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# Patient experience of taking adjuvant endocrine therapy for breast cancer: a tough pill to swallow

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## **Cover Page Footnote**

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## Patient experience of taking adjuvant endocrine therapy for breast cancer: a tough pill to swallow

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### Abstract

Adjuvant endocrine therapy (AET) has substantially improved the mortality rate among breast cancer survivors. Despite the proven efficacy, the non-adherence rate to therapy is still high. This study is aimed to examine women's challenges related to AET adherence and management. Semi-structured interviews were conducted with six Caucasian and six African American breast cancer survivors who were prescribed for AET. The transcripts of audio-taped interviews were qualitatively analyzed. Key themes were: 1) positive beliefs in AET, 2) uncertainty about long-term adherence, 3) experiences with side effects, 4) forgetting and remembering, 5) other concerns and information needs, 6) potential intervention format, and 7) culturally-coping among African American women. The findings provided insight into women's experiences and beliefs and how these behaviors might influence AET adherence. Although most women in this study took AET as prescribed, many experienced a range of side effects and emotional distress, often without seeking support or help. New models of programs to promote adherence, support symptom management, and ultimately improve survival are critically needed. Developing culturally sensitive interventions for African American women is desirable.

### Keywords

Breast cancer survivorship experience, medication adherence, adjuvant therapy, qualitative interview, perceptions

### Notes

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### Introduction

Both national and international guidelines have recommended the long-term use of tamoxifen and aromatases inhibitors (AIs) for breast cancer surveillance management over the past few decades <sup>1,2</sup>, and recently, updated guidelines recommended 10 years of adjuvant endocrine therapy (AET) in women with hormone receptor-positive breast cancer <sup>3</sup>, approximately 75-80% of all breast cancer cases. Despite significant implications for survival, adherence to AET, which is prescribed as a daily oral tablet, is not optimal with the rate of nonadherence as high as 59% for tamoxifen and 50% for AIs in some studies <sup>4</sup>. The cost of non-adherence to AET is significant resulting in lost quality-adjusted life-years, increased medical costs, and increased mortality, highlighting the importance of developing adherence-promoting interventions for this fast-growing population <sup>5</sup>.

Breast cancer survivors have consistently reported that severe adverse events and side effects, or concerns of their development, are reported as a major barrier to discontinue AET <sup>6-13</sup>. Common side effects of tamoxifen include gynecological symptoms such as vaginal bleeding and discharge <sup>11</sup>. AIs use may be accompanied by musculoskeletal problems (i.e., arthralgia and osteoporosis), cardiovascular effects, and sexual dysfunction <sup>11,14</sup>. Both therapies are associated with an increase in vasomotor symptoms (i.e., hot flashes) and cognitive impairment <sup>11</sup>. Emerging quantitative studies have linked factors of cost, doctor-patient communication, health beliefs, fear of recurrence, self-efficacy, and lack of information and social support to intentional non-adherence <sup>15,16,17,18</sup>. To date, qualitative studies in adherence research in patients taking oral anticancer drugs are emerging but still limited. Gaining an in-depth knowledge of the important factors that contribute to women's beliefs about the use or discontinuation of AET

will allow us to develop intervention strategies promoting women's long-term adherence. Further, studies have reported that compared with other racial/ethnic groups, African American women have a higher rate of discontinuation of AET treatment, which might contribute to the differences in breast cancer mortality between African American and White women<sup>1,2,21</sup>. Thus, understanding African American women's unique experience and developing tailored strategies to enhance adherence to AET may help reduce disparities in breast cancer outcomes between African American and White women.

The goal of this qualitative study is to investigate women's barriers and facilitators to their adherence to AET and experiences with AET-related symptoms, and to explore any racial differences between Caucasian and African American women in their experiences and needs.

## Methods

### Sample

Participants were recruited from Fox Chase Cancer Center (FCCC) in Philadelphia, Pennsylvania, USA. Participants were women who had been diagnosed with primary breast cancer and had been prescribed Tamoxifen or AI between one and five years after primary treatment completion. 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. African American women were purposively sampled for the study. Sixteen women were approached and screened for the study; two ineligible, two with no interest, resulting in a total of six White and six African American women participating in the interview.

