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Barriers and Facilitators to Endocrine Therapy Adherence among Underserved Hormone-Receptor Positive Breast Cancer Survivors: A Qualitative Study

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CONFLICT OF INTEREST

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Abstract

Purpose—To evaluate the barriers and facilitators to taking anti-hormonal medications among medically and historically underserved breast cancer survivors within the first five years post chemotherapy, radiation, and/or surgery.

Methods—The current study was framed within The National Institutes of Health Centers for Population Health and Health Disparities Model (NIHCPHHD Model). Twenty-five historically or medically underserved breast cancer survivors participated in an in-depth interview, in either English or Spanish. Interviews were audio recorded and transcribed verbatim. Interview data were analyzed using content analysis.

Results—Anti-hormonal medication adherence was facilitated in several ways, including establishing a routine of medication taking, leaving the medicine in a visible or easily accessible place, taking the medication with other medications, reducing the cost of medicine, using a pillbox, understanding the negative consequences of lack of adherence, and having positive interactions with physicians. Side effects were the most commonly mentioned barrier to medication adherence.

Conclusions—Similar to other research, this qualitative study of medically and historically underserved breast cancer survivors in the United States found that side effects are the most frequently endorsed barrier to anti-hormonal medication adherence. Conversely, there were a number of facilitators of correct and consistent anti-hormonal medication use. The management of side effects is critically important to increase adherence to anti-hormonal medications. Health care providers, support providers, and caregivers can encourage breast cancer survivors to better adhere to anti-hormonal medications using a number of approaches that have been successful for other women.

Keywords

breast neoplasms; medication adherence; breast cancer; oncology; cancer

INTRODUCTION

There are nearly three million breast cancer survivors living in the United States [1,2]. It is projected that by 2022, there will be nearly four million breast cancer survivors [2]. Two-thirds of women diagnosed with breast cancer have hormone receptor positive (HR+) breast cancer [3]. The American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) best practice guidelines recommend 5–10 years of adjuvant treatment with oral anti-hormonal medications (also known as hormonal or endocrine therapy) [4–6]. There are two main types of oral anti-hormonal medications: 1) Tamoxifen, a selective estrogen receptor modulator, recommended for both pre- and post-menopausal women; and 2) aromatase inhibitors (e.g., letrozole, anastrozole, exemestane), recommended for post-menopausal women only [7–9]. Regular anti-hormonal medication use is associated with decreased mortality related to cancer recurrence [4,5,10–12].

Despite the life-saving benefits of anti-hormonal medications, rates of adherence and persistence are often low. During the first year post chemotherapy, radiation, and definitive surgery, adherence rates range from 68.2% to 87.3%; by five years, the rates of adherence range between 52.4% and 79.9% [13,14]. Between 11.1% and 16.6% of women are non-compliant during the first year of any anti-hormonal treatment, and 34.5% to 47.9% of women are non-compliant by their fifth year [13,14].

Intolerable side effects are the most common reason patients discontinue using anti-hormonal medication [13,15–18]. Side effects vary by medication and can include weight gain, joint pain, hot flashes, headaches, fatigue [19], decreased libido, mild arthritis, vaginal discharge, abdominal bloating, and bone density loss [15]. There is limited evidence regarding the efficacy of strategies for side effect management [9].

Research investigating other determinants of adherence and persistence to anti-hormonal medications is limited. A recent systematic review of 29 studies conducted by Murphy et al. [13], identified demographic, psychosocial, and behavioral factors associated with adherence. With respect to demographic factors, age, specifically being older than 65–75 years or younger than 45–50 years, was the only characteristic clearly associated with decreased adherence. In addition, socioeconomic status was associated with decreased persistence [13]. It is not clear if there are differences in anti-hormonal medication adherence and persistence by race or ethnicity. Murphy et al. [13] found that African-American women were at risk for decreased adherence, while Hispanic and Asian-American women showed increased persistence compared to Non-Hispanic White women.

In the past, cost has been identified as the main logistical and environmental barrier to anti-hormonal medication adherence and persistence in the United States [13,17,19]. Cost, however, may become less of a barrier as anti-hormonal medications become generic (as two of the medications are) and much less expensive [9,20]. Health system characteristics associated with decreased adherence or persistence include switching hormonal therapies and receiving follow-up care from a general practitioner rather than an oncologist [13].

