

This material is protected by U.S. copyright law. Unauthorized reproduction is prohibited. To purchase quantity reprints, please e-mail reprints@ons.org or to request permission to reproduce multiple copies, please e-mail pubpermissions@ons.org.

# Older Women's Reflections on Accessing Care Across Their Breast Cancer Trajectory: Navigating Beyond the Triple Barriers

Huibrie C. Pieters, PhD, DPhil, RN, MarySue V. Heilemann, PhD, RN, Marcia Grant, RN, DNSc, FAAN, and Rose C. Maly, MD, MSPH

**M**alignancies may strike at any age, but cancer burden is disproportionately high among older adults as 60% of survivors are older than 60 years (National Cancer Institute, 2010; Reuben, 2004). After gender, age is the highest risk factor for breast cancer (Chapman & Moore, 2005); median age at diagnosis is 61 years (Yancik, 2005). Despite similarities with younger breast cancer survivors, such as feeling shocked when learning of the cancer diagnosis (Crooks, 2001; Pelusi, 1997; Utley, 1999), unique aspects of the experience for older breast cancer survivors warrant attention. The breast cancer journey in women of all ages is shaped by the social context of the disease (Thorne & Murray, 2000), but older survivors' initial experiences involve social constructions of breast cancer that were formed decades before those of younger women. For example, reviews of information about breast cancer published in popular women's magazines from 1929–1949 (Black, 1995) and from 1974–1995 (Clarke, 1999) showed the assumption that surgery caused breast cancer to spread.

Preexisting comorbidities are more frequent among older adults with or without cancer (Hewitt, Rowland, & Yancik, 2003; Kurtz, Kurtz, Stommel, Given, & Given, 1997; Piccirillo et al., 2008) and have been found to be more predictive of quality of life for older breast cancer survivors than age itself (Ganz et al., 2003). In addition, cancer treatments and follow-up usually require many visits to healthcare providers that can increase the burden of family members (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003), causing feelings of guilt (Sulik, 2007).

Despite the complex interface between aging and cancer survivorship (Hughes, Closs, & Clark, 2009; Overcash, 2004) in the rapidly aging population (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009), older breast cancer survivors are seldom the focus of research (Boyle, 2006; Hewitt, Greenfield, & Stovall, 2006). Although age-appropriate nursing care is based on un-

**Purpose/Objectives:** To describe the experiences of older women regarding barriers to care for breast cancer in their prediagnostic period and throughout their diagnoses, treatments, and beyond.

**Research Approach:** Qualitative, descriptive study guided by grounded theory.

**Setting:** Participants' homes or apartments in southern California.

**Participants:** 18 women aged 70 years or older who recently completed treatment for breast cancer.

**Methodologic Approach:** Semistructured, individual interviews. The analytic approach was constructivist grounded theory.

**Main Research Variables:** Gero-oncology perspective of accessing care across the breast cancer trajectory.

**Findings:** Three interconnected, age-related barriers to care were described by the women throughout their cancer trajectories: knowledge deficits, preexisting comorbid diseases, and multiple appointments with healthcare providers. The women navigated beyond the triple barriers to life after cancer. Women described how the services of an oncology nurse navigator facilitated their progress.

**Conclusions:** Despite diverse sociodemographic circumstances and challenges in the healthcare system, all women successfully navigated the triple barriers.

**Interpretation:** Effective age-appropriate care requires sensitivity to the unique needs of older people newly diagnosed with cancer. Awareness of the triple barriers can be a catalyst for nurses to enhance access to care for older adults who fight to overcome a life-threatening disease and move on with their lives. More research is needed that specifically focuses on the role of oncology nurse navigators in older populations.

derstanding the general as well as the individual needs of the patient (Thomé, Dykes, Gunnars, & Hallberg, 2003), older breast cancer survivors have been considered the "silent population" (Kantor & Houldin, 1999) whose needs may not be known because little research has given voice to their experiences. As a result, this

article aims to describe the experiences of women aged 70 years and older who recently completed treatment for early-stage primary breast cancer, regarding barriers to care in the prediagnostic period and throughout their diagnoses, treatments, and beyond.

## Methods

### Research Design

Constructivist grounded theory (Charmaz, 2006) directed all aspects of the research. Charmaz (2006) noted that classical grounded theory is derived from the positivist tradition with a greater focus on the data itself and less on the process of emergence. In contrast, constructivist grounded theory is more aligned with the interpretive tradition and holds a strong commitment to self-reflexivity as an element of the emergent process of data collection and analysis. The focus is on exposing and examining emerging as well as latent biases that may influence interpretations by researchers and participants (Charmaz, 2009). Grounded theory is based on symbolic interactionism (Charon, 2007). Symbolic interactionism posits that human beings dynamically act on their surroundings instead of simply responding to them, and do so in unique ways (Charon, 2007). In addition, symbolic interactionism accentuates that human beings are engaged in a continuous stream of social interactions with the intention of meeting their goals (Charon, 2007). Applied to this research, women's reflections about their breast cancer experience were studied across time and involved numerous interactions with others.

### Recruitment, Participants, and Data Collection

Flyers approved by the institutional review board (IRB) of the University of California, Los Angeles, were displayed in public areas and waiting rooms in 24 sites in Los Angeles, rural areas in Southern California, and two neighboring states. Sites included oncology departments of medical centers, cancer support agencies, offices of private oncologists and primary care providers, churches, senior community centers, and retirement centers. After the IRB of Loma Linda University Medical Center approved the research, a flyer also was displayed in the medical center and sent to prospective participants. Women who elected to respond to the flyer called the first author on their own initiative. Participants also were recruited with the snowball technique (Marshall & Rossman, 2006) and advertisements in newspapers.