Table 1 summarizes participant's demographic and medical characteristics (n=12). The mean age of participants was 52 years (range 33-72). The majority of the participants had some college (66.7%), reported an annual household income of more than \$30,000 (58.4%), were unemployed (66.7%), were married (66.7%). Seven women were diagnosed either with stage II or stage III breast cancer (58%) and the majority completed chemotherapy (88.3%). Five women were prescribed Tamoxifen and seven were prescribed an AI daily. In average, women had been taking AET for two years. While taking AET, four women stated they never missed their AET tablets but seven reported they had occasionally missed their tablets. One woman had stopped AET temporarily and another stopped permanently following her own volition.

### Procedures

The study was approved by the FCCC Institutional Review Board. Recruitment of study participants occurred between June and December 2014. Women were recruited

through clinician referral, study registry, and in person approach in medical oncology practices. Eligible women signed a consent form and completed a short demographic and medical characteristics survey before the interview. Interviews were conducted by the lead researcher (KYW) or the trained research coordinator (RS) in a private consultation room. Interviews lasted between 20 minutes and 1 hour. All participants received a \$10 gift card for their time and effort.

### Measure

The interviews were semi-structured and informed by topics from two recent review of factors associated with AET use<sup>19,20</sup>. The interview guide was designed to probe topics on their understanding and expectations of AET, their experience with taking AET as prescribed, their experiences with AET-related side effects, and their suggestions on how to improve AET adherence and symptom management.

### Analytic Strategies

Interviews were recorded, transcribed and checked for accuracy. Two phases of analysis were conducted. Initial coding was carried out using an a priori coding scheme based on the interview guide questions<sup>21</sup>. After the first round of coding, a research team group discussion was held to elicit new themes emerging from the data and to further refine the coding framework to include sub-themes that describe more concrete units of the higher-level themes. Themes and sub-themes were iteratively extracted, discussed, and agreed on by all research team members<sup>22</sup>.

## Results

Analysis identified seven themes: 1) positive beliefs in AET; 2) uncertainty about long-term adherence; 3) experiences with side effects; 4) forgetting and remembering; 5) other concerns and information needs; 6) potential intervention format and 7) coping among African American women.

### Theme 1: Positive Beliefs in AET

Reasons to take AET was greatly shaped by participants' perceptions and beliefs about the benefits of the therapy among this small group of women who adhered to AET.

For survival. Most women stated that they knew the therapy was important for their long-term survival, and that was the reason for taking their prescribed AET.

*The oncologist explained to me the benefits long term of taking it, and that is why I continued to take it.*  
[3-year survivor, White]

**Table 1. Demographic and Medical-Related Characteristics of Participants**

Characteristics n (%)	Total n = 12	White n = 6	African American n = 6
Age (Mean, SD) (range 33-72)	52 (11.8)	55 (6.0)	50 (14.5)
Education			
Some college	8 (66.7)	4 (66.7)	4 (66.7)
College complete	4 (33.3)	2 (33.3)	2 (33.3)
Household income			
< \$30K	5 (41.7)	2 (33.3)	3 (50)
\$30K to \$60K	5 (41.7)	2 (33.3)	3 (50)
\$60K and above	2 (16.7)	2 (33.3)	
Employment			
Employed	4 (33.3)	2 (33.3)	2 (33.3)
Unemployed	7 (58.3)	4 (66.7)	3 (50)
Retired	1 (8.3)		1 (16.7)
Marital status			
Married	8 (66.7)	6 (100)	2 (33.3)
Married separated/divorced	2 (16.7)		2 (33.3)
Never married	2 (16.7)		2 (33.3)
Breast cancer stage			
I	5 (41.7)	2 (33.3)	3 (50)
II/III	7 (58.3)	4 (66.7)	3 (50)
Treatment completion			
Lumpectomy	7 (58.3)	2 (33.2)	5 (83.3)
Mastectomy	4 (33.3)	3 (50)	1 (16.7)
Chemotherapy	10 (83.3)	5 (83.3)	5 (83.3)
Radiation	9 (75)	3 (50)	6 (100)
AET medication			
Tamoxifen	5 (41.7)	2 (33.3)	3 (50)
AI: Exemestane	2 (16.7)		2 (33.3)
AI: Letrozole	2 (16.7)	2 (33.3)	
AI: Anastrozole	3 (25)	2 (33.3)	1 (16.7)
Years on AET (Mean, SD)	1.9 (1.2)	1.8 (1.6)	2 (0.9)
1 year	6 (50)	4 (66.7)	2 (33.3)
2 - 3 years	5 (41.7)	1 (16.7)	4 (66.6)
4 - 5 years	1 (8.3)	1 (16.7)	
Ever miss a tablet while taking it			
No	4 (33.3)	3 (50)	1 (16.7)
Yes	7 (58.3)	3 (50)	4 (66.7)
Unsure	1 (8.3)		1 (16.7)
Currently taking			
Yes	10 (83.3)		
Stopped temporarily	1 (8.3)		1 (16.7)
Stopped permanently	1 (8.3)	1 (16.7)	

