ORIGINAL ARTICLES

Transitioning to Breast Cancer Survivorship: Perspectives of Patients, Cancer Specialists, and Primary Care Providers

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BACKGROUND: Limited research exists regarding views of patients, oncology specialists, and primary care providers (PCPs) concerning breast cancer survivorship care.

OBJECTIVE: To qualitatively explore the needs and priorities of breast cancer survivors, oncology specialists, and PCPs.

METHODS: Focus groups were conducted of survivors (21 in 5 groups), PCPs (15 in 2 groups), and oncology specialists (16 in 2 groups). One survivor group consisted of four African-Americans. Discussions used a semi-structured guide, were transcribed verbatim, and were analyzed qualitatively. Groups explored transitions to follow-up, communication, patient needs, and provider roles.

RESULTS: Survivors form intense relationships with specialists for reassurance and expertise. Many believed PCPs lacked necessary oncology expertise. Survivors reported psychosocial and communication issues. African-Americans cited concerns about access to care and clinical trials, as well as taboos to discussing cancer. Specialists reported that they struggle with discharging survivors due to protective relationships. PCPs were concerned about time and training to provide survivorship care and communication problems with oncologists. Written survivorship care plans were regarded by all groups as possibly helpful, but insufficient to ease the transition.

CONCLUSIONS: Breast cancer patients may experience difficulties transitioning to survivorship, including ongoing psychosocial issues. African-American patients may face additional and unique barriers to successful survivorship. Oncology specialists may have concerns about discharging cherished patients. These findings suggest a psychological component that may influence the use of written survivorship care plans. PCPs may need additional training and greater access to specialists in order to care for survivors.

INTRODUCTION

The incidence of breast cancer, which is the second most prevalent cancer in women,¹ and the subsequent number of survivors are expected to grow over the next 2 decades.² The expanding survivor population creates complexity for the medical system. Breast cancer survivors face multi-faceted medical and psychosocial needs as they shift from initial treatment to survivorship.^{3,4} This transition must be made seamless and explicit, as long-term follow-up patient care can be fragmented, uncoordinated, and, in some cases, completely absent.⁴⁻⁶

It is increasingly difficult for oncology specialists to provide care indefinitely to the growing number of asymptomatic survivors. Recognizing this, the American Society of Clinical Oncology has published guidelines on the long-term care of breast cancer survivors.⁷ New models have been proposed for long-term survivorship care wherein PCPs assume greater responsibility for ongoing cancer care needs.^{3,8-10} A well-executed hand-off with information sharing and guidance from oncology specialists to PCPs would facilitate a smooth transition.^{4,11,12} Some research has focused on the need for a specific written plan of survivorship care as part of the solution.^{4,11-13} Patient and PCP perspectives on shifting survivorship care away from oncology, however, are poorly understood. We present the results of a qualitative study exploring the experiences of female breast cancer survivors, PCPs, and oncology specialists and what these stakeholder groups believe is the best approach to survivorship care.

METHODS

Study Design

Focus groups were conducted to explore the perspectives of female breast cancer survivors, PCPs, and oncology specialists who would be affected by new models of survivorship care delivery. Qualitative thematic analysis was utilized to assess perspectives among the three participant categories. To minimize bias in interpretation, the oncology specialists on the study team did not directly participate in data analysis. The analytic team included an internist (MK) and two social scientists with expertise in qualitative data methods (GG, EM). Other team members included a breast cancer survivor (LS), oncology specialists (AW, LS), and a social scientist with

cancer survivorship expertise (CS). The study was conducted with the approval of the Johns Hopkins Medicine Institutional Review Board.

Participant Engagement

Female Breast Cancer Survivors. Female breast cancer survivors who had completed their treatment by a year or more were recruited. The first survivor group consisted of women who volunteered at a breast center. Subsequent participants were assigned to groups based on their node status (i.e., node positive versus node negative) and self-identified racial group (African-American versus Caucasian). This approach was developed on the premise that the experience of breast cancer and subsequent survivorship may vary by type of treatment, prognosis (influenced by node status), and race/ethnicity. Recruitment occurred through advertisement via physicians, breast cancer advocacy groups, churches, and breast cancer support groups. Prospective participants called the study coordinator to express interest.

