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Perspectives of Postmenopausal Breast Cancer Survivors on Adjuvant Endocrine Therapy-related Symptoms

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Abstract

Purpose—To conduct an investigation of women's experiences related to taking AET and managing AET-related symptoms.

Design—Qualitative.

Setting—Main campus of the University of Pittsburgh.

Sample—Four groups with a total of 14 breast cancer survivors, aged 50 years with AET-related symptoms.

Methods—Semi-structured discussion guides were used to elicit recollections of conversations with health care providers about starting AET, symptom experiences, symptom management, and suggestions for improving management. Audiotaped discussions were transcribed and analyzed to identify themes.

Findings—Women reported that initially AET was not viewed as a choice, but rather as the necessary next step to save their lives. After starting AET, women experienced difficulties making sense of, communicating about, and managing unanticipated AET-related symptoms. Women who

experienced persistently bothersome symptoms began weighing the pros and cons of AET in order to decide whether to continue treatment.

Conclusions—Focus group findings suggest multiple opportunities to better prepare patients for AET and to improve assessment and management of AET-related symptoms.

Implications for nursing—exploring AET-related symptom experiences, nurses may be able to promote AET adherence in breast cancer survivors, aged 50 years.

Introduction

The majority (approximately 65%) of non-metastatic breast cancer survivors undergo adjuvant endocrine therapy (AET) with agents such as estrogen-receptor-agonists-antagonists and/or aromatase inhibitors (Burstein et al., 2010). AET is a long-term therapy that is currently administered for 5-years, although an updated ASCO guideline, reflecting emerging data, recommends that women completing 5 years of adjuvant tamoxifen should be offered continuation of adjuvant endocrine therapy for a total of 10 years to further improve morbidity and mortality outcomes (Davies et al., 2012; Burstein et al., 2014).

Breast cancer patients receiving any kind of AET can experience multiple, persistent, symptoms, including vasomotor symptoms, sexual dysfunction, insomnia, fatigue, anxiety, depression, and arthralgias (Amir, Seruga, Niraula, Carlsson, & Ocana, 2011; Burstein et al., 2010; Cella et al., 2006; Fontein et al., 2013; Hickey et al., 2008; Rechis et al., 2010; Stearns & Hayes, 2002; van Londen G, 2013). These symptoms negatively affect survivors' functional status and quality of life (QoL) (Cella et al., 2006; Conde et al., 2005; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Gupta et al., 2006; Land et al., 2006; Perry, Kowalski, & Chang, 2007; Stein, Jacobsen, Hann, Greenberg, & Lyman, 2000; Wilson & Cleary, 1995). Negative symptom experiences reported in the clinical literature appear to contribute to lack of adherence to AET (Bender et al., 2014; Cluze et al., 2011; Fink, Gurwitz, Rakowski, Guadagnoli, & Silliman, 2004; Henry et al., 2012; Hershman et al., 2010; Murphy, Bartholomew, Carpentier, Bluethmann, & Vernon, 2012) which, in turn, has been linked to higher mortality (Hershman et al., 2011). To date however, there has been little patient-oriented research focused on breast cancer patients' experiences of AET-related symptoms, how they try to manage symptoms, or how these experiences influence their decision making around AET continuation. This focus on symptom experience may be particularly relevant for those aged 50 and over who are already at risk for menopausal symptoms (Blumel et al., 2000; Chedraui, San Miguel, & Avila, 2009; Schwarz et al., 2007), comorbidities (Baumeister, Balke, & Harter, 2005; Mor, 1992), and/or effects of normal aging (Motl & McAuley, 2010; van Londen et al., 2013).

The purpose of this focus group study was to explore survivors' recollection of the conversation with the medical oncologist about starting AET, experiences with AET-related symptoms, AET-related symptom management, challenges to taking AET, and views about how AET-related symptoms might be better managed.

Methods

Design and sample

A focus group design was used to foster dynamic discussion and gain formative insight into patient experiences (Patton, 2002). The size of each group was intentionally small (3–4) to maximize individual input (Hagan & Donovan, 2013). Female breast cancer survivors who met the following eligibility criteria were invited to participate in the study: 1) aged 50 years or older; 2) self-reported to have been undergoing *adjuvant* endocrine therapy for more than 1 year (to limit the confounding influence of chemotherapy-related symptoms), and; 3) experiencing at least one moderately distressing symptom, as assessed by the Breast Cancer Prevention Trial (BCPT) symptom scale, a validated measure of physical symptoms in breast cancer survivors (Stanton, Bernaards, & Ganz, 2005). Patients rated symptoms on a Likert-type scale of not at all (0), slightly (1), moderately (2), quite a bit (3), extremely (4). Women taking endocrine therapy as part of treatment for metastatic disease were excluded as this study focused on the perspectives of women taking AET to prevent recurrence. As cancer stage might affect one's AET experience (Aiello Bowles et al., 2012), women of similar severity of illness (based on self-reported lymph node status) were included within groups. Additional focus groups were conducted until no new themes emerged. A total of four focus groups were conducted (2 lymph node negative, and 2 lymph node positive). High levels of participation by women in each group and similar findings across the lymph node positive and negative groups increased our confidence to end the study after the fourth focus group (Kuzel, 1992; Morse, 2000).

