitment flyer, which had the focus group coordinator's name and contact information. The second method involved the identification of prospective participants through medical records obtained from the cancer center's registry. When patients were identified as meeting the eligibility criteria, the study coordinator was provided with the prospective participant's name and mailing address. A recruitment letter explaining the focus groups and survey was sent to the prospective participants asking them to contact the study coordinator if they were interested. Women who contacted the study coordinator were screened to verify they met eligibility criteria. The study goals and responsibilities were explained, and then the participants were asked whether they were willing to participate. Eligible and interested participants were provided a date and time to attend a focus group session. Written, informed consent, as well as a HIPAA waiver to collect basic demographic and clinical characteristics from their medical records, were obtained from all participants.

Focus Groups

Two separate focus groups took place at the participating clinic in February and May of 2018, respectively. Once the focus groups began, the conversation followed a discussion guide (Appendix A), which covered participants' experiences, thoughts, and feelings regarding SCPs; the usefulness of these plans; opinions about how to improve these plans; and barriers to following the SCP recommendations. A definition of SCPs as well as a copy of the SCP distributed by the medical center were provided to participants. All focus groups were audio recorded and lasted approximately 90 minutes. All participants received a US\$25 gift card for their time. The Institutional

Table 1. Participant Demographics.^a

| Variables | % or Mean (SD) |
|-------------------------------|----------------|
| Age in years | 62.8 (10.7) |
| Race | |
| Non-Hispanic white | 13 (86.7) |
| Non-Hispanic black | 2 (13.3) |
| Time since diagnosis (months) | 40.2 (38.6) |
| AJCC stage at diagnosis | |
| 1A | 6 (40.0) |
| 1B | 1 (6.7) |
| 2A | 4 (26.6) |
| 2B | 2 (13.3) |
| 3C | 1 (6.7) |
| 4 | 1 (6.7) |

Abbreviations: AJCC, American Joint Committee on Cancer; SD, standard deviation.

^aN = 15.

Review Boards of the participating clinic and University approved the informed consent procedures and study protocols.

Analysis

Audio recordings of the focus groups were transcribed verbatim by the focus group facilitator who led both groups. Transcripts were reviewed for accuracy. Two research staff members trained in qualitative analysis read the focus group transcripts and generated a list of themes that categorized the experiences shared by participants. All transcripts were coded using NVivo qualitative software and coded independently. Both staff members then reviewed codes, and discrepancies were resolved through consensus. Names of participants and other identifiers were removed. Descriptive statistics and frequency distributions were used to characterize research participants' demographic and clinical characteristics. Quantitative analyses were conducted using IBM SPSS Statistics version 23.

Results

Sample Demographics

Out of the 93 potentially eligible participants identified in the registry and in the clinic, 15 (16.1%) took part in the 2 focus groups (n = 8 in the first; n = 7 in the second group). The average age of the participants was 63 years with a range of 53 to 82 years, with the majority being white, non-Hispanic. The average time since their breast cancer diagnosis was 40.2 months (range = 13-58 months) and the majority were diagnosed at stage 1A (40%; Table 1).

Focus Group Results

Three major themes emerged from the focus groups. The first was identification and development of the SCPs; the second was communication of survivorship issues and health maintenance; and lastly, suggestions to improve SCPs.

1. Identification and development of SCPs. According to their medical records, all study participants received a SCP, but only 4 (26.7%) clearly recalled receiving the SCP and discussing it with their health-care team. Four participants were able to describe, in detail, the process of creating a SCP in partnership with their providers, specifically the identification of the plan components, the establishment of goals, and the development of a timeline. These participants mentioned that the process was "really thorough" and "very intensive about all kinds of subjects" and that they "created some goals" with nurses, but not oncologists.

The focus group participants could not recall the administration of SCPs very clearly. For example, one participant asked, "I never had a survivorship meeting or plan. I didn't even know there was such a thing." Another said, "Can I have an explanation of what the survivor care-ship plan is? Is it like for exercise and how to eat or is it just coming back to your doctors? What is it even?" Lastly, one participant stated, "I did not realize I had one [a SCP] . . . and then I was going through my papers, and I did find one . . . so obviously it didn't make a whole lot of impression on me at the time."