Oncology Specialists. Focus groups were held with a total of 16 oncology specialists. The first group engaged a convenience sample of providers from Johns Hopkins. The second engaged a convenience sample following a breast cancer specialist conference with providers from the mid-Atlantic region.

Primary Care Providers. Fifteen PCPs participated in two focus groups. Recruitment to the first group occurred through e-mail to PCPs in the Johns Hopkins Community Physician network. None of the participating providers were previously known to the study team. A participant at a breast cancer continuing medical education course volunteered to schedule the second focus group at her practice. Two of the participating providers were acquainted with members of the study team.

Data Collection

Nine focus groups were held between October 2007 and March 2009. Each focus group was attended by MK and by at least one of the social scientists (EM, GG), with every group being facilitated by one of the study team (MK, GG). Semi-structured discussion guides were developed for the three types of focus groups. Although the guides were worded slightly differently depending on the particular stakeholder group, the topics were parallel in all three guides. The patient guides addressed the medical, social, and psychosocial experiences of transitioning to survivorship and their relationship with different physician groups. The provider guides focused on the needs of survivors and the roles of oncology providers and PCPs in their long-term follow-up care (see [appendix](#)). Every focus group was instructed that the purpose of the discussion was to learn about the full range of perspectives, not to build consensus. A stenographer recorded discussions verbatim. After each session, the researchers in attendance recorded immediate impressions and met periodically thereafter to review transcripts and identify themes.

Focus groups were held on the Johns Hopkins campus in Baltimore, Maryland and in locations within the surrounding community. All participants received a 25 dollar gift card and refreshments. No identifying personal information was maintained.

Data Analysis

Qualitative theme analysis was used to explore the data. Three members of the study team (MK, EM, GG) were responsible for data collection and analysis activities. Two of the study team members (GG, EM) have several years of experience conducting qualitative research. Study team members independently reviewed each transcript and identified the major themes and illustrative quotes. Study team members met multiple times to reconcile thematic discrepancies. The major thematic findings within the three participant categories included transitions from initial treatment to follow-up, patient-provider communication, patient needs, provider roles, and survivorship care plans, with selected quotes illustrating the themes. Due to the limited literature on the experiences of minority population survivors, data from the African-American group are presented as a separate subsection.

RESULTS

Sampling and Participant Demographics

Twenty-one (21) female breast cancer survivors participated in five focus group sessions. Twelve¹² survivors were within 5 years of diagnosis, and three survivors were more than 10 years from initial diagnosis. Sixteen¹⁶ participants were Caucasian, and 18¹⁸ were node negative.

The 16 specialists represented a diverse professional profile, including medical oncology, radiation oncology, breast radiology, breast surgery, oncology nursing, nurse practitioners, and nurse navigators. Participants worked in large academic medical systems, smaller hospital settings, and community or private practice settings.

The 15 PCPs represented a diverse practice profile. The first group included four family physicians and one family NP from several practices in suburban and rural Maryland. Participants in the second group were nine internists and one NP in Baltimore. Participants' experience ranged from recently joining a practice to having an established practice for 35 years.

Survivors' Perspectives

Survivors Derive Reassurance from Specialty Care and Surveillance. Survivors frequently noted that they relied on their oncology providers for support, and some associated the emotional connection with their providers with more effective treatment. Survivors held a special regard for the expertise of oncology specialists. Many women expressed their ambivalence about completing chemotherapy or radiation.

"I can remember my last day of treatment. It was the worst day of my life. I don't know why. I was afraid to go..."

While their oncology providers used positive language such as "graduation" to describe the completion of active treatment, survivors associated this transition with anxiety. Many survivors used language of abandonment. This sentiment was articulated both by women with positive relationships with specialty provi-

ders and women who had more procedural relationships with their specialists.

