The Experience of Initiating Oral Adjuvant Treatment for Estrogen Receptor–Positive Breast Cancer

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Purpose/Objectives: To describe the experience of women with estrogen receptor–positive breast cancer who are initiating oral adjuvant therapy and to determine what they describe as facilitating and/or hindering this experience.

Research Approach: Qualitative inquiry.

Setting: Massachusetts General Hospital Cancer Center in Boston.

Participants: 14 women aged 48–81 years.

Methodologic Approach: Qualitative, descriptive study using content analysis.

Findings: Five themes were identified: (a) feeling overwhelmed and abandoned despite highly skilled medical care, (b) processing the trauma and putting it in perspective, (c) keeping up the facade while feeling vulnerable, (d) needing to connect cautiously, and (e) moving toward healing and being aware.

Conclusions: Each participant who was initiating oral adjuvant treatment described many unmet needs. Women who were caregivers, were older aged, had several chronic illnesses, and were on several medications reported more difficulty transitioning to oral adjuvant therapy.

Interpretation: This study suggests that nurses need to collaborate with other members of the healthcare team to assess the needs of and provide comprehensive care to women initiating oral adjuvant therapy. This is particularly true for women who are older aged, self-reported caregivers, and on several medications, and who have chronic comorbid conditions.

Breast cancer survivors face many physical, psychosocial, informational, and supportive care needs, and those needs are often unmet (Armes et al., 2009; Burris, Armenson, & Sterba, 2014; Cappiello, Cunningham, Knobf, & Erdos, 2007; Hewitt, Greenfield, & Stovall, 2005; Kantsiper et al., 2009). As a result, intervention research (Meneses et al., 2009; Mishel et al., 2005; Scheier et al., 2005; Stanton et al., 2005) has begun to address the survivorship needs of women during this vulnerable time. In these large-scale studies, all women with breast cancer are considered collectively; however, some are no longer on treatment, and others are in a phase of initiating oral adjuvant therapy. In research to date, the specific needs of individuals who are faced with initiating oral treatment for estrogen receptor (ER)–positive breast cancer are indistinguishable from all breast cancer survivors.

ER-positive breast cancer accounts for the majority of breast cancers in women older than age 45 (Anderson, Katki, & Rosenberg, 2011). Women with ER-positive breast cancer undergo primary treatment that is usually one year in duration and includes some combination of surgery, chemotherapy, and radiation. After primary treatment, these women are prescribed oral, endocrine-based hormone therapy (adjuvant therapy) to prevent recurrence for 5–15 years.

During this time, follow-up oncology care becomes less frequent, and the illness shifts from acute to chronic in nature.

Clinical trial research indicates that oral adjuvant therapy improves the risk of recurrence and survival after a diagnosis of primary breast cancer (Burstein et al., 2010; Dowsett et al., 2010; Early Breast Cancer Trialists' Collaborative Group, 2005). Evidence from clinical trials reporting side effects of oral adjuvant treatment shows that therapy is associated with a range of physical and psychosocial symptoms, including cognitive and emotional changes, musculoskeletal and vasomotor symptoms, vaginal dryness, sexual dysfunction, urinary problems, weight gain, insomnia, and fatigue (Early Breast Cancer Trialists' Collaborative Group, 2005; Ochayon, Zelker, Kaduri, & Kadmon, 2010; Stan, Loprinzi, & Ruddy, 2013). If persistent, these symptoms can result in increased healthcare use (Hanchate, Clough-Gorr, Ash, Thwin, & Silliman, 2010), decreased quality of life (Bloom, Petersen, & Kang, 2007; Janz et al., 2007; Ochayon et al., 2010), and decreased adherence to endocrine therapy (Aiello Bowles et al., 2012; Henry et al., 2012; Murphy, Bartholomew, Carpentier, Bluethmann, & Vernon, 2012). Notwithstanding the untoward effects, oral adjuvant therapy remains an important part of treatment for patients with ER-positive breast cancer (Burstein et al., 2010).

