

# Women's Experiences With Antiestrogen Therapy to Treat Breast Cancer

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An estimated 230,480 new cases of invasive breast cancer and 57,650 new cases of noninvasive breast cancer were diagnosed in American women in 2011 (American Cancer Society [ACS], 2011). More than 11.9 million cancer survivors are estimated to be living in the United States (National Cancer Institute [NCI], 2011a) and, of those, about 2.6 million are women living with a diagnosis of breast cancer (ACS, 2011). Women with breast cancer make up the largest percentage of survivors that are five years post-treatment (NCI, 2011a). The American Society of Clinical Oncology (ASCO, 2009), Institute of Medicine (IOM) (Hewitt, Greenfield, & Stovall, 2006), NCI (2011b), and the Oncology Nursing Society (2009) have identified interventions aimed at improving cancer survivorship as essential to patient care and research. A first step in addressing the survivorship care of women on antiestrogen therapy (AET) is to understand the experience from the perspective of these women.

Curative treatment for early-stage breast cancer involves a triad of possible treatment modalities that occur over a one-year period, including surgery, radiation therapy, and chemotherapy with various agents, which requires women to have frequent visits and interactions with the oncology team for management of symptoms and side effects. At the end of the treatment phase, women with estrogen-receptor-positive cancers are prescribed and expected to initiate oral AET to further reduce the risk of cancer recurrence. More than 80% of breast cancers in women older than 45 years are found to be of the estrogen-receptor-positive type (Glass, Lacey, Carreon, & Hoover, 2007). For AET to be successful, women must adhere to treatment for five to 10 years, often despite distressing side effects and during which time less contact is made with the healthcare team (Winters, Habin, & Gallagher, 2007).

Notwithstanding the evidence from clinical trials suggesting distressing side effects and decreased

**Purpose/Objectives:** To understand the experiences of women undergoing antiestrogen therapy (AET) to treat breast cancer.

**Research Approach:** Content analysis of tape-recorded focus group interviews.

**Setting:** Breast oncology center of a large medical center in the northeastern United States.

**Participants:** Purposive sample of 21 women undergoing AET to treat breast cancer.

**Methodologic Approach:** A nonexperimental qualitative, descriptive design using open-ended interviews and content analysis to isolate themes.

**Main Research Variables:** Women's experiences with AET.

**Findings:** Five themes were isolated and were focused on the overall experience of having breast cancer: symptoms related to AET, shared decision making, being strong for others, discovering new priorities, and recognizing vulnerability.

**Conclusions:** Oral therapies are an increasingly popular treatment option for various types of cancer, particularly in women with estrogen-sensitive breast cancer. Although this type of treatment has been efficacious in terms of disease-free and overall survival, women undergoing AET face many challenges related to treatment. Healthcare providers need to understand women's perceptions of AET and its effects as a first step in the process of developing interventions to improve care.

**Interpretation:** More research is needed to distinguish whether the presence of preexisting chronic illness, differences in type of AET, age, and ethnicity impact the overall experience of women on AET. Individual interviews may be necessary to fully explore the experience. Oncology nurses should implement surveillance care to explore the effects of AET on women with breast cancer.

adherence over time, a gap exists in knowledge from a nursing perspective focused on describing the experience of women on AET. The current study aims to address that gap in knowledge by exploring women's experience of AET.

## Background and Significance

Most women with early-stage, endocrine-sensitive breast cancer receive oral adjuvant AET such as tamoxifen or the aromatase inhibitors (AIs) anastrozole, letrozole, and exemestane. Irrespective of age and menopausal status, tamoxifen is known to improve disease-free survival and survival in women with estrogen-receptor-positive, node-negative breast cancer (Fisher et al., 2004). Tamoxifen also has been shown to benefit women with node-positive breast cancers and reduce the risk of contralateral breast cancers (Gennari et al., 2008). AIs can provide additional improvements in disease-free survival beyond that of tamoxifen in postmenopausal women with breast cancer (Baum et al., 2003; Breast International Group 1-98 Collaborative Group, 2005; Coombes et al., 2004). AIs are recommended by ASCO (2009) for postmenopausal women either as up-front therapy or sequentially following two to five years of tamoxifen (Burstein et al., 2010) for a total treatment period of 5–10 years.