"I sort of felt strange because it was almost like it was this cutoff point; you know, okay, I'm finished with you; move along. I haven't talked to her since."

Some survivors did receive reassurance that their oncologists would not be ending the relationship once active treatment was complete.

"The last day I had chemo I brought in a huge tray of cookies and we celebrated and then...the doctor came up to see me to just say, you know, you're done, but you're not leaving me. You're coming to see me."

Some participants were willing to accept oncology NPs as substitutes for indefinite visits with their original cancer specialist.

"Well, it was 6 years after surgery. I took Tamoxifen 5 years. I saw my oncologist last November, and at that point he's telling me I'm dismissed. I'm sure because of the horror that he saw on my face, he agreed that this year I could be seen by a nurse practitioner. I have never seen this nurse practitioner before, but had I not expressed some concern, I would have been completely dismissed."

Some patients were comfortable that these oncology NPs would have the necessary specialty training to provide ongoing cancer care.

"[H]opefully, [my medical center] will bring on more nurse practitioners who can work closely with the oncology department and be pretty up on what is going on in the studies. I don't expect my primary care to do that, but I do feel like I have a lifeline..."

Some asymptomatic patients valued routine blood tests or scans, in addition to visits with the oncologist, to reassure them that they were cancer free. Women felt more comforted by active surveillance than statistics and guidelines.

"I feel like I'm thrown out there to figure this all out on my own...They never have done a scan on me, and he doesn't even do blood work. He printed me out the ASCO guidelines. He printed them for me. He said here is your homework. You can read this, and it will tell you why we're not doing it...That to me is frightening that it's all left for me to figure out because they don't do anything."

Survivors' Perceptions of PCPs Role in Survivorship Care. Some survivors had long-term PCPs, others changed PCPs after their cancer diagnosis, while others did not have a PCP. However, even when participants had established PCPs, most patients did not regard them as having a central role in their cancer-related needs. Most participants viewed breast cancer differently than other diseases.

"[M]y primary care physician as far as my cancer has basically been useless. They're not up on the studies.

They can do a breast exam. They can do blood work for cholesterol, stuff like that. That's fine. As an internal medicine doctor she's wonderful, but as far as my breast cancer, when she walks in the room and says do you have a history of breast cancer in your family or a history of cancer of any kind, it's like 'read the chart.'"

Some survivors perceived that their PCP did not want to 'overstep' their position and role in the cancer care relationship.

"If [PCPs] see anything abnormal, of course they, you know, they are very proactive. 'I hate to do this but you are going to have to do a little biopsy'. Oh, great. But, you know, I don't think they try to overstep their bounds though. Maybe that's part of it. I mean, they don't want to claim to be—you know, that's why you go to specialists, to the oncologists, because they know that. But they can certainly refer you to the appropriate person."

Unmet Needs of Survivors. Survivors commonly described symptoms such as concerns over weight gain and altered body image, hot flashes, sexual dysfunction, and challenges relating to family members. Some participants indicated that neither their oncology specialists nor their PCPs had adequately addressed these needs. Survivors were uneasy about raising these issues with either provider group, and in their experience few providers initiated discussion about psychosocial needs.

"[I would like to hear] 'How are you doing? Are you still on your antidepressants? Are you feeling better now that this is'—you know, all this treatment is over...just some kind of conversation to find out how I am emotionally."

Use of Cancer Survivorship Care Plans. Survivors felt that a written document or ongoing communication between their specialty providers and PCP would be an asset to coordinating their care. Many women believed that they had to be advocates for their health and a conduit for information exchange between members of their care team. While survivors reacted positively to the idea of a survivorship care plan, they did not view it as supplanting the active participation of oncology specialists in their health care.