Screening for eligibility was done by phone. Inclusion criteria were women aged 70 years and older who spoke English and had completed treatment for primary breast cancer within the prior 3–15 months. Exclusion criteria were stage IV disease or a history of a previous cancer (excluding nonmelanoma skin cancers). Thirty-five women called from September 2008–July 2009. Of

them, 17 were not eligible because they had completed treatment more than 15 months previously ( $n = 9$ ), had a history of previous cancers ( $n = 5$ ), were younger than 70 years ( $n = 1$ ), or did not speak English ( $n = 2$ ). All 18 eligible women gave informed consent to participate in the research, which involved semistructured interviews lasting from 1–2.5 hours ( $\bar{X} = 104$  minutes) at a place of their choice, all in urban or suburban areas. Most chose their home or apartment, but some preferred a quiet area in their place of worship, a hospital cafeteria, or a cancer support organization. Ten women were asked and agreed to second interviews to give further descriptions of their experiences. At that point, no new data were emerging and analysis showed nuanced categories; therefore, no further interviews were done (Corbin & Strauss, 2008).

An interview guide was created from previous pilot study data to guide the interviews, which were tape-recorded with participants' permission and then transcribed verbatim and checked for accuracy (see Figure 1). Sociodemographic data and clinical characteristics were collected at the first interview. Initially, a cash incentive of \$20 was given to the first four women for their time and participation. However, the women spoke for much longer periods of time during the initial interviews than originally anticipated. Therefore, the investigators obtained IRB approval to increase the cash remuneration to \$50 for the subsequent 14 women interviewed. All recruitment, screening, and interviews were done by the principal investigator and first author.

### Data Analysis

Systematic initial coding was done to closely scrutinize the data line by line. Then, focused coding was performed with ATLAS.ti, version 6.0, to identify significant and frequent codes in the data. This allowed for the sorting and synthesis of large amounts of data that were compared within and across interviews (Charmaz, 2006) and enhanced understanding of the codes in different contexts and under different conditions. The iterative process of coding and comparison allowed categories

- Please tell me about your life after the cancer was diagnosed. What happened?
- What decisions did you have to make about treating the cancer? How did you make these decisions? Who was involved in these decisions? How were they involved?
- What was treatment like for you?
- Tell me about the people who were especially helpful during the treatment. Now that you think back, what stands out about this person's help?
- Now, let's focus on your life immediately after the cancer treatment was over. What stands out about that time?
- Was there a time when you had to deal with something difficult, such as a major adversity during your experience with cancer? What happened? How did you get through that?

**Figure 1. Examples of Interview Questions**

and their subcategories, properties, and dimensions to emerge (Charmaz, 2006; Clarke, 2005). Theoretic coding was conducted to understand the data on a more abstract level. Memos, field notes, and diagrams were written throughout to conceptualize the data in different ways and to create an audit trail.

Several measures were taken to ensure qualitative rigor. Interviews were coded independently by two researchers (the principal investigator and another researcher experienced with grounded theory analysis) and then collaboratively analyzed and compared. In the interpretive tradition of grounded theory, extensive use was made of reflexive and other memos to hold the researchers accountable to their biases (Charmaz, 2006). Overall credibility was established with continuous member checking informally throughout data collection and formally with reinterviewing two participants after data analysis was completed (Lincoln & Guba, 1985).

## Results

### Sample Characteristics

Tables 1 and 2 show demographic and disease characteristics. Fifteen of 18 participants had at least one chronic disease at the time of cancer diagnosis. Seven participants were diagnosed and treated at one private community medical center that employed an oncology nurse navigator.

### Cancer Journey Marked by a Series of Events

The group of women aged 70 years and older conceptualized their cancer experience as a series of events. To work their way to where they wanted to be (life after cancer), they had to navigate past three barriers: lack of information, preexisting comorbid diseases, and multiple appointments with healthcare providers. As patients described navigating a path riddled with impediments, waiting for healthcare appointments also emerged as a category. The oncology nurse navigator was remembered as being particularly helpful throughout the cancer trajectory.

The cancer journey for the participants involved what one woman called “the whole rigmarole,” which began with diagnostic testing, proceeded to the diagnosis and treatment of breast cancer, and continued beyond primary treatment to a follow-up phase. The diagnosis came as a “total surprise” and “a death nail.” Whether women detected changes during breast self-examination or unsuspectingly received a call with abnormal mammogram results, they felt ill-equipped to deal with the diagnosis. Once the diagnosis was confirmed, women reported an initial reaction of “immediately wanting it out.” The next step involved selecting the best treatment options. However, one woman remembered that making treatment decisions was scary with “all the things that

**Table 1. Sociodemographic Characteristics**

| Characteristic                     | $\bar{X}$ | SD    | Range |
|------------------------------------|-----------|-------|-------|
| Age (years)                        | 76.06     | 5.83  | 70–94 |
| Years divorced                     | 32.5      | 5.39  | 25–40 |
| Years married or living as married | 50        | 13.58 | 24–52 |
| Years widowed                      | 10.2      | 13.42 | 2–34  |

| Characteristic                       | n  |
|--------------------------------------|----|
| <b>Marital status</b>                |    |
| Divorced                             | 6  |
| Married or living as married         | 6  |
| Widowed                              | 5  |
| Never married                        | 1  |
| <b>Race or ethnicity</b>             |    |
| Caucasian                            | 11 |
| African American                     | 1  |
| Chinese                              | 1  |
| Filipino                             | 1  |
| Indian                               | 1  |
| Mexican                              | 1  |
| Persian                              | 1  |
| Puerto Rican                         | 1  |
| <b>Education (highest completed)</b> |    |
| Some high school                     | 2  |
| Graduated from high school           | 9  |
| Some college                         | 2  |
| Bachelor’s degree                    | 1  |
| Some graduate school                 | 1  |
| Graduate degree                      | 3  |
| <b>Annual household income (\$)</b>  |    |
| 20,999 or less                       | 8  |
| 21,000–40,999                        | 3  |
| 41,000–60,999                        | 3  |
| 61,000–100,999                       | 2  |
| 101,000 or more                      | 2  |

N = 18

are coming at you a mile a minute out of nowhere when you weren’t thinking of it for yourself.”