2. Communication of survivorship issues and health maintenance.

All participants shared their experiences following treatment, their communication with providers, and factors that impacted their ability to maintain their physical and mental health following treatment. Patients perceived poor communication with and among providers resulting in confusion and frustration. For example, one participant stated, "Doctors are just so businesslike," and another said, "I felt like the time wasn't taken for patient care, the patient concern . . ." Another participant stated, ". . . I had an after care thing with my surgeon and I had after care with my oncologist, but it just seemed like they never connected on one page." The participants perceived that there was poor communication and coordination between their oncologists and primary care physicians. Participants explained, "They kind of leave out your general practitioner" and, "they're not really incorporating into the SCP your primary care physician." Another said, "Who is 'Team [participant's name]' and who is going to discuss that and communicate that from every angle? Because I feel like that's where there's a disconnect . . . it's like they're all on their team."

These perceptions of poor communication and coordination often placed an undue burden on patients and resulted in survivors feeling confused and neglected. Patients felt providers were not interacting on a personal level because much of the information regarding after care was conveyed in the form of written materials. Despite receiving this written information, the women were overwhelmed by the amount of information delivered during and after treatment and felt they were unable to process it properly. As one participant said, "You get so much information. I mean you are inundated . . . I mean when you talk about a binder that thick with everything . . . and my daughter came with me and she was overwhelmed." Similarly, a participant shared, "And even if they give you a paper,

someone needs to go over it and say, ‘This and this and this is what this is for,’ because so much is going on, you’re not going to remember that anyways!’”

Amid this perceived confusion, survivors were also experiencing symptoms and side effects of treatment that hampered survivors’ ability to focus on instructions and follow through on after care including SCPs. One participant shared, “You’ve had chemo and you can’t think of anything, so they are telling you things and you just can’t even deal with it.” Another participant mentioned the emotional strain impairing her ability to process the vast amount of information, saying, “I happen to be forgetful, I don’t think because of the chemo, but because of the emotional aspect, you know.” Among the women who did receive a SCP, they expressed their appreciation for the detailed outline of their SCP. For example, one participant said, “I did like that fact that it was a summary of everything. It was kind of like a one stop shop if I needed the information down the line.”

Despite the perceived communication and coordination difficulties with their health-care team, personal relationships with other survivors who fully understand the journey that survivors face helped participants to understand and navigate treatment and after care. For example, one participant said, “It helps when they have someone who’s been through it also . . . Because you cannot explain that to anyone in words.” Support groups and classes were another opportunity for patients to interact with survivors and to talk honestly and openly. A participant shared, “. . . we had support groups [and] more like talked about what we was experiencing . . . it’s just different mental things, different stages, and different survivor groups that I had an opportunity to reach out to. I guess from going to so many of them, which was very helpful at the time that I was attending them . . .”

3. Suggestions to improve SCPs and survivorship care. Communication of the responsibility for survivorship care was noted in the focus groups. One participant said, “. . . I had read about the survivorship plan, and I had to ask for it. I did not actually remember anybody offering it to me.” Another stated, “. . . it [communication] was all piecemeal and all things that I put together myself rather than having somebody else tell me, ‘Here’s the plan, Do it.’”

Participants suggested education and personalization regarding the SCPs as a way to improve survivorship care. Women wanted details regarding proper nutrition, particularly foods that would mitigate symptoms and side effects of treatment, suggestions for appropriate physical activity, and information on potential symptoms and side effects. First, participants stressed that diet and nutrition should be a core component of any SCP. One participant mentioned, “Specific foods . . . there’s certain vegetables, certain fruits and so I just kind of learned them on my own . . . so to be able to specify things like your diet . . . the only way you can combat those side effects is to exercise and to eat right and get good rest of course.” Because of the frustration surrounding the amount of written material provided, women suggested a dietician be

“part of the package.” Women also expressed frustration with the lack of guidance regarding physical activity. For example, a participant stated, “The only thing the doctor says was, ‘Well move your arm. It’s going to hurt like hell, but move it.’ . . . What kinds of movements? I didn’t know . . .” As a way to improve SCPs, the survivors stressed the importance of tailoring fitness recommendations to breast cancer survivors, keeping in mind the side effects a survivor may be experiencing during and after treatment. A suggestion was made to include, “someone who works with women with breast cancer” with the SCP recommendation so women “. . . have a much better idea of what sort of exercises, what your limits should be . . .” Another suggestion was “. . . putting some kind of exercise plan together” and knowing “what exercises are the one that would be best suited for our needs.”