Procedures

The University of Pittsburgh's Institutional Review Board approved the study. Women were recruited from outpatient clinics of the University of Pittsburgh Medical Center. All focus groups were held at the nearby university campus, between May and September 2011. Recruitment of study participants occurred through advertisements in medical oncology practices, research registry, and word-of-mouth. Potentially eligible subjects were screened by phone and, if eligible, mailed a consent form, directions, a short demographic survey, and the Breast Cancer Prevention Trial (BCPT) symptom scale (Stanton et al., 2005). Prior to conducting the focus group, the investigator introduced the purpose and process of the study, reviewed and signed consent forms, and collected completed, self-reported surveys. All participants received parking reimbursement, a \$20 gift-card, and refreshments.

Each focus group was facilitated by a member of the study team (GvL or EB) and also attended by a third investigator (MAD). The 90-minute sessions were audio-recorded and deleted following transcription and review.

Measures

A semi-structured interview guide was developed for the study that included a series of discussion prompts that addressed survivors' recollection of the conversation with their medical oncologist about starting AET, experiences related to successfully taking AET as prescribed, experiences with AET-related symptoms, AET-related symptom management,

and views about how AET-related symptoms might be better managed. See Table 1 for examples of specific discussion prompts.

Analytic strategy

Analysis of each focus group's transcripts was carried out in two phases (Patton, 2002; Ryan & Bernard, 2003). Initial coding was done by pairs of team members using an a priori coding scheme based on the questions in the semi-structured interview guide. Each pair included GvL and one of three team members with qualitative data methods expertise (AC, EB, or MAD) (Strauss & Corbin, 1990). HD and GvL then individually reviewed the coded text; themes (the essence of the phenomena or aspects of the text that provide meaning to the phenomena) and sub-themes (more concrete units of information) were extracted, discussed, and agreed upon using an iterative process (Morse, 2008). No differences in themes or sub-themes were identified between the lymph node positive and negative focus groups, so results are presented together.

Results

A total of 14 female breast cancer survivors participated in the focus groups. Demographic and clinical information for study participants is included in Table 2.

Five themes emerged: 1) initially, taking AET was not viewed as a choice to be made, but rather a next necessary step in curative treatment; 2) after starting AET, women experienced unanticipated symptoms; 3) during AET women faced difficulties in making sense of and managing their symptoms; 4) frustration in managing symptoms, and; 5) over time, women became aware that taking AET is a choice and began weighing the pros and cons of continued treatment.

Theme 1: AET as a non-decision initially

At the time of being prescribed AET, breast cancer survivors often did not feel they had a real choice; they viewed AET as the next necessary step in treatment to avoid a breast cancer recurrence and death. They did not inquire much about AET-related risks, or if they did, they felt like the risks were not central to the discussion.

“It shocks me because I felt the fear of God in me. I had to take this. I didn't ask the questions which is so unusual for me”.

“I don't think it was really explained to me, all the things that might happen. I don't remember. I'll be honest with you; I really don't remember.

Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do”.

Theme 2: Unanticipated symptoms

Survivors talked about being surprised by the wide range of symptoms, including vasomotor symptoms, sexual dysfunction, insomnia, fatigue, cognitive dysfunction, pain, functional limitations, mood disturbance, anxiety. More importantly, women talked about the negative effect of symptoms on their lives.

“I am more forgetful. I work harder at work to do the same job that I used to just do. It’s harder for me to stay focused, to concentrate, to think clearly, to remember everything.

“Because of the side effects and my hands. I’m an artist. I’m a floral designer. I couldn’t I still can’t pick up a straight pin I can’t pick up anything small like a needle”.

“I didn’t expect the night sweats to be so bad. I didn’t expect them to interfere with my sleep”.

“I wouldn’t have ever thought that it would interfere so much that I don’t feel like myself. I don’t have the energy. I can’t sleep. I’m having trouble at work”.

Theme 3: Difficulty making sense of symptoms

Women talked about a wide range of issues that made it difficult for them to understand or make sense of their symptoms. Three sub-themes were identified:

Uncertainty in determining the cause of their symptoms—Women talked about the frustration and worry that came from not being able to determine whether symptoms were caused by AET, aging, comorbidities, or cancer recurrence.

“I think it’s so hard to know what is causing what and like I said if you didn’t have that other things factor in, age and all that, but I do think the medications, like you say [referring to comment by another participant], exacerbated”.

“And if you do get aches in your joints, I mean, you get scared, you know? What is going on with my body?”

Lack of understanding by friends and family—Survivors told us about their frustration when trying to talk with others about symptoms. Friends and family members who had not experienced cancer were not always able to relate or understand.

“You really can only go so far with, even your husband. They only want to hear what’s going on for a couple of minutes“.

“Well your friends and relatives don’t want to hear about it [symptoms].”

Concern that talking about symptoms was seen as a sign of emotional/ psychological problems by providers—Women talked extensively about how difficult it was to talk with their providers about symptoms. Providers’ responses made them feel like they were either over-reacting or that the symptoms were a result of psychological or emotional problems.