Results from clinical trials examining the effectiveness of AET have emphasized these important findings in regard to nonrecurrence and improved survival. However, AET widely is known to cause distressing symptoms that affect daily living, including arthralgias, hot flashes, fatigue, weight gain, decreased libido, and changes in mood and memory (Fallowfield et al., 2004; Fellowes, Fallowfield, Saunders, & Houghton, 2001; Tchen et al., 2003; Whelan et al., 2005). Those symptoms can affect a woman's ability to adhere to the long-term treatment plan on AET.

As many as 21% of women older than 65 years discontinue the use of tamoxifen within the first year of treatment (Fink, Gurwitz, Rakowski, Guadagnoli, & Silliman, 2004). In women with early-stage breast cancer on tamoxifen, nonadherence rates range from 25% in the first year of therapy to 50% by year four (Partridge, Wang, Winter, & Avorn, 2003). Partridge et al. (2006) reported that within the first year on an AI, one in five women with early-stage breast cancer did not adhere to treatment.

The experience that women on adjuvant hormonal therapy for breast cancer face is poorly understood. Stopping treatment early because of side effects or other reasons has the potential to decrease a patient's rate of survival from breast cancer (Fink et al., 2004; Ruddy, Mayer, & Partridge, 2009). Emerging evidence suggests that those who experience more intense side effects may in fact experience a greater treatment effect (Cuzick, Sestak, Cella, & Fallowfield, 2008). Oral therapies are an increasingly popular treatment option for various types of cancer, particularly for women with estrogen-sensitive breast cancer. As a result, patients are asked to take responsibility for the administration and management of their cancer treatment at home. Because of the less frequent interaction with the healthcare team in this post-acute treatment phase, healthcare providers need to

better understand women's perceptions of this long-term treatment and its effects on their lives. To date, however, no studies exist in the literature that focused on the experience of women on AET to treat breast cancer.

## Theoretical Framework

Rogers' (1992) Science of Unitary Beings (SUB) provides a nursing framework that has methodologic congruence with the study design. Several assumptions inform this type of inquiry, including what it means to be human, health, authentic presence, mutuality, and openness. According to Rogers (1992), people are holistic, complex, irreducible beings who are greater than the sum of their parts, which implies that an event such as breast cancer or its treatment cannot be separated from the whole of who the person is. People are historical beings with many life experiences, which add to the complexity of who they are as people. In addition, health and disease are not viewed as separate entities, but are integral to the whole of the person.

In choosing this theoretical lens, one underlying assumption is that the researcher does not assume knowledge of the experience. In addition, the researcher is open to the potential of what may be unearthed through the process of mutual dialogue with the participant. For that to occur, the researcher must be attendant to the person and be open to all possibilities. Rogers' SUB provides a nursing theoretical framework that is consistent with the methodology and further clarifies assumptions of the inquiry.

## Methods

### Design

A nonexperimental qualitative, descriptive study design was used to understand the experience of women on AET. Focus group interviews provide an opportunity for people who share a similar experience to come together and talk about it in a nonthreatening environment. In addition, Stewart and Shamdasani (1990) suggested that the use of focus groups is appropriate when the researcher is (a) attempting to obtain information about the topic of interest, (b) trying to understand how a new program works or not, and (c) learning or coming to know how respondents talk about the overall experience, which then may guide and stimulate quantitative studies. Patton (1990) recommended the use of focus group interviewing for the purpose of program evaluation. An underlying assumption with this approach is that the events are meaningful and of interest to all persons who share this circumstance.