*I know it is one of the things that you have to do or you don't have to, but I choose to based on the research. It is kind of what it is to survive. [1-year survivor, White]*

**Benefits outweigh the risks.** Many women spoke about their fear of cancer recurrence motivating them

to take their AET medication regardless of the side effects. They believe the benefits of their therapy outweigh the risks.

*I guess the benefits, in my opinion, outweigh the risk and the side effects. [1-year survivor, White]*

*Personally, I thought it was to my benefit for me to take the medication even with the side effects. [4-year survivor, African American]*

*While I am on it, the cancer won't come back. That is the reason why I am taking it and going through what I am going through because I don't want the cancer to come back. [4-year survivor, African American]*

**Extra protection.** Some women perceived taking AET after primary treatment as a maintenance drug. This makes them feel that they have extra protection against a recurrence of breast cancer, and that they have control over their health.

*I feel it is a maintenance drug after having breast cancer. [1-year survivor, White]*

*I feel better knowing that I am on something that I feel is preventive, so I guess I feel a little safer taking something rather than being completely without treatment. [2-year survivor, White]*

**Theme 2: Uncertainty about Long-Term Adherence**  
Is 10 the magic number for Tamoxifen? Although being currently compliant, some women who have been on Tamoxifen have expressed their uncertainty or confusion about extending the use of Tamoxifen from 5 years to 10 years, given the new updated guideline. Two women explicitly spoke about their concern of the increased risk of uterine cancer with possible longer duration of Tamoxifen use.

*I am starting to hear that you might benefit from being on it longer, so when I hit my five-year mark, that will be a big concern ... Going off of it is going to be a concern because you kind of feel like once you go off medication, what's going to happen? So, it is like a roller coaster of emotions ... I am concerned about effects that can happen down the line ... I think I have read that it can cause thickening of your uterine lining. [2-year survivor, African American]*

*I was told two different time frames. One time, I was told 5 years and then the next time, 10 years ... they told me we would look at it when I get closer to the 5-year point ... my concern is I have an increased risk of uterine cancer while on it. [1-year survivor, White]*

**Uncertainty in the context of not knowing.** Women talked about their lack of information on the medication itself and related side effects, especially the impact of the medication in the long term. Uncertainty about the impact of the medication on survival or adverse effects might contribute to potential nonadherence beliefs.

*Is this just the side effect I will have for five years or will there be other side effects that will follow, or how is it going to work afterward, I do not know. I am not going to drop the medicine yet, but honestly, I don't think I am going to take it for 5 years. [1-year survivor, White]*

*I do not have much information on the medication, like the side effects and like the outcome...when you take an antibiotic and you take it for 5 days, and you start feeling better ... it's like I am taking this hoping that it will repress the cancer cells, but do I have or don't I have cancer cells? I am just taking it in the dark. [2-year survivor, African American]*

### **Theme 3: Experiences with Side Effects**

Although most women reported taking their medication as prescribed, many described their challenging experience with side effects both emotionally and physically.