“So then I think, well, am I being a hypochondriac? You know, you go home, and it’s like, well, should I call another doctor? He seemed like everything’s fine. If it was really serious, he would say so”.

“I would rather have somebody tell me that they don’t know why I had a reaction to this or that, rather than just make me feel like I’m a child or it’s just your hormones or it’s just your mental incapacity”.

“I cried, I lost it, and then right away, he wants me to go see the psychiatrist! I don’t need a psychiatrist or psychologist”.

Theme 4: Frustration in managing symptoms

Survivors often expressed a great deal of frustration when talking about their attempts to manage symptoms. The following sub-themes were identified.

Dissatisfaction with symptom management information from healthcare providers—Women felt like there was no one provider who had the time for, expertise in, and/or interest in helping them to manage symptoms.

“She [gynecologist] doesn’t do anything but her thing. I don’t think she would answer my questions. Or even if she did it, you know, would be a brush off kind of thing. She doesn’t spend that much time with her patients. I don’t think they know about the drugs”.

“They [providers] just go by what they read in a book... I learn more from people who have been through it”.

Responsible for own symptom management—Several women reported that they felt like they needed to identify symptom management approaches on their own. They reported spending a lot of time reading about different strategies and interacting with other survivors to get advice.

“When you first started to develop the side effects, she [MD] would tell you things that you would try to do to just sort of get over, or get through, or alleviate some of them. When they didn’t work, then you sort of figured it out on your own”.

“I spend hours and hours researching”.

“To have these symptoms and at some point you feel like there’s no one to talk to outside of other people who are going through it or have been through it”.

Few effective and tolerable symptom management strategies—Women reported that they came to realize that there were few effective symptom management strategies available and these often also have their own side effects.

“I feel like there isn’t any help really available...”.

“You can take the suppository [estrogen containing for vaginal atrophy]. First thing the pharmacist says ‘well I thought you weren’t supposed to be taking estrogen’ and I said ‘well they told me I can take these’ “.

“I’m tired of taking [pills]. When someone says ‘take a pill for this [symptom]’, I don’t want to start another pill. I think about all these other side effects. The lesser of two evils”.

Theme 5: Weighing pros and cons of ongoing treatment

Upon development of persistent and difficult to manage symptoms, survivors begin to rethink their willingness to take AET and to weigh the pros and cons of ongoing treatment. Some women told us that they decided to continue AET and accept its related symptoms, while others reported that they were coming to the decision that the reduced risk of recurrence was not worth the loss of quality of life.

“I’m going to take my medication, regardless. I mean I’m just going to take it. I’m convinced that taking it for five years with the other therapies that I’ve had increases my survival rate up to ten years, but having talked to other women who have quit, they just really couldn’t get past the symptoms and I understand that”.

“Okay, I have a choice: I either continue this medicine and know the side effects or I stop taking this medicine and know that there’s always a chance I’m going to get the cancer back. I think that’s what it is. You just know this medicine has side effects and you take it for what it’s worth”.

“Well that was my big thing about taking Aromasin. If I have to take it for 5 years and my quality of life is so bad, do I want to take it? These are probably the last good 5 years of my life. I’m 60. Do I take it and have all these side effects?”

“You do get to a point where it just isn’t worth it to fight it [staying on AET]”.

Women’s Suggestions for Improving Care of Women Experiencing Symptoms on AET

Following the discussion of AET symptom experiences, survivors were asked about ways the health care system could be improved to better meet their needs.

Survivors told us that they wished they had access to a knowledgeable source that would be able to provide more education about AET.

“What’ll help is taking the load off the oncologist, because their days are so busy. And when you know they’re dealing with people that are sick and going through treatment and we need someone to discuss these things now”.

“There has to be somebody helping us with those things. Why am I going off of this [AET] in 5 years? We need a theory about what this Arimidex is doing to us. I worked in the medical field. I really don’t understand. It stops estrogen, ok, that’s all I know. I think that would really be helpful to help people understand why they’re taking it”.

“Things that would help with the side effects rather than waiting until you see the doctor 6 months later. You probably could have solved it within the first week starting therapy, or not had so much trouble with it, because nobody told me.

While survivors were consistent in terms of *what* they needed, there was not a consensus about *how* best to get this support. Various delivery options were mentioned, e.g. printed materials, phone, (a)synchronous messaging, email, telemedicine, face-to-face. In terms of its timing, some women told us that they would prefer frequent, proactive interactions, while

others preferred a less intense, more flexible support system that they could access themselves if/when desired.

“Email works for me, but it doesn't work for everybody”.

“I'd rather just pick up the phone instead of like putting it all in an email”.

Lastly, survivors indicated the need for more options for effective, affordable and non-pharmacologic treatment options for AET-related symptoms.

“I just know it's very frustrating though. When you have estrogen positive tumors, that everything they recommend for these sleepless hot flashes are estrogen based. It's like ok well what's plan B? I can't take that so what else can I do?”

“Insurance wouldn't pay for a chiropractor. Insurance doesn't pay for physical therapy either”.