### Data Collection Procedure

To ensure rigor, the following data collection procedure was followed. Participants were purposively recruited

from a breast oncology practice in a large academic medical center in the northeastern United States. Prior to the start of data collection, the institutional review boards (IRBs) of Massachusetts General Hospital and Boston College approved the study. All female patients diagnosed with estrogen-receptor-positive, early-stage breast cancer (stages 1–3) undergoing AET were eligible to participate in the study.

Patients who agreed to participate were given a consent form to review. They were contacted by telephone at home by a research assistant who first obtained verbal consent for the study and then obtained demographic measures. Afterward, patients were invited to attend a focus group interview. Once patients arrived for the focus group interviews, the focus group leader reviewed the IRB-approved consent and obtained participants' written permission.

The focus group leader facilitated the discussion and opened each session with the following standardized question posed to the group: "What has the experience of being on oral hormone therapy been like for you?" Each participant was provided with an opportunity to speak. Three focus groups of six patients each were arranged to take place at the hospital and one was scheduled by teleconference call. Data were collected until no new themes emerged.

A second member of the research team was present during each session to assist the leader with refocusing the interview as necessary, ensuring that each person spoke, and recording notes about the process. All interviews were tape-recorded and transcribed verbatim. In complying with ethical conduct of research, patients were ensured confidentiality, all data were coded and kept in a locked cabinet, and names were omitted in this article.

## Data Analysis

Descriptive statistics were applied to the demographic tool. Sources of qualitative data for the current study include transcribed materials, audiotapes, and field note observations. To ensure rigor in the process of data analysis, a conventional content analysis approach, as suggested by Morgan (1999), was used. The process required listening to all the tape-recorded sessions, followed by a total reading of all the transcribed materials. Then, data from each focus group were reread word by word to identify codes. Key words and phrases that captured the experience were highlighted. The codes then were labeled into categories based on how the codes were similar and dissimilar, such as being upset about the experience of breast cancer or recognizing that the experience resulted in a shift in priorities. The data then were reexamined to organize the codes into meaningful clusters under the categories. After examining data within each focus group, the clusters were examined across all focus groups and, through this process, five themes were identified.

To ensure trustworthiness of the findings regarding women's experience of AET, a number of steps were taken. First, the themes were reviewed with three nurse clinicians on the research team, each with experience in caring for these women and one who was a nurse practitioner with direct involvement in some of the participants' care. Themes were discussed and, once consensus was reached, the nurse practitioner reviewed themes with her panel of patients (none of whom were in the study) on AET to treat breast cancer. Women reported that these themes captured their experience and that they had nothing to add to the findings.

## Findings

Four one-to-two-hour focus groups with six to seven participants per group were held over a six-month period from summer to fall 2009. In total, 21 women ranging from 39–73 years of age participated in the study (see Table 1). The women attended a focus group session within 30 days of being recruited. All women who agreed to participate did so. Each focus group session resulted in 80–95 minutes of recorded data.

Generally, the topics discussed during the interviews included recounting being diagnosed with breast cancer; the side effects of treatments; personal changes that occurred since the diagnosis; and discussions around the care they were receiving, their fears, and overall concerns. Five themes were isolated: (a) being more than my disease, (b) getting old before my time, (c) needing to be in the driver's seat, (d) saving face and braving the storm for others, and (e) discovering new priorities and being vulnerable. The themes captured the essence of the women's lived experience of AET. Although little variation existed in responses of the women, such findings are presented as alternative perspectives.

### Theme 1: Being More Than My Disease

When asked to share the experience of being on AET to treat breast cancer, most participants countered with, "Where do you want me to begin?" The women overwhelmingly shared that discussing treatments was not necessarily the right place for them to begin the story. Participants wanted to share stories about themselves as people and not from the perspective of breast cancer and treatments. The reason they chose to participate in the focus group, they said, was because they felt no one really had asked them what their experience was like and they saw the focus group as an opportunity to explore this with other women and to be heard. All participants also expressed concern that focus groups may not be helpful because they had "heard bad things about support groups." In addition, women were challenged with where to begin their story. Often, women stated, "You should start at my diagnosis." Consistently, others