Many women mentioned that they struggled with long-term aftercare and available resources. One participant stated, “You go to your appointment, and that’s kind of like they put a little bow on it, and they’re like, ‘Ta da! You’re done. You come every three months,’ and so forth, and you get lost because you’re like, ‘Oh my gosh, I’m by myself.’” Another said, “As I got farther out, it felt like people kind of wanted me to go away because there were lots of services for people that were newly diagnosed but not lots of things for people that were far out there . . . you’re supposed to go away and not talk to anybody else pretty much.”

In order to address these feelings of inattention, the participants felt that providers, particularly health coaches or other designated professionals should maintain contact with them further out from treatment if possible. For example, one participant said, “We had talked about making goals, setting some goals. Which I did, but I think I need to do goals ‘part two’, because once I had reached those, I felt like I was lost again and had to start over . . .” Health coaches and “a coach who’s in charge” were suggested as a way to maintain long-term goals and relationships. As one woman said, “I think it would be nice to have coaches, you know like . . . they have so many people and they call you or you know, meet with you . . . yeah, and meet you and review it.” Another participant had a similar suggestion: “It’s just that we needed someone with experience to teach us and to sympathize with us about the different emotions and the different things that we was experiencing physically and mentally.”

Discussion

This pilot study sought to identify the utility, communication, and areas of improvement regarding SCPs and survivorship care among a sample of older breast cancer survivors. Results indicated a general lack of awareness of SCPs, negatively perceived coordination and communication issues related to cancer survivorship among older breast cancer survivors, and multiple areas for improvement. The small sample of women who developed a SCP in collaboration with their providers valued the personal care and attention they received. The SCP allowed women to understand their treatment clearly and to

anticipate next steps. Previous studies^{2,16,17} found that among breast cancer survivors who have received SCPs, the response was positive, particularly in cancer worry and understanding of care coordination. For example, Faul and colleagues (2014) found that SCP receipt was associated with greater knowledge and understanding of requisite follow-up care.

Positive assessments of SCP utility have also been observed in previous studies with younger and/or racial minority populations.¹⁸⁻²³ In interviews with younger and middle-aged breast cancer survivors, Collie et al²⁰ found that survivors appreciated the individualized attention and comprehensiveness of the SCPs distributed by nurses. Similarly, Ashing-Giwa et al¹⁸ in reported that African American breast cancer survivors endorsed the utility of SCPs and that they were inspired to pay more attention to their health. It is important to note that previous studies have found age differences in the problems reported in survivorship.^{2,23-26} Older women are likely to have more comorbidities^{4,27} and lower social support^{28,29} while younger women may report more physical and psychosocial concerns including body image, anxiety, cognitive difficulties, and fear of recurrence.^{18,25,29,30} It is important for researchers and clinicians to understand potential differences in survivorship experiences despite the positive assessments of SCP utility across age and racial groups. Additional efforts should be taken to communicate with survivors about their difficulties and tailor SCPs and support to their unique needs.

Generally, survivors reported poor communication with their providers and among providers who were a part of their health-care team. This caused participants to feel that they were ultimately responsible for their own treatment and aftercare outside the cancer center. This perceived responsibility, in addition to the stress of managing their diagnosis, treatment, and symptoms and side effects, led women to feel overwhelmed and unable to effectively manage their health. Similar findings have been observed in previous studies^{31,32} that found that patients reporting confusion and anxiety regarding the continuity of care, and had unmet information needs with respect to SCPs are common. This study's findings may be the result of the minimal involvement in the development and communication about their SCPs in the study sample. Future research needs to determine the effectiveness of SCPs among older breast cancer survivors with greater input and understanding of their SCPs.