**Frustration with symptoms.** Several provided graphic descriptions of extreme symptoms including hot flashes and night sweats, joint and bone pains, vaginal dryness, insomnia, weight gain, diarrhea, fatigue, and mood swings.

*I get very, very hot like in my face and all around my body ... I have to take all my covers off immediately ... and like in ten minutes, I get this chill going through my body ... when it starts, it goes back and forth for a while. [1-year survivor, White]*

*I had insomnia for about three months. I couldn't go to sleep. I slept for maybe two to three hours within a day. [2-year survivor, African American]*

*I have the ups and downs ... you know, one day I am up and one day I am down ... I can feel like when I am becoming angry, and I don't know why, or if I am just feeling like depressed. [2-year survivor, African American]*

*I have new aches, I have back pains, I have headaches. I could be fine today and tomorrow, I can be sick as a dog. [4-years survivor, African American]*

**Impact of symptoms.** Some women described the profound impact that side effects had on their daily lives. Side effects, such as fatigue, impede women in performing their normal daily activities.

*I was never told that I would have been incapacitated to the point where it would be difficult getting out of bed to shower and dress and to just do those things in normal daily living. [2-year survivor, African American]*

*I am going through so much with this new medication that I am taking, that I have not worked a full week since this year. [4-year survivor, African American]*

**Emotional adjustment.** Some described the impact of side effects on their emotional wellbeing. Their distress was also caused by the deterioration of their body image and impaired efficiency because of tiredness and hot flushes.

*I was psychologically unprepared to the extent of the side effects because I have been an extremely busy, active person ... but the medication did something to me emotionally where I couldn't do it ... so not being able to function in the capacity that I am used to doing really affected me psychologically [4-year survivor, African American]*

*It affected my skin, became dry, my hair became brittle ... everything is dropping and sagging. The emotional effects of going through menopause for me was the most challenging, where the physical effects not so much for me. [2-year survivor, African American]*

*The side effects caused a lot of my negative attitude. [1-year survivor, White]*

**Coping with symptoms.** Several women reported that their providers suggested they take the medication at night to avoid the symptoms. Women also reported using supplements to cope with symptoms.

*The nurse recommended taking it at night because with the symptoms that can happen, it might be more tolerable while you are sleeping over night as opposed to in the middle of the day, so I take mine before I go to bed and that did work for me. [2-year survivor, African American]*

*I started to take the vitamin B. It helped my energy level. I am still tired, but not as tired as I was a few months ago. [2-year survivor, African American]*

*I take this with a vitamin D 200 for my bones and my age. [4-year survivor, African American]*

*I have a lot of bone pain, and I do have arthritis and my calcium level is low, so I am taking calcium pills. [4-year survivor, African American]*

*About two months of being on the medication, I began to have chronic diarrhea. I started to take a probiotic and it helped. [3-year survivor, White]*

#### **Theme 4. Forgetting and Remembering**

**Unintentional non-adherence.** Women reported unintentional non-adherence, which was usually a result of an unestablished routine at the initiation of the therapy or an interrupted routine because of change of personal schedule. Feeling tired or sick was also reported interfering with staying on their medication schedule.

*At the beginning, I didn't remember if I took it or not. [4-year survivor, African American]*

*Sometimes, it takes a while to get into the routine to remember to take it. I am sure there were many days that I missed, one here and there. [5-year survivor, White]*

*When I am out maybe on the weekend or at a conference. I did not bring my pill bottle with me. It is like a break of my normal routine. [2-year survivor, African American]*

*Sometimes, I missed a day or two because I get too tired and I fall asleep. [2-year survivor, African American]*

**Strategies to aid in remembering.** Women reported different strategies that helped them remember to take their medications including using visual cues

(e.g., by the bed), external aids (e.g., a reminder app), and organization medicines (e.g., a pillbox). As a result of implementing these strategies, women were able to integrate taking their medication as part of their daily routine.