### Waiting

Waiting for active treatment stretched out while the various necessary diagnostic tests and procedures were scheduled and performed and while results were analyzed before any diagnosis was made. In addition, women had to endure waiting at appointments for healthcare providers who were late. Waiting was experienced in different, challenging ways. Prediagnostic waiting was frustrating and poorly understood by the women because their main concern was to begin treatment as soon as possible. Although the women understood that professionals were pressured for time, they believed having to wait for healthcare providers was disrespectful to them. A woman who waited longer than two hours for her first appointment with an oncologist said,

My nephew and niece got so mad because they are busy. . . . We were not happy to sit because two or three times we went to the reception and said, “We

**Table 2. Clinical Characteristics**

| Characteristic                               | $\bar{X}$ | SD   | Range |
|--|-----------|------|-------|
| Months since diagnosis                       | 12.5      | 7    | 3–30  |
| Months since completion of primary treatment | 8.5       | 4.34 | 3–15  |

| Characteristic                        | n  |
|---------------------------------------|----|
| <b>Stage</b>                          |    |
| Ductal carcinoma in situ              | 1  |
| I                                     | 4  |
| II                                    | 4  |
| III                                   | 2  |
| Unknown                               | 7  |
| <b>Primary treatments received</b>    |    |
| Lumpectomy                            | 12 |
| Mastectomy                            |    |
| • Unilateral total                    | 5  |
| • Unilateral partial                  | 1  |
| • Bilateral total                     | 1  |
| Radiation                             | 11 |
| Proton therapy                        | 1  |
| Chemotherapy                          | 1  |
| <b>Hormonal therapy</b>               |    |
| Aromatase inhibitor                   | 10 |
| Selective estrogen-receptor modulator | 1  |

N = 18

can't wait so long." And then we had an argument with one of the nurses there.

The actual physical burden on participants' bodies to wait was problematic. One woman said, "The waiting kills my back now and I have to go to the bathroom more frequently." Waiting for clinicians often included family members who provided transportation, which resulted in further difficulties for the participants. In addition, waiting in areas with other patients with cancer had psychological implications of burden. A woman said, "Emotionally, it was hard seeing other people who were being treated." Women described their emotions while waiting with other patients with cancer as, "I know the woman is like me, the man is like me," and, "I feel bad for them and I start feeling like I'm them."

Despite the emotional burden of waiting with other patients who were perceived to be sicker, no woman spontaneously spoke about survivorship guilt. When asked, all participants denied experiencing guilt. Rather, they described empathy for others and gave examples of wanting to reach out to help other patients. For example, a participant who saw a woman crying in the waiting room said, "[I] wanted to help because I felt for her."

### Constellation of Triple Barriers

Within the context of their age, busy lives, and the urgency of wanting treatment, participants encountered

three unique obstacles during their cancer journey that influenced their access to care and decision making. The triple barriers were knowledge deficits, preexisting comorbidities that made life complicated, and the burden of multiple appointments with healthcare professionals. The work of "beating cancer" included finding one's way around one or more of the barriers to reach what the women referred to as "life now." When available, the services of an oncology nurse navigator facilitated the women's movement across the cancer trajectory (see Figure 2).

**Lack of information:** "Knowing nothing" about breast cancer or treatment options at the time of diagnosis was common for the participants. Most women were uninformed that breast cancer was associated with age. One woman described her reaction after hearing the diagnosis for the first time.

I went to my car and I sat in my car for a couple of minutes and tears just, whoosh! Two minutes of grief, and then my mind said, "Okay! Have to do this." It was shocking because I'm never having cancer problems at all, and here I am at 72 years old and boom! There it is. I never knew the statistics that as you get older your chances rise.

A woman who was active with fund-raising for breast cancer before and after diagnosis said,

I didn't know that breast cancer was age-related. I'm 78 and I didn't know that. . . . I think that maybe they would show that grandmas do get cancer of the breast. . . . Show someone's grandma's age and say: "And she got it at 78, good Lord," you know?

The women also reported misinformation about breast cancer. Participants were surprised that their breast cancer did not present with pain, and many believed that a family history was the most important risk factor for developing breast cancer.

Despite ignorance and misinformation, women felt pressure to make decisions because they knew that breast cancer was a life-threatening disease and they wanted to live. Therefore, they learned new information as quickly as possible so they could make informed treatment decisions. One woman joked, "It's amazing what happens when you go through the process. You learn a whole lot in a hurry and you probably wouldn't do that otherwise."

Participants described beliefs about cancer that they gleaned from the past. One woman was reluctant about surgery because she perceived that her grandmother had prolonged her life by avoiding surgery for breast cancer. She explained that her grandmother "refused to have surgery so she lived 25, 30 years longer." The woman doubted whether she should have had a lumpectomy. "Back in my time, they always said anytime you have surgery on the cancer, it usually spread. They say 'no'

today and they didn't even have lumpectomies back then, so it's a different time." Despite being told differently by healthcare providers, the woman was still clinging to the fear that her recent surgery might have aggravated the cancer.

As a rule, it did happen. They didn't know the things they know now, but when they operated on people with cancer, usually it bought some time but then it spread to other parts of the body. I don't know if disturbing it caused more problems.

All participants retold memories of loved ones who had received treatment for cancer, including breast cancer, who either were still living or had died from the disease. The experiences of their friends and relatives left them fearful of recurrence, mutilation, or side effects. One woman whose parents died from cancers and whose older sister died of metastatic breast cancer decided to have a double mastectomy because the surgeon said, "Maybe later on, couple of months, couple of years, the cancer might come back again." She said her family history influenced her decision to have a double mastectomy. "And then I make up my mind. One-two-three, I say, 'Okay, take the two out.' I make up my mind right away. I say, 'Cut two.'"