| Table 1. Demographic Characteristics |           |       |
|--------------------------------------|-----------|-------|
| Characteristic                       | $\bar{X}$ | Range |
| Age (years)                          | 55        | 39–73 |
| Characteristic                       | n         |       |
| <b>Highest education</b>             |           |       |
| High school graduate                 | 3         |       |
| Associate degree                     | 3         |       |
| College graduate                     | 6         |       |
| Graduate education                   | 7         |       |
| No response                          | 2         |       |
| <b>Marital status</b>                |           |       |
| Single                               | 4         |       |
| Married                              | 12        |       |
| Separated                            | 1         |       |
| Divorced                             | 2         |       |
| Widowed                              | 2         |       |
| <b>Cancer stage</b>                  |           |       |
| I                                    | 8         |       |
| II                                   | 11        |       |
| III                                  | 2         |       |
| <b>Caucasian</b>                     | 21        |       |
| <b>Current antiestrogen therapy</b>  |           |       |
| Tamoxifen                            | 4         |       |
| Aromatase inhibitor                  | 17        |       |
| N = 21                               |           |       |

offered, “No, make it before that—let us tell you what was going on before we got the cancer.”

Several women stated in a rather frustrated tone a need to be viewed by providers as a whole person and not in a reductionist way limited by the disease of breast cancer. Women overwhelmingly described not identifying with common breast cancer symbols. Several stated, “I do not even like pink” or “I am sick of the whole pink campaign.” Others noted, “It feels like we are being marketed.” One participant captured that sentiment.

I do not see myself as a breast cancer victim and I really hate . . . the pink ribbons, the bracelets, the walks, the fund-raisers. I want to scream when people who are really only trying to be nice give me pink things. I’m so much more than that. I do not identify with breast cancer and this “I’m a survivor” thing.

Both the focus group leader and observer noted that none of the participants who came to the focus groups wore any pink items, breast cancer bracelets, or any other symbols associated with breast cancer. As a result, the authors asked the women who participated by phone whether they wore such items and the response was a loud, collective “No.”

The conversation flowed naturally from general topics to treatments, and women shared what it was like to be on AET. When the participants did so, it was in the context of how treatment affected the whole; how they saw themselves being changed by the treatments as an individual, mother, sister, wife, friend, aunt, and daughter.

## Theme 2: Getting Old Before My Time

When women discussed what the experience of AET was like for them, they focused primarily on symptoms they were experiencing on a day-to-day basis and how that made them feel. A comment that many participants frequently made was “I feel like an old man.” Women described severe arthralgia and found it to be a very discouraging symptom. Other symptoms included hot flashes, weight gain, sleep disturbance, fatigue, decreased libido, and changes in mood. One participant described the multitude of symptoms.

Well, the surgery and initial treatments took away some of my feeling about being a woman, and just as that was getting better this just zaps that away. I have no—and I mean no—libido, I’m tired all the time, my brain is shot—chemobrain, they call it—and to top it off, I move like an 84-year-old man. When I go out, I actually wait for everyone else to get up from the table so no one can watch me get up because at first I just don’t get up. I’m stiff. I’m slow. It takes so much effort.

Most women described trying to manage symptoms on their own through a variety of methods, including yoga, swimming, herbal remedies, over-the-counter drugs, and “drug holidays.” Whether women always shared the multitude of symptoms with their providers was unclear, but one participant reported, “I did not say anything. I wanted to fight this.” Others reported they were offered a “drug holiday” if they did bring the symptoms up with their provider, but that the option to do so was both welcomed and feared. As one participant described, “It’s taken three weeks, but I feel good physically, but mentally I’m a wreck.” Some women expressed concern about oncology providers describing them as “lucky.” Those participants probably were told that because the type of cancer they had was considered treatable, but participants described that that statement made them feel like they had no right to complain about symptoms. They described feeling even more alienated from their healthcare providers at a time when follow-up visits already were less acute and less frequent.

