

# The Potential of Survivorship Care Plans in Primary Care Follow-up of Minority Breast Cancer Patients

Mary Ann Burg, PhD<sup>1</sup>, Ellen D. S. Lopez, PhD<sup>2</sup>, Amy Dailey, PhD<sup>3</sup>, Mary Elspeth Keller, MA<sup>1</sup>, and Brendan Prendergast, MD<sup>4</sup>

<sup>1</sup>Department of Community Health & Family Medicine, University of Florida, Gainesville, FL, USA; <sup>2</sup>Department of Behavioral Science and Community Health, University of Florida, Gainesville, FL, USA; <sup>3</sup>Department of Epidemiology and Biostatistics, University of Florida, Gainesville, FL, USA; <sup>4</sup>Colorado Health Foundation, Denver, CO, USA.

**BACKGROUND:** When the clinical care of minority breast cancer survivors is transferred from oncology settings to primary care, quality of care may be compromised if their primary care providers do not have adequate cancer treatment records and follow-up care guidelines. Survivorship care plans (SCPs) given to survivors before they transition to primary care settings are designed to improve the transfer of this information. This study examined these issues in a sample of minority breast cancer survivors.

**DESIGN:** During four focus groups with minority breast cancer survivors, data were collected about the types of information survivors remember receiving from their oncologists about follow-up health care needs. Survivors were also asked their opinions on the value and content of a survivorship care plan.

**RESULTS:** Minority breast cancer survivors received variable amounts of information about their cancer treatments. They were dissatisfied with the amount of information they received on cancer-related side-effects, including race-specific information. The American Society of Clinical Oncology's breast cancer survivorship care plan was viewed as important, but too highly technical and limited in information on side-effects and self-care approaches.

**CONCLUSIONS:** Survivorship care plans may help increase information transfer from oncologists to patients and primary care providers, but the content of care plans needs to be adapted to minority patients' concerns. Primary care physicians may be challenged by survivors to explain recommended surveillance guidelines and to respond to untreated physical and psychosocial problems.

**KEY WORDS:** breast cancer; primary care; minority; survivorship.  
J Gen Intern Med 24(Suppl 2):467-71  
DOI: 10.1007/s11606-009-1012-y  
© Society of General Internal Medicine 2009

## BACKGROUND

The percent of breast cancer survivors with outpatient visits to primary care physicians is increasing due to the numbers of patients surviving longer and consequently being discharged from routine oncology follow-up.<sup>1-3</sup> The process of discharge to follow-up care may be especially important for the health of minority and particularly African American breast cancer survivors who are at risk for higher overall mortality than Caucasian women.<sup>4,5</sup> Managing the complex clinical needs of high-risk breast cancer survivors is complicated if there is limited communication with or records from the treating oncologist. In these cases the primary care physician may have to rely on the patient's recall of their cancer and treatment as their only guide for determining appropriate cancer-related health care.

Survivorship care plans (SCPs) have been proposed as a tool to improve the transfer of clinical information from oncology to primary care settings.<sup>6,7</sup> SCPs are portable records (printed or electronic) of tumor characteristics, treatments received, surveillance and follow-up guidelines meant to be completed by the treating oncologist and given to cancer patients and their primary care physicians at the commencement of active cancer treatment.

The purpose of this study was to explore minority breast cancer survivors' recall of information from their oncologists about their cancer and follow-up care and their views on the potential use of SCPs. We hoped to discover any minority-specific considerations that might bear on the design of SCPs for breast cancer survivors. The study was also intended to explore the types of cancer-related questions minority survivors might bring to the primary care encounter.

## DESIGN

We conducted four focus groups with minority breast cancer survivors living in a Southeastern urban area. Focus groups provided an opportunity for minority breast cancer survivors to explore similarities and differences in their communications with their oncologists about follow-up care and to gather critical feedback on the design and content of SCPs.<sup>8,9</sup>

All protocol & materials were approved by the university human subjects' committee and oral consent was gained prior to subject recruitment. Purposive sampling ensured recruitment of eligible participants, including female breast cancer survivors between the ages of 18 and 65 whose

**Part 1: ASCO Breast Cancer Adjuvant Treatment Summary**

- Tumor and treatment information
- Breast cancer site
- Family history
- Breast surgery date/type
- Axillary dissection
- Tumor type/stage/ER status
- Adjuvant treatment
  - Chemotherapy types/regimens
  - Serious treatment related toxicities
  - Radiation and reconstruction plans/dates
- Endocrine therapy
  - Type/regimen
- Survivorship Care Provider Contacts list