Memories of seeing loved ones die from cancer did not result in a display of fatalism about life. One woman spoke of her sister, who was breast cancer free since she completed treatment 13 years prior, and her own husband, who died at home after a protracted battle with cancer. Although the circumstances of her husband's death made her emotionally vulnerable, the woman spoke more about what she learned from her sister's cancer experience and how the sister's example gave her insight. In addition, she had learned from her husband that "the most important thing is to fight depression and not let cancer take over your life."

Memories of seeing radical mastectomy scars decades ago either on their mothers or friends left some

women feeling vulnerable. A woman who underwent a partial mastectomy and radiation repeatedly described herself as fortunate that she did not have to undergo a full mastectomy. Toward the end of the interview, her face filled with emotion as she described an interaction with a coworker from long ago.

She was gone for quite a while so when she came back maybe she wanted to show somebody. She just said, "Do you want to see it?" And I'm not much on blood and cuts and things, but I was curious enough that she took me to the restroom and showed me. I'll never forget my whole life, this major cut under her arm. And I felt so bad for her. She needed to show somebody.

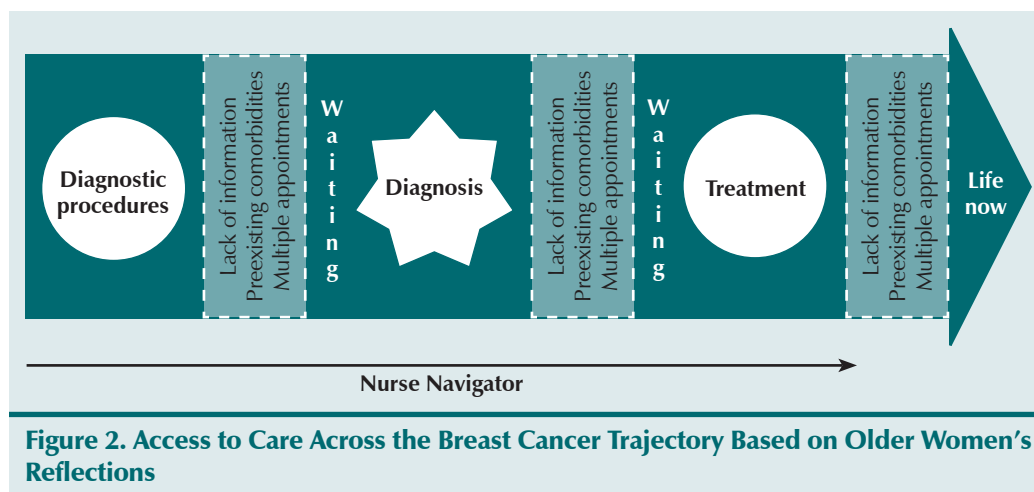
After more than four decades, the woman still remembered the powerful incident with grave and sober feelings.

**Preexisting comorbidities:** Fifteen of 18 participants experienced preexisting chronic diseases such as osteoarthritis, hypertension, and diabetes. While acknowledging their chronic diseases, participants often used humor to describe the new cancer diagnosis as just "one more thing" to be dealt with among the various comorbidities they experienced. An octogenarian said, "Other women may say, 'Why me?' I said, 'Oh no, not another one!'" In other cases, age rather than a chronic disease brought added difficulties such as "slowing down." A 94-year-old woman said, "I haven't been able to do much for a long time because of being so old." Another woman reflected, "I was a very strong woman when I was young but now my age is giving a pain here and a pain there." Both women neglected follow-up visits.

Complex clinical comorbidities increased the illness burden of breast cancer as well as women's risks for adverse effects from cancer treatments and influenced which treatment they could tolerate. A woman with a history of arthritis switched from one selective estrogen-receptor modulator (SERM) to another because of "a lot of hot flashes," but she then experienced worse side

effects on the second SERM such as "pains in my joints, a lot of knee problems." She wanted to restart the first SERM, saying, "I'd rather have hot flashes and not the joint pain."

Preexisting chronic diseases also complicated participants' access to care. An octogenarian described how her complex clinical situation led her to discontinue follow-up appointments with her oncologist.



**Figure 2. Access to Care Across the Breast Cancer Trajectory Based on Older Women's Reflections**

He said, "Can you climb up on the table so I can examine you?" He had the old-fashioned kind of table, with one step and then up, high. And I said, "I don't think I could do it." And he said, "Oh yes you can do it, yes you can do it, I can help you." Now he's a little slim doctor [chuckles] built on a small scale, and he's going to help me, with what I weigh, get up on this table? So because he's helping me, and it's an embarrassing situation, I pushed with my right ankle, and these are my problems, this is why I'm not walking, because of my ankles, and my feet. So, I got up there on the table, and he made the examination. And I had to go to the foot doctor the next day and he took X-rays, and I pulled a muscle, it was bleeding in there, all from pushing from the appointment with the breast cancer doctor. It's so hard on me physically to do these things and I sure can't climb up on his table anymore. Either I go to a new oncologist or forget the whole thing. So I just quit going.

Unfortunately, difficulties from her coexisting disabilities caused the woman to sever her access to oncology care.

Mental health comorbidities included lifelong histories of generalized anxiety disorder in two women. One woman said she was more disturbed by "my nervous thing" than by breast cancer. She had started on a SERM with calcium supplements but had questions that worried her. Her oncologist and pharmacist both failed to definitively answer her questions about blood calcium levels and simply dismissed her questions. She explained, "Whenever they don't know what's wrong with me, they say, 'Oh you have anxiety.' Well sure you have anxiety when you're worrying about it!"

Receiving care for comorbidities contributed to participants' awareness that the current healthcare system was unlike that of their past, and they were disappointed in present day care. One woman poignantly described the fragmented healthcare services and impersonal care.

