Survivorship Care Plans

Rural, low-income breast cancer survivor perspectives

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BACKGROUND: Despite increasing implementation of survivorship care plans (SCPs), cancer survivors still experience unmet needs post-treatment. Rural, low-income survivors experience less planning for supportive care during treatment, which is difficult to overcome after patients complete treatment.

OBJECTIVES: This pilot study explores post-treatment survivorship care planning execution, perception, and needs among rural, low-income cancer survivors.

METHODS: A longitudinal, descriptive, qualitative design with semistructured interviews was used.

FINDINGS: Rural survivors’ responses reflected lack of knowledge about post-treatment care, including how to assess for cancer recurrence. Delivery of the SCP during the final treatment appointment was inadequate for knowledge retention. Individualized assessment of survivorship needs and education post-treatment may improve long-term health outcomes for this population.

SURVIVORSHIP CARE PLANS (SCPs) ARE DOCUMENTS intended to clearly and effectively incorporate specific guidelines for monitoring and maintaining patients’ health following treatment (American Cancer Society, 2017). Providers typically review SCPs with patients after primary cancer treatment. The Institute of Medicine, now known as the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine, recommends including specific supportive care elements in SCPs to help survivors cope with the psychosocial and existential aspects of cancer (Hewitt, Greenfield, & Stovall, 2006). At a minimum, SCPs should address the following supportive care elements: health-promoting behaviors; potential effects of cancer on relationships, sexual functioning, work, and parenting; potential need for psychosocial support, including spiritual care; and potential insurance, employment, and financial consequences of cancer (Hewitt et al., 2006).

Although these recommendations were published more than a decade ago, unmet supportive care needs continue to be documented in survivorship research (Salz, Oeffinger, McCabe, Layne, & Bach, 2012; Smith, Singh-Carlson, Downie, Payeur, & Wai, 2011). Cancer treatment providers have struggled with the preparation and delivery of SCPs, likely related to the time it required to develop them (Dulko et al., 2013; Hewitt et al., 2006; Stricker & O’Brien, 2014).

Little research has evaluated the impact of SCPs on rural survivors (Dulko et al., 2013; Schootman, Homan, Weaver, Jeffe, & Yun, 2013); however, rural residents may be more vulnerable to deficiencies in SCPs than their urban counterparts because they live farther away from care (DeGuzman, Sheffield, Hauser, Sherman, & Keim-Malpass, 2015). Although estimates vary based on measurement of rurality (Meilleur et al., 2013), more than 20% of U.S. survivors are estimated to live in rural counties (Weaver, Geiger, Lu, & Case, 2013). Post-treatment rural cancer survivors may be further disadvantaged because of lack of financial access (Fuchsia Howard et al., 2014; Palmer, Geiger, Lu, Case, & Weaver, 2013; Pesut, Robinson, Bottorff, Pyles, & Broughton, 2010), assistance with health literacy (Franklin et al., 2010; Katz et al., 2010; Wilson, Andersen, & Meischke, 2004), and support for psychosocial issues like depression (Glasser, Nielsen, Smith, & Gray, 2013; Livaudais et al., 2010). In addition, rural survivors may experience appointment stacking (i.e., scheduling all medical treatment appointments on one day to eliminate the need

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for repeated travel to multiple appointments and the cost of an overnight stay). Unintended consequences of stacking include a prioritization of critical medical treatments and neglect of supportive care services (DeGuzman et al., 2015; Keim-Malpass, Mitchell, Blackhall, & DeGuzman, 2015). Understanding rural, low-income cancer survivors’ perspectives on SCPs and supportive care needs can provide insight into unmet needs and facilitate the development of interventions that deliver SCPs appropriately to this population to better meet their needs.

**Methods**
A longitudinal, descriptive, qualitative design was employed using semistructured interviews (Sandelowski, 2000b). This provides rich, patient-centered data, a broad range of experience, and aspects of care specific to rural, low-income cancer survivors. Approval was obtained from the University of Virginia Institutional Review Board prior to the study commencing.

