Older Women in Appalachia: Experiences with Gynecological Cancer

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Purpose of the Study: The purpose of this study was to explore how older women in rural Appalachia with gynecological cancer construct and interpret their experience with cancer. Design and Methods: Grounded in social constructionist theory, semistructured in-depth interviews were conducted with 20 women, aged 51–82, who had been treated for gynecological cancer. Transcripts were analyzed using the constant comparative method. Results: Although women narrated their experience along a common trajectory from symptoms to diagnosis to treatment, four distinct patterns of posttreatment perceptions were described: (a) positive: women believed they were cancer survivors, (b) cautious: women saw themselves as survivors but not risk free, (c) distanced: women viewed themselves as cured and equated survivor with victim, and (d) resigned: women refused more treatment. All of the women acknowledged an inner strength in how they experienced cancer, requiring a more nuanced framework for understanding how negative and positive feelings coexist with faith in a higher power and the capacity to endure a devastating threat to life and health. Implications: The findings expand the concept of survivor identity, suggesting that the women’s perception that they had met life’s challenges with fortitude and inner strength may have more resonance in later life than the concept of survivorship. Family members and medical and public health professionals need to support older women’s individual response to cancer recovery and acknowledge their complicated reactions to a cancer diagnosis and prognosis. Key Words: Appalachia, Cancer survivorship, Gynecological cancer, Middle aged, Women

With advances in early detection and treatment modalities, the number of cancer survivors in the United States increased from 3 million in 1971 to 13.7 million in 2012 (Centers for Disease Control and Prevention, 2011; Parry, Kent, Mariotto, Alfano, & Rowland, 2011; Siegel, Naishadham, & Jemal, 2012). As reported in the Surveillance Epidemiology and End Results (SEER) tumor registry program, the median age at diagnosis for cancers of all sites is 66 years of age; approximately 60% of survivors are at least 65 years old (National Cancer Institute, 2013; Parry et al., 2011). Despite the fact that older adults are affected disproportionately by cancer, their experience with cancer has only recently begun to receive attention in the cancer survivorship literature (Avis & Deimling, 2008; Mohile et al., 2009; Parry et al., 2011; Pieters & Heilemann, 2011; Stava, Lopez, & Vassilopoulou-Sellin, 2007). Among older survivors, the limited research has focused primarily on female breast cancer survivors (Aziz, 2007). Far less is known about older survivors of gynecological cancer (e.g., cervical, ovarian, and uterine), which accounts for approximately 10% of primary cancers among women aged 50 and older (Kornblith et al., 2007;
Experiencing and Surviving Cancer

The concept of cancer survivor was introduced into the nomenclature to replace the concept of cancer as a “death sentence” (Deimling, Bowman, & Wagner, 2007). The term survivorship is intended to promote empowerment for living after a cancer diagnosis for the rest of one’s life (Park, 2013). Research reveals that the majority of individuals living with cancer find meaning in the survivor identity (Deimling et al., 2007; Park, Zlateva, & Blank, 2009). Yet, the identity of survivor is not a one-size-fits-all phenomenon. Individual reactions to the experience of having had a cancer diagnosis range from considering it a life-altering event to de-emphasizing its importance (Blank, 2012).

The concept of survivorship has also generated some controversy (Khan, Rose, & Evans, 2012). First, there is ambiguity and variation in the definition of a cancer survivor and when in the cancer trajectory a person becomes a survivor. Critics also charge that the dominance of the survivor concept limits options in defining and coping with a devastating illness to strictly positive connotations (Sulik, 2010). Kaiser (2008) found that women with breast cancer who did not embrace the survivor identity often were made to feel uncomfortable in their adjustment to life postcancer treatment. Although older women with breast cancer did not intrinsically identify with the term survivor, they used comparisons and self-judgments to contemplate how much they deserved the survivor title (Pieters & Heilemann, 2011). Self-identified survivors were actively engaged in their primary treatment. They adopted a lifestyle that would decrease recurrences or enhance early detection of future cancers. For some older women, the uncertainty associated with the reoccurrence of cancer prevented them from identifying themselves as survivors.