Findings from studies exploring the experience of women on oral adjuvant therapy suggest that women struggle to manage symptoms associated with treatment, with little guidance from the healthcare team (Flanagan, Winters, Habin, & Cashavelly, 2012; van Londen et al., 2014). Women who participated in one of these studies suggested that the most critical time period was the first year during which they were expected to initiate oral adjuvant therapy (Flanagan et al., 2012). The experience of these women during the initiation of oral adjuvant treatment for ER-positive breast cancer informs the basis for this study.

The specific aims of this study are (a) to describe the experience of women with ER-positive breast cancer who are initiating oral adjuvant therapy and (b) to determine what women initiating oral adjuvant therapy describe as facilitating and/or hindering this experience.

Methods

This study employed van Manen's (1997) hermeneutic phenomenologic design for data collection and analysis. Hermeneutic phenomenology is an appropriate design when little is known about the phenomena of concern, which, in this case, is the lived experience of initiating oral adjuvant therapy. According to the design, a conceptual framework is not called for; however, the team thought recognizing and bracketing ideas or conceptualizations was important. The members of the research team either care for women on oral adjuvant therapy or have been involved in research aimed at understanding these women's experiences. All members of the team were required to bracket previous experiences and to note what they thought they understood about women with breast cancer who were initiating adjuvant therapy.

Setting and Participants

A convenience sample was used to invite 15 women with ER-positive breast cancer who were initiating oral adjuvant therapy. The setting for the study was Massachusetts General Hospital Cancer Center, a large academic cancer center in Boston. To be eligible for study enrollment, participants had to be in the first year of initiating oral adjuvant therapy, be aged 18 years or older, have stage I–III ER-positive breast cancer, and be willing to discuss their experience of initiating oral therapy.

Before commencement of this study, institutional review board (IRB) approval was obtained. The principal investigator (PI) ensured privacy and confidentiality for the research participants by coding and deidentifying all data, keeping data in a locked cabinet in a locked office, and providing participants with pseudonyms.

Procedure

Nurse practitioners (NPs) who provided direct care to the potential participants used eligibility criteria to screen patients during a routine clinic visit. The NPs invited and provided interested patients with a recruitment flyer and an informed consent form for review. If the patient stated interest in participation, the NP notified the PI.

Within two weeks, the PI contacted patients by telephone to determine if there was ongoing interest in participation, reviewed the consent form, and obtained verbal consent. Participants were invited to choose the location for the interview. The plan was for at least one interview per person, with an option for a second interview. The demographic tool was then completed by telephone. The tool captured sample characteristics, including age, stage of disease, comorbid conditions, and medications.

Prior to each interview, the PI took time to do guided imagery to center and bring focus and attention to listening to each participant's story. To begin the dialogue, an open-ended question, such as, "What has it been like for you to initiate oral adjuvant therapy?" was asked of each participant (see Figure 1). All interviews were conducted by the PI, who is an expert in

qualitative research methods. Interviews were digitally recorded and transcribed verbatim. The PI also kept a reflexive journal to capture nuances and thoughts about the process of data collection and analysis.

The process for the qualitative data collection is iterative. Therefore, other steps of data collection included listening to and reading the transcripts and initial interpretation of the data. After each recorded interview, the PI listened to the recording to obtain a gestalt of the participant's story. Van Manen (1997) suggested that this gives the PI the opportunity to begin initial coding and to determine if a need exists for further exploration of ideas that emerge.

Analysis

The sources of data for this study were the qualitative interviews, the PI's reflexive journal, and the demographic tool. Descriptive statistics were used to analyze the demographic tool. Data analysis of the qualitative data was conducted using van Manen's (1997) approach. The observations in the reflexive journal included times when participants hesitated to answer a question, changed the topic, cried, or asked for the question to be rephrased. For example, it listed participants who either hesitated to answer or changed the topic when asked for confirmation of treatment initiation.

Several steps were used to ensure trustworthiness, including immersion in the data collection period, an in-depth analysis of the data, and confirmability. Immersion in the data collection included interviewing participants until data saturation was achieved and ensuring that no follow-up interviews were necessary. Data saturation was achieved by the 12th interview. However, interviews were conducted with two more participants. When recruited, each of these participants had agreed to participate prior to data saturation being reached; as a result, they were interviewed. The reasons for the delay between recruitment and enrollment/interview varied. One participant delayed treatment and could not be enrolled until she initiated treatment, and one had agreed to participate but required a total hip replacement and wanted to wait until she was home again.