Historical Influences and Spirituality Affect African-American Cancer Survivors. African-American participants noted many of the same needs, priorities, and experiences as the Caucasian participants. However, participants also identified concerns about poor care quality and insurance coverage due to race. They believe that continuing fear and suspicion from the Tuskegee case can discourage African-American women from participating in research. They also discussed the importance of spirituality and personal growth as a result of experiencing breast cancer. After the initial shock of diagnosis, some felt empowered to help other women with breast cancer.

"I know I promised God if—if He kept me here, that I was going to talk about it and I was going to help as many people as I can..."

Some participants believed that women in African-American communities avoid discussing breast cancer and that this social taboo can inhibit diagnosis, treatment, and support for survivors. Several noted that, prior to their diagnosis, they did not think that they knew any women with breast cancer, and they were surprised to learn how many friends and relatives they had who shared the diagnosis.

"I went to a friend of mine...I said, 'They told me I have cancer.'...She said 'Are you having any more babies?' I was like 'What? No.' And she said, 'Well, that's the only reason God put them on you,' and she threw her prostheses on the table...And I said to myself if she can do it, I can do it. And that's how I got through it."

Oncology Specialists' Perspectives

Ambivalence over Discharging Survivors. Specialists stated that they struggle with discharging survivors because of the bonds that develop with patients and their deep concern for survivors' needs. Specialists reported that they become emotionally invested in the success of patients and want to remain involved. Many providers stated that they have expertise in identifying recurrences or side effects that PCPs lack. Specialists acknowledged the role of PCPs in addressing other health concerns but viewed cancer care as a special domain. Participants felt protective of and possessive of some patients.

"Sometimes I think we're as scared as the patients...like how the patients don't trust anyone but us, and then, you know, we don't trust them either."

Many providers enjoyed visits with healthy survivors, since these patients provide reinforcement of the success of breast cancer therapy.

"...You also get kind of close to the patient and then when you start talking about oh, go to your primary care, I'll see you in a year, you can see that they feel so shocked. You feel bad to let go, and they feel bad to let go of you."

Support for Cancer Survivorship Care Plans. While specialists reported that they seek to maintain connections with their survivor patients, they expressed that communication with PCPs could be improved. When asked about written survivorship care plans, specialists agreed that some form of communication or tool to be shared between providers would be valuable.

Primary Care Providers' Perspectives

Ambivalence over Assuming Survivorship Care Responsibility. The strongest theme expressed by PCPs was their ambivalence about assuming responsibility for survivors' cancer-related needs. Many rarely became directly involved in that aspect of care, relying on the assumption that their breast cancer patients were continuing to see their oncologists for cancer-related issues.

"I guess I'm taking the path of least resistance, because I'm sure I have many cancer survivors. Most of the time

they get a pit stop once a year in oncology...that means I'm saying if you have a problem, you have an oncologist..."

Some PCPs felt that they *could* assume this role if necessary, but many felt that specialty providers should continue to see patients. One provider expressed this sentiment strongly.

"I want [oncologists] to do their job and so that's my feeling about that. I want them to take care of that, that's their thing. I will—if I have big concerns, I may tell them to change oncologists—I will supervise it, but I tend not to want to intervene and get involved in that care because that's their thing. That's what they do. They're oncologists."

Many providers were concerned about missing a recurrence of cancer in their patients. In their experience, when breast cancer survivors presented with a symptom, they wanted reassurance that they were not having a recurrence. And the PCPs were not always confident in providing this reassurance. Moreover, the providers did not routinely discuss psychosocial needs with breast cancer survivors. One NP did note that her patients sometimes had questions about proper diet, supplements, and maintaining health and wellness after cancer treatment. This was an area where she thought PCPs might have a role to play, and she was pursuing additional training.

"I still have so much to learn, and I don't know how much is primary care. It's almost like you have to kind of pick and choose what is your little subspecialty to get more in depth..."

Concern in Managing Specialty Health Needs in a Complex System. PCPs did not have ready access to information about the latest clinical trials, treatment options, and related opportunities for survivors. PCPs felt challenged by the many issues that emerge during routine encounters and could not envision taking on additional specialty care responsibilities for breast cancer survivor patients.