In a longitudinal study of 321 older adults with common cancers (e.g., breast, colorectal, and prostate), 86% identified with a positive view of themselves as survivors or ex-patients, rather than as victims (Deimling et al., 2007). Characteristics associated with survivor identity included an optimistic orientation toward life in general, higher self-esteem, and viewing oneself as a whole person. By taking an active role in coping with their illness (e.g., managing symptoms), survivors were able to place their cancer experience in perspective and moved forward (Deimling et al., 2007). Life stage may also influence the perspectives of cancer survivors (Blank, 2012). Compared with younger survivors of female breast and endometrial cancer, older survivors reported significantly better psychosocial adjustment (e.g., less psychological distress). This finding suggests that older women may be more skillful and experienced in coping with major illness and the possibility of cancer-related death than younger women (Kornblith et al., 2007).

Rural Appalachia

Rural Appalachia is considered a “place-based disparity population” (Behringer et al., 2007, p. 40). Persons in rural Appalachia carry a disproportionate share of the cancer burden, with higher incidence rates for primary cancers such as cervical cancer (Appalachia Community Cancer Network, 2009). When cancer diagnosis occurs, the unique physical, cultural, and social environmental factors of this region can create major challenges for treatment and survival.

Residents of Appalachia live in underresourced communities and suffer from lifelong health disparities. Quality of life in rural Appalachia often is compromised by poor socioeconomic conditions, including low population density in isolated communities; low income, education, and employment; poor housing; and lack of reliable transportation and specialized medical care (Behringer & Friedell, 2006). Personal characteristics prominent among persons in rural Appalachia, such as strong values of individualism, independence, fatalism, and familism, render them both similar to and different from the mainstream population (Keefe, 2005) and may influence experience with cancer. Faith is also an important frame of reference for persons living in rural Appalachia. They typically describe their health in the context of a religious worldview (Schoenberg et al., 2009).

Conceptual Framework

Our investigation of older women’s experiences with gynecological cancer is grounded in a social constructionist theoretical framework, where the focus is on individuals’ perceptions and interpretations of their everyday experiences and relationships (Holstein & Gubrium, 1995; Park, 2013). Constructing meaning is an inherently
social process. Individuals develop meanings together and draw from the various subcultures, or sources of knowledge to which they are exposed in order to provide the context for interpretation of their realities (Crotty, 1998; Fry, 2009). Relevant to this study, we view the experience of having cancer within the context of several subcultures that intertwine to provide older women with the implicit and explicit grounds for making meaning out of their experiences. One subculture is that of cancer survivorship, where medical discourse about disease, diagnosis, treatment, recovery, and chances for survival are common constructions (Deimling et al., 2007; Kaiser, 2008; Park et al., 2009). A second subculture is the locality in which women experience their cancer. Rural Appalachia is a region valued for its natural beauty and strong family and religious ties, yet marred by high rates of poverty, isolation, disease, and substandard health care (Schoenberg et al., 2009). A third relevant subculture is the intersection of gender and age (Krekula, 2007). Older women’s experience of the inherently female condition of gynecological cancer has been ignored, in part because of the tendency for older women to become invisible once they are past menopause and no longer capable of reproduction (Dillaway, 2005; Winterich & Umberson, 1999). Taken together, these subcultural contexts of (a) cancer survivorship as a medical discourse, (b) rural Appalachia as a place-based disparity locale, and (c) being an older, postmenopausal woman with gynecological cancer provide the cultural knowledge base for women’s interpretation process.

Our study is a critical first step toward understanding how older women in rural Appalachia with gynecological cancer construct and interpret their personal experiences with cancer, given the culture and geographic isolation of their region. The particular subcultural contexts in which their lives unfold remain largely invisible in the scholarly literature. This invisibility is linked not only to the discomfort or reticence that older rural women may feel about their aging bodies but also to the historically unique region of Appalachia, where cancer is disproportionately experienced and health care options are lacking. Thus, these women are an invisible gender and age minority within an invisible cultural minority, and their experiences with this inherently female form of cancer have yet to be chronicled. Understanding how they view their own experiences creates a new space for practitioners and family members to direct treatment and recovery efforts toward them in culturally sensitive ways. Toward this end, two overarching questions guided our study: (a) How do older women describe their experiences with diagnosis and treatment from gynecological cancer? (b) How do older women experience living with cancer posttreatment?