Minimal research evaluating psychosocial and behavioral characteristics associated with decreased adherence and/or persistence has been conducted, as indicated by a systematic

review that only yielded 14 studies with various psychosocial predictors [21]. While research on psychosocial and behavioral determinants of anti-hormonal medication use is extremely limited, factors found to be associated with lack of adherence or persistence include having less than desired social, healthcare provider, and/or material support; making treatment decisions alone or experiencing a limited role in the treatment-decision process; forgetting to take a dose; experiencing side effects not described by a physician; and finally, low perceived need for medication or a lack of belief in its benefits [13,21].

The majority of the limited research conducted to date has been performed using secondary data sources, such as pharmacy records or secondary analyses of data from clinical trials testing the efficacy of the medications. Thus, most medical or sociodemographic characteristics associated with lack of adherence to or persistence with anti-hormonal medications (e.g., age) are not modifiable through intervention. There have been two qualitative studies among patients in France [22] and Scotland [23] assessing breast cancer survivors' experiences with endocrine therapy in general [23] and Tamoxifen [22] specifically. Both studies used in-depth interviews and collectively found patients experienced confusion regarding how endocrine therapy works and lack knowledge about the fact that missing doses of medication reduced the efficacy of treatment [22,23]. Although patients reported experiencing medication side effects, they did not necessarily stop taking the medication or seek treatment for the side effects [23]. To our knowledge, there have been no qualitative studies of U.S. women's perceptions of anti-hormonal medication. There also have been no studies of the perceptions of medically or historically underserved breast cancer survivors' experiences with anti-hormonal medications. Thus, the objective of the present study was to evaluate the barriers and facilitators to taking anti-hormonal medications among medically and historically underserved breast cancer survivors within the first five years post chemotherapy, radiation, and/or definitive surgery. Historically and medically underserved breast cancer survivors were defined as those who are members of a historically underserved ethnic or racial minority group and/or those who lack financial resources to obtain survivorship care. This qualitative study was conducted using semi-structured, in-depth interviews with 25 HR+ underserved breast cancer survivors at a comprehensive cancer center in the southeastern United States.

METHODS

Overview

This cross-sectional qualitative study was approved by the Institutional Review Boards at two universities. Participants provided informed consent prior to participation. A five member Community Advisory Board provided guidance. The study was framed within The National Institutes of Health Centers for Population Health and Health Disparities Model (NIHCPHHD Model). The model suggests there are multiple factors that lead to disparities in health outcomes [24], such as: distal factors (social conditions [e.g., culture] and institutional context [e.g., health care system]), intermediate factors (social and physical context [e.g., social support, availability of transportation]), and proximal factors (individual demographics [e.g., education] and individual risk behaviors [e.g., lack of adherence to medical care]).

Participants

Breast cancer survivors were recruited from a National Cancer Institute designated comprehensive cancer center located in an urban area of the southeastern United States. Breast cancer survivors were eligible if their medical records indicated they were from a group considered historically or medically underserved. This was defined by meeting one or more of the following criteria: 1) being a member of a historically underserved ethnic or racial minority group (i.e., African American, Asian American, Native American, Hispanic American); 2) lacking private health insurance; 3) participating in the hospital charity care program; 4) receiving public health insurance (e.g., Medicaid); or 5) receiving Medicare without a supplemental insurance or prescription plan. In addition, participants were also required to: 1) be >18 years old; 2) be female; 3) be able to speak English or Spanish; 4) have been initially diagnosed with HR+ breast cancer in stages 1 to 3 within the past five years or have experienced a recurrence of HR+ breast cancer in stages 1 to 3 within the past five years; 5) have completed all surgery, chemotherapy, and/or radiation; 6) live in the geographic area served by the cancer center; and 7) be able and willing to provide informed consent.

Procedure

Participants were identified using hospital administrative and medical records and interviewed between August 2012 and June 2013. A trained bilingual research coordinator contacted potential participants by telephone to review study procedures, conduct initial study screening, and schedule an appointment for an individual in-depth interview.

The interviews were conducted by Spanish-English bilingual and bicultural research coordinators, both of whom possessed a Master's degree and had been specifically trained in conducting qualitative research by the principal investigator and a co-investigator. Both individuals had experience in conducting qualitative interviews prior to conducting interviews for the present study. The research coordinators met potential participants at a private location of their choice. Each participant verified that she met inclusion criteria and provided informed consent. A semi-structured in-depth interview guide was used to conduct the individual interviews, which lasted between 30 and 102 minutes (M=38.41; SD=14.95). Interviews were conducted in the participants' preferred language of either English or Spanish. The interview guide was developed in consultation with the project community advisory board and assessed the experiences of taking anti-hormonal medications as well as barriers and facilitators to taking these medicines at various levels of the NIHCPHHD Model. In addition, all participants completed a written form, in either English or Spanish, that assessed demographic and cancer-related information. All interviews were audio recorded, transcribed verbatim, and then translated into English by a professional Spanish-to-English translator when necessary. After 25 participants had been interviewed, the transcripts of all participants were reviewed, and it was determined that theoretical saturation had been achieved (i.e., respondents were no longer providing new information during interviews) [25].