**Part 2: Breast Cancer Survivorship Care Plan**

- Follow-up care tests and recommended regimens
  - Provider to contact for each follow-up care test
- Breast cancer follow-up and management schedule
  - History and physical frequencies for years 1-3 and 4-5
  - Mammography frequency
  - Statement of risk of breast cancer recurrence
  - List of symptoms of recurrence
  - List of tests not recommended

**Text Box. Components of the ASCO Breast Cancer Treatment Summary and Breast Cancer Survivorship Care Plan.**

active treatment for breast cancer was completed. Focus groups participants were recruited from members of the “Sisters Network” (a national African American organization with regional breast cancer support groups) and urban public health department outpatient clinics serving a high proportion of minority patients. Recruitment flyers were distributed at Sister’s Network meetings and at the outpatient clinics. During a screening call interested survivors were provided information about the protocol and purposes of the study (e.g., focus groups would last approximately one hour, be audiotaped for research purposes, and be confidential). All participants received a \$50 gift card to compensate time and travel expenses.

Four focus groups were conducted with 6–12 breast cancer survivors in each group (n=32 participants). Three focus groups comprised only African American women; the fourth group included six African American women, one Hispanic woman and two Caucasian women. Each focus group was moderated by the project director (who is a trained facilitator)

and used a standard set of procedures and discussion questions. After introductions, each woman was given three blank index cards. On two of the cards, the women were asked to write the first things that came to mind when asked the following two open-ended questions: (1) What did your oncologist tell you about what to expect in terms of your health and the types of health care you should get after treatment was complete? (2) What do you *wish* your oncologist told you about what to expect in terms of your health and types of health care you should get after treatment ended? Facilitated discussion followed.

Next participants examined the breast cancer SCP from the Association of Clinical Oncology (ASCO), and recorded their reactions to the template. Discussion included whether they would want an SCP for themselves, what they liked and disliked about the structure and content of the ASCO SCP, and what other types of information they would like included. The ASCO SCP template was used for the study because it was specifically designed for breast cancer patients, and because it was designed by a prominent group of oncology researchers and was endorsed by a leading clinical oncology organization in the U.S.<sup>10,11</sup> Part one of the ASCO SCP, the “Breast Cancer Adjuvant Treatment Summary,” is a two-page form designed for oncologists to complete (Text Box). It includes a record of the patient’s tumor type and stage, chemotherapy(ies) delivered, and treatment completion dates. Part two is the one-page “Breast Cancer Survivorship Care Plan,” meant to provide patients and their primary care providers with recommendations for follow-up care (e.g., medical history and physical examination, post-treatment mammography, breast self-examination, pelvic examination, coordination of care and genetic counseling referral), follow-up frequency and a list of “symptoms of recurrence” patients should report to their doctor.

Focus group discussions were audio-taped and transcribed verbatim. Data were analyzed using a multistage process involving two research team members and the project principal investigator. First, all four focus group transcripts were read in full by each team member who then conducted independent coding to identify and label major concepts and themes relayed in each transcript. The principal investigator used constant comparison with the two sets of coded data to derive a saturated set of overarching themes. The team subsequently identified the womens’ quotations that best reflected each theme. Results are presented in order of the three open-ended questions posed to the focus group participants.

**MAIN RESULTS****What Did Your Oncologist Tell You about How to Care for Yourself at the End of Active Treatment?**

Focus group participants felt inadequately prepared for long-term survivorship. Even when they were provided information about the types and frequency of follow-up care they should receive, the women often did not fully understand the purpose for prescribed procedures. As this survivor expressed:

“I was told nothing, that for me to see him [oncologist] back in three months...We didn’t know what to ask, he

just told me that my blood work was good and the tests I had taken previously were okay..."

Confusion about appropriate care was attributed, in part, to the lack of a specific point of contact for follow-up care coordination. While some women had one person (oncologist or primary care provider) who "acted as the manager of their care", other women found themselves caught between the conflicting opinions of two or more providers who gave contradictory information. Some women felt as if they were lost in the shuffle of multiple appointments, as was the experience of this survivor:

"I was just told by the surgeon that I would come back in three months for a check. I was told by the oncologist that I would come back six months later, and by the gynecologist a year later for my regular exam, so I wasn't really given any information. Anything that I got I had to look up on my own."