Discussion

Results of this qualitative research study suggest that breast cancer survivors on AET therapy encounter substantial challenges related to their experience and management of AET-related symptoms. Initially, taking AET was often perceived as a non-decision, driven by their medical oncologist's recommendation and fear of cancer recurrence. Women did not remember detailed discussions with their health care provider about the potential adverse effects associated with AET. AET is the cornerstone treatment modality for women with hormone receptor positive breast cancer to reduce their cancer recurrence risk (Burstein et al., 2010). To derive most survival benefit, it is, therefore, essential to find ways to support women to stay on therapy whenever possible. Further research is warranted to explore whether experiences with AET reflected in this study were due to insufficient education by providers and/or by survivor's ability to participate in and remember this conversation. Findings would help prioritize the development of individualized educational interventions to improve AET adherence (Feldman-Stewart et al., 2013). Oncology nurses play a critical role in the development and implementation of these types of educational interventions

The type and nature of the AET-related symptoms discussed in the focus groups were consistent with previous clinical reports in the literature (Burstein et al., 2010; Hickey et al., 2008; Rechis et al., 2010; Stearns & Hayes, 2002; van Londen, 2013). However, the magnitude of bothersome symptoms was not always anticipated by patients, nor was the extent of interference with sleep, daily life activities, and functioning. The survivors, recruited at age 50 and over, described great frustration with their difficulty in determining the etiology of symptoms (AET, aging, and/or comorbidities). The women described receiving little understanding and support about symptoms from family and friends. Survivors expressed concerns that providers lacked time and expertise, and gave them the feeling that experiencing AET-related symptoms was a sign of emotional weakness. This could contribute to a downward spiral of discouragement, worsening of symptoms, and AET discontinuation (Aiello Bowles et al., 2012; Cuijpers et al., 2012; Riegel et al., 2009) that can occur when experiencing chronic symptoms without adequate relief. These findings are consistent with Christensen's (2000) Patient-by-Context Interaction Framework of

adherence. In this framework, adherence is best understood as an interaction between patient individual factors (e.g. personal traits, expectancies, coping processes) and illness/treatment context factors (e.g. treatment controllability and illness severity). The framework has received recent attention as a useful framework for examining the influence of symptoms on adherence to AET (Bender et al., 2014). Future research could further explore patient factors that are associated with increased risk for AET discontinuation as well as adaptive coping processes among women who persist on AET. These findings could assist researcher and clinicians in developing targeted interventions to promote adherence to AET. Educational, navigational, and behavioral interventions that target empowerment and improvement of self-care (Beekman, Smit, Stek, Reynolds, & Cuijpers, 2010; Loh, Packer, Chinna, & Quek, 2013; Wrosch & Sabiston, 2012), and are adaptable to survivors' changing needs (Krebbler et al., 2012), might be particularly beneficial.

At some point, upon persistent experience of bothersome AET-related symptoms, survivors reported gradually beginning to recognize that they had a decision to make regarding whether they wanted to continue AET and accept the related symptoms, or discontinue AET prematurely and accept the potential for increased risk of recurrence. This has very important implications. These findings reflect serious unmet educational needs at the time of treatment initiation, namely that they may not fully understand the major risks of deciding to stop a treatment that is known to optimize survival in this patient population. Of note, all women in our sample were on AET at the time of their participation in the focus group. However, this reflects our inclusion criteria requiring that women be on AET therapy for one year in order to be eligible to participate. This resulted in a sample of women who had decided to persist with AET. Literature has shown that about 17–32% of initial AET users discontinue its intake within the first year (Henry et al., 2012; Partridge, Wang, Winer, & Avorn, 2003), although they might tolerate alternative AET options (Henry et al., 2012). Future research should explore whether earlier, pro-active, intermittent provision of education about the benefits and anticipated risks of AET as well as assessment and management of AET-related symptoms can improve survivors' ability to persist with AET.

There are several limitations to this study. First, our study sample may affect the generalizability of our findings. Most of the survivors in our study were Caucasian, married, and not employed and therefore may have had supportive resources not available to all survivors. This distribution does not represent all breast cancer survivors, as other ethnicities are underrepresented and most breast cancer survivors in their 50s are employed (Rechis et al., 2010). Our recruitment also focused on women on AET for at least a year. For these women symptoms have not (yet, at least) led to early termination of therapy. However, we could assume that the challenges as described in this manuscript might even be more pronounced in those with less access to support and health care, as well as those who may have dropped out of treatment earlier. Next, we did not find a difference between the self-report lymph node status groups. While it could be a function of women not remembering their lymph node status, it could also be due to the structure of the focus group interviews that did not specifically explore the relationship between lymph node status and perception of AET therapy. Lastly, we were unable to fully differentiate between symptoms related to AET vs. chemotherapy. However, women were only eligible if they had been on AET for at least one year. In general, AET is not initiated until chemotherapy sessions have been

completed. Therefore, women in our study were at least one year out from their last chemotherapy session, which should have allowed for recovery from chemotherapy-related symptoms.