Data Analysis

After having been de-identified, all transcripts were read by five of the study authors. Initially, three of the study authors used content analysis to develop a preliminary code list, based on the *a priori* themes of the interview guide. The data were then organized into these *a priori* code categories and re-examined for emergent themes and new codes. The final codebook contained the agreed upon codes, definitions, and specific examples of each code. Using Atlas.ti [26], data were further analyzed using the code mapping function [27]. Three of the study authors completed the final coding. The data were summarized according to two themes: 1) barriers and 2) facilitators of anti-hormonal medication use. An inter-coder reliability rate of 90% was achieved (determined by counting the number of content areas to be coded divided by number of agreements) [28,29]. Demographic data were entered into an SPSS database for descriptive analysis [30].

RESULTS

Medical records of 745 breast cancer survivors were reviewed, and of these, 676 did not meet inclusion criteria. Of the 69 participants who met inclusion criteria, 33 were unreachable, and 11 declined participation, resulting in 25 participants providing informed consent and completing an in-depth interview and demographic survey. Participants' ages ranged from 46 to 71 years (M=59.92; SD=6.82). The highest year of education completed ranged from three to 18 years (M=13.6; SD=2.99). The number of people living in a participant's household ranged from zero to six (M=1.48; SD=1.56). Additional demographic and clinical characteristics of the 25 female study participants are reported in Tables 1 and 2. Three participants reported they were no longer taking prescribed anti-hormonal medications, without completing the recommended course. The rest of the participants reported taking their medication as prescribed, with persistence recorded as a discrete variable in all participants who continued taking their medication.

Facilitators of Medication Adherence

The majority of participants reported that having a routine and a scheduled time and place to take their medication reduced the number of missed medication doses and increased medication adherence. Participants who reported a routine of taking medication stated they would often take it in the morning or at night with their meal and kept the medication in plain sight. One participant stated, *"In the morning my routine is I'm going to go to the kitchen, I'm going to get my coffee ready, I'm going to get out the pills and then I'm going to drink them with water and then I'm going to have my breakfast and my coffee."* Other facilitators of medication adherence reported by at least half of the respondents included ease of access to medication, reduction of medication costs, taking anti-hormonal medications with other medications, negative consequences associated with not taking the medication (e.g., recurrence of cancer, death). A minority of respondents reported other facilitators, including using a pillbox, keeping the anti-hormonal medication within view, experiencing few medication side effects, doctor reminders and positive interactions with healthcare staff, phone alarms, and family reminders. Commonly reported medication adherence facilitators and techniques are shown in Table 3.

Although only a few participants indicated they struggled to pay for medications, the majority of participants reported health insurance and the cancer center helped them to obtain medications at a low cost, allowing them to continue taking the medication without having to worry about these expenses. These participants expressed gratitude towards the cancer center for helping them get their medication at a low cost and making the process easy. One participant described the experience, *"[name of cancer center] again helped me get the medication that I needed because I could never, I think Arimidex was like 300 and some dollars… [name of cancer center] came in and they worked with the pharmaceutical house to get me the medication. So that was wonderful."*

Barriers to Medication Adherence

Almost all participants reported either physical or psychological side effects attributed to the anti-hormonal medication that made it difficult for them to take their medication as prescribed. Physical side effects attributed to the medications for the majority of respondents included pain, fatigue, drowsiness and sleepiness, hot flashes, skin problems, and weight gain. Fewer respondents reported difficulty sleeping, cough, nausea, hair loss, and constipation. Participants disclosed that physical side effects of the medication made it difficult for them to do basic daily living functions (e.g., clean the house, cook meals, drive). One participant described the extreme debilitating pain she experienced as a side effect from the medication, *"There are days that all of you is in pain, all the body…. A pain that you don't know what is hurting…. And it is so horrible … you try to be still so it doesn't hurt. You can't cook, you can't clean, you can't even bathe because… the pain is in all your body."* Three participants reported that physical side effects were so severe that they led to feelings of depression. One participant described her personal experience, *"There are days that I feel very tired, I don't want to get out of bed, there are also days that I feel a lot of pain in my muscles, all my body hurts, very depressed, depression, I feel like crying."*