A few women recalled receiving a large volume of information from their oncologists about follow-up medical care, self-care and prevention of secondary cancers—though, the quality, detail, and adherence to standard clinical guidelines varied.

Many participants felt they had to act "bossy" and aggressively ask questions during doctor visits if they were to gain the information they needed. The women believed that doctors would be less compelled to provide information if they viewed them as being passive or patients "who would take anything they [doctors] would say without asking questions." In response, survivors often resorted to outside sources of information, including the internet, support groups and other survivors.

The Sister's Network was an important source of information sharing on the survivorship issues they faced. They learned through the group to be actively involved in their health care and to be assertive with information seeking, referrals and resources:

"So I learned that I was supposed to walk the wall with my arm, I learned what to eat, what not to eat, and I asked my oncologist to send me to a nutritionist so I could know what to eat because you don't know. The Sisters Network has done so much for me that I just can't thank them enough."

### What Do You Wish Your Oncologist Had Told You about How to Take Care of Yourself at the End of Treatment?

Information about potential side effects and prevention and/or treatment approaches is not consistently delivered to breast cancer survivors. These women wished they were better prepared for the range of physical and psychological side effects that emerged during, immediately following and years after completing treatment. Without such knowledge, warning and/or guidance about treatment, many women reported being unnecessarily startled and distressed. Such issues included those that are more commonly known (hair loss, lymphedema, hot flashes), while some were less commonly

known (memory loss, sleep apnea, sexuality changes, and skin pigment changes). As this woman described:

"One of the physical changes that's really frightening is when your nail beds turn black and your toenails turn black and the palms of your hands."

The distress caused by these often unanticipated side-effects emerged as a central theme and was manifested in expressions of frustration, uncertainty about the future and feelings of abandonment. There was a general consensus that more attention needs to be paid to the types of emotions breast cancer patients may experience after treatment.

"Much of my anxiety started once I stopped treatment because it was like, now what am I doing? I'm a sitting duck. As long as I was having treatment I was doing something about my cancer. I would have liked for them to talk to me about symptoms of metastases to be aware of. I would have liked to know about genetic counseling because I have kids and I was anxious for them. Talk to me about further imaging, blood tests, and scans. Don't tell me no, talk to me about the pros and cons."

### What Do You Think about the ASCO Survivorship Care Plan (SCP)?

Focus group participants were unanimous in their approval of the concept of an SCP and believed that all survivors should have one for themselves, although they had recommendations for revising the content and structure of the ASCO SCP template.

Part One, the "Breast Cancer Adjuvant Treatment Summary," received mixed reviews. Most women said that they wished they been given a similar summary that provides accurate documentation of the type of cancer and cancer treatments they received. Not only would this summary assist the women in communicating their cancer history to primary care providers, it could also help make up for the lack of information women received about their cancer and their treatment regimens, as this woman explained:

"I wasn't told what type of cancer I had. And to this day I don't know what type of cancer I had."

Survivors had particular concern that the treatment summary portion used a lot of medical jargon and overly technical terminology (e.g., neurotoxicity), and that "plainer English" was required. The women also felt survivors need this information to be explained and discussed with them by a health professional.

"When you're somebody who has no health care background and you're looking at this form, it's not going to help you much."

Part two, the "Breast Cancer Survivorship Care Plan" also received mixed reviews. Across all four focus groups discussion centered on the section that reviews ASCO's clinical guidelines for recommended screening for recurrence. Many

of the participants perceived the guidelines to be extremely conservative—especially guidelines related to “tests that are not recommended” (e.g., breast MRI, FDG-PET scans, complete blood cell counts, automated chemistry studies, chest x-rays, bone scans, liver ultrasound, and tumor markers). Several participants believed that given that there is “technology out there that can detect these cancers before they get to the point where you get symptoms,” these recommendations were a form of medical rationing, and that providers who follow them will provide less than optimal follow-up:

“Now it’s spread to your brain...because there might have been an opportunity that a scan or tumor marker or blood count or chemistry test run once a year or twice a year, at the cost of \$10 or \$15 for a blood test...scans are expensive, but life is precious.”

The section on symptoms of recurrence also caused some alarm with the women in the focus groups:

“Now if you don’t get any follow-up other than a mammogram and we’re waiting for bone pain, chest pain, and shortness of breath...[by the time a symptom is picked up] that is at a point now where they’re going to say ‘Nothing we can do about it.’”