Implications for Nursing

Oncology nurses have a responsibility to provide individualized education, not only at the time of AET initiation, but also over time. Key topics that may be particularly useful include information on 1) the fact that once breast cancer has reoccurred, it will likely not be curable anymore, however the many different lines of therapy available might be able to provide long-term disease control and survival, 2) a woman's individual risk of cancer recurrence, and 3) the expected reduction in risk associated with taking AET as prescribed (Burstein et al., 2010). Taking AET therapy consistently for 5 years can cut the breast cancer recurrence risk in about half; an additional 5 years of AET can result in an additional modest reduction. Another important topic for patient education by nurses includes an explanation of how the prescribed anti-estrogen agent works, why their cancer provider selected this particular agent (out of all the available anti-estrogen agents), and the possible adverse affects associated with the prescribed AET (Burstein et al., 2010). For example, estrogen-receptor-agonists-antagonists, such as tamoxifen, target the estrogen receptor, while the more effective aromatase inhibitors decrease the circulating levels of female gonadal hormones by inhibiting its peripheral production. Administration of aromatase inhibitors to premenopausal women is contra-indicated as the ovaries might (over)compensate for the aromatase inhibitor mediated decreased levels of female gonadal hormones. Hence, if a woman should develop vaginal bleeding on an aromatase inhibitor, she should contact her prescribing provider, as it might be indicative of a resumption of ovarian function. A recently updated ASCO guideline recommends that "addressing patient beliefs about the benefits and risks of medications is warranted in patient-provider interactions about the use of adjuvant endocrine therapy. Helping patients understand the rationale for therapy, and the likely adverse effects, is likely to enhance treatment compliance and persistence" (Burstein et al., 2014).

This study also highlights the important role that nurses can play in the ongoing assessment and management of AET-related symptoms. An explicit assessment of whether symptoms are affecting a woman's willingness or ability to persist with AET could help nurses to intervene early to prevent cessation of treatment. Specific strategies include the development of pro-active telephone follow-up protocols to evaluate the effectiveness of symptom management strategies, modify the approach if necessary, and reinforce the benefit of persisting with treatment. Referral to supportive care services should also be considered for women with persistent symptoms.

Conclusions

This study highlights the potential impact of AET-related symptom experience on survivors' willingness to continue on AET. Although women in this study were highly adherent despite unanticipated symptoms, women's insights provide opportunities for patient and provider targeted interventions to improve AET-related symptom management, which could

ultimately improve AET adherence, and survival. These findings may be instrumental in guiding the involvement of oncology nurses in survivorship care in order to help women gain a more comprehensive understanding of the benefits and risks of AET (dis)continuation and feel supported in making informed decisions to maximize quality of life *and* survival.

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References

- Aiello Bowles EJ, Boudreau DM, Chubak J, Yu O, Fujii M, Chestnut J, Buist DS. Patient-reported discontinuation of endocrine therapy and related adverse effects among women with early-stage breast cancer. *Journal of Oncology Practice*. 2012; 8:e149–157.10.1200/JOP.2012.000543 [PubMed: 23598850]
- Amir E, Seruga B, Niraula S, Carlsson L, Ocana A. Toxicity of adjuvant endocrine therapy in postmenopausal breast cancer patients: a systematic review and meta-analysis. *Journal of the National Cancer Institute*. 2011; 103:1299–1309.10.1093/jnci/djr242 [PubMed: 21743022]
- Baumeister H, Balke K, Harter M. Psychiatric and somatic comorbidities are negatively associated with quality of life in physically ill patients. *Journal of Clinical Epidemiology*. 2005; 58:1090–1100.10.1016/j.jclinepi.2005.03.011 [PubMed: 16223651]
- Beekman AT, Smit F, Stek ML, Reynolds CF III, Cuijpers PC. Preventing depression in high-risk groups. *Current Opinion in Psychiatry*. 2010; 23:8–11.10.1097/YCO.0b013e328333e17f [PubMed: 19901835]
- Bender CM, Gentry AL, Brufsky AM, Casillo FE, Cohen SM, Dailey MM, Sereika SM. Influence of patient and treatment factors on adherence to adjuvant endocrine therapy in breast cancer. *Oncology Nursing Forum*. 2014; 41:274–285. [PubMed: 24769592]
- Bindman AB, Blum JD, Kronick R. Medicare's transitional care payment — A step toward the medical home. *New England Journal of Medicine*. 2013; 368:692–694.10.1056/NEJMp1214122 [PubMed: 23425161]
- Blumel JE, Castelo-Branco C, Binfa L, Gramegna G, Tacla X, Aracena B, Sanjuan A. Quality of life after the menopause: a population study. *Maturitas*. 2000; 34:17–23. [PubMed: 10687878]
- Burstein HJ, Prestrud AA, Seidenfeld J, Anderson H, Buchholz TA, Davidson NE, Griggs JJ. American Society of Clinical Oncology clinical practice guideline: update on adjuvant endocrine therapy for women with hormone receptor-positive breast cancer. *Journal of Clinical Oncology*. 2010; 28:3784–3796.10.1200/JCO.2009.26.3756 [PubMed: 20625130]
- Burstein HJ, Temin S, Anderson H, Buchholz TA, Davidson NE, Gelmon KE, Griggs JJ. Adjuvant Endocrine Therapy for Women With Hormone Receptor-Positive Breast Cancer: American Society of Clinical Oncology Clinical Practice Guideline Focused Update. *Journal of Clinical Oncology*. 2014 Advance online publication. 10.1200/JCO.2013.54.2258
- Cella D, Fallowfield L, Barker P, Cuzick J, Locker G, Howell A. Quality of life of postmenopausal women in the ATAC (“Arimidex”, tamoxifen, alone or in combination) trial after completion of 5 years' adjuvant treatment for early breast cancer. *Breast Cancer Research and Treatment*. 2006; 100:273–284.10.1007/s10549-006-9260-6 [PubMed: 16944295]
- Chedraui P, San Miguel G, Avila C. Quality of life impairment during the female menopausal transition is related to personal and partner factors. *Gynecological Endocrinology*. 2009; 25:130–135.10.1080/09513590802617770 [PubMed: 19253110]