You usually see two to three people before you see the doctor. When the doctor arrives, they walk in and they see a heart, they walk in and they see crippled feet, they walk in and they don't see any of the rest of you.

In addition to the multiple appointments associated with breast cancer diagnosis and treatment, the fragmentation of healthcare services further complicated access to care for participants. Along with their disillusionment with the way the healthcare system has developed, the women understood that receiving health care in the present day required initiating action. For example, a woman said "bugging" doctors who "are all so busy" for referrals was her responsibility. She said, "It's sort of up to me if I really want something."

Despite living with various chronic diseases for years prior to breast cancer diagnosis, the participants did not consider cancer as a chronic disease. They perceived

cancer as treatable and not contributing to functional limitations, whereas a comorbidity such as osteoarthritis interrupted their daily activities. They saw cancer as different from other chronic ailments because it was treated aggressively and efficiently. A woman clarified this point by stating that her cancer was "treated so radically compared to my blood pressure and my thyroid." Another woman assumed that being free of cancer disqualified it as a chronic disease. She said, "I felt I survived cancer, the cancer is gone from my body. But my cholesterol, I have to treat that constantly."

#### **Multiple appointments with healthcare professionals:**

Participants displayed their personal calendars during interviews and the pages showed how involved they were in various activities outside of their cancer-related appointments and how the diagnostic process and treatment added demands to their already busy lives. Noting the numerous entries related to magnetic resonance imaging (MRI), "ultrasounds, needle exams, on and on and on," women described the distress they felt about juggling the many appointments involved in their cancer journey. One woman who said that cancer was an "incredible interruption in my life, my work, my finances, and my time" explained how "three weeks [of] radiation and 28 MD visits" had to be fit into her schedule in the past year. Another woman said her husband had accompanied her to 25 appointments related to her cancer experience, excluding her radiation treatments. Women claimed they were "always, constantly going to appointments." Multiple appointments were particularly challenging to women who were caretakers of frail husbands. Also, women with serious or several comorbidities had to juggle multiple appointments for cancer care in addition to appointments for their other diseases.

An octogenarian with severe osteoarthritis described how the interconnection between multiple appointments for radiation along with those for her comorbid osteoarthritis caused her to decline radiation treatment after careful consideration of the whole situation.

The thing when you're over seventy, and you have something like the cancer happen, one of the worst things, which has nothing to do with the cancer, is the logistics of you getting in the positions they want you to, climbing up on tables and . . . turning here and turning there. When you're old, that isn't easy. You don't bend like other people, like when you're younger. That's the very reason I didn't take radiation, because it's a five-day, six-week thing. That is wear and tear on me and I probably would collapse at the end of the week.

Another dimension of having multiple appointments was that many women were reliant on others to get to appointments. Those women described the heaviness of the burden that their physical limitations placed on their children and other caregivers. One woman described the

many steps necessary for her daughter to help her get to appointments. "She pushes me to her car, she takes me to the doctor, and she brings me back." One simply referred to herself as the problem, stating with a sense of frustration, "I disrupt their lives."

## Services of the Oncology Nurse Navigator

Five of seven women who had access to oncology nurse navigator services agreed that they benefited from the RN who coordinated their care and facilitated their movement across the cancer trajectory. Four of five women who used the service spontaneously brought up the topic during interviews. The two women who did not use the service only had surgeries without radiation or hormonal therapy.

Many months after working with the nurse navigator, one woman described the navigator as "one of the main people" of her cancer experience. She remembered that the nurse navigator was present when she was diagnosed. "I was pretty shook up. She knew I didn't have any family to support me. She said that I could call her at any time and I did." Another woman said the healthcare provider who informed her that she had breast cancer spent "a few minutes" with her and then asked whether she had "any questions." She continued, "I mean I didn't have questions then! I was kind of still puzzled about it." Then the provider left and sent in the nurse navigator. "[She] gave me a big file of information. She was going over everything with me. . . . She was very responsive to my questions and she had information. . . . She explained exactly how they schedule appointments." She then reflected on the differences between the two healthcare providers and said the nurse "probably knew how it would feel to talk about it, a shock like that." The woman, who had a lifelong history of generalized anxiety, explained how well-timed information and an approachable provider helped her along her treatment trajectory. Following the first meeting with the nurse navigator, the coordination of services was particularly helpful for this participant. She said,

[The nurse navigator] takes over everything. She schedules your appointments for oncology, the surgeon, she schedules everything, MRIs, everything is put in her hands, and it's marvelous because she takes control of it. I dealt with her for the whole entire thing from beginning to end, she was my guide. When I say to her, "Oh God, how come I can't do this ultrasound sooner than that?" And she just explained to me that of all the people that are involved, she explained that it was no big rush because it wasn't going to go any further.

Another woman also recalled the nurse navigator from the time of her diagnosis. Although she only had one interaction with the navigator, she remembered receiving valuable information. In addition, she valued that the nurse navigator was present when she heard the diagno-

sis. "They tell you, 'You have cancer,' and she was there then, too. She was very helpful, a very warm, friendly person. And she put together this little folder for me." When asked whether and how this made a difference, the woman said, "Yes, yes, because she told me everything that was going to happen. That really helps because there are no surprises." The woman also benefited because she perceived that the coordination of services caused less waiting. "She don't dilly dally along, and she sets things up for you; it was very convenient. You have a plan and you don't have to go out and say, 'Oh, God, what do I do next?'" She also valued the autonomy that she received from the nurse navigator. "You don't have to do all of what they tell you, but if you let them guide you, they will guide you. They just kind of lead you along the way."

Trust in the nurse navigator was associated with trust in the other providers whom she recommended. A woman described this trust by proxy as follows.

I felt that the people that were guiding me were very competent and knew what they were doing and what they were talking about, and they work with these people so they know them. I don't think that they let somebody in there, in that group that they're recommending, if they don't have confidence in them.