Overall, the feeling of getting old had other consequences for these women. Many participants described a sense of time both speeding up and slowing down. All described an awareness about and fear of death. Several women described time as fleeting. As one participant explained, “I now know I will not accomplish all I had hoped for.” Another said she felt as though time was “standing still, as if I am watching from the outside looking in.” One woman offered,

I’m keenly aware that everything has sort of stopped, slowed down from the day I heard I have breast cancer. And, at the same time, I’m getting older fast, faster than I could have ever imagined.

Some younger women added that this awareness of time also contributed to a need to face the possibility of “death out of sequence” because they felt they may die before they saw their children grow up, were ready, or before their parents died. Several women expressed it as feeling “old before my time.”

Several participants in each focus group also expressed concern about how symptoms may impact their overall health, particularly when considering the potential to develop other chronic illnesses such as heart disease. Multiple symptoms related to oral agents contribute to a sense of aging. As a result, women of all ages expressed concern about what those symptoms may mean for their overall health, particularly in relation to ongoing treatment that extends for years. Women described family histories of heart disease and worried that depleting their estrogen stores may place them at risk for that comorbidity. They worried that the decreased level of activity and weight gain they were experiencing would make them susceptible to cardiac disease; others worried that it might cause arthritis or osteoporosis. Although women reported that the specialist care was the best, they expressed a concern about other healthcare needs not being addressed. Participants described feeling caught between primary care and specialty care. One woman stated succinctly, “For everything else that can go or be wrong—no one owns you.”

### Theme 3: Saving Face and Braving the Storm for Others

Many women expressed a need to hide the way they were feeling from others. They tried “to act like nothing was wrong.” The participants also felt that people asked many questions in the time period immediately following diagnosis, but now they questioned why people did not ask how they were anymore. The women discussed why that might be the case and wondered whether they sometimes hid how they were feeling too well. The participants realized that perhaps it had taken them this long after diagnosis to recognize that nothing would ever be the same for them. Several women wondered aloud whether the need to pretend everything was alright in some way contributed to them getting cancer in the first place. As one participant described,

So, at work, I know I have to hide it. Here, I am the boss, always in control, busy, overcommitted . . . [it] could explain how I got here in the first place. Now, not so much—hiding my hot flashes, my mood, my need to say who cares? It just doesn't matter to me, but I feel like if I say what I want to say, everyone will be like, “Whoa, what happened to her?” So I don't talk about it there. They all think “She had breast cancer and now she's fine,” and I think, “Well, I'm still on this treatment . . . miserable . . . never will be the same again, and guess what? I just do not care if we ever make another deadline.”

Participants questioned the role of stress in relation to their diagnosis. Several women stated that they had a particularly stressful time one year prior to their diagnosis. One exemplified that idea when she said, “If I could tell you about what was going on the year before this happened, you'd see what stress had to do with it.”

None of the women in the current study described having a large social support system, although a few described having one close friend they could talk to about “some things.” Many did not share what was going on in their lives related to breast cancer or its treatment with coworkers, friends, or family. Women reported husbands or boyfriends either as a source of support or added burdens. Most women reported their partner as the one person who was helpful and “with them the all the way.” When partners were not a source of support, several women described the men as being unable to deal with the situation and “checking out.” For most women, that presented added stress, but some women recognized it as the way they always coped and responded to each other and, therefore, not stressful.

### Theme 4: Needing to Be in the Driver's Seat

Women recognized in themselves a lifelong pattern of being in control and saw this as a personal strength that helped them get the best care possible once diagnosed with breast cancer. They also considered it important to tackle the disease in the way they had tackled other situations in their lives. One woman described it as “bringing in all the resources,” and another recounted, “I called everyone I knew to get their opinion, researched everything, and then went at it head on.” Most women also attributed this quality to having a positive attitude about their cancer, the treatments, and outcomes.

Participants emphasized the importance of being an equal partner in their care, but reported feeling left out of many decisions, which they found frustrating. One woman described,

They keep saying, “We are going to get you through this;” I think—I mean, I thought—that meant *with* me, but I've learned it means you're supposed to let them *take* you through it and not ask too many questions.