Finally, the “Follow-up Care” section was seen as incomplete, because it does not provide information on some of the common issues women face in trying to stay healthy and avoid cancer recurrence. Participants believed it should be expanded to include guidance on self-care including nutrition and exercise and resources for information and support.

## DISCUSSION

There was general enthusiasm for the concept of an SCP in these focus group discussions with minority breast cancer survivors and our results suggest that SCPs have great potential for meeting minority breast cancer survivors’ information needs. However, these minority breast cancer survivors found the particular version of the ASCO template used in this study to be too technical, too generic in follow-up care guidelines and surveillance tests, and short on resource and wellness guidelines. These findings are similar to those of the Hewitt et al. focus group study where survivors (men and women with various cancers) reviewed an SCP template for colorectal cancer and also expressed a great interest in having SCPs that were more personalized, presented in layman’s terms and which included attention to their psychological needs.<sup>12</sup> The current study adds to the former research by demonstrating similar outcomes in a subgroup of minority breast cancer survivors responding to the ASCO breast cancer template.

A well-designed SCP has potential to help minority breast cancer survivors overcome their information gaps about their cancer diagnosis and effects of treatments. SCPs could serve minority survivors in several ways: by reducing their distress at the completion of cancer treatment; preparing them for side-effects they may experience over time; increasing utilization of recommended follow-up tests, and increasing their confidence

to ask questions and express survivorship concerns with their primary care providers.

Will SCPs actually facilitate better coordination of care for cancer survivors and/or serve as useful tools for primary care physicians who care for cancer survivors? The promise of an SCP as a quality improvement tool is dependent on a large part on system level issues.<sup>13</sup> Many oncologists are not able to spend the time necessary to create an SCP or to thoroughly discuss the content of an SCP with patients. Currently, there are no clear mechanisms for reimbursement for this activity for oncologists or other members of the oncology team. This poses a major obstacle to SCPs being established as a standard of survivorship care.

It remains to be seen whether SCPs can be efficiently incorporated into the primary care encounter or if their use will be helpful to primary care providers. There is already published evidence that without the use of SCPs follow-up care from primary care physicians leads to similar outcomes in recurrence related events and quality of life as care provided by oncologists.<sup>14</sup> Minority breast cancer survivors have expressed high ratings of the care they receive from primary care doctors.<sup>15</sup> Prospective studies are warranted to provide evidence of any value added by SCPs.

To increase primary care physicians’ confidence in their ability to manage survivorship care for all subgroups of cancer survivors we must expand training opportunities in survivorship care within our academic medical centers and through continuing medical education programs. Primary care providers also need to be armed with information about race differentials in cancer staging and treatment side-effects, along with more specific guidance in how to tailor evidence-based guidelines for individual patients depending on their cancer histories and other health status indicators.<sup>16</sup>

Meeting the psychosocial needs of breast cancer patients can be particularly challenging in the primary care setting.<sup>17</sup> Our study identified the value of psychosocial and informational support provided by the Sisters Network to these mainly African American breast cancer survivors. Community-based, population-specific cancer support programs are important referral sources for primary care providers caring for cancer survivors. It is important that physicians be aware of local and on-line resources to support breast cancer survivors in coping with their cancer-related problems. Psychosocial support resources may be especially difficult to find in rural and/or underserved settings and patient navigator programs could be especially important in the coordination of care and support of minority, underinsured and rural survivors.<sup>18,19</sup>

The study’s findings are limited by having participants review only one version of an SCP template and without the supplementation of verbal guidance and explanation from a provider. The ASCO SCP template was not designed to be utilized as a stand-alone handout. Future studies should explore survivors’ reactions to the use of an SCP within the context of actual clinical care, i.e. giving the survivor a personalized SCP completed by their treating oncologist, along with ample consultation about the details of the SCP, especially the reasoning behind the SCP’s evidence-based surveillance guidelines. Then the effectiveness of the SCP in the transition to primary care follow-up can be more specifically measured. Secondly, we cannot assume that the concerns raised in our focus groups are related to minority-group status per se, since we did not include a comparison group.

Efforts are underway to create online, interactive SCPs that can be populated with diagnostic and treatment data and with follow-up guidelines and patient resources.<sup>20</sup> A well-designed SCP for the minority cancer survivor will also integrate information that is relevant to the minority survival experience including treatment-related pigment changes, information on the potential merits of genetic testing and minority specific supportive care resources. Meanwhile, primary care physicians can encourage minority breast cancer survivors to ask questions and voice their concerns about appropriate clinical care and support resources.