The women's stories revealed how they received invaluable help to navigate beyond the triple barriers within the context of feeling unprepared for a first diagnosis of breast cancer, knowing the disease to be potentially deadly from various personal encounters with loved ones, and feeling urgency while having to wait.

## Discussion

At the beginning of their cancer trajectory, participants were busy juggling the work of being diagnosed and treated for cancer in addition to orchestrating their many other responsibilities. They immediately encountered one or more of the triple barriers experienced by older women with breast cancer: knowledge deficits, preexisting comorbid diseases, and multiple appointments with healthcare providers.

Feeling unprepared for an unexpected diagnosis was associated with misinformation or lack of information about breast cancer, particularly that the disease was associated with aging. As the participants had lived long lives, the emotional power of their old memories and beliefs that functioned as powerful myths about breast cancer influenced the women's treatment decisions. The effect of the memories, beliefs, or myths varied from helping some women make a clear and easy decision to making other women feel vulnerable.

Knowledge deficits mainly influenced treatment decision making, whereas concurrent comorbidities complicated decision making as well as access to care. Comorbidities, particularly diseases that affected mobility

or resulted in chronic pain, limited tolerance of side effects and led to the discontinuation of care in some cases. Women with preexisting mental health problems spontaneously spoke of complications that arose with treatment decisions. The common assumption among healthcare professionals that cancer is a chronic disease (Feuerstein, 2008) was not evidenced in this sample of older breast cancer survivors who had lived experiences of chronic diseases. Breast cancer was perceived as a one-time occurrence that needed to be treated and then was over.

Multiple appointments related to diagnosis and treating cancer also influenced treatment decision making. This barrier made women painfully aware of the caregiving burden on loved ones. The women, who themselves often were full- or part-time informal caretakers of family members, had to rely on others to get to appointments, which impeded autonomy. Multiple appointments involved waiting, which was very hard for this sample. Younger breast cancer survivors also have reported that waiting is extraordinarily hard (Gaudine, Sturge-Jacobs, & Kennedy, 2003). Waiting, particularly for long periods, was physically challenging for participants, especially for those who did not have their own transportation and were reluctant to trouble family members with their care. The findings confirm previous reports of older breast cancer survivors (Bowman et al., 2003; Sinding, Wiernikoski, & Aronson, 2005). Although the women described seeing others in waiting areas who were sicker than themselves as difficult, they did not experience survivor guilt as described elsewhere (Cooper, 2006).

The triple barriers were raised by participants in dialogue during the interviews, but not as fully formed concepts. Rather, women talked about how they made decisions in the course of living their daily lives and how they considered their options. They subsequently discussed how they confronted impediments that complicated their paths from diagnosis to treatment and beyond. The constellation of three barriers emerged through the interviews and became evident in specific ways for different women, but always within the larger context of the women's lives.

Maneuvering the three barriers was made smooth for participants who were able to work with a nurse navigator. The rapid response of patient navigation programs (Moore, 2010) that may target older populations deserves attention. Shockney (2011) noted that although breast cancer nurse navigators fulfill many roles, they focus on facilitating the patient through the different components of the healthcare system to receive quality care in an efficient and effective manner. However, navigation programs are not streamlined, and their purpose is not clear in many oncology care centers (Pedersen & Hack, 2010). Nonetheless, nurse navigation has been found to decrease barriers to care (Campbell, Craig, Eggert, & Bailey-Dorton, 2010) and enhance adherence after abnormal mammograms in urban minority (Ferrante, Chen, &

Kim, 2007) and low-income (Ell, Vourlekis, Lee, & Xie, 2007) women.

Participants who had access to an oncology nurse navigator found the service very helpful. When interviewed again months after their diagnoses, most women spontaneously disclosed the importance of the nurse navigator without prompting. The finding is particularly noteworthy because the nurse navigator's role was not conceptualized as a part of this research when originally designed. While allowing autonomy, which the women valued, the nurse navigator provided women with the necessary resources (specifically information, coordination of services, and emotional support) to move beyond the triple barriers.

The current findings are in sharp contrast with those from Swanson and Koch's (2010) retrospective chart review of hospitalized patients in a rural-urban setting that included six patients with breast cancer. Swanson and Koch (2010) stated that older populations benefited significantly less than younger patients from the assistance of a nurse navigator. They proposed that younger populations may have more stressors that are amenable to successful nurse navigation interventions or that younger populations are more comfortable talking about the sources of their distress with nurses compared to older populations. Swanson and Koch (2010) suggested that their findings can help oncology nurse navigators prioritize their workloads to favor patients younger than 65 years. However, the current qualitative research with older breast cancer survivors who had received care in urban and suburban communities showed that the women spontaneously demonstrated the value of the nurse navigator for older breast cancer survivors. The small sample size in both the current study and in Swanson and Koch's (2010) study point to caution in generalizations as well as the urgent need for additional research before reprioritizing nurses' workloads.

## Limitations

The current study captured diversity among participants in terms of the type of breast cancer, the treatments received, their culture, and socioeconomic and marital status. However, qualitative research studies are not population based, which limits generalizability. In addition, selection bias may have influenced the findings because women who responded to the research flyer may have presented different views from other older breast cancer survivors who did not participate. Therefore, the current study's findings are not intended to be generalized to all women aged 70 years and older.

## Implications for Nursing

The primary clinical implication of the triple barriers encountered by women aged 70 years and older in their breast cancer trajectory is that healthcare providers should



acknowledge the context of the whole person, not just the disease or one of its components. Knowledge deficits, multiple appointments, preexisting comorbidities, and fragmentation of services provided unique challenges for this population. To the authors' knowledge, the unique needs of older patients with cancer waiting for healthcare providers who are late for appointments have not been studied. Although women may not have reported that accessing care was too difficult, the results suggest women may skip treatment or follow-up appointments and thus fall through the cracks. No systematic studies have simultaneously considered the many complex factors that influence how older adults with a new cancer diagnosis navigate the healthcare system. Research is needed that goes beyond the triple barriers to uncover the unique factors faced by older populations who may experience unusual problems with access to care and decision making. Two women in the current sample reported lifelong histories of a generalized anxiety disorder. The data suggest a topic for future research because preexisting mental health comorbidities in older people with cancer are particularly understudied (Boyle, 2006; Rowland, 2008).