The in-depth analysis included the PI considering initial themes within cases, listening to each recording again and rereading each transcript to determine themes across cases. The PI listened to the recordings to determine if ideas required further exploration through a second interview but determined no follow-up interviews were needed.

The PI achieved confirmability by meeting with the other members of the research team to review the findings and discuss whether they mimicked stories they had heard from patients. The PI also asked the members of the research team to share the emerging and final themes with patients in their practices who were in the same phase of transition but not enrolled in the study. The nurses and patients who heard the early and final themes reported that they captured their experience.

- What has it been like for you to initiate oral adjuvant therapy? What has this been like for you in terms of your day-to-day life?
- Have you had challenges initiating oral adjuvant therapy? If so, would you please describe some of the challenges you have had to deal with during this time period?
- If you have had challenges, what or who has helped you to handle the challenges?
- Have there been things or people that have not been helpful for you during this transition period?
- Have you had things that have gone well during this time?
- What or who has been supportive to you? Why is this so? What has this been like for you?
- Describe ways the healthcare team did help or could have helped you through the initiation of oral adjuvant therapy.
- What type of information would you want to receive from your healthcare providers to ease your transition?
- Describe suggestions you would make to the healthcare providers to make the initiation of oral therapy better for other people like you.
- What would be the best way for you to receive information from your healthcare team (for example, in-person clinic visits, hospital- or community-based support groups, telephone follow-up calls from your providers, web-based information, a handheld device, a newsletter)?

FIGURE 1. Interview Guide

Sample

Fifteen patients were approached and invited to participate. All provided consent, but only 14 were enrolled because one person did not initiate oral adjuvant treatment and could not be enrolled. All participants were Caucasian. Although the original intent was to enroll only those with stage I–III ER-positive breast cancer, another participant who had stage III breast cancer also initially delayed initiating oral adjuvant treatment. She later initiated treatment and was enrolled. It was not until the interview was nearly complete that this participant revealed that she had recently been informed that her breast cancer was now stage IV. A protocol deviation requiring no action was filed with the IRB. The final sample included 15 women with stage I–IV ER-positive breast cancer aged from 48–81 years, with a median age of 62.8 years (see Table 1).

Participants opted to be interviewed at home by telephone. Although the focus of this study was on the initiation of oral adjuvant therapy, participants began the interview by describing the primary treatment phase before describing the initiation of oral adjuvant

therapy. The interviews were digitally recorded and lasted an average of 40–60 minutes. Data collection occurred from 2013–2014 during an eight-month period. Five themes were identified: (a) feeling overwhelmed and abandoned despite highly skilled medical care, (b) processing the trauma and putting it in perspective, (c) keeping up the facade while feeling vulnerable, (d) needing to connect cautiously, and (e) moving toward healing and being aware (see Figure 2).

Findings

Feeling Overwhelmed and Abandoned Despite Highly Skilled Medical Care

Participants who were in the process of initiating oral adjuvant therapy described being overwhelmed by what they had been through during primary treatment. They described feeling numb and reported that they needed a break. The participants wanted to get their lives back and, as a result, made choices about following the recommendations of the oncology team. One such decision was delaying initiation of prescribed oral adjuvant therapy. Of the participants who enrolled in this study, four delayed initiating oral therapy, which was revealed in the consenting process. Although women expressed a desire to enroll in the study, they were not initially eligible, but each person who was found to be ineligible asked to be contacted again because they planned to start treatment. Once they initiated treatment, they were enrolled. The delay in treatment ranged from several weeks to three months.

Once they were enrolled, these women were asked about delaying the initiation of treatment, and a typical response was, "Over this last year, I did everything I was supposed to. I have other worries I need to take care of before starting that." Another was, "I owe so many people favors. They've had enough of me and my cancer. So have I." When asked if they had discussed this decision with the healthcare team, women described not feeling comfortable to do so because they were concerned that they would disappoint their providers for not following the treatment plan as prescribed. One person said,

> I just keep refilling the prescription. . . . I said I was taking it. They seemed happy I had no symptoms. . . . I mean, I planned to start it, and I did. I just needed to get other [health-related] things in order, but after all they have done for me, I could never just say I didn't start yet. As I am saying this to you, I know how crazy it sounds. I could not imagine what it would be like for them to hear me say it.