**Sample and Setting**
The sample included breast cancer survivors from a National Cancer Institute–designated cancer center within the University of Virginia Health System in Charlottesville. Despite its large wealthy urban and exurban areas, Virginia contains very poor and rural regions. About 400,000 Virginians are cancer survivors (American Cancer Society, 2016), and about 15% of them live in rural areas (Rural Health Information Hub, 2017), where the poverty rate reaches 21% (Cable, 2013). Two academic medical centers serve as safety nets, mandated by the state to provide services to residents who cannot afford them. Rural Virginians, typically poorer than their urban counterparts (Rural Health Information Hub, 2017), sometimes travel hundreds of miles to receive care. The cancer center from which the sample was drawn serves more than 4,000 individuals annually, one-quarter of whom live in nonmetropolitan areas (Ingram & Franco, 2014). The center is one of two top providers of indigent care in Virginia, and is closest to the most rural regions in the state.

Breast cancer survivors were eligible for the study if they were aged older than 21 years, spoke English, had completed treatment within the past two years or were expected to complete treatment within six months, resided in a rural area at least 45 minutes from the cancer center, and reported difficulty meeting their household financial obligations. Only breast cancer survivors were

**FIGURE 1. SEMISTRUCTURED INTERVIEW GUIDE**

**INITIAL INTERVIEW**
- Have any of your care providers talked to you about a survivorship care plan (SCP)? (If yes, probe: Can you tell me what elements were in the plan?)
- What have you been told about taking care of yourself once you have finished your treatment?
- What providers other than your physician and nurses have you seen during treatment? (Probe: chaplain, social worker, financial counselor, nutritionist)
- What in your community do you think will be helpful to you when you go home?
- How do you plan to travel back and forth to your follow-up appointments?
- Do you have to stay overnight?
- If you worked before your diagnosis, do you plan to return to work?
- What are your questions or concerns about your care once you finish treatment?

**THREE-MONTH INTERVIEW**
- Did you receive an SCP when you completed treatment?
  - If yes, do you have a copy of the plan? If not, can you tell me about what was in the plan? Which resources have you used that were planned for you?
  - Were there things that you feel you need now that were not in your SCP?
  - If no, what information were you given about your follow-up treatment once you had completed treatment?
  - Were you given information about caring for yourself for nonmedical issues? (Probe: spiritual care, support groups, other psychosocial needs, financial assistance, employment assistance, nutritional care, employment, transportation)

- How is your primary care provider or regular doctor involved in your care?
- Do you have any difficulties getting to your medical appointments?
- Do you have any difficulties getting to other appointments (nonmedical providers)?
- What questions or concerns about your care do you still need answers to?
- What would improve cancer survivorship for you?

**SIX-MONTH INTERVIEW**
- Which resources that were planned for you have you used? (This refers to elements that were in the SCP or that the patient said he or she used at the three-month appointment.)
  - For patients who had an SCP: Were there things that you feel you need now that were not addressed in your SCP? (Probe: spiritual care, support groups, other psychosocial needs, financial assistance, employment assistance, nutritional care, employment, transportation)
  - For patients who did not have an SCP: Are there things that you feel you need that you have not had help with? (Probe: spiritual care, support groups, other psychosocial needs, financial assistance, employment assistance, nutritional care, employment, transportation)
- How has your primary care provider or regular doctor been involved in your care?
- Are you having difficulties getting to your medical appointments and other appointments (nonmedical providers)?
- What questions or concerns about your care do you still need answers to?
- What would improve cancer survivorship for you?
included because, at the time of recruitment, the medical center’s policy instituted SCPs exclusively for patients with breast cancer. After treatment, during the final visit with the provider, patients received and reviewed an SCP. No further follow-up occurred until a visit six months later.

Data Collection and Analysis
Individuals who responded and met inclusion criteria provided verbal consent via telephone. Three telephone interviews were scheduled: one immediately or within the week of first contact, one three months later, and another at six months. Participants received a $20 gift card after the initial interview and $15 for each subsequent interview. Sample baseline demographics, including age, race and ethnicity, highest level of education completed, employment status, and date of last treatment, were collected during the first interview.