**Method**

**Sample**

The sample consisted of 20 White women, aged 51–82 (M = 67.1 years; Median = 66.5 years), living in rural Appalachia (southwest Virginia and West Virginia) who had been treated for gynecological cancer. We recruited the women from cancer centers where program directors and physicians identified women from their caseloads who met the study criteria. They secured the women’s permission to provide their contact information to the research team. Inclusion criteria included women aged 50 and older diagnosed and treated for gynecological cancer. Exclusion criteria included women who had Stage IV cancer and did not speak English. Because this study focuses on older survivors, we included women who, based on the stage of diagnosis and the clinical assessment of the gynecologic oncologist who assisted with recruitment, were thought to have a high likelihood for an extended life expectancy. The age criterion of 50 and older is based upon the median age at diagnosis for gynecologic cancers (i.e., cervical, age 48, National Cancer Institute, 2010a; ovarian, age 63, National Cancer Institute, 2010b, and uterine, age 62, National Cancer Institute, 2010c). Sixteen of the 20 women were aged 62 and older at the time of the interview.

**Procedure**

The Institutional Review Board of the authors’ university approved this research. The first author contacted each woman to arrange a face-to-face semistructured open-ended interview in which to discuss her experience with cancer and to gather demographic and health-related data. None of the women who gave permission for us to contact them refused to participate in the study.

The first author conducted the interviews from October 2011 to December 2012. Face-to-face interviews were conducted in the women’s homes (n = 8); in a private room at the cancer center (n = 6); in a private room at a public library (n = 3); or on the telephone (n = 3). The women received a gift card to help cover transportation costs and...
time for their voluntary participation in the study. The telephone interviews, which proceeded in the same manner as the face-to-face interviews, were conducted at the participants’ request or because of difficulty in scheduling a face-to-face interview. Single interviews were conducted and ranged from 40 to 180 min in length (M = 103.75 min; Median = 112.50 min). By the 18th interview, we sensed that we had reached saturation, the point at which no new data were emerging (Corbin & Strauss, 2008). We continued with two more interviews to ensure that our data collection process was sufficient. The interviews were tape-recorded and transcribed by a professional transcriptionist verbatim. The research team verified each transcript to ensure that the audiotape matched the transcribed content. No difference in the quality or depth of the interviews was found between interviews conducted in person and by telephone.

The in-depth interview began by asking the women to tell their cancer story. Probes included type of cancer, when diagnosed, type of treatment, and recovery issues. The women were asked how their life has changed since they began treatment for cancer, in terms of their typical daily activities and personal relationships. They were also asked what they thought when they first heard the news about having cancer, what they believe about the nature of cancer now, and their attitudes and behaviors during their recovery. In addition to the in-depth interview questions, a demographic questionnaire was given (e.g., age, length of time in the community, ethnicity/race, education, employment status, income, marital status, and number of children).

Data Analysis

The constant comparative method of constructivist grounded theory (Charmaz, 2006) was used to analyze the data. The process of continuous coding and analysis allowed us to develop an explanation about older women’s perspectives on cancer survivorship that is grounded in the data (Charmaz, 2006). The two authors read the transcripts and developed and validated the codes, concepts, and patterns found in the data. The transcripts were analyzed through line-by-line or open coding, a process of breaking data apart and creating the initial conceptualization. At this stage, data were studied closely, and a conceptual label or code was applied to words, phrases, or blocks of text. After several discussions of our independent open coding of perceptions and insights about patterns and contradictions in the data, we utilized focused coding, a process of synthesizing data into related themes, to develop a shared coding scheme (Charmaz, 2006). The process of verification was enhanced by on-going meetings to discuss interpretation and placements of codes. The final themes were organized into a coding scheme of major themes and supporting coding categories that insured uniformity and served as a guiding document (Bernard & Ryan, 1998). For example, a pattern began to emerge from the initials codes of “I’m a miracle,” “I’m lucky,” “I fear I could get it again,” and “I’m not a victim.” In the example above, the theme became “Perspectives on the survivorship narrative,” with four supporting coding categories: (a) “Yes, I’m a cancer survivor;” (b) “Maybe, but I’m at risk for getting cancer again,” (c) “I refuse to take more treatment,” and (d) “I’m not a victim; I do not identify with cancer at all.” We continued to revise the entire coding scheme until 100% consensus was obtained and then applied it to all cases, thus providing evidence for the transferability of findings (Anfara, Brown, & Mangione, 2002). Exemplifying quotes and outliers and negative case evidence are utilized to illustrate the findings. The participants were assigned pseudonyms to maintain confidentiality.