Overwhelmingly, the participants in this study reported feeling that initiating oral treatment was difficult. This was primarily because the number of visits to their care team became less frequent. Although the women reported they were happy to not have to see providers as often, they also reported being concerned about feeling that they had no one to answer their questions, many of which were related to symptoms associated with chemotherapy, radiation, surgery, and oral adjuvant therapy. These included "chemobrain," joint achiness, hot flashes, anxiety, and changes in sexual function, such as dyspareunia.

When questioned about this sense of disconnectedness to providers, they conceded that they knew they could call their providers, particularly their oncology providers, but that a lack of coordinated care between all of their providers (e.g., primary care provider, cardiologist, orthopedist, oncologist) and a

TABLE 1. Participant Characteristics (N = 14)

Characteristic	n
Age (years)[a]	
44–49	1
50–54	3
55–59	1
60–64	4
65–69	2
70 or older	3
Marital status	
Single	1
Widowed or divorced	3
Married or living as married	10
Living situation	
Living with another person	12
Living alone	2
Education level	
High school graduate	1
Associate's degree	2
College graduate	7
Post-college graduate	4
Cancer stage	
I	3
II	7
III	3
IV	1
Prior treatment	
Surgery only	2
Surgery and radiation	1
Surgery and chemotherapy	3
Surgery, radiation, and chemotherapy	8
Number of other comorbid conditions	
1–2	2
3–4	4
5–6	4
7 or greater	4
Number of other medications	
2–4	3
5–7	5
8 or greater	6

[a] Range = 48–81 years

lack of a bridge to primary care existed. As a result, they reported feeling like they were "left to figure it out in their own." The women reported that a lack of understanding about all of their concerns existed and that no one provider knew their whole story. They also reported that no one asked and that it was too uncomfortable for them to bring up certain topics, such as sexual discomfort. This resulted in care that was fractionalized and left them feeling abandoned.

In addition, women reported that, as they were initiating oral adjuvant treatment, they were also attempting to resume normalcy. The women noted that this coincided with an awareness of friends, who had previously been a support, no longer being available. The women felt these supports now viewed them as being "better" and not needing help. In addition, the women described feeling a void in care because there was such a significant gap in the intensity of care, and little guidance was offered once primary treatment ended.

Several women described the need to refocus on all aspects of their lives, including being a caregiver and other health problems. This was particularly true if they were aged 60 years or older, reported being a caregiver, had several comorbid conditions (particularly cardiac disease), or if surgery for other health problems was pending. They described this as a time when they needed help navigating and prioritizing their health concerns but felt this was not something they could discuss with their oncology, primary care, or other specialty teams. They also described that, with less contact with the healthcare team, they felt they were alone and without guidance about initiating oral adjuvant treatment. They reported making decisions independently that seemed reasonable based on their perceived risk. One participant described balancing resuming caregiving and her own health concerns.

> I'm a mother, I have a family, a job, and now any help or kindness I had over the past year, well, that's gone. Now it's back to me caring for others—something I do all too well and, in the process, forget me.

Participants reported enjoying being part of the research because of the ability to share concerns with a nurse not directly involved in their care. They reported that telephone follow-up would be an appropriate way to stay connected but that they would "not want to sit by the telephone waiting for a call."

They also reported a need for their oncology providers to communicate better with other care providers, so each person knew and understood the treatment plan and all related health issues, as opposed to only the breast cancer and its treatments. One person who delayed initiating treatment said,

FEELING OVERWHELMED AND ABANDONED DESPITE HIGHLY SKILLED MEDICAL CARE

"It's not easy to bring up things like painful intercourse. I wish [healthcare providers] brought it up."

"I ask my oncologist what to do about my hip, and he tells me to talk to my primary. I talk to my primary, and he tells me to talk to an orthopedist. Then I finally meet with him, and he told me talk to my oncologist."