Semistructured questions were developed based on survivorship and SCP literature, as well as a consultation with practicing breast cancer advanced practice nurses and RNs. Interviews focused on adequacy of SCPs and unmet supportive care needs. Participants were queried about their use of social work, nutrition, psychology, chaplain, financial, transportation, and physical therapy services. Initial questions focused on participants’ treatment experience, including discussions about SCPs, interactions with nonmedical providers, knowledge of resources, and plans for nonmedical needs following treatment. At the three- and six-month post-treatment interviews, participants were asked again about receipt of an SCP, elements of care in the plan, and knowledge of any provision of supportive care. The semistructured interview guide is provided in Figure 1.

Interviews were conducted via telephone and ranged from 30–60 minutes. Interviews were audio recorded using an MP3 player and transcribed verbatim by a professional transcription service. Data were analyzed cross-sectionally and longitudinally using textual data from each interview by (a) immersion in the data by reading it several times; (b) line-by-line analysis and data reduction of the textual data through inductive open coding, with tentative categories listed with each line of data and organized into nodes (clusters of lines or terms that fall under the same category); and (c) grouping of the nodes to form tentative themes (Sandelowski, 2000a). Open coding (inductive code development) was performed by several members of the study team, and data were organized using Dedoose, a software application for qualitative research. Trustworthiness was addressed by (a) iterative refinement of the interview guide through frequent debriefing (credibility), (b) maintaining an audit trail and opening all aspects of the design for review by the research team (dependability), (c) contextual review of the results (transferability), and (d) ongoing consensus building among team members about thematic classifications (confirmability) (Lincoln & Guba, 1985). Saturation was achieved when no new codes or themes were identified.

Results
Twenty-eight breast cancer survivors were screened; 19 were found to be ineligible because of region or income criteria, and two withdrew after consent but prior to their first interview. Three of the remaining seven completed three interviews, two completed two interviews, and two completed only one interview. Characteristics of the individual participants are presented in Table 1.

The interviews were intended to occur at about three and six months, but the authors had trouble contacting participants. They extended the time until follow-up could be scheduled. The time of the discussions with participants and illustrative quotes of the survivors are presented in Figure 2. Five themes emerged from the data.
Themes or Perspectives on Supportive Care and Survivorship Care Plans

None of the seven women reported receiving or hearing of an SCP during or after treatment. Several of the women reported receiving a packet of information after treatment but recalled no specific information contained therein. One survivor recalled being given information specifically about post-treatment screening for cancer but said that no one reviewed the information with her. Another recalled receiving general survivorship information but said that it was part of a pile of papers she received, which she never looked at again.

When asked specifically about receiving information that addressed nonmedical supportive care needs, only two participants reported receiving this information, and five participants responded that they had not received any. In addition, none of the survivors reported having met with any supportive care specialists (e.g., nutritionist, chaplain) during treatment for self-care information or for post-treatment care planning. Four women reported that they would have benefited from these services had they been presented with the opportunity.

Participants were informed about the medical aspects of survivorship. Most recited what therapies they had undergone and what medication they took. One woman even recalled the date of her next visit with her physician. Another survivor expressed confidence in the knowledge she gained from her treatment team, recalling the thoroughness of the medical information she received. At the same time, only one survivor could recall information about how to address nonmedical aspects of her care. One