"...Actually most of our patients have five or six issues, and so we're trying to manage their diabetes or hypertension or renal insufficiency and then end up with a breast issue, and it's impossible...that's like more than an hour's worth of time where you have like four patients scheduled in 15-min increments, and it's overwhelming."

PCPs cited concerns about the medical-legal implications of providing oncology follow-up.

"Frankly, I'm not very eager to take on that care. Medical-legally, family doctors are held to the same standard of care as oncologists and, if we goof up, that oncologist that just jettisoned the patient to us to follow up could be testifying against us in court saying what they would have done instead of what we did."

PCPs were frustrated with the limited or delayed communication with cancer specialists. This was a common complaint,

whether the PCP shared patients with private oncology groups or large cancer centers. One internist stated,

"We see this a lot with other specialties too, but I think oncology probably might be even worse than anybody else in terms of keeping it to themselves, and not feeling like they have to integrate things back to what's going on in the primary care doctor's office."

One PCP suggested the idea of a "re-entry" visit to primary care, after a patient completes initial cancer treatment, dedicated to addressing the transition to survivorship.

Support for Cancer Survivorship Care Plans. Some PCPs reported that they would be comfortable taking on more responsibility for cancer survivors if ongoing training or tools such as a written survivorship care plan and a way to stay connected to the oncologist were available. Several voiced concerns that plans for individual patients would need to be periodically updated by the oncologist as guidelines changed. PCPs felt comfortable addressing patient concerns with new or ongoing physical symptoms outside of survivorship cancer care. However, they felt that specialists should stay actively engaged as a complementary party to address a patient's needs.

"[T]he patients want to be seeing the oncologist and we want them to be seeing the oncologist is the bottom line."

DISCUSSION

This study supports prior findings that breast cancer survivors are at risk for developing medical and psychosocial sequelae arising from their cancer and its treatment.^{3,14,15} Survivors expressed that ongoing or "usual" follow-up care is not systematic, is not adequately coordinated between teams of specialty providers, and is focused on a narrow set of concerns. Survivors feared recurrence of disease, and some were reassured by regular blood tests and scans, even though current guidelines do not support their use for asymptomatic patients.⁷ Moreover, both oncology specialists and PCPs underestimated the informational and psychosocial needs articulated by breast cancer survivors. Our study supports the finding that survivors wish to collaborate with providers in making medical decisions and want to receive care plan information directly.¹³⁻¹⁶ Creating a written plan that directly acknowledges psychosocial elements of survivorship to ease the transition may be a subject for future research.

Findings from the African-American group include the role of spirituality in the experience of disease, barriers to participation in clinical trials, and cultural taboos regarding the discussion of cancer history. This supports limited prior research on the views of African-American survivors.^{17,18} Further examination of these findings and their potential impact on survivorship care and communication with providers is warranted.

This study highlights the value attributed to the relationship between patients and oncology specialists by all stakeholder groups, and the difficulties in defining a role for both oncology specialists and PCPs. Strong bonds form between breast cancer

survivors and oncology specialists during initial treatment. Following treatment, patients continue to rely upon oncology specialists for emotional support, medical expertise, and reassurance that they are cancer free. Although one might expect patients to form these attachments, it was somewhat surprising to hear how uncomfortable oncology specialists can be with transitions of care. Transitioning to oncology NPs for routine follow-up may be acceptable to some patients who wish for ongoing cancer expertise. However, other patients may prefer to continue with the oncologist who provided initial care, in part because of the relationship that was formed at initial diagnosis and treatment. These alternatives would need to be further investigated in future research.