PROCESSING THE TRAUMA AND PUTTING IT IN PERSPECTIVE

"It's like your last infusion is ending, and you can see everyone thinks, 'OK, finally [you're] back to normal.' It feels like they are ready to pounce on you. I'm thinking, like, really, I need a minute. I've been to hell and back."

"You just need a way to put this all in perspective."

KEEPING UP THE FACADE WHILE FEELING VULNERABLE

"You know what they say, fake it to make it, but I'm a wreck on the inside."

"I do not want to look at my husband or kids and see worry in their eyes. . . . That, I can't take."

NEEDING TO CONNECT CAUTIOUSLY

"While it would be nice to talk to others, I do not want to take on their issues."

"I'd only want talk to others if it in some way helped me. I cannot do more than that now."

MOVING TOWARD HEALING AND BEING AWARE

"I have a lot to live for, be grateful for. . . . I just have to have my head catch up to that idea."

"I need to make new priorities, refocus my energies."

FIGURE 2. Themes Identified and Supporting Quotes

"My whole family has cardiac illness. . . . I worry . . . my weight, my lipids. . . . No one seems worried about my heart anymore." Another participant who reported inconsistent use of oral adjuvant therapy described the following.

> At my age [64 years old], for every year I take the pills, they say you get five years, so that takes me to 69. So, say I take them for two [years], is 74 reasonable? I think, given my family history of cardiac problems, that would be good. But cardiac problems, arthritis? No one seems to remember that anymore. You need it to be individual.

Processing the Trauma and Putting It in Perspective

Women described the experience of ER-positive breast cancer and its treatment as "traumatic," "numbing," and "trance-like." Many described experiencing fear and anxiety about initiating oral adjuvant therapy because of a fear of new symptoms that might contribute to them not functioning optimally. In addition, the time period of initiating therapy coincided with the end of

the primary treatment period. They reported that they needed to "get through" or "put up a fight" during the primary treatment phase, but now there was a natural pause in the process of care that resulted in them reflecting about what they had been through.

Although they described being well supported during primary treatment by the team because of frequent visits at regular intervals, they also described not being able to discuss the trauma related to the experience or their concerns related to life goals and priorities now that they had faced a life-threatening illness. All participants worried about being an ongoing burden to others as they initiated oral adjuvant therapy. They discussed a strong need to work through issues around fears related to death, life's purpose and meaning, and how they transitioned from caring for others first to prioritizing self.

The participants also described feeling as if they had post-traumatic stress syndrome. They also felt they had little to no support to help them deal with all the emotions they were experiencing as they were initiating oral adjuvant therapy. One participant said, "Just as I was feeling ready to talk, no one was there to listen. Care changes; friends move on to the next big thing." Another participant said, "I was in a trance, traumatized really, but, at this point . . . you're somehow supposed to be over it."

Participants consistently recalled that, during the primary treatment phase, performing daily routines, such as working or parenting, helped to "keep their mind off things" or "stay on a schedule, stay focused." At the time of initiating oral adjuvant therapy, participants described a need to process the experience of what they had been through during the past year and, more importantly, realign priorities. One participant said, "Everything in my life was on hold while I did this thing called the fight [breast cancer]. Now I need to get back to living but not the same way. That takes work." Another participant said, "I need to work with someone who could help me redefine who I am, what's important . . . really, in every aspect of my life." This need to discuss what had happened and realign priorities was related to many aspects of the participants' lives, such as self-care, other health-related concerns, family, and work.

Keeping Up the Facade While Feeling Vulnerable

As they transitioned to oral adjuvant therapy, participants described a need to appear "normal." One participant said, "I tried to act like nothing had happened. I dressed nice, did my makeup, all of it. I had to . . . for my family." Although some admitted to doing this to be strong for family, others described not wanting to focus on breast cancer and not wanting sympathy.

> I didn't, I don't want sympathy. . . . It's best to act like nothing happened. If you do that, everyone goes on with their life. . . . People get busy.

Some participants were able to acknowledge that this facade of appearing as if things were "fine" while they initiated oral therapy and had many concerns contributed to a lack of support from the healthcare team, family, friends, and coworkers. They reported that, retrospectively, they recognized they were acting as if they did not need support when they actually needed more support as they initiated oral adjuvant therapy. Although they described being very aware of the need to appear normal, they also described "not knowing what else to do," "not wanting pity," and a "need to be in denial for a little bit." One participant said, "Part of the so-called fight is to look good." Another said, "Rather than encourage this phoniness, the nurses and doctors should call us on it. It's like all of us are in denial."