Findings

Background of the Women

Twelve of the women were married, three were divorced, one was separated from her husband, two were widowed, one was widowed but living with her current partner, and one had never married. Of the four women between the ages of 51 and 58, three were married. Five of the 6 women aged between 62 and 65 were married, whereas only 4 of the 10 women aged 65 and older were married. Five women did not have children; two had one child; seven had two children; five had three children; and one had four children. Their children’s ages ranged from 21 to 61 years (M = 41.06 years; Median = 42 years). Two of the 15 women with children had adopted their children because of infertility issues. Additional demographic information for the study sample is provided in Table 1.

Seven women had uterine cancer; six had ovarian/peritoneal cancer; four had endometrial cancer; two had vaginal cancer (one of whom also had uterine cancer previously); one woman had...
cervical cancer; and one woman had fallopian tube cancer. Younger women were more likely to have ovarian cancer (5 of 10), whereas older women (5 of 10) were more likely to have uterine cancer. The women’s age at diagnosis ranged from 45 to 82 years ($M = 64.1$ years; Median = 64 years). The trajectory of their experience with cancer from diagnosis to the time of the interview ranged from 5 to 76 months ($M = 37.65$ months or about 3 years; Median = 29 months or about 2.5 years).

When asked to tell their cancer story, all of the women began with a description of symptoms. As they proceeded with the interview, they described their experiences with diagnosis and treatment and revealed an array of reactions and realizations about what was happening to them and how they were handling having cancer.

### From Symptoms to Diagnosis and Active Treatment

**Symptoms.**—Eighteen of the women described having some symptoms that led them to contact their physicians; two women did not have symptoms prior to diagnosis. Although nearly all of the 18 women who experienced symptoms indicated that they felt tired and lacked energy, their initial symptoms seemed to differ depending upon the type of cancer. For example, the uterine, endometrial, and cervical cancers typically began with some spotting or bleeding. Iris, aged 71, diagnosed with endometrial cancer, said, “I had some very slight spotting”; Wilma, aged 82, diagnosed with uterine cancer, said her bleeding was more pronounced: “It was like I started my period again.”

The women with ovarian cancer began with bloating and a lump or hardness in the abdomen. Rita, aged 57, said, “I was laying on the floor and felt a hardness on the left side of my abdomen.” Abby, aged 64, described the symptoms typical of ovarian cancer although she was diagnosed with peritoneal cancer, a very rare cancer that is treated like ovarian: “I had no energy. There was days I could hardly push one foot in front of the other and then I had the bloating and constant indigestion. Even water would give me indigestion.”

### Getting a Diagnosis

Women traveled several pathways on the road to get a gynecological cancer diagnosis. Eleven women went to a physician immediately upon experiencing symptoms and had a diagnosis soon after their initial physician’s appointment. For example, Millie, aged 73, had a straightforward experience in getting her uterine cancer diagnosed:

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample $n$</th>
<th>Women aged 51–65 $n$</th>
<th>Women aged 68–82 $n$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school</td>
<td>2 (10)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>High school diploma</td>
<td>5 (25)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Some college/Associate’s degree</td>
<td>5 (25)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>4 (20)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>4 (20)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full or part time</td>
<td>3 (15)</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Retired</td>
<td>15 (75)</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Homemaker</td>
<td>2 (10)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td><strong>Previous occupation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unskilled/Skilled worker (bus driver, factory worker, and personal care aide)</td>
<td>8 (40)</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Professional worker (bank teller, administrative aide, teacher, nurse, and editor)</td>
<td>10 (50)</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td><strong>Annual income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$10,000</td>
<td>2 (10)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>$10,000–$19,000</td>
<td>4 (20)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>$20,000–$29,000</td>
<td>5 (25)</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>$30,000–$39,000</td>
<td>2 (10)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>$40,000–$49,000</td>
<td>3 (15)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>&gt;$50,000</td>
<td>4 (20)</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
I found it myself. I had a doctor’s appointment with my surgeon and I told him about the bleeding and stuff I was having, and he checked me. He sent me to the gynecologist in [another city], and he did a D&C. He said it was cancerous, and said he couldn’t do [surgery] because he needed the lymph nodes checked. . . . So I went down [to an even larger city], and had my surgery done.