Women found it particularly frustrating that the entire plan, including each treatment and how long it would take, was not provided to them at the time of the first consultation. They felt left out of the loop in their care and as if they were being protected, and described this as wrong. One participant captured the essence of this sentiment when she said,

I feel like you try to read everything you have to [read] to get through this and you do your best to be informed, ask questions, and get straightforward answers, but they hold things back. . . . There is the surgery, and you think, “I guess I don't need any

of these other treatments because they would have told me,” but they don’t—they protect you, I guess? So then it’s radiation and you read up on that . . . then it is the chemo[therapy], and you read more . . . then it is five years of tamoxifen and, finally, you think this is it and then they mention the next drug for the next five years . . . always a carrot in front of you, but never a plan *with* you.

Overwhelmingly, the women wanted and expected to be a partner in their care. Many of the women found the medical system difficult to navigate and secretive when it should be an open partnership.

### Theme 5: Discovering New Priorities and Being Vulnerable

While recognizing their need to be in control as a personal strength, women in the study also recognized its limitations. All participants described a sense of being forever changed (e.g., “You can’t go back”). As women recognized the need to reorganize priorities, they also reported fearing change. Several described always being in control and that letting go would be scary. Some noted that this was a process that would take time, from diagnosis through years of treatment. Most described feeling vulnerable and afraid of “what may be.” A few participants described wanting to make changes, realizing it was the right thing to do, but reported being unable to do so. One participant summarized that, saying,

I always had all these things I was going to do when I had time . . . maybe when I retired, and now I realize I may not live so I should just do them, but to do that I have to sort of stop being who I am, so that’s a little scary because what if I stop being who I am and those things no longer seem so important to me . . . then what?

Women were able to identify this need to shift as something they needed help with and also described not knowing how to get the kind of help they needed. They felt that being left on their own to do this was wrong and they reported feeling abandoned by the healthcare team at a vulnerable time. Participants suggested that maybe they “needed to talk this through in a group like this,” or “go to some classes that helped address this.” All participants reported that not having an ability to talk with each other with a nurse leading the group was a major gap in care.

Participants reported feeling connected to one another through the focus group process. Often, the members of each group exchanged telephone numbers so they could stay in touch after the initial group. In addition, they used the focus group as a way to share nonconventional strategies to improve symptom management with each other, including herbal remedies, over-the-counter drugs, and other complementary strategies not supported by research to date.

Although the women seemed to enjoy the experience and support they found in the focus groups, field note observations and comments made by some participants suggested that not all women felt as comfortable talking in the group about their experience. For example, one woman was particularly concerned about sexuality issues, but was very hesitant to discuss this. Other examples of topics related to AET that women did not talk as openly about included work or family issues, stopping treatment, and concerns about other chronic health problems.

## Conclusion

Patient-centered care is defined by the IOM (2001) as care that “encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient” (p. 48). Relaying their experience through focus groups allowed the participants of the current study an opportunity to validate distressful symptoms, share their experiences, and receive support from one another. Focus group interviews either in person or by telephone were an effective way to gather information. In the current study, the focus groups also provided participants with peer support, which served more as a much-needed intervention—something that should be explored further.

Not all women were comfortable sharing all concerns in a group format, which suggests that although focus groups provided insight to the overall experience, individual interviews may be necessary to understand the issues in more depth. In addition, because many women described other chronic health problems or concerns related to a family history of other health issues, a need exists to understand the coexisting health problems of these women as they initiate and try to continue with the treatment plan.