One particular concern women discussed was a need to address concerns about death and dying. Participants described that initiating oral adjuvant therapy resulted in them reflecting on what they had been through. They described wanting to put the experience they were going through in perspective and to make meaning of what had occurred. This time period allowed them to recognize their vulnerability. One woman said,

> Death, now that [I'm thinking about it], does not fit into fighting breast cancer. I was in as much denial [about facing death] as the next person before my diagnosis, but now I do. But I think [the doctors and nurses] go along pretending it's not something you are thinking about or need to discuss.

Another participant said,

> [Death] never comes up, but now I'm aware that this thing I never really gave much thought to is very possible, and I wonder: Have I done all I want to do? Heck, what is it I even wanted to do? Did my life have meaning? Is there something I should be doing?

Women expressed frustration with what they perceived as a lack of balance between a need to fight cancer and appear strong and a need to have discussions about life's purpose, personal meaning, and death. Although they attributed their need to do this with a need to "be strong for others," they perceived the healthcare team as being insensitive by not addressing what participants described as "obvious concerns for anyone who has faced cancer."

Needing to Connect Cautiously

Participants were asked how they thought the team could provide care that better addressed their needs

as they initiated oral therapy and transitioned from very frequent visits to less frequent visits. The participants all described wanting to connect with others who shared the experience, but they also described wariness because they recognized a need to focus on themselves. One participant said, "I would like to talk with others, and this will sound horrible, but I don't want to focus on their problems. I want to focus on me, so I have to navigate that." Although the idea of a support group sounded good, participants recognized that getting involved in such a thing would cause them to not be able to set appropriate boundaries. They also feared that they would start taking care of others rather than oneself. One participant said,

> I like the idea, but I wouldn't do a group thing because my tendency is to be a caregiver, and I'd be afraid I would be helping everyone else and forget about my own needs.

The participants reported that, although they were relieved that they no longer had to go to the hospital for frequent appointments, initiating oral adjuvant treatment and having such a gap in time between provider visits contributed to feeling a loss of connection. They reported that they thought it would be helpful to have some sort of ongoing interaction with the experts that had cared for them as they initiated oral adjuvant therapy. They also thought it would be important for all of their doctors—from the oncologists to primary care physicians to other medical or surgical specialists—to communicate better with one another so that everyone was aware of a comprehensive plan of care that addressed all of their health problems and concerns.

Participants wanted more information about specific threats to future health based on (a) their treatments, (b) other comorbid conditions and medications to treat those problems, and (c) family history. In addition, they wanted to discuss and/or have more information about (a) the latest relevant trends in breast cancer treatment, (b) optimal diet and exercise regimens, (c) healing and stress reduction, (d) sexual health, and (e) meaning and purpose.

Participants initiating oral adjuvant treatment described that they wanted this support to be individualized. Participants were specifically asked about the best way to deliver this sort of care (e.g., in person, telephone, web-based communication, a newsletter, a mobile application). They uniformly reported that they would not come back to the hospital for a support group or an education, exercise, or nutrition class. They reported enjoying the opportunity and anonymity of talking by telephone for this research, but they reported not wanting to be "tied to a telephone" for all care. They thought telephone communication might be useful for follow-up related to some care, including working through more challenging issues, but they expressed that such a forum needed to address their concerns and not be a checklist from providers.

Several participants suggested that a website with the ability to chat with their providers or with women who shared their experience of initiating oral adjuvant therapy might allow them the opportunity to explore information at times that were convenient to them and the choice of whether to participate. They reported that information about oral adjuvant therapy on the Internet was overwhelming, not individualized, and sometimes fraudulent. They also recounted that, at the time of diagnosis, searching the Internet was terrifying because they did not know what to believe. As a result, they specifically stated that they wanted their care providers to vet any information posted on a website.