Although only a few participants reported that they suffered from psychological side effects from their medication (i.e., anxiety and depressive symptoms, mood swings, intense rage), these participants reported that these symptoms often made it difficult for them to get out of bed and significantly impaired their daily functioning. One participant described her struggle with the psychological side effects of the medication, *"And she [a nurse] told me, she said yeah that's Tamoxifen. That's one of the side effects. So I told her wow, …I never knew….Because the first time when I was on the Tamoxifen, it's like sometimes I would be in a rage."*

Four participants reported they researched side effects associated with anti-hormonal medications, which led them to make a decision about which medication to take or whether to avoid taking the medications altogether. One participant described her research process, *"I was on crutches. I was using a cane. I couldn't get out of a chair because my knees were so bad. I mean they still are, but they're 100% better, and it's been a year and a half, and I went on a site called askapatient.com…. I read case histories from age 37 to 73, who had been on just Arimidex, and I was blown away at how many women have suffered this knee problems… And so… I Googled Arimidex and started to read about it…. I mean I have a folder that's probably this thick about it. It's nasty. It's terrible stuff."* Not all participants

researched the medications to this extent, but a few participants also mentioned searching information about the medications on websites and asking others who were taking these medications what side effects to expect. Participants suggested doctors and the information on the medication bottles did not provide enough detail about the side effects. They felt that having additional information regarding side effects of the medications is important and that it would help inform their decision about which medication to take and what side effects to expect. One participant described the benefits of knowing the side effects, *"Well you need to know the side effects, that's the first thing because you want to know how you can pace your day and what to expect throughout that day and what to do."*

Other barriers to medication adherence mentioned by participants included financial costs, difficulty with remembering to take the medication, and personal reasons (e.g., faith and belief in God). For example, one participant stated, "*the medication is not cheap, it is expensive."* Another participant commented, "*I tried doing it in the morning, but I'd forget it because I'd be too busy doing…other stuff.*" Another participant mentioned: "*the reason I'm not taking drugs anymore is my faith. I very firmly believe that God healed me. I prayed. My church prayed for me. I did exactly what God tells us to do in the Bible and that is to go to Him and ask Him and give Him all the credit for it first, and He did heal me*." Commonly reported medication adherence barriers are shown in Table 4.

DISCUSSION

Nearly two-thirds of breast cancer survivors are prescribed oral anti-hormonal therapy that significantly reduces breast cancer recurrence and increases survival [4–6,10–12]. Despite the life-saving benefits of these medications, adherence and persistence to these medications are not ideal [13,14]. Most research evaluating predictors of anti-hormonal medications prescribed to reduce the risk of breast cancer recurrence has focused on non-modifiable demographic predictors of adherence and persistence [9,13]. Relatively little research has been conducted regarding psychosocial and behavioral characteristics associated with adherence to and persistence with anti-hormonal medications, and most has utilized secondary data sources [21]. There have been two qualitative studies of breast cancer survivors' experiences with anti-hormonal medicine, and both studies were conducted outside the United States [22,23]. There have been no qualitative studies of medically and historically underserved women's experiences with anti-hormonal medicine.

New findings from the present study indicate there are a number of facilitators of adherence to anti-hormonal medications, including taking the anti-hormonal medication with other medications, using a pillbox, and having positive interactions with doctors who provide reminders regarding the importance of the medications. Similar to a previous research, understanding the negative consequences of not taking anti-hormonal medications [21,31], making medications easily accessible and visible, and establishing a routine or habit of taking the medication also facilitated adherence to the medications [23].

As noted in other studies [13,15,16,18,23], the present study found that the side effects attributed to anti-hormonal medications by survivors were the main barrier for non-adherence. Most side effects described were physical, but some survivors also reported

psychological side effects. While participants attributed a wide variety of side effects to the medication, it is not clear whether all of the side effects were actually caused by anti-hormonal medicines. Many participants reported that they were not provided with enough information regarding side effects, either at the time of prescription of the medication or at the time of the side effect occurrence. Unlike participants in a previous study [23], survivors sought additional information from a variety of sources, including from internet websites, people they met in the community, and from other survivors who were prescribed anti-hormonal medications. Many participants reported that it was important for breast cancer survivors to be better informed regarding the side effects of anti-hormonal medications so that they could make a more informed decision about taking the medication. Similar to other studies [17,19], costs were a barrier to medication adherence for some participants, but other survivors indicated that the health care system and their insurance had overcome these financial barriers to the medicines.