The findings reported in the current article suggest that these women balanced many issues and concerns related to side effects of treatment, as suggested by clinical trials and nurses working with this population of patients (Winters, Habin, Flanagan, & Cashavelly, 2010; Winters et al., 2007). Many participants in the study reported that, despite finding the symptoms associated with AET difficult to manage, they tried to do so on their own. Although they reported receiving state-of-the-science oncology care, participants also reported feeling alienated from their providers as the treatment shifted to long-term, less acute care. Those findings are supported by prior research with those who have described the burden of breast cancer as ongoing past the initial diagnosis and active treatment phase (Ashing-Giwa et al., 2004; Kookan, Haase, & Russell, 2007). Participants in the current study reported that they attended the focus groups because they were seeking solutions to



the problems they were experiencing and because they felt they were left on their own to manage symptoms, which suggests a need exists for interventions aimed at improving symptom management and the overall survival experience.

Women described feeling that they were left to independently manage the distressing symptoms of AET (e.g., arthralgia, hot flashes, fatigue, depression, cognitive changes) for a prolonged period of time. That vulnerable time between acute oncology care and the resumption of primary care is an issue ASCO (2009), Hewitt et al. (2006), NCI, (2011b), and the Oncology Nursing Society (2009) have begun to address. Women with estrogen-sensitive breast cancer are on oral AETs for a period of 5–10 years, with minimal follow-up from oncology providers. In addition, primary care providers often are unfamiliar with the AET trajectory and are tentative about managing the symptoms and long-term effects (Hewitt et al., 2006). Findings from the current study suggest that the existing survivorship models may not address the needs of women on ongoing AET treatment.

Findings from studies of breast cancer survivors indicated that women who received nurse-led interventions had improved outcomes in relation to quality of life (Meneses et al., 2007, 2009), physical and psychological functioning (Scheier, 2005), fatigue and depression (Stanton et al., 2005), and enhanced cognitive reframing (Mishel et al., 2005). Despite the promise of that work, women with breast cancer on AET have been excluded from the sample of many studies to date (Mishel et al., 2005; Scheier et al., 2005; Stanton et al., 2005) or not specifically been the focus (Meneses et al., 2007, 2009). A need exists for more research that identifies the needs of women on AET and, second, develops and tests interventions aimed at improving women's overall experience of AET over the entire treatment trajectory.

Lastly, the participants in these focus groups did not identify with breast cancer as a disease and found the need to do so limiting. They wanted to be known by more than "pink ribbons" and "breast cancer pins, walks, and yogurt." That suggests congruency existed with the theoretical assumptions of Rogers (1992), who stated that human beings cannot be reduced to a disease entity.

## Limitations

Although the sample of patients recruited for the current study was representative of the patient population at the cancer center, the sample was homogenous and well educated, and lacked ethnic and racial diversity. Another limitation of the study was that patients were grouped irrespective of type of AET (selective estrogen receptor modulator versus AI) or menopausal status. In future studies, care should be made to reach out to a

larger, more diverse population. Participants should be stratified by type of AET and menopausal status. Lastly, individual interviews may be necessary to more fully understand the experience, as the group process seemed to inhibit some women.

## Implications for Nursing

Oral therapy is an increasingly popular option for many types of cancer. Although many advantages exist to this type of treatment, it does create challenges. Women on AET are on treatment that extends 5–10 years and, as a result, require different healthcare surveillance, ongoing support, and evidence-based strategies aimed at improving their experience. Identifying the unique needs of women on AET is a first step in developing targeted intervention strategies to improve care. The current study contributed to nursing knowledge by providing insight into women's experiences of long-term oral AET. Oncology nurses must be sensitive to women's concerns of long-term therapy. Nurses in these settings have a role in assessing the patient's response to ongoing treatments and they should consider implementing improved surveillance care with women on AET to explore not only symptoms, but the overall experience of what it is like to be on long-term treatment.

Additional studies should be done with women individually to understand the experience more fully and to determine whether differences in age, ethnicity, and type of AET affect the overall experience. Research aimed at reducing the gap in survivorship care of these women has the potential to impact long-term outcomes such as quality of life, adherence to the treatment plan, and long-term survival. Although data on the presence of other chronic conditions was not collected as part of the current study, given some participants' concern about other chronic conditions, this information should be obtained in future studies.

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