Moving Toward Healing and Being Aware

Many women in this study described a desire or actual movement "toward healing" that was occurring as they were initiating oral adjuvant therapy. They described this as finding peace and a new appreciation for life. One woman said, "It takes time and being able to work it through. . . . I know, I mean, it sounds trite, but I am so appreciative of things now. I move, I breathe, I'm in tune with things." For the women who wanted to experience healing, but had not, this process was particularly challenging and upsetting. They recognized a need to change the way they had been living but reported being overwhelmed with where or how to begin. These participants reported feeling a lack of guidance in this area. The healthcare team confused them by suggesting that they set new priorities while simultaneously encouraging them to continue to work, be involved with family, and "live life." They reported recognizing that cancer may be presenting them with an opportunity to reexamine their lives but also acknowledging they did not know how to do so.

The participants also reported that this time of initiating oral adjuvant therapy is an ideal time to consider new changes. However, because of the lack of ongoing visits with providers who knew them, added challenges existed in terms of obtaining assistance. One participant said, "Now that this fighting part is over, no one addressed this new me I am to become. [There is] no help navigating it." Another participant said,

> I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost . . . abandoned. Who is

going to help me figure this out? If I knew how to do it, I would have done it already.

Participants described a need to refocus their energy, time, and commitments, but they feared the unknown. One participant said, "I know I need to not be that person I was, but who I will become? That scares me." Participants reported that time may help, but they reported needing a nurse who "knew and understood all the complexities" of their health-related issues. One participant described being very frustrated that her team did not address this part of her experience. She said, "I need a GPS. I need a nurse. . . . I'm afraid I will just not do the work I need to do to really be better."

Knowledge Translation

- Women with estrogen receptor–positive breast cancer who were starting oral adjuvant endocrine therapy reported many concerns that, in some cases, resulted in women not initiating treatment as prescribed.
- The intersection of being older aged and a caregiver, starting oral adjuvant therapy for breast cancer, and having at least one comorbidity requires interventions by providers to improve women's experience of beginning oral adjuvant endocrine therapy.
- Findings suggest that a combination of face-to-face, telephone, and Internet follow-up may be most beneficial for patients starting oral adjuvant endocrine treatment.

Discussion

This study addresses several important and new findings about women initiating oral adjuvant therapy for ER-positive breast cancer. In this study, four of the women reported delaying the initiation of treatment. This convenience sample included an older aged population of patients than expected. Nine participants were aged 60 years or older, 12 had three or more comorbid illnesses, and 11 were taking five or more medications. As a result of many clinical research trials, researchers know that symptoms affect adherence to oral adjuvant therapy for the treatment of ER-positive breast cancer (Burstein et al., 2010; Partridge et al., 2008; Ruddy, Mayer, & Partridge, 2009). Women who have more intense side effects of treatment are more affected regarding adherence (Cuzick, Sestak, Cella, & Fallowfield, 2008). However, it is less clear how comorbidity, age, and roles and responsibilities affect a woman's decision to initiate and adhere to oral adjuvant therapy.

Although the literature supports that comorbidity is a strong predictor of overall survival in patients with breast cancer (Edwards et al., 2014; Ording et al., 2013) and that endocrine therapy may affect metabolic syndrome (Redig & Munshi, 2010), a small but concerning number of women in this study were making decisions about initiating and adhering to treatment without discussing this with their healthcare team. This was particularly true if they were older aged and had other comorbid illnesses.

The finding that four of the women who eventually enrolled in this study initially reported delaying the initiation of treatment is disturbing. When approached by the NPs in the practice to determine interest in this study, these women agreed to be contacted by the research team. Despite knowing they would receive a follow-up call by a member of the research team, this cohort of women had not begun treatment. It is unknown what role receiving a call for participation in a study may have had on these women's eventual decision to start treatment, but the telephone call may have had an impact. This requires further investigation, but it could support the need for continuous contact with nurses to ensure that treatment is initiated.

Other reasons participants provided for not initiating treatment included worrying about returning to the caregiver role and resuming a "normal life." Although not a characteristic specifically captured in this study, the majority of participants reported being caregivers of other people in the process of sharing their story. Roles, such as caregiver, and their impact on a woman's decision to initiate and/or adhere to treatment have not been explored and, as such, are not well understood. These study findings suggest that role may have had an impact on women's decision making regarding initiating treatment.