PCPs also respect the relationship between patients and their oncologists. They may be hesitant to provide breast cancer survivor care due to lack of training and time restrictions. It is possible that with improved access to patient records, updates in cancer care recommendations, and ready communication with oncology specialists, PCPs might be more confident in their ability to care for survivors. Recent data support the complementary role of PCPs and oncology specialists as well as the need for further investigation of the best approaches to coordinate follow-up care.^{19,20}

Several limitations of this study should be considered. First, patients who participated may not be representative of all breast cancer survivors, particularly those who were active survivor volunteers or were engaged in advocacy groups. To minimize the impact of this limitation, efforts were made to recruit patients through a range of medical providers and advocacy groups. Review of the transcripts did not show differences between patients who were active in the breast cancer community versus patients who did not participate in such activities. Second, recruitment of African-American node-positive women did not result in sufficient numbers to hold a separate focus group. Third, providers who participated may have had a special interest in survivorship care and may not be representative of all medical providers. In addition, many of them were part of the Johns Hopkins network of providers, although from different practices and parts of Maryland. Fourth, patients in the survivor volunteer group, the African-American survivor group, and the provider groups were acquainted with many of their group members prior to the focus group. While this lack of anonymity between participants could affect some of the responses, participants appeared comfortable with one another and answered the questions directly and in detail. Fifth, although the results of this study may not be generalizable to all breast cancer patients or to cancer patients in general, qualitative research is not intended to obtain generalizable data.

CONCLUSION

Breast cancer patients, oncology specialists, and PCPs would like to see improved care for long-term survivors. Survivors face issues of abandonment at the end of initial treatment, as well as ongoing psychosocial issues that their medical providers may not be addressing. African-American patients may face additional or unique barriers to successful survivorship. Oncology specialists concurrently recognized the need to transfer care of healthy survivors, but had concerns about trusting other providers and letting go of cherished patients.

This finding suggests a psychological component to the transition to survivorship care exists for both patients and oncology providers, which may influence the use and success of written survivorship care plans. PCPs may be able to accept more responsibility for survivor care but may need additional training and improved access to oncology specialists. Further qualitative and quantitative studies exploring the delineation of provider roles, in light of the needs and priorities of breast cancer survivors, as well as the specialists and generalists who care for them, is needed in order to design a long-term survivorship care plan that will be successful.

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REFERENCES

1. National Cancer Institute Office of Cancer Survivorship: Estimated US cancer prevalence counts: who are the survivors in the US? (2005). Retrieved from <http://dceps.nci.nih.gov/ocs/prevalence/index.html>. Accessed April 14, 2009.
2. Erikson C, Salsberg E, Forte G, et al. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3:79–86.
3. McCabe MS, Jacobs L. Survivorship care: models and programs. *Semin Oncol Nurs*. 2008;24(3):202–7.
4. Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in translation. Washington, DC: The National Academies Press; 2006.
5. Earle CC, Burstein HJ, Winer EP, Weeks JC. Quality of non-breast cancer health maintenance among elderly breast cancer survivors. *J Clin Oncol*. 2003;21(8):1447–51.
6. Earle CC, Neville BA. Under-use of necessary care among cancer survivors. *Cancer*. 2004;101(8):1712–9.
7. Khatcheressian JL, Wolff AC, Smith TJ, Grunfeld E, Muss HB, Vogel VG, Halberg F, Somerfield MR, Davidson NE. American Society of Clinical Oncology 2006 update of the breast cancer follow-up and management guidelines in the adjuvant setting. *J Clin Oncol*. 2006;24(31):5091–7.
8. Sisler JJ, Brown JB, Stewart M. Family physicians' roles in cancer care. Survey of patients on a provincial cancer registry. *Cancer Family Phys*. 2004;50:889–96.
9. Grunfeld E, Fitzpatrick R, Mant D, et al. Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial. *Br J Gen Pract*. 1999;49:703–10.
10. Grunfeld E, Levine MN, Julian JA, et al. 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(6):848–55.
11. Miller R. Implementing a survivorship care plan for patients with breast cancer. *Clin J Oncol Nurs*. 2007;12(3):479–87.
12. Ganz PA, Hahn EE. Implementing a survivorship care plan for patients with breast cancer. *J Clin Oncol*. 2008;26(5):759–67.
13. Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. 2007;25(16):2270–3.
14. Hurria A, Hudis C. Follow-up care of breast cancer survivors. *Crit Rev Oncol/Hematol*. 2003;48(1):89–99.
15. Partridge AH, Winer EP, Burstein HJ. Follow-up care of breast cancer survivors. *Semin Oncol*. 2003;30(6):817–25.
16. Lewis L. Discussion and recommendations: addressing barriers in the management of cancer survivors. An invitational symposium identifies obstacles and ways to overcome them. *Am J Nurs*. 2006;106(3):91–5.
17. Royak-Schaler R, Passmore SR, Gadalla S, et al. Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncol Nurs Forum*. 2008;35(5):836–43.
18. Thompson HS, Littles M, Jacob S, Coker C. Post-treatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: an exploratory qualitative study. *Cancer Nurs*. 2006;29(6):478–87.
19. Snyder CF, Frick KD, Kantsiper ME, Peairs KS, Herbert RJ, Blackford AL, Wolff AC, Earle CC. Prevention, screening, and surveillance care for breast cancer survivors compared with controls: changes from 1998 to 2002. *J Clin Oncol*. 2009;27(7):1054–61.
20. Snyder CF, Frick KD, Peairs KS, Kantsiper ME, Herbert RJ, Blackford AL, Wolff AC, Earle CC. Comparing care for breast cancer survivors to non-cancer controls: a 5-year longitudinal study. *J Gen Intern Med*. 2009;24(4):469–74.