Four women went to a physician immediately after experiencing symptoms but endured an arduous process of physicians’ visits, tests, misdiagnoses, travel, and waiting to receive their diagnosis. For Carla, aged 54, it took a year to get a diagnosis of ovarian cancer:

I went to my gynecologist, just mentioned that I had a little bit of bloating and I was tired. He immediately told me that, you know, “That’s a red flag for ovarian cancer. There’s a test we can do, CA125. However, your insurance probably won’t pay for that.” I was, “That’s okay, I’ll pay for it, you know, I don’t want to take that chance, let’s just do the test.” We did the test, and about three weeks later, it was normal. . . . I can remember him saying to me, “I think you might just be starting through the change of life.”

When Carla was not improving, she went back to the physician who, over the next 10 months, reluctantly ordered more tests (e.g., pelvic ultrasound, endometrial biopsy, endoscopy, colonoscopy, and transvaginal ultrasound), and all came back normal. At that point, her symptoms were advancing, and she was referred to a specialist in a larger city. The specialist agreed with her that although the tests were normal, something must be wrong. Eventually, she went to a renowned cancer center in another state where they determined she had ovarian cancer.

Three women waited to go to their physicians until the time that they felt they could no longer put it off. Violet, aged 65, who had ovarian cancer said,

I started to feel like I had a little bump or something, a little fullness in my abdomen, but I was really busy. My son and his wife were about to have a baby; they needed help. And then my daughter was getting married. I was aware that something didn’t seem quite right, but there were so many important things going on that I didn’t want to go to the doctor at that point, because I was needed to help them [my children] out. . . . In the back of my mind I was like, you should get this checked, you should get this checked.

Finally, two women were unaware of their cancer until it was discovered during a routine examination by a health care professional. For example, Fannie, aged 62, was living in a part of Appalachia where a Remote Area Medical Center provided medical services to local residents. She went in for a routine checkup and was shocked when the nurse practitioner called to tell her to return to the Center immediately because she had endometrial cancer.

**Initial Reactions to the Cancer Diagnosis.**

Women expressed a variety of reactions to learning that they had been diagnosed with gynecological cancer. Primary reactions included denial. Fannie, 62, expressed her denial this way: “I didn’t believe it when they told me. . . . You’re never prepared to hear you’ve got cancer. You don’t know how you feel.” Thelma, 65, said, “I was in denial, I guess. I cried at the physician’s office the first day I went. I’m sitting in the office, like, “Everybody here has cancer, why am I here?” A second reaction was relief that they finally knew what was wrong with them. Grace, 82, said, “I was just tired all the time and my appetite wasn’t good and I had pain in my side. . . . This cancer must have been coming on for some time.” Other women felt relief because of the length of time it took to have the cancer diagnosis confirmed. Finally, women felt acceptance about their diagnosis; Millie, 73, expressed this belief as, “If it’s going to happen, it’s going to happen.”

**Treatment and Side Effects.**

All of the women received at least one of the standard forms of cancer treatment. Seven women received surgery only (typically a complete hysterectomy for uterine cancer). Eleven women received two types of treatment: eight women received surgery and six to eight treatments of chemotherapy (this type of treatment occurred for all of the women with ovarian cancer); three women received surgery and radiation (all of these women were treated for uterine cancer). Finally, two women received all three (surgery, chemotherapy, and radiation).

Six of the women reported that they did not have any side effects from treatment. Of the six, four women experienced only surgery and were in and out of the hospital relatively quickly (from outpatient surgery to less than a week). The other two women without side effects had surgery and one other type of treatment, either chemotherapy or radiation, without any problems.

Conversely, 14 women reported substantial problems following complications from surgery,
chemotherapy, or radiation. Lila, aged 64, said that complications that happened after her hysterectomy for uterine cancer were harder on her than the cancer itself. Her experience in the hospital made her very sick. She believed it was from the narcotic she received during surgery, saying, “I was constantly throwing up.” Then,

I developed hernias where I had the hysterectomy. There were three of them, so I had that surgery for the hernias. . . . Then I developed a staph infection. I went home with the drain tube in me . . . so they didn’t sew me back up, they left me open . . . and then I got an allergy to the tape. . . . The cancer surgery wasn’t that big of a deal. It was after that that all the problems come. That was the hard part; I didn’t mourn over losing my uterus.