The specific follow-up care needs of women with ER-positive breast cancer who are on oral adjuvant therapy have been described (Flanagan et al., 2012; van Londen et al., 2014). This study reports similar findings to previous studies in terms of the challenges women on oral adjuvant therapy face regarding lack of follow-up care and coordinated care between oncology and other healthcare providers. However, this study adds new information about the shift of breast cancer from acute to more chronic in nature, comorbid illness, age, and roles and those factors' impact on the initiation of oral adjuvant treatment.

For women initiating oral adjuvant therapy, several factors should be considered, including proper health maintenance, thorough assessment and management of other comorbid illnesses, appropriate consideration of the impact of the initiation of endocrine therapy on comorbid conditions, roles and responsibilities, and age. Assessment by providers aimed at understanding all these factors is needed to provide holistic care to these women. The findings from this research are congruent with a review of the literature that suggests

the discussion of comorbidity and other factors related to aging is absent from breast cancer clinical practice guidelines (Meneses, Benz, Azuero, Jablonski-Jaudon, & McNees 2015). The authors call for a comprehensive geriatric assessment for patients with breast cancer.

When asked how they would like to receive follow-up from their providers in assisting them with the initiation of oral adjuvant therapy, the participants suggested receiving this information in a web-based format so that they could do so at their own pace. They reported a need for information about strategies vetted by their healthcare team that supported wellness and healing. They also expressed a need for either telephone contact or an online forum that would allow them to connect one-on-one with their provider or designee regarding more emotionally distressing issues. Because participants reported feeling disconnected from the treatment team, reaching out to women initiating oral adjuvant therapy via a combination of in-person meetings and telephone calls after intense treatment may be an effective approach. Although not specifically focused on women with ER-positive breast cancer initiating oral adjuvant therapy, this study suggests that the work of Meneses et al. (2009), who found that a combination of face-to-face and telephone follow-up were effective strategies that provided educational support and improved quality of life in rural breast cancer survivors, could serve as a model for how follow-up care could be delivered.

The women in this study reported enjoying the opportunity to participate in this research because they were able to speak to a nurse who understood the experience but was not directly involved in their care. Each participant described the overall experience as traumatic and identified many unmet needs throughout the breast cancer experience. Participants were seeking, but reported not receiving, ongoing emotional support from providers, particularly in terms of being able to discuss their healing process and fears about death and dying.

Limitations

The limitations of this study are that the sample was a small, Caucasian, well-educated sample. A larger, more culturally and racially diverse sample of women is needed to understand this experience more fully and to determine whether differences in type of adjuvant therapy, comorbidity, all other medications, age, caregiver status, race, and ethnicity affect treatment decisions and overall experiences.

Implications for Nursing

This study provides information about the initiation of oral adjuvant therapy for women with ER-positive breast cancer. Findings suggest the need for nurses to comprehensively assess and understand the needs of women initiating oral adjuvant therapy. In addition, tailored treatment plans should be provided for women initiating oral adjuvant therapy, particularly if they are older aged, self-reported caregivers, taking several medications, and/or have chronic comorbid conditions. These study findings suggest that women initiating oral adjuvant therapy wanted some way to continue to connect with their oncology providers, but, consistent with the findings of van Londen et al. (2014), women were less clear on how this contact should continue.

The women in this study reported comorbidities, role and relationship issues, use of several medications, and questions about prioritizing health risks. Holistic care that addresses all of these concerns is essential to improve the experience of women initiating oral adjuvant therapy. Attention to the many needs of these women in terms of considering age, roles, and comorbidities has the potential to affect initiation of and adherence to treatment.

Conclusion

Findings from this study indicate that initiating oral treatment presents many challenges that have the potential to affect women's initiation of treatment and long-term survival. Findings also suggest that women who are older aged, have chronic comorbidities, are taking several medications, and/or have caregiving role responsibilities may be particularly vulnerable. These study findings suggest that women initiating oral adjuvant therapy received care that lacks continuity, which resulted in women making decisions that were not ideal. Research aimed at reducing this critical gap in care has the potential to affect long-term outcomes, such as quality of life, initiation of and adherence to the treatment plan, and long-term survival.

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