Providers, health coaches, and other health-care professionals must take the time to form relationships with patients to develop a SCP that addresses the patient's health holistically and reduces the stress and uncertainty associated with long-term survivorship. As encouraged by this study and previous studies,^{9,33} these health-care providers must take a leadership role in facilitating the creation and management of these plans as well as empowering patients to maximize their health outside of the cancer centers. One way to improve the health of older breast cancer survivors is through the adoption of healthy lifestyle behaviors, mainly diet and exercise.³⁴⁻³⁶ This study corresponds with previous studies^{18,19,22,37} that reported breast cancer survivors' desire for additional information within SCPs

related to self-care strategies and guidance for diet, nutrition, and exercise. A 2019 study by Shay and colleagues³⁸ demonstrated found that SCP receipt was associated with exercise in the past month among cancer survivors, offering preliminary evidence that SCPs are helpful in promoting healthy behaviors.

Findings also indicated the importance of a health coach or another designated health-care professional to continue long-term contact with survivors to assist them in maintaining their health and provide them a metric to review their progress since diagnosis and treatment. Recent studies^{39,40} have begun to examine the role of health coaches among breast cancer survivor populations. A 2016 POSTCARE trial³⁹ tested the effect of a health coach using motivational interviewing to improve SCP-based patient outcomes and care coordination. However, this intervention was a one-time encounter and additional long-term interventions are needed to explore the effect of health coaches on SCP development and subsequent follow-up, surveillance, symptom management, and health behavior as determined by the ASCO model of SCPs. Furthermore, additional research needs to be conducted with older breast survivors, as this understudied population will continue to include the largest portion of the breast cancer survivor population. Strategies such as comprehensive geriatric assessments⁴¹ and input from interdisciplinary teams with aging expertise³ would be paramount to holistically approaching long-term survivorship of older women with breast cancer. Community health-care providers should recognize this need for additional support of older breast cancer survivors posttreatment and consider implementing these strategies in their practices.

Some limitations of this study should be noted. The first limitation is the small sample size of the focus groups. However, this study was a pilot and the number of persons who participated in the focus groups was adequate to produce data saturation. The small sample may be attributed to the eligibility criteria of including only women who received a SCP in their medical records. The limited sample limits some generalizability, but the inclusion of patients at all stages at diagnosis sought to reduce this limitation. Furthermore, previous qualitative studies on SCPs and survivorship have had similar sample sizes ranging from 7 to 51.^{9,42,43}

Our eligibility criteria sought to recruit older women, yet due to misinterpretation of eligibility criteria, some middle-aged women were enrolled in the study, which lowered the mean age of the study sample. Thus, the focus groups did not highlight the challenges of the health complexities of aging and geriatric issues during cancer survivorship. Lastly, the sample was homogenous, primarily non-Hispanic White English-speaking breast cancer survivors, which limits generalizability of study results to other cancer survivor populations.¹⁹

Conclusion

This pilot study examined older breast cancer survivor's perspectives of survivorship and SCP utility, communication with the health-care team during survivorship, and strategies for improving SCPs and quality of life. Results indicated that,

despite all receiving SCPs, very few participants reported receiving SCPs, and many were unaware of these plans. In addition, survivors felt overwhelmed at the amount of information provided, and the lack of personal communication with their health-care providers. Areas of improvement suggested by the focus group participants included clearer communication with the health-care team regarding survivorship care, more long-term survivorship resources, and the use of health coaches to facilitate participants' adherence to SCPs. More research is needed with larger and more diverse survivors to aid providers and women in the implementation of and adherence to SCPs to maximize health outcomes during survivorship.

Appendix A

Focus Group Guide

1. Did you develop a follow-up plan after successfully completing breast cancer treatment (breast cancer survivorship plan) with your oncologist or doctor? What did it entail?
2. Was it clear? Why or why not?
3. Was it communicated to your primary care physician? Has your primary care physician discussed your follow-up plan with you? Why or why not?
4. How can your care plan be more useful for you?
5. Looking back to when you first developed your plan, what would you include now in your care plan?
6. Do you follow your survivorship care plan and/or follow-up recommendations (ie, screening surveillance and adjuvant hormone therapy)? Why or why not? Can you share with me what are some barriers to following this plan?
7. How do you handle following your survivorship care plans and/or follow-up recommendations while managing other chronic diseases? What could be done to improve this? How has your primary care physician addressed this?
8. Being a breast cancer survivor, do you have any advice for how to improve your cancer survivorship experience?

Authors' Note

Out study was approved by the Ohio State University Research Ethics Committee (approval no. 2017C0124). All patients provided written informed consent prior to enrollment in the study.

Declaration of Conflicting Interests

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