Combined with other research, the present study indicates several areas of improvement for increasing adherence to endocrine therapy. First, at the time an anti-hormonal medication is prescribed, breast cancer survivors need comprehensive information regarding the side effects associated with the prescribed medication and the likelihood of these side effects occurring. Because survivors reported that understanding the negative consequences of non-adherence was an important facilitator to medication adherence, information should also be presented regarding the risk of breast cancer recurrence associated with not taking the medication compared to taking it as prescribed. The use of decision aides may be warranted to provide this information; however, additional research should be conducted to determine the most effective approaches to communicating this information. Provision of information regarding a medication has been associated with long-term adherence to other types of medication [32]. Second, ongoing assessment and management of side effects are necessary throughout the five-year period that these medications are prescribed. Third, there are a number of facilitators of medication adherence that could be incorporated into behavioral interventions or regular medical care, including instructing patients to place anti-hormonal medication in a visible location, establishing a routine that links the taking of anti-hormonal medications to daily events or to the taking of other medications, using a pillbox, and decreasing the costs of the medication for survivors. Less frequently mentioned by participants in the present study was the use of reminders, which has been found to be effective in improving adherence to other types of medications [32].

Although the results obtained from this qualitative study are novel, the study does have limitations. While the participants were diverse in terms of age, ethnicity, race, marital status, and number of years of education, all 25 participants were recruited from one comprehensive cancer center in the southeastern United States. In addition, all participants were still receiving health care at the comprehensive cancer center up to five years after surgery, chemotherapy, and radiation had been completed for breast cancer. Therefore, the present study findings may not generalize to patients from other areas of the United States or from other countries, as well as to breast cancer survivors who are either not receiving survivorship care or who are receiving survivorship care outside of a comprehensive cancer center. Future studies should engage HR+ breast cancer survivors who become lost to

follow-up post chemotherapy, radiation, and surgery to determine if they experience other barriers to care not reported in the present study.

This qualitative study of medically and historically underserved breast cancer survivors in the United States found that side effects are the most frequently endorsed barrier to anti-hormonal medication adherence. On the other hand, there were a number of facilitators of correct and consistent anti-hormonal medication use. These findings contribute to the scientific literature regarding adherence to anti-hormonal medications and will be used to develop a patient navigation intervention to improve receipt of breast cancer survivorship care, including adherence to anti-hormonal medications. Findings from this research have been used to develop patient navigation intervention modules which help patients overcome barriers to endocrine therapy adherence. Future studies are necessary to evaluate the generalizability of these findings and to evaluate the patient navigation intervention.

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Table 1

Demographic Characteristics of Breast Cancer Survivor Participants ($N = 25$).

Characteristic	Number of Participants	%
Hispanic/Latina		
No	15	60.0
Yes	10	40.0
Race		
White	13	52.0
African American or Black	7	28.0
Asian	1	4.0
Other	4	16.0
Primary Language		
English	16	64.0
Spanish	8	32.0
Other	1	4.0
Marital Status		
Single	4	16.0
Married	8	32.0
Separated	11	44.0
Widowed	2	8.0
Employment		
Not currently employed	11	44.0
Part-time	8	32.0
Full-time	6	24.0
Country of Birth		
Colombia	2	8.0
Cuba	2	8.0
Dominican Republic	1	4.0
Germany	1	4.0
Honduras	1	4.0
Panama Canal Zone	1	4.0
Puerto Rico	3	12.0
United States	14	56.0

Table 2

Clinical Characteristics of Breast Cancer Survivor Participants ($N = 25$).

Characteristic	Number of Participants	%
Year of Breast Cancer Diagnosis		
2005	2	8.0
2006	1	4.0
2007	3	12.0
2008	4	16.0
2009	5	20.0
2010	4	16.0
2011	6	24.0
Treated By Surgery		
No	1	4.0
Yes	24	96.0
Treated By Chemotherapy		
No	13	52.0
Yes	12	48.0
Treated by Radiation		
No	7	28.0
Yes	18	72.0
Currently Taking Hormone Medication		
No	3	12.0
Yes	22	88.0
Brand of Prescribed Medication		
Anastrozole	17	68.0
Tamoxifen	6	24.0
Missing	2	8.0

Table 3

Facilitators of Medication Adherence.

Facilitators of Medication Adherence	Number of Participants
Ease of access	17
Routine/habit	16
Reduction of medication costs	13
Taking medication with other medications	11
Negative consequences	11
Pillbox	9
Within view/accessible	8
Few side effects	8
Doctor reminders and positive interactions	7
Phone alarms	3
Family reminders	3

Table 4

Barriers to Medication Adherence.

Barriers to Medication Adherence	Number of Participants
Side effects	23
Medication costs	4
Trouble remembering to take medication	4
Personal reasons	2