- Christensen AJ. Patient-by-treatment context interaction in chronic disease: A conceptual framework for the study of patient adherence. *Psychosomatic Medicine*. 2000; 62(3):435–443. [PubMed: 10845357]
- Cluze C, Rey D, Huiart L, Bendiane MK, Bouhnik AD, Berenger C, Giorgi R. Adjuvant endocrine therapy with tamoxifen in young women with breast cancer: determinants of interruptions vary over time. *Annals of Oncology*. 2011; 23:882–890. mdr330 [pii]. 10.1093/annonc/mdr330 [PubMed: 21788360]
- Conde DM, Pinto-Neto AM, Cabello C, Sa DS, Costa-Paiva L, Martinez EZ. Menopause symptoms and quality of life in women aged 45 to 65 years with and without breast cancer. *Menopause*. 2005; 12:436–443.10.1097/01.GME.0000151655.10243.48 [PubMed: 16037759]
- Cuijpers P, Beekman AT, Reynolds CF III. Preventing depression: a global priority. *Journal of the American Medical Association*. 2012; 307:1033–1034.10.1001/jama.2012.271 [PubMed: 22416097]
- Davies C, Pan H, Godwin J, Gray R, Arriagada R, Raina V, Peto R. Long-term effects of continuing adjuvant tamoxifen to 10 years versus stopping at 5 years after diagnosis of oestrogen receptor-positive breast cancer: ATLAS, a randomised trial. *Lancet*. 2012; 9869:805–816.10.1016/S0140-6736(12)61963-1
- Feldman-Stewart D, Madarnas Y, Mates M, Tong C, Grunfeld E, Verma S, Brundage M. Information for decision making by post-menopausal women with hormone receptor positive early-stage breast cancer considering adjuvant endocrine therapy. *Breast*. 2013.10.1016/j.breast.2013.04.020
- Fink AK, Gurwitz J, Rakowski W, Guadagnoli E, Silliman RA. Patient beliefs and tamoxifen discontinuance in older women with estrogen receptor--positive breast cancer. *Journal of Clinical Oncology*. 2004; 22:3309–3315.10.1200/JCO.2004.11.06422/16/3309 [PubMed: 15310774]
- Fontein DB, Seynaeve C, Hadji P, Hille ET, van de Water W, Putter H, van de Velde CJ. Specific adverse events predict survival benefit in patients treated with tamoxifen or aromatase inhibitors: an international tamoxifen exemestane adjuvant multinational trial analysis. *Journal of Clinical Oncology*. 2013; 31:2257–2264.10.1200/JCO.2012.45.3068 [PubMed: 23610112]
- Ganz PA. Quality of care and cancer survivorship: the challenge of implementing the institute of medicine recommendations. *Journal of Oncology Practice*. 2009; 5:101–105.10.1200/JOP.0934402 [PubMed: 20856744]
- Ganz PA, Rowland JH, Desmond K, Meyerowitz BE, Wyatt GE. Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal of Clinical Oncology*. 1998; 16:501–514. [PubMed: 9469334]
- Gupta P, Sturdee DW, Palin SL, Majumder K, Fear R, Marshall T, Paterson I. Menopausal symptoms in women treated for breast cancer: the prevalence and severity of symptoms and their perceived effects on quality of life. *Climacteric*. 2006; 9:49–58.10.1080/13697130500487224 [PubMed: 16428125]
- Hagan TL, Donovan HS. Ovarian cancer survivors' experiences of self-advocacy: a focus group study. *Oncology Nursing Forum*. 2013; 40:140–147.10.1188/13.ONF.A12-A19 [PubMed: 23454476]
- Henry NL, Azzouz F, Desta Z, Li L, Nguyen AT, Lemler S, Storniolo AM. Predictors of Aromatase Inhibitor Discontinuation as a Result of Treatment-Emergent Symptoms in Early-Stage Breast Cancer. *Journal of Clinical Oncology*. 2012.10.1200/JCO.2011.38.0261
- Hershman DL, Kushi LH, Shao T, Buono D, Kershenbaum A, Tsai WY, Neugut AI. Early discontinuation and nonadherence to adjuvant hormonal therapy in a cohort of 8,769 early-stage breast cancer patients. *Journal of Clinical Oncology*. 2010; 28:4120–4128. JCO.2009.25.9655 [pii]. 10.1200/JCO.2009.25.9655 [PubMed: 20585090]
- Hershman DL, Shao T, Kushi LH, Buono D, Tsai WY, Fehrenbacher L, Neugut AI. Early discontinuation and non-adherence to adjuvant hormonal therapy are associated with increased mortality in women with breast cancer. *Breast Cancer Research and Treatment*. 2011; 126:529–537.10.1007/s10549-010-1132-4 [PubMed: 20803066]
- Hickey M, Saunders C, Partridge A, Santoro N, Joffe H, Stearns V. Practical clinical guidelines for assessing and managing menopausal symptoms after breast cancer. *Annals of Oncology*. 2008; 19:1669–1680. mdr353 [pii]. 10.1093/annonc/mdn353 [PubMed: 18522932]