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FIGURE 2.
THEMES AND QUOTES FROM BREAST CANCER SURVIVORS

DESIRE AND NEED FOR INDIVIDUALIZED SUPPORT SYSTEMS

- “I go to church, and I got my brothers and sisters at church, and they are always supportive.” (Survivor 6, less than one month)
- “Support groups, I don’t know where they’re at [or] if there are any out here and stuff, and I really don’t want to be involved with a bunch of women, or women and men, sitting around crying about their life and everything. I want to look at this as a stumbling block, not as a wall.” (Survivor 8, less than one month)
- “I don’t have any assistance at home and nobody to call, you know, really to call on. You know…you think you have people you can depend on, but you really don’t!” (Survivor 6, seven months)
- “Yeah, [support groups] would have been nice. It really would.” (Survivor 2, 25 months)
- “My youngest son, well, he always goes with me. He likes to come along with me when I go to [the cancer center] for my appointment. He always drives me.” (Survivor 7, three months)
- “My daughter picked me up and brought me home [from my surgery], and she’s been lookin’ out for me ever since. She and my sister. I have a lot of sisters, though. I never run out of those.” (Survivor 9, one month)
- “I don’t drive, and that makes it difficult, living in the country. I have to rely on my better half to get me to all my appointments.” (Survivor 5, 13 months)

FINANCIAL TOXICITIES

- “Finances are always a concern. I mean, it’s just a way of life. I stay stressed constantly about financial, like living paycheck to paycheck. . . . That’s always a stressor, a huge stressor.” (Survivor 6, one month)
- “It ain’t only the bills; it’s the gettingbackward and forward and stuff [and] having gas money to put in your vehicle to go. I’ve been over there sometimes on a whisper and a prayer, and when you’ve got to drive an hour and a half, two hours, away from your home to receive treatment, it is a strain.” (Survivor 8, less than one month)
- “The gas, it’s a problem, you know?” (Survivor 4, four months)

LACK OF KNOWLEDGE ABOUT SURVIVORSHIP CARE PLANS

- “I didn’t know that [a survivorship care plan] existed.” (Survivor 5, 13 months)
- “A survivor care [plan]? . . . I don’t remember. I really don’t. More likely, I probably did [receive it], but I don’t remember.” (Survivor 2, 21 months)

UNANSWERED QUESTIONS

- “I’m [on hormonal therapy] for five years. They’re going to follow me very closely. But then, what happens after five years?” (Survivor 5, three months)
- “I’m taking the Femara® for approximately three years. That was what they told me I needed to do next and then, once I did that, I was done. That’s about the extent of the survivorship information I was provided.” (Survivor 5, 10 months)
- “What are my chances of it coming back, or what are the chances of other cancers happening?” (Survivor 2, 17 months)
- “What effects will losing weight have if I had reconstruction? Would . . . that one breast be the same as the other one?” (Survivor 5, three months)
- “It’s unbalanced. And, nope, they didn’t say nothing about [how] it would be like that. And that’s what I would have [liked] to have known because you cannot buy no bra [with] two sides like [a] different cup size.” (Survivor 2, 21 months)

UNDERSTANDING OF MEDICAL ASPECTS OF SURVIVORSHIP

- “Dr. D put me on a cancer pill, which I gotta take for five years.” (Survivor 7, six months)
- “Before treatment began, I met with all my doctors. . . . We talked about various radiation treatments and how . . . they would be done so I could basically make an informed decision on which radiation I wanted to do.” (Survivor 5, three months)
- “I haven’t heard nobody talk about [support groups]. Ain’t nobody mentioned. None of the places I’ve been to mentioned nothing about no support groups.” (Survivor 2, 25 months)
- “They didn’t tell you what to eat or nothing, but they did tell you to keep a balanced diet.” (Survivor 2, 21 months)
Survivor, who had completed treatment more than a year prior, recalled having received information about the importance of a balanced diet but could not recall specific dietary recommendations. Although interviewers probed for specific information typically included in SCPs, none of the survivors reported having received information about spiritual care, employment after cancer, available support groups, or financial aspects of survivorship.

Despite certainty in the knowledge of medical treatment, questions and uncertainty remained during later months. One survivor reported uncertainty about her future post-treatment at two consecutive interviews seven months apart. Uncertainty most often involved the likelihood and detection of a recurrence, with one survivor wondering how to remain vigilant for recurrence. Other survivors had specific questions about their breasts. One woman focused on potential changes related to reconstructive surgery, whereas another did not understand how to manage the imbalance in her post-treatment breast size. For this cohort of survivors, these questions continued for as long as 21 months post-treatment.