Among the 14 women who had adverse side effects to treatment, six had dealt with or were concurrently dealing with new cancers: Three women had experienced breast cancer; one woman had cancer of the appendix before her two gynecological cancers; and two women had either lung cancer or leukemia concurrent with their gynecological cancers. All of these women seemed to take their multiple cancers in stride. For example, Edie, 68, who had two bouts of breast cancer and two bouts of vaginal cancer, said, “I’ve got another place on my vagina that they’re watching that may be cancer.” Rita said, “I’m a cancer prone person, so I have to be very vigilant.”

Posttreatment: Living With and Surviving Cancer

As women told their cancer stories, they addressed the issue of whether they considered themselves cancer survivors. We found four patterns associated with women’s perspective on their own cancer survivorship. Regardless of their perspective on whether they considered themselves as cancer survivors, that is, whether the language of survivorship resonated with them or not, all of the women expressed a belief in their own strength. This strength was often bolstered by faith in God, for the life they had endured, and the way in which they had gotten through their cancer experience. Thus, all of the women acknowledged an inner strength that transcended how they viewed their prognosis for the future.

Positive.—Eleven women expressed a positive identification with being a cancer survivor. Abby, aged 64, who was diagnosed with ovarian cancer, regarded herself not only as a survivor but also as a miracle. She expressed a very positive attitude about survivorship and described the signs that convinced her along the way:

From the very beginning I knew that the treatments were working. . . . I ate healthy and I read the instructions that they gave me religiously before each treatment and I did exactly what they said. I stayed nauseated and had that terrible feeling most of the time, but it’s a learning experience and I’m grateful to be here. Grateful. I told my husband the day that we went for my first treatment that we were going on a great excursion. We’d do okay and we did. . . . And as far as health wise, I guess I’m really healthier now than I was before because my husband and I eat healthier now than we did.

Indeed, Abby tried to find ways to stay positive in every aspect of her experience with cancer:

I actually told my doctor that there was some good things to taking chemo and she said she’d never had anybody say that. She said, “What are they”? [laughter] And I said, since I lost my hair I don’t have to shampoo my head. I don’t have to dry my hair. . . . You just have to think of those things. . . . You’ve got the neuropathy and you have to stop and think, well, which do I want to have? Do I want to have the neuropathy or would I rather have suffered with the cancer? And it doesn’t take long to make a decision there.

Millie, aged 73, who survived both breast and uterine cancer, explained her positive perspective on survivorship in very practical terms:

I’m a survivor, and the doctor tells me I’m doing good with it. I guess it’s just something you’ve just got to learn to live with. I’m living pretty good with it. I get tired, but I clean my own house. I pace myself. I can do a little, rest, and go back, and do some more.

Olivia, 51, was typical of other women with a positive perspective on survivorship in her strong determination “to beat this,” each time she got cancer (appendix, uterine, and vaginal). Not only did she credit her survival to an inner strength, but she also firmly believed that,

If you don’t trust God, not everybody’s going to live through it. He chose for me to be recovered, and that tells me that there’s something on this earth that he wants me to do. I’m waiting for him to tell me what it is because I wouldn’t have survived cancer three times unless he had something he’s got planned for me.
**Cautious.**—Four women expressed more caution about being a cancer survivor. They did not rule out the idea that they might be survivors, but they were also concerned that they were at risk for getting cancer again. Julia, aged 58, who had been treated for fallopian tube cancer, was pleased with the way that she had responded to treatment. She had few side effects, which she attributed to her lifelong commitment to healthy eating and exercise. Yet, the fear lingered, “You always wonder, could it come back?” Deborah, 74, too, wondered whether her cancer would return. She had already experienced breast cancer before her ovarian cancer. She attributed her strength to survive in her absolute faith in God: “Cancer has brought me to God. If you’re a believer, it’s a win-win. You win here or you win in heaven. Salvation is the perfect treatment for all diseases.”