---

**Acknowledgements:** This paper was presented at the 36th North American Primary Care Research Group Annual Meeting, November 15–19, 2008, Rio Grande, PR. This research was funded by the Florida Breast Cancer Research Coalition and by the University of Florida Cancer Center.

**Conflict of Interest:** None disclosed.

**Corresponding Author:** Mary Ann Burg, PhD; Department of Community Health Family Medicine, University of Florida, P.O. Box 100237, Gainesville, FL 32610-0237, USA (e-mail: burg@ufl.edu).

## REFERENCES

- Mandelblatt JS, Lawrence WE, Cullen J, Stanton AL, Krupnick JI, Kwan L, Ganz PA. Patterns in care for early-stage breast cancer survivors in the first year after cessation of treatment. *J Clin Oncol*. 24:77–84.
- Wender RC. Preserving primary care: the front line in the war against cancer. *CA Cancer J Clin*. 2007;57:4–5.
- Grunfeld E. Primary care physicians and oncologists are players on the same team. *JCO*. 2008;26:2246–7.
- Jemal A, Siegel R, Ward E, Murray T, Xu J, Thun MJ. Cancer statistics, 2007. *CA Cancer J Clin*. 2007;57:43–66.
- Ries LAG, Melbert D, Krapcho M, Stinchcomb DG, Howlander N, Horner MJ, Mariotto A, Miller BA, Feuer EJ, Altekruse SF, Lewis DR, Clegg L, Eisner MP, Reichman M, Edwards BK, eds. SEER Cancer Statistics Review, 1975–2005. National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/csr/1975\\_2005](http://seer.cancer.gov/csr/1975_2005) (accessed April 22, 2009).
- Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Committee on Cancer Survivorship: Lost In Transition. Institute of Medicine and National Research Council, 2005.
- Hewitt M, Ganz PA. Implementing Cancer Survivorship Care Planning: Workshop Summary. Washington DC: National Academies Press; 2007.
- PR, Robinson ET, Tolley EE. Qualitative Methods in Public Health: a Field Guide for Applied Research. San Francisco: Jossey-Bass; 2005.
- Morgan DL, Krueger RA. When to use focus groups and why. In: Morgan DL, ed. Successful Focus Groups. Newbury Park: Sage Publications; 1993:1–19.
- American Society of Clinical Oncology's "Cancer Treatment Summaries" available at <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries> accessed April 22, 2009.
- American Society of Clinical Oncology. ASCO's library of treatment plans and summaries expands. *JOP*. 2008;4:31–6.
- Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses and physicians. *J Clin Oncol*. 25:2270–3.
- Ganz P. CANCER.NET, Expert Corner. Available at: <http://origin.plwc.org/patient/Library/Cancer.Net+Features/ASCO+Expert+Corner/ASCO+Expert+Corner%3A+ASCO+Cancer+Treatment+Plans+and+Summaries>. Accessed April 22, 2009.
- Grunfeld E, Levine MN, Julian JA, Coyle D, Szechtman B, Mirsky D, Verma S, Dent S, Sawka C, Pritchard KI, Ginsburg D, Wood D, Whelan T. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol*. 2006;24:848–55.
- Mao JJ, Bowman MA, Stricker C, DeMichele A, Jacobs L, Chan D, Armstrong K. Delivery of survivorship care by primary care physicians: the perspective of breast cancer patients. *JCO* 2008, In press.
- Nissen MJ, Beran MS, Lee MW, Mehta SR, Pine DA, Swenson KK. Views of primary care providers on follow-up care of cancer patients. *Fam Med*. 2007;39:477–82.
- Burg MA, Grant K, Hatch R. Caring for patients with cancer histories in community-based primary care settings: a survey of primary care physicians in the Southeastern United States. *Primary Health Care Research & Development*. 2005;6:244–50.
- Lopez ED, Eng E, Randall-David E, Robinson N. Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: blending the techniques of photovoice and grounded theory. *Qual Health Res*. 2005;15(1):99–115.
- Freeman H. Patient navigation: a community-based strategy to reduce cancer disparities. *Journal of Urban Health, Bulletin of the New York Academy of Medicine*. 2006;83:139–41.
- Journey Forward: Guiding Survivors As They Move Ahead. <http://www.journeyforward.org/>, accessed April 22, 2009.