APPENDIX. FOCUS GROUP GUIDES

CANCER PROVIDER FOCUS GROUP GUIDE

A. INTRODUCTIONS

Name
What do you do?
Do any of you know each other?
Why you were interested in participating in this group?

B. BACKGROUND OF PROJECT

Describe the purpose/goals of the overall project
Describe why we're conducting focus groups; where the focus groups fit in to the overall scheme. Describe the other focus groups that are planned.

C. RULES OF FOCUS GROUPS

- Food and bathroom breaks
- Being recorded
- If you must address one another, please use first names only
- Try not to interrupt one another
- Not interested in building consensus; want the full range of experiences so feel free to disagree with one another. Any questions? Let's begin.

D. QUESTIONS AND PROBES

1. Please describe your experience with taking care of breast cancer survivors, that is, patients who have completed initial surgery, chemotherapy, and radiation therapy. Probes: How often do you see them? How would you describe those relationships?
2. What roles and responsibilities do you think your patients want you to have in their follow-up care?
3. What roles and responsibilities should primary care providers have in a survivor's follow-up care?

4. If you could design the ideal relationship among you, your patients, and primary care providers, what would it look like?
5. What areas of breast cancer follow-up care do you think primary care providers would like more information about or need more training in? Probes: Do you think primary care providers need more education regarding hormone therapy, screening recommendations, common sequelae of breast cancer therapy, and psychosocial sequelae of breast cancer? What educational or informational format would be most useful, e.g., lectures, DVDs, websites, pocket guides?
6. If a patient's oncologist created a written survivorship care plan for her at the end of treatment, summarizing the details of her diagnosis and treatment, listing the possible side effects, and outlining a plan for her follow-up care, how would you feel about primary care providers providing the breast cancer follow-up care for these patients?
7. What are the most important challenges or barriers to coordinating follow-up care for breast cancer survivors?
8. If written survivorship care plans are widely adopted, how will they affect these barriers?
9. In general, what do you think are patients' greatest needs and priorities following breast cancer treatment?

3. What roles and responsibilities should primary care providers have in a survivor's follow-up care?
4. If you could design the ideal relationship among you, your patients, and cancer care providers, what would it look like?
5. What areas of breast cancer follow-up care do you think primary care providers would like more information about or need more training in? Probes: Do you think primary care providers need more education regarding hormone therapy, screening recommendations, common sequelae of breast cancer therapy, and psychosocial sequelae of breast cancer? What educational or informational format would be most useful, e.g., lectures, DVDs, websites, pocket guides?
6. If a patient's oncologist created a written survivorship care plan for her at the end of treatment, summarizing the details of her diagnosis and treatment, listing the possible side effects, and outlining a plan for her follow-up care, how would you feel about providing the breast cancer follow-up care for these patients?
7. What are the most important challenges or barriers to coordinating follow-up care for breast cancer survivors?
8. If written survivorship care plans are widely adopted, how will they affect these barriers?
9. In general, what do you think are patients' greatest needs and priorities following breast cancer treatment?