*I take it at night. I just remember to take it like a birth control pill, that is how I look at it. [2-year survivor, African American]*

*I know every time that I eat lunch, I take my medication. I keep the bottle in my pocketbook, so when I go to lunch, I take my phone, and when I take my phone, I always see the medication in my pocketbook. [4-year survivor, African American]*

*My bottle is right next to my bed, so typically, like 10 o'clock is when I start winding down, so that is sort of my routine. [2-year survivor, African American]*

*I have a pillbox, and basically, my reminder is when I give my husband his insulin at 9 and I take my pill. [1-year survivor, White]*

*I have an app on my phone. At the time, the app sends you a reminder and if you don't click I took my medication in like 15 minutes, it plays a tune. [1-year survivor, White]*

*I take it every night after dinner, as a joke, they call it my staying alive pill, and we always joke about it so I took it. [2-year survivor, White]*

**Theme 5. Other Concerns and Information Needs**  
**Impact of medication on fertility.** A main concern that was reported by younger participants is the fertility issue. They were worried about their fertility status and wanted a clear understanding on the impact of the medication on family planning.

*Me and my husband discussed he wants another baby, and with me being on the Tamoxifen, they told me I couldn't have children. So that's the only thing that is a big problem in my personal life, that might be one of my questions when I go to the doctor. [2-year survivor, African American]*

*I know that I have to be on it for 10 years, but what I want to know is, if after 10 years, would I be able*

*to become pregnant? [2-year survivor, African American]*

**Drug interactions.** Given comorbidities are not uncommon among cancer patients, some women expressed their concern about the timing of taking their AET in relation to other chronic disease drugs and any potential drug interaction that they should be aware of.

*If someone is new to the Tamoxifen and they are taking different medications, the hospital should say okay this drug is compatible with this drug so that way, for people who take different medication, Tamoxifen might not be good for me or I can't mix the medication. [2-year survivor, African American]*

*I normally take Arimidex in the morning after breakfast, then I normally take my blood pressure medications in the evenings because I don't know, I haven't been told if there are any contraindications to taking all of them together. [2-year survivor, aged 62, African American]*

**Nutrition and Diet.** Some participants discussed their desire to receive information on nutrition and to have opportunities to discuss their dietary questions with a dietitian. They would like to receive practical advice on food selection during AET. Dietary information includes types of foods to eat to minimize side effects from AET, particular vitamins and minerals to help prevent cancer recurrences, and general nutrition information to feel better.

*One thing that was lacking with the medication was the proper nutrition [4-year survivor, African American]*

*I would love to be able to be in touch with researchers who are doing work with natural remedies to prevent recurrence of breast cancer. I would love to be in touch with a nutritionist to learn how to eat well. [2-year survivor, African American]*

**Theme 6: Potential Intervention Format**  
Following the interview about AET experiences and concerns, survivors were asked “how” to get the support or information they desire.

**Intervention delivery modality.** When discussing what could have helped women learn about and



continue to use AET, some participants brought up the idea of using portal websites that present individual prescription and related information that can be easily accessible. Using a portable feature on a cell phone or using text messaging was also mentioned as a potential modality for delivering any medication tips and reminders.

*If you are able to have like our medications in a portal website where you can go to and there would be resources available specific to the prescriptions that you are on and symptoms that you can kind of look up [2-year survivor, African American]*

*If there are any tips to help me to remember to take it on a daily basis instead of skipping occasionally. Some reminder, like portable on my phone. [5-year survivor, White]*

*Because if I do forget, text messages would be an extra back-up to remind me. [2-year survivor, White]*

**Long-term follow-up.** While some women reported receiving information about AET from their providers at the time of treatment initiation, they also expressed that it was difficult to recall the information they had initially received, or it was too overwhelming to comprehend the information at the time. The possibility of a long-term follow-up to reiterate the importance of AET and potential new side effects was suggested.

*Maybe after a year or two or maybe two or three years, another reminder of possible side effects. I know they gave me a handout, but I don't know what I did with it. [5-year survivor, White]*

*My provider gave me a lot of information which I was not able to truly initially comprehend I was so upset. [4-year survivor, African American]*

**Theme 7: Coping Among African American Women Religion and spiritual coping.** Our data suggest that religion and spirituality might play a major role in the lives of our African American participants. In our study, African American women coped with their symptoms and fear of recurrence through their religious and spiritual beliefs. Their positive perceptions were empowered by their faith in God.