The women experienced highly individualized needs related to support from others. One woman described having abundant support in place through her church. Another woman was not knowledgeable about the existence of support groups in her region and was adamant about her refusal to join one. One survivor reported a strong desire to receive support from a group, and only one of the women reported difficulty finding transportation to appointments, citing living “on the other side of the mountain” as being the barrier to getting someone to drive. Three of them reported relying on family members to drive them, and two reported difficulty with the financial aspects of transportation.

Three women reported financial stressors that were related either to treatment or had been worsened by undergoing treatment. For a sample struggling to meet basic household needs, one of the most common cited stressors was the financial impact of treatment. Participants who had already reported struggling financially now had the additional financial stressor of cancer treatment. For this cohort of survivors, these questions continued for as long as 21 months post-treatment.

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Discussion
Unmet survivorship care needs of rural, low-income breast cancer survivors did not differ greatly from the needs of other breast cancer survivors; other studies have found fear of recurrence, need for information, and uncertainty about the future to be among the most common unmet needs (Hodgkinson et al., 2007; So et al., 2014). In addition, the current authors found variability regarding the need for support groups and transportation, suggesting that post-treatment needs cannot be generalized but must be individually assessed.

Another major finding of this pilot study was patients’ lack of knowledge about survivorship well into the survivorship phase. None of the women reported knowledge of SCPs. Providers may not have used the term “survivorship care plan” when reviewing this information, although few participants recalled specific care planning beyond medical aspects of care. Despite providers’ confirmation that this education was delivered, many women had unanswered questions about self-care management.

Objective financial consequences of cancer and subjective financial concerns and distress have been broadly defined as “financial toxicity” (p. 476) within the survivorship literature (de Souza et al., 2017). Research has found that financial worry is related to lower quality of life among survivors, which persists throughout survivorship (Keim-Malpass, Levine, Danhauer, & Avis, 2016). In addition, studies have shown that perceptions of financial toxicity are a common concern among rural survivors (Katz et al., 2010; Loughery & Woodgate, 2015). The current authors’ confirmation of this finding suggests that screening for financial distress should occur after active treatment has been completed.

Implications for Nursing
This pilot study’s findings revealed that the timing and setting of survivorship education need to be reconsidered. In addition, delivering the SCP during the final treatment appointment may be inadequate for knowledge retention. Several of the women remained focused on their treatment-related stressors several months after treatment concluded, and unanswered questions related to critical aspects of survivorship, such as surveillance for recurrent cancers, persisted into later stages. Research has indicated that care providers may have little or no time to discuss SCPs, particularly with rural patients (DeGuzman et al., 2015; Keim-Malpass et al., 2015). Even if time were available, the final treatment appointment may not be the best time to have this discussion.

Rural survivors must pay for commuting to care sites (Loughery & Woodgate, 2015), so removing this burden should be explored. Perhaps conducting follow-up survivorship care planning and education later via telemedicine should be considered. Telemedicine directly connects patients to providers using multiple avenues of electronic communication (U.S. House of Representatives, 2014). Oncology nurses are in a position to assess unmet needs and coordinate post-treatment survivorship care (Hewitt et al., 2006); however, few studies evaluating telemedicine provided by nurses have included cancer survivors (Cady et al., 2015; Looman et al., 2015).
Limitations
This pilot study included only seven individuals, despite targeting a large cancer center serving a rural population. The timing of these interviews were not standardized as planned because of difficulty reaching participants. In addition, participants who could travel for care at a major center may not be reflective of all rural, low-income cancer survivors. Researchers should seek to strengthen ties with nurses working in rural areas to improve recruitment of this vulnerable population (Burnett, Bullock, Collins, & Hauser, 2016).

Conclusion
Rural, low-income cancer survivors need individualized, post-treatment assessment of survivorship needs and education that is geographically and financially accessible. This study’s findings suggest that the current practices of delivering SCPs following treatment may leave rural survivors with unmet needs, unanswered questions, and few resources for addressing concerns. Exploring alternative methods and timing of delivery of post-treatment education and care planning with oncology nurses presents numerous opportunities to improve navigation and care coordination for rural cancer survivors.

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