Women in this sample knew they had little specific knowledge about breast cancer at diagnosis. However, they were open to learn, and the cancer brought a "teachable moment" for them (Rowland, 2008). In fact, they did discover many details about the disease and were capable of learning even more. Nurses can create an environment in which older breast cancer survivors feel comfortable to share misinformation. Consequently, nurses can empower older women by providing them with appropriate and user-friendly information. Age-appropriate care includes providing information targeted to individual patients as well as the public. Research is needed on how to more accurately tailor information to facilitate the needs of the growing population of women aged 70 years and older during their cancer trajectory.

Participants made informed decisions about treatment, and sometimes they decided to refrain from treatment. When this occurs, nurses should consult with their patients and listen to how they chose their options so that nurses can understand how much thought the women put into the decisions. Then nurses and patients can solve the problem together if a new solution is presented

that was not considered. If not, nurses are positioned to offer respect and support for women's decisions and acknowledge the complexities of their choices. Relationships between nurses and patients must be well preserved so that patients are not lost to follow-up.

## Conclusions

Older women in the current sample who had worked with an oncology nurse navigator voiced their appreciation for the expert care that they received, whereas those without a nurse navigator had to face their cancer journey without such advocacy. Regardless, the current sample of older women with breast cancer faced difficulties when accessing care, including the trio of barriers (lack of information, preexisting comorbidities, and multiple appointments with healthcare providers). The development of the role of the oncology nurse navigator holds promise for facilitating timely access to care, coordination of services, continuity of care, translation and interpretation of information, and the provision of emotional support (Gentry, 2009; Melinyshyn & Wintonic, 2006; Wilcox & Bruce, 2010). Although research on this rapidly emerging practice is limited and investigation of age-appropriate care is urgently needed, the current study is one step toward the realization of this goal.

*The authors gratefully acknowledge Sandra Harding, PhD, Sally Maliski, RN, PhD, and Jan Mentes, PhD, APRN, BC, for their valuable insight regarding this work, and the participants whose stories are represented in this article.*

Huibrie C. Pieters, PhD, DPhil, RN, is an adjunct assistant professor and MarySue V. Heilemann, PhD, RN, is an associate professor, both in the School of Nursing at the University of California, Los Angeles; Marcia Grant, RN, DNSc, FAAN, is a professor and the director of Nursing Research and Education at City of Hope in Duarte, CA; and Rose C. Maly, MD, MSPH, is an associate professor in the Department of Family Medicine in the David Geffen School of Medicine at the University of California, Los Angeles. This research was funded, in part, by an ONS Foundation Ann Olson Doctoral Scholarship, sponsored by Pfizer, and a Sigma Theta Tau, Gamma Tau Chapter, Annual Research Grant. Pieters can be reached at hpieters@sonnet.ucla.edu, with copy to editor at ONFEditor@ons.org (Submitted April 2010. Accepted for publication April 14, 2010.)

Digital Object Identifier: 10.1188/11.ONF.175-184

## References

- Black, M.E. (1995). What did popular women's magazines from 1929 to 1949 say about breast cancer? *Cancer Nursing, 18*, 270–277.
- Bowman, K.F., Deimling, G.T., Smerglia, V., Sage, P., & Kahana, B. (2003). Appraisal of the cancer experience by older long-term survivors. *Psycho-Oncology, 12*, 226–238. doi: 10.1002/pon.630
- Boyle, D.A. (2006). The older adult with breast cancer. In D.G. Cope & A.M. Reb (Eds.), *An evidence-based approach to the treatment and care of the older adult with breast cancer* (pp. 103–134). Pittsburgh, PA: Oncology Nursing Society.
- Campbell, C., Craig, J., Eggert, J., & Bailey-Dorton, C. (2010). Implementing and measuring the impact of patient navigation at a comprehensive community cancer center. *Oncology Nursing Forum, 37*, 61–68. doi: 10.1188/10.ONF.61-68
- Chapman, D.D., & Moore, S.M. (2005). Breast cancer. In C.H. Yarbro, M. Goodman, & M.H. Frogge (Eds.), *Cancer nursing: Principles and practice* (6th ed., pp. 1022–1088). Sudbury, MA: Jones and Bartlett.
- Charmaz, K. (2006). *Constructing grounded theory*. Thousand Oaks, CA: Sage.
- Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In J.M. Morse, P.N. Stern, J. Corbin, B. Bowers, A.E. Clarke, & K. Charmaz (Eds.) *Developing grounded theory: The second generation* (pp. 127–149). Walnut Creek, CA: Left Coast Press.