- Howell D, Hack TF, Oliver TK, Chulak T, Mayo S, Aubin M, Sinclair S. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. *Journal of Cancer Survivorship*. 2012; 6:359–371.10.1007/s11764-012-0232-z [PubMed: 22777364]
- Jefford M, Rowland J, Grunfeld E, Richards M, Maher J, Glaser A. Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. *British Journal of Cancer*. 2012;10.1038/bjc.2012.554
- Krebber AM, Leemans CR, de Bree R, van Straten A, Smit F, Smit EF, Verdonck-de Leeuw IM. Stepped care targeting psychological distress in head and neck and lung cancer patients: a randomized clinical trial. *BMC Cancer*. 2012; 12:173.10.1186/1471-2407-12-173 [PubMed: 22574757]
- Kuzel, Anton J. Sampling in qualitative inquiry. In: Crabtree, BF.; Miller, WF., editors. *Doing qualitative research. Research methods for primary care*. Vol. 3. Thousand Oaks, CA, US: Sage Publications, Inc; 1992. p. 31-44.p. xvip. 276
- Land SR, Wickerham DL, Costantino JP, Ritter MW, Vogel VG, Lee M, Ganz PA. Patient-reported symptoms and quality of life during treatment with tamoxifen or raloxifene for breast cancer prevention: the NSABP Study of Tamoxifen and Raloxifene (STAR) P-2 trial. *Journal of the American Medical Association*. 2006; 295:2742–2751.10.1001/jama.295.23.joc60075 [PubMed: 16754728]
- Loh SY, Packer T, Chinna K, Quek KF. Effectiveness of a patient self-management programme for breast cancer as a chronic illness: a non-randomised controlled clinical trial. *Journal of Cancer Survivorship*. 2013;10.1007/s11764-013-0274-x
- Mayer DK, Gerstel A, Leak AN, Smith SK. Patient and provider preferences for survivorship care plans. *Journal of Oncology Practice*. 2012; 8:e80–86.10.1200/JOP.2011.000401 [PubMed: 23181005]
- Mor V. QOL measurement scales for cancer patients: differentiating effects of age from effects of illness. *Oncology (Williston Park)*. 1992; 6:146–152. [PubMed: 1532730]
- Morse JM. Confusing categories and themes. *Qualitative Health Research*. 2008; 18:727–728.10.1177/1049732308314930 [PubMed: 18503013]
- Morse JM. Determining Sample Size. *Qualitative Health Research*. 2000; 10:3–5.10.1177/104973200129118183
- Motl RW, McAuley E. Physical activity, disability, and quality of life in older adults. *Physical Medicine and Rehabilitation Clinics of North America*. 2010; 21:299–308.10.1016/j.pmr.2009.12.006 [PubMed: 20494278]
- Murphy CC, Bartholomew LK, Carpentier MY, Bluethmann SM, Vernon SW. Adherence to adjuvant hormonal therapy among breast cancer survivors in clinical practice: a systematic review. *Breast Cancer Research and Treatment*. 2012; 134:459–478.10.1007/s10549-012-2114-5 [PubMed: 22689091]
- Partridge AH, Wang PS, Winer EP, Avorn J. Nonadherence to adjuvant tamoxifen therapy in women with primary breast cancer. *Journal of Clinical Oncology*. 2003; 21:602–606. [PubMed: 12586795]
- Patton, MQ. *Qualitative Research & Evaluation Methods*. Sage Publications; 2002.
- Perry S, Kowalski TL, Chang CH. Quality of life assessment in women with breast cancer: benefits, acceptability and utilization. *Health and Quality of Life Outcomes*. 2007; 5:24.10.1186/1477-7525-5-24 [PubMed: 17474993]
- Rechis R, Arvey SR, Beckjord EB. Perspectives of a lifelong cancer survivor-improving survivorship care. *Nature Reviews. Clinical Oncology*. 2012;10.1038/nrclinonc.2012.212
- Rechis, R.; Boerner, L.; Nutt, S.; Shaw, K.; Berno, D.; Duchover, Y. *How cancer has affected post-treatment survivors: a LIVESTRONG report*. Austin, TX: LIVESTRONG; 2010.
- Riegel B, Moser DK, Anker SD, Appel LJ, Dunbar SB, Grady KL, Whellan DJ. State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation*. 2009; 120:1141–1163.10.1161/CIRCULATIONAHA.109.192628 [PubMed: 19720935]