**Distanced.**—Three women distanced themselves from the idea of cancer survivorship; they did not identify with the concept of being a survivor. For example, Sadie, aged 65, did not wish to be associated with what she saw as the culture around women’s cancer care. Sadie had recently retired from the urban north to rural Appalachia. She lived a comfortable life compared with many of the women who originally hailed from her new community. She found the cheery atmosphere at the cancer center where she was being treated following surgery for endometrial cancer discordant to her personal identity:

They had some volunteers who would come by and talk with you. I found that to be the least [helpful]. I really wanted them to go away, because they were just so [in a high-pitched, exaggerated voice] “How are you?” . . . I didn’t need to have my hand held. I’m just independent. I didn’t want to talk to them.

Sadie further explained that she did not identify with having cancer, “I’m having a specific problem; I’m not a cancer victim”; nor did she identify with other women who had cancer:

Going to a gym and exercising with a bunch of women who have cancer wasn’t my identity. I didn’t want to stand around and talk about cancer. I didn’t want to be around people that I might not, in ordinary life, want to be around, period. I didn’t want to be put in a group where the only thing that was drawing us together was that we had cancer.

Like all of the women in the sample, Sadie saw herself as strong, but she attributed her strength to her being an exception to the typical cancer survivor. For example, she said she had been “incredibly healthy,” she was “always optimistic,” and she had the “best physicians.” Sadie believed that she was healed, that cancer was behind her, and that she no longer wanted to dwell on it.

Nora, 72, also considered her cancer “cured.” For her, becoming a widow “was a whole lot bigger issue than cancer.” She attributed her cure to her own independent and health-conscious actions. Although a religious woman, Nora did not lay the blame for getting cancer or the credit for recovery on God:

I don’t put God in my recovery. My doctor was probably as responsible for my recovery [as me], my actions, my health orientation, to make sure I’m healthy, to make sure I exercise. All the things that have happened to me, I don’t want to use the word illness. . . . I’m doing fine.

**Resigned.**—Two women did not use the language of surviving cancer. Their views reflected a fourth pattern, one of being resigned to the fact that they had cancer and cancer had robbed them of what was left of the rest of their lives. They had recently decided not to endure the additional treatment recommended by their physicians. Wilma, aged 82, refused radiation following surgery for her uterine cancer, saying, “I don’t care what happens, to tell you the truth, I’m 82. I’ve lived my life.” Helen, 68, had her port removed and refused additional treatment for both cervical and lung cancers, saying she was just tired of “going through this horrible disease”:

I’m just worn out, with the tests, and just not getting anywhere, and I decided, as of right now, I’m just not going to do anything . . . the pain, it hardly ever stops. . . . I go by this paper they [doctors] gave me, but everything [food] is so expensive, you know, when you run out. . . . I get so tired of being poor.

Despite being resigned to the fact that cancer has gotten the better of them, both women expressed their inner strength in the way that they made conscious choices to stop their treatment. They were supported in their decision-making process by families, prayer, and health care providers. Yet, they alone came to terms with their condition and their future. As Helen concluded:

I realize that I’m just one of so many that’s going through this, and they’re all going through it in a different way, and I’m blessed to have a family around me that deeply care and will do anything in their power to help me. It’s hard, but they manage.
Discussion

Our findings provide three new perspectives that contribute to the literature on older women's gynecological cancer survivorship. First, although the 20 older women all narrated their cancer stories in similar ways, they followed four different routes in learning they had cancer: (a) Receiving a diagnosis immediately upon suspecting symptoms; (b) enduring a series of tests and waiting up to a year for confirmation; (c) living with the suspicion that something was wrong but delaying medical confirmation until after meeting family responsibilities; and (d) having their cancer discovered during a routine gynecological exam. Although women with more financial resources were able to travel to major cancer centers to confirm their diagnoses or have their surgeries, nearly all of the women who had chemotherapy or radiation took it at the cancer center in their local Appalachian community. The fact that they were close to home, with family and friends nearby, was an important source of comfort and support for all of the women as they were going through treatment and recovery.

Second, there was great variation among the women in their beliefs about their cancer. They revealed four different patterns of cancer survivorship. As others have found (Deimling et al., 2007; Kornblith et al., 2007; Park et al., 2009), most of the women in our sample had a positive attitude about being a survivor. The second most common pattern was a cautious one, where women felt positive about survival, but still worried about the risk of getting cancer again. The third pattern was a distanced one, where these women rejected the notion that they were survivors of cancer, equating cancer survivor with cancer victim. This distinction is in contrast to the primary conceptualization of survivor in the literature, where survivor was a term generated to replace the concept of victim (Deimling et al., 2007), and has been promoted in health care practice, funding, and research; the breast cancer movement; and the corporate world (Kaiser, 2008; Sulik, 2010). A fourth pattern was resigned, where women also did not resonate with a survivor identity. Instead, they rejected more treatment, believing that what would come from not continuing to “treat” their cancer was better than the actual treatment.