*I prayed about it (Tamoxifen) and went to God, and I knew that everything was going to be ok. [2-years survivor, African American]*

*Through prayers, lots of meditation, it is a lot better, but I am still dealing with the emotional part of it (side effect). [4-year survivor, African American]*

*I have a strong belief in God. I have a strong belief in prayer. I feel that when I found my tumor myself is a gift from God. [2-year survivor, African American]*

**Peer-support.** Relationship with other breast cancer survivors was reported important to most of our African American participants. In some instances, they shared information and support with other breast cancer women, either one-on-one or through support groups.

*I have started a breast cancer survivor group at my church for women diagnosed and going through the daily day-to-day problems. [2-year survivor, African American]*

*Talking to some close friends who have gone through the medication. I am involved in my church cancer program, and I am asked to comment on it so other people have been led to me because of my experience. [4-years survivor, African American]*

*I found that the Facebook group that I belong to is really helpful for me, you post things or I see other women posting things, and everybody kind of chimes in and that's helpful. [2-year survivor, African American]*

## Discussion

The aim of this study was to explore and understand women's experiences and adherence behaviors after initiation of AET from 1 to 5 years. As found in other studies, most of the women interviewed in this study believed that taking the prescribed AET would improve their survival, despite the presence of side effects. This finding is consistent with the "necessity-concern" model<sup>23</sup> in that women who adhere to the therapy trusted and believed that the medication will prevent the recurrence of cancer, which to them was a motivation to adhere to the therapy although they had to tolerate significant side effects. The type and nature of AET-related side effects reported in the interviews were consistent with previous

clinical reports in the literature<sup>24,25</sup>. However, women reported receiving little support from their providers and the magnitude of symptoms sometimes strongly interfered with their daily activities. Further, providers might perceive side effects that affect the quality of life of patients taking AET are usually not life-threatening and differ from those that providers are mostly concerned about<sup>26</sup>. Therefore, AET-related symptom information might not be discussed with patients comprehensively. Unbiased and objective information about AET side-effects for patients is desired and critical. As the recommended duration of AET is being extended<sup>27</sup>, management of these symptoms is becoming increasingly important because these side effects can adversely impact both patient's quality of life and adherence to prescribed treatment. Future research needs to develop effective interventions to address a patient's doubt about the necessity for AET and concerns about side effects to enhance adherence.

Most women in our study believed that they were adherent and had implemented strategies in establishing a daily routine to help them remember to take their tablets. These routines generally consisted of a combination of keeping the medication somewhere they would be seen and/or taking the medication at a very specific time each day. Occasionally, forgetfulness usually occurred when the routine was not established yet (e.g., at the beginning of treatment initiation) or when the routine was interrupted (e.g., on vacation). Therefore, future research needs to inform initiation of care, where patterns of behaviors are established and carried out through the entire AET treatment regimen.

While patients of all ages may contend with challenges surrounding their treatment, younger women, who are interested in having biological children after treatment, face added complexity. Consistent with previous studies that younger women have questions regarding fertility<sup>28</sup>, our data suggest that some younger women might have unmet information needs about their fertility status during or after AET treatment. Interest in receiving fertility-related information was even identified among those who already have children at diagnosis, suggesting the importance of not overlooking the fertility issue among breast cancer patients with children. Clinicians need to be aware of and have an understanding for their younger patients' values regarding childbearing in order to assist them to make truly informed decisions and, thereby, adhere with their AET treatment.

Cancer patients often receive numerous medication, including anticancer drugs and drugs to treat comorbid conditions. These multiple treatments increase patient's uncertainty about drug interactions and any potential adverse effects, as suggested in our patient's responses. Considering that a significant number of patients with hormone receptor-positive breast cancer would use AET

treatment in the future, communication about the safety use of other drugs in relation to AET is an important part of survivorship care. Furthermore, our findings are also similar to those of previous studies that showed breast cancer patients desire information regarding nutrition and diet<sup>29</sup>. In particular, some of our participants expressed their strong desire to receive information about what to eat that would ease the AET-related side effects and improve their survival. Despite the availability of a range of resources and information sources that exist on the subjects of diet and nutrition in cancer, breast cancer patients continue to report unmet needs in the area of diet<sup>30,31</sup>, perhaps indicating available information lacks specificity (e.g., in the context of AET). Our findings suggest an increase in provision of diet and nutrition information during AHT is needed.