- Charon, J.M. (2007). *Symbolic interactionism: An introduction, an interpretation, and integration* (9th ed.) Upper Saddle River, NJ: Pearson Education.
- Clarke, A.E. (2005). *Situational analysis: Grounded theory after the post-modern turn*. Thousand Oaks, CA: Sage.
- Clarke, J.N. (1999). Breast cancer in mass circulating magazines in the U.S.A. and Canada, 1974–1995. *Women and Health, 28*, 113–130.
- Cooper, P.G. (2006). Guilt. In R.M. Carroll-Johnson, L.M. Gorman, & N.J. Bush (Eds.), *Psychosocial nursing care across the cancer continuum* (2nd ed., pp. 315–326). Pittsburgh, PA: Oncology Nursing Society.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Crooks, D.L. (2001). Older women with breast cancer: New understandings through grounded theory research. *Health Care for Women International, 22*, 99–114. doi: 10.1080/073993301300003108
- Ell, K., Vourlekis, B., Lee, P.J., & Xie, B. (2007). Patient navigation and case management following an abnormal mammogram: A randomized clinical trial. *Preventive Medicine, 44*, 26–33.
- Ferrante, J.M., Chen, P.H., & Kim, S. (2007). The effect of patient navigation on time to diagnosis, anxiety, and satisfaction in urban minority women with abnormal mammograms: A randomized controlled trial. *Journal of Urban Health, 85*, 114–124.
- Feuerstein, M. (2008). Impacting the lives of cancer survivors: Reflections of the first year of the journal of cancer survivorship: Research and practice. *Journal of Cancer Survivorship, 2*, 2.
- Ganz, P.A., Guadagnoli, E., Landrum, M.B., Lash, T.L., Rakowski, W., & Silliman, R.A. (2003). Breast cancer in older women: Quality of life and psychosocial adjustment in the 15 months after diagnosis. *Journal of Clinical Oncology, 21*, 4027–4033.
- Gaudine, A., Sturge-Jacobs, M., & Kennedy, M. (2003). The experience of waiting and life during breast cancer follow-up. *Research and Theory for Nursing Practice, 17*, 153–168.
- Gentry, S. (2009, September/October). The role of the nurse navigator in the management of a patient with HER2+ breast cancer. *Breast Health Navigation, 1*–8.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hewitt, M., Rowland, J.H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *Journals of Gerontology. Series A: Biological Sciences and Medical Sciences, 58*, 82–91.
- Hughes, N., Closs, S.J., & Clark, D. (2009). Experiencing cancer in old age: A qualitative systematic review. *Qualitative Health Research, 19*, 1139–1153. doi: 10.1177/1049732309341715
- Kantor, D., & Houldin, A. (1999). Breast cancer in older women: Treatment, psychosocial effects, interventions, and outcomes. *Journal of Gerontological Nursing, 25*, 19–25.
- Kurtz, M.E., Kurtz, J.C., Stommel, M., Given, C.W., & Given, B. (1997). Loss of physical functioning among geriatric cancer patients: Relationships to cancer site, treatment, comorbidity and age. *European Journal of Cancer, 33*, 2352–2358.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Marshall, C., & Rossman, G.B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage.
- Melinyshyn, S., & Wintonic, A. (2006, May). The role of the nurse navigator in the breast assessment program at Hotel Dieu Hospital. *Nursing Journal, 1*–11.
- Moore, S. (2010). Making room at the table [Editorial]. *Oncology Nursing Forum, 37*, 9. doi: 10.1188/10.ONF.9
- National Cancer Institute. (2010). Estimated U.S. cancer prevalence. Retrieved from <http://dcccps.nci.nih.gov/ocs/prevalence/prevalence.html#age>
- Overcash, J.A. (2004). Using narrative research to understand the quality of life of older women with breast cancer. *Oncology Nursing Forum, 31*, 1153–1159. doi: 10.1188/04.ONF.1153–1159
- Pedersen, A., & Hack, T.F. (2010). Pilots of oncology health care: A concept analysis of the patient navigator role. *Oncology Nursing Forum, 37*, 55–60. doi: 10.1188/10.ONF.55–60
- Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum, 24*, 1343–1353.
- Piccirillo, J.F., Vlahiotis, A., Barrett, L.B., Flood, K.L., Spitznagel, E.L., & Steyerberg, E.W. (2008). The changing prevalence of comorbidity across the age spectrum. *Critical Reviews in Oncology/Hematology, 67*, 124–132. doi: 10.1016/j.critrevonc.2008.01.013
- Reuben, S.H. (2004). *Living beyond cancer: Finding a new balance*. Bethesda, MD: National Cancer Institute.
- Rowland, J.H. (2008). What are cancer survivors telling us? *Cancer Journal, 14*, 361–368. doi: 10.1097/PPO.0b013e31818ec48e
- Shockney, L.D. (2011). *Becoming a breast cancer nurse navigator*. Sudbury, MA: Jones and Bartlett.
- Sinding, C., Wiernikowski, J., & Aronson, J. (2005). Cancer care from the perspectives of older women. *Oncology Nursing Forum, 32*, 1169–1175. doi: 10.1188/05.ONF.1169–1175
- Smith, B.D., Smith, G.L., Hurria, A., Hortobagyi, G.N., & Buchholz, T.A. (2009). Future of cancer incidence in the United States: Burdens upon an aging, changing nation. *Journal of Clinical Oncology, 27*, 2758–2765. doi: 10.1200/JCO.2008.20.8983
- Sulik, G.A. (2007). On the receiving end: Women, caring, and breast cancer. *Qualitative Sociology, 30*, 297–314.
- Swanson, J., & Koch, L. (2010). The role of oncology nurse navigator in distress management of adult inpatients with cancer: A retrospective study. *Oncology Nursing Forum, 37*, 69–76. doi: 10.1188/10.ONF.69–76
- Thomé, B., Dykes, A.K., Gunnars, B., & Hallberg, I. (2003). The experiences of older people living with cancer. *Cancer Nursing, 26*, 85–96.
- Thorne, S.E., & Murray, C. (2000). Social constructions of breast cancer. *Health Care for Women International, 21*, 141–159. doi: 10.1080/073993300245221
- Utley, R. (1999). The evolving meaning of cancer for long-term survivors of breast cancer. *Oncology Nursing Forum, 26*, 1519–1523.
- Wilcox, B., & Bruce, S.D. (2010). Patient navigation: A “win-win” for all involved. *Oncology Nursing Forum, 37*, 21–25. doi: 10.1188/10.ONF.21–25
- Yancik, R. (2005). Population aging and cancer: A cross-national concern. *Cancer Journal, 11*, 437–441.