PRIMARY CARE PROVIDER FOCUS GROUP GUIDE

A. INTRODUCTIONS

Name
 What do you do?
 Do any of you know each other?
 Why you were interested in participating in this group?

B. BACKGROUND OF PROJECT

Describe the purpose/goals of the overall project
 Describe why we're conducting focus groups; where the focus groups fit in to the overall scheme. Describe the other focus groups that are planned.

C. RULES OF FOCUS GROUPS

- Food and bathroom breaks
- Being recorded
- If you must address one another, please use first names only
- Try not to interrupt one another
- Not interested in building consensus; want the full range of experiences so feel free to disagree with one another. Any questions? Let's begin.

D. QUESTIONS AND PROBES

1. Please describe your experience with taking care of breast cancer survivors, that is, patients who have completed initial surgery, chemotherapy, and radiation therapy. Probes: How often do you see them? How would you describe those relationships? How often does the subject of their cancer come up in your visits?
2. What roles and responsibilities do you think your patients want you to have in their follow-up care?

PATIENT FOCUS GROUP GUIDE

A. INTRODUCTIONS

Name
 Family status (married? children?)
 What do you do?
 Do any of you know each other? (for groups of non-volunteers)
 Why you were interested in participating in this group?
 Other than participating in focus groups, have you ever participated in other kinds of health or medical research? (or generally identify their attitudes toward research?)

B. BACKGROUND OF PROJECT

Describe the purpose/goals of the overall project
 Describe why we're conducting focus groups; where the focus groups fit in to the overall scheme. Describe the other focus groups that are planned.

C. RULES OF FOCUS GROUPS

- Food and bathroom breaks
- Being recorded
- If you must address one another, please use first names only
- Try not to interrupt one another
- Not interested in building consensus; want the full range of experiences so feel free to disagree with one another. Any questions? Let's begin.

D. QUESTIONS AND PROBES

1. Before you developed breast cancer, what sorts of health-care providers did you go to for your general medical care? Probes: Did you have an ongoing

- relationship with a primary care provider? A gynecologist? How often would you see them? How would you describe that/those relationship(s)? What were your expectations of that/those provider(s)? What are the medical and psychosocial needs for which you depend on your health-care providers? In what ways were your expectations met/not met?
2. Once you developed breast cancer, did you continue to see those providers? If not, why not? If so, did the nature of your relationship/expectations change? How so?
 3. What sorts of oncology specialists have you seen? How often have you seen them? What have been your personal experiences with those specialists? What were your expectations of that/those specialists? In what ways were your expectations met/not met?
 4. Since you transitioned from active treatment to survivorship, have your relationships with your oncology specialists changed? Should they change? If so why? If not, why not?
 5. What roles and responsibilities do you want your oncology specialists to have in your follow-up care?
 6. What roles and responsibilities do you want your primary care provider(s) to have in your follow-up care?
 7. If you could design the ideal relationship between you, your oncology specialists and your primary care provider(s), what would it look like?
 8. What sort of information would you want your oncology specialists and primary care providers to know about you and to exchange with each other?
 9. What suggestions or recommendations do you have for coordinating your follow-up care between PCPs and oncology specialists?
 10. Let's say a patient's oncologist created a written survivorship care plan for her at the end of treatment, summarizing the details of her diagnosis and treatment, listing the possible side effects, and outlining a plan for her follow-up care. How would you feel about allowing primary care providers to assume the breast cancer follow-up care for these patients?
 11. In general, what do you think are patients' greatest needs and priorities following breast cancer treatment?