Although previous interventions with patient educational materials and phone reminders have had minimal success in increasing AET adherence<sup>32-34</sup>, as some of our participants mentioned, future interventions should consider how to use technology (websites or text messaging or other "out-of-the-box" approaches) to promote AET adherence. Text messaging is one of the most accessible forms of mHealth communication, and evidence is emerging on the use of text messaging for a wide range of health and behavioral programs including medication adherence<sup>35</sup>. Text messaging might be an effective modality to promote AET adherence, as it can be integrated into women's daily life and adapted to individual needs in real time<sup>36</sup>. Using web-based or mobile platforms to offer medication reminders, symptom management, compliance comparison with the patient population, and survival rate improvements could be used to encourage women to comply with treatment recommendations. Future research should aim to quantify preferences for information tools and communication strategies in a larger sample with a focus on tailoring the interventions for women with different information needs and cultural ethnic background. Longitudinal interventions with long-term follow-ups at different time points to reiterate the importance of AET and strategies for managing new side effects would be also important, as updated guidelines recommend consideration of 10 years of AET in women with hormone receptor-positive breast cancer<sup>27</sup>.

Our findings suggest that religion and spirituality were important components in our African American women's breast cancer experience. Previous research showed that faith in God helped African American women cope during and after treatment, as they believed they could endure their treatment and related side effects and ultimately survive the disease<sup>37,38</sup>. Further, the benefit of peer-communication was suggested in our African American subgroup. Therefore, future interventions targeting African American breast cancer women might want to consider utilizing spiritual ties or peer-led approaches for

strengthening AET beliefs and promoting its adherence. Additional research focusing on African American breast cancer women's experience with AET is needed as our sample was limited.

Our study was not without limitations. Our sample size was small and relatively well-educated, therefore, the views expressed by women in our study were not representative of the entire population of women receiving AET for their breast cancer. Future research should aim to extend our findings across a more diverse sample including different ethnic groups and low-literate populations. As identifying the cultural factors that contribute to ethnic variation in AET adherence is important, we also want to emphasize that individual patient's needs might be different, requiring personalized care and support. The majority of the women in our limited sample adhered to the AET so far, thus, findings from their experience might not be informative about non-adherence. Women who stopped AET completely were under-represented in this study (only one in our sample). It is possible that we were not able to reach non-adherent patients due to their loss for follow-up survivorship care or the lack of knowledge of their clinicians. Further qualitative studies targeting women who are known to be non-adherent would enhance the knowledge base in this area. Further, participants in this study were all recruited at a cancer center, thus participants were likely to respond to some doctor-patient relationship questions with socially desirable answers. The results obtained by the present study might be influenced by recollection bias. Prospective studies of women's AET-related needs and how their experience change over time are critical.

### Implications for patient-centered care practice

The findings from our study have several implications for patient-centered care practice<sup>39</sup>. First, for breast cancer patients making decisions to initiate and continue AET, information and communication from clinicians are important. Clinicians may encourage medication adherence by focusing on and communicating the value of the medication that the patient is taking, as well as providing complete and unbiased information about potential side effects. Second, clinicians need to listen to and respect patient's perspectives, concerns, and cultural beliefs about AET so that doctor-patient communication can be adjusted accordingly to positively influence patient medication adherence. Third, patients and families need to be encouraged with tools and resources to participate in decision-making about AET and in management of adherence behaviors and side effects through collaboration with clinicians. Taken together, our findings provide insight into the needs and experience of breast cancer survivors prescribed for AET. Although women in our study are generally highly compliant with their AET despite significant negative side effects, women's insights

provide opportunities for targeted interventions to improve survivor's experience and symptom management, which could ultimately improve adherence, quality of life, and survival.

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