- Ryan, Gery W.; Bernard, H Russell. Techniques to Identify Themes. *Field Methods*. 2003; 15:85–109.10.1177/1525822x02239569
- Schwarz S, Volzke H, Alte D, Schwahn C, Grabe HJ, Hoffmann W, Doren M. Menopause and determinants of quality of life in women at midlife and beyond: the study of health in Pomerania (SHIP). *Menopause*. 2007; 14:123–134.10.1097/01.gme.0000227860.58097.e9 [PubMed: 17019378]
- Stanton AL, Bernaards CA, Ganz PA. The BCPT symptom scales: a measure of physical symptoms for women diagnosed with or at risk for breast cancer. *Journal of the National Cancer Institute*. 2005; 97:448–456.10.1093/jnci/dji069 [PubMed: 15770009]
- Stearns V, Hayes DF. Approach to menopausal symptoms in women with breast cancer. *Current Treatment Options in Oncology*. 2002; 3:179–190. [PubMed: 12057081]
- Stein KD, Jacobsen PB, Hann DM, Greenberg H, Lyman G. Impact of hot flashes on quality of life among postmenopausal women being treated for breast cancer. *Journal of Pain and Symptom Management*. 2000; 19:436–445. [PubMed: 10908824]
- Strauss, AC.; Corbin, JM. *Basics of qualitative research: Grounded theory procedures and techniques*. 2. Sage; Newbury Park, CA: 1990.
- van Londen G, Beckjord EB, Dew MA, Cuijpers P, Tadic S, Brufsky A. Breast cancer survivorship symptom management: current perspective and future development. *Breast Cancer Management*. 2013; 2:71–81. [PubMed: 23814614]
- Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *Journal of the American Medical Association*. 1995; 273:59–65. [PubMed: 7996652]
- Wrosch C, Sabiston CM. Goal adjustment, physical and sedentary activity, and well-being and health among breast cancer survivors. *Psychooncology*. 2012; 22:581–589.10.1002/pon.3037 [PubMed: 22287027]

Knowledge Translation

- AET-related symptoms are persistent and not always anticipated, contributing to a gradual reevaluation of the benefits and risks of AET.
- Oncology nurses must ensure that patients have adequate preparatory information regarding anticipated risks/side effects, plan for management and the important benefits of AET.
- Upon AET initiation, oncology nurses should pro-actively monitor and manage AET side effects.
- For those considering AET discontinuation, oncology nurses can provide education to support informed decision-making and ensure clear understanding of the survivors' individual benefits and risks of AET.

Table 1

Focus group discussion topics and examples of discussion prompts

Topic	Examples of Discussion Prompts
Understanding of rationale for hormonal therapy (recollection of the conversation with their medical oncologist about starting AET)	<ul style="list-style-type: none"> We'd like to start with asking women about their perspectives on WHY they are taking hormonal therapy. How well do you feel like you understand the benefits and risks of treatment?
Experiences related to consistently taking AET as prescribed	<ul style="list-style-type: none"> What has made it challenging to successfully and consistently take your adjuvant hormonal treatment? Have you ever considered adjusting the therapy yourself or stopping therapy?
Experiences with AET-related symptoms	<ul style="list-style-type: none"> What sorts of side effects or symptoms have you experienced related to your adjuvant hormonal treatment?
AET-related symptom management	<ul style="list-style-type: none"> What sorts of things have you tried to control your symptoms related to your treatment? How well have they worked? What challenges did you face in managing your symptoms?
Views about how AET-related symptoms might be better managed	<ul style="list-style-type: none"> What is the one thing that could be done to help women successfully and consistently take their hormonal treatment? We are looking for answers that can really be acted on, things that could improve the care women receive or other ways that you think women could be best supported.

Table 2

Personal and Disease Characteristics of Breast Cancer Survivors (n=14)

Characteristic	n(%) or Mean \pm SD
Personal Characteristics	
Race (n)	
Caucasian	14 (100)
Marital status	
Married	11 (79)
Occupational status	
Employed	4 (21)
Not working (retired, disabled, not able to find a job)	10 (79)
Age (yr)	58.8 \pm 6.7
Disease and Treatment Characteristics	
Time since breast cancer diagnosis (months)	35 \pm 20
Self-Reported Lymph-Node Status (n)	
Negative	8 (57)
Positive	6 (43)
Cancer Treatment	
Mastectomy	6 (43)
Lumpectomy	8 (57)
Radiation therapy	13 (93)
Chemotherapy	9 (64)
HER2/neu receptor antibody	2 (14)
AET	14 (100)
Time (months) since AET initiation	28.3 \pm 17.9
Type	
Aromatase Inhibitor	12 (86)
Tamoxifen	1 (7)
Unknown	1 (7)
Adjustment of AET	5 (36)
Reasons for AET adjustment	
Menopausal transition (eligible for tamoxifen to aromatase inhibitor conversion)	2 (14)
Intolerable adverse effects	2 (14)
No reason given	1 (7)
Percentage of AET related symptoms rated 2 or higher	44.6 \pm 17.2
Most bothersome symptoms as rated on the BCPT	
Symptom Scale	
General Aches	2.9 \pm 0.7
Joint Pains	2.9 \pm 1.0
Muscle Stiffness	2.7 \pm 1.1
Lack of Interest in Sex	2.5 \pm 1.6
Hot Flashes	2.3 \pm 0.9

Of note: Numbers may not sum to total due to rounding.

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