The third main finding is that although not every woman resonated with being a cancer survivor, every woman did perceive herself to be strong. In this sense, our findings disentangle the survivor identity from an identity of optimism. This finding suggests that the language of survivor may be less salient in late life than the alternative perception that one has met life’s challenges with the courage and fortitude that accompany an inner strength. Even the two women in this study who were resigned to their cancer diagnosis and rejected further treatment saw themselves as strong. They viewed their cancer experience within the context of having lived a long life. They felt supported by strong family ties and strong connection to a higher power. Although they expressed an attitude of coping with life crises throughout their lives, like the women in both Kornblith et al.’s (2007) and Deimling et al.’s (2007) research, they utilized the language of strength, and not of survivor, in explaining their experience with end-of-life decisions.

We recognize that our study is not without limitations. Our research focused on White, older women living in only one geographic area of rural Appalachia; thus, the findings may not be applicable to women of different race and ethnic backgrounds or those in other geographic locations. In addition, by excluding women with Stage IV cancer, the findings may not apply to women with more severe diagnoses and less chance for recovery. Nevertheless, our findings contribute important insights to the literature on survivorship by identifying ways in which older women did or did not embrace the survivor narrative, yet uniformly perceived themselves as strong.

Implications for Practice and Research

The growing certainty of cancer survivorship, particularly for older women, promises to create significant challenges (American Cancer Society, 2012). As Park (2013) suggests, it is important to attend to the meaning-making process during different points along the survivorship continuum. How women view their experience as survivors is a critical starting point for entering into a dialogue about the diagnosis, treatment, assistance needed, and recovery. Although both the National Cancer Institute and American Cancer Society definitions of cancer survivorship begin from the time of diagnosis (Park et al., 2009; Siegel et al., 2012), our findings suggest that the way women respond to the suspicion of cancer can inform treatment practices. Health care providers and practitioners working with older women posttreatment
can benefit from having a more complete and personalized understanding of the woman’s cancer experience (Khan et al., 2012) as it provides insight into the ways the women view their cancer and their recovery.

The women in this study responded to the medical confirmation of cancer in multiple ways. Medical and public health professionals, as well as family members, need to support older women’s individual response to cancer, beyond a uniform discourse of positive survivorship, and acknowledge their complicated feelings and reactions to a cancer diagnosis and prognosis. Older women, and women in Appalachia in particular, may not receive pap tests and other diagnostic screening due to body discomfort and feeling stigmatized when interacting with physicians regarding gynecologic care (Schoenberg, Hopenhayn, Christian, Knight, & Rubio, 2005; Schoenberg et al., 2009).

Practitioners may need to take time in eliciting women’s perceptions about their cancer, and what it means to them, rather than imposing a “one size fits all” approach to managing their cancer.

Providing support for older women with cancer in remote rural areas also requires practitioners to consider the use of delivery systems beyond individual visits. Many of the women in our study commented on the distance they needed to travel to see their providers. Approaches shown to be effective with cancer survivors, such as psychoeducation by videotapes and telephone counseling (Sherman et al., 2012) may be ideal for providing supplemental information and support for rural older women during all phases of their cancer journey.

The literature on Appalachian culture documents traditions of fatalism, religiosity, strong family loyalties, and lack of access to health care, including feeling stigmatized when interacting with physicians about gynecologic care (Schoenberg et al., 2005). Although we found support for these attitudes, many of the women were self-reliant, also characteristic of people in Appalachia. They saw themselves as fighters and persisted in finding a physician who would take their concerns seriously and provide an accurate diagnosis. Fung (2013) noted that individuals make sense of life events through internalizing the values of their cultures. She argued that when mortality becomes a salient issue, such as when faced with cancer, aging individuals derive emotional meaning from life through affirming and internalizing their culture. Future research is needed to further examine the nuances of Appalachian cultural background (i.e., religion and social class) and the ways in which older rural women utilize their own resources (i.e., personal beliefs, family support systems; activism with physicians) to navigate their cancer journey.

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References


