



Published in final edited form as:

Int J Behav Med. 2020 December ; 27(6): 687–697. doi:10.1007/s12529-020-09908-2.

The Patient's Voice: Adherence, Symptoms, and Distress Related to Adjuvant Endocrine Therapy after Breast Cancer

Jamie M. Jacobs, PhD^{1,2}, Emily A. Walsh, BA¹, Elyse R. Park, PhD, MPH^{1,2}, Jonathan Berger, BA¹, Jeffrey Peppercorn, MD, MPH^{1,2}, Ann Partridge, MD, MPH^{2,3}, Nora Horick, MS¹, Steven A. Safren, PhD⁴, Jennifer S. Temel, MD^{1,2}, Joseph A. Greer, PhD^{1,2}

¹Massachusetts General Hospital, Boston, MA

²Harvard Medical School, Boston, MA

³Dana-Farber Cancer Institute, Boston, MA

⁴University of Miami, Coral Gables, FL

Abstract

Background—While adjuvant endocrine therapy (AET) for early-stage, hormone sensitive breast cancer confers a 40–50% reduction in recurrence risk, adherence to AET is suboptimal, and no efficacious interventions exist to improve adherence. A qualitative study was conducted to understand patient experiences on AET, motivators and barriers to adherence, side effects, and distress, with the goal of developing a patient-centered, evidence-based intervention.

Methods—From 11/2017–11/2018, female patients with early-stage, hormone-receptor positive breast cancer taking AET were recruited. Patients with low and high medication adherence of varying ages, levels of distress, and years taking AET were purposefully enrolled. In-depth semi-structured interviews were conducted, audio-recorded, and transcribed. Study staff created a thematic framework, and three independent researchers coded interviews using NVivo 11, achieving high inter-coder agreement ($Kappa=.96$).

Results—Thirty interviews were conducted with patients who were, on average, 55.13 years old ($SD=12.37$) and had been taking AET for a mean of 1.76 years ($SD=0.75$). The sample was stratified by adherence level (low=20; high=10). Recurrent themes related to adherence included a commitment to AET to prevent recurrence despite distressing side effects, lack of strategies to

Terms of use and reuse: academic research for non-commercial purposes, see here for full terms. <http://www.springer.com/gb/open-access/authors-rights/aam-terms-v1>

Corresponding Author: Jamie Jacobs, PhD, 55 Fruit Street, Yawkey, Suite 10B, Massachusetts General Hospital, Boston, MA 02114, jjacobs@mgh.harvard.edu.

Conflict of Interest Declaration: Dr. Peppercorn reports research funding from Pfizer, GlaxoSmithKline. All other authors declare that they have no conflict of interest.

Publisher's Disclaimer: This Author Accepted Manuscript is a PDF file of an unedited peer-reviewed manuscript that has been accepted for publication but has not been copyedited or corrected. The official version of record that is published in the journal is kept up to date and so may therefore differ from this version.

Statements Page

Informed consent: Informed consent was obtained from all individual participants included in the study.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

cope with symptoms and distress, and desire for emotional support from others taking AET. Patients were highly accepting of a proposed psychosocial intervention to manage AET.

Conclusions—Patients are committed to taking AET to prevent breast cancer recurrence, but need and desire psychosocial support and skills training. Themes from this study are modifiable targets for a psychosocial, evidence-based intervention to promote adherence, coping with side effects, and distress management.

Keywords

Breast cancer; oncology; adjuvant endocrine therapy; adherence; side effects; distress; qualitative; hormonal therapy

Approximately 60–75% of early-stage breast cancers are hormone sensitive and treated with a 5–10 year regimen of adjuvant endocrine therapy (AET) [1]. AET in the form of tamoxifen or aromatase inhibitors (e.g., Arimidex) significantly reduces risk of breast cancer recurrence by up to 50% and improves 15-year survival by a third [2]. Despite clinical benefits, adherence to AET is remarkably poor [1], with up to 59% of patients not taking the medication as prescribed [3]. This statistic is concerning given that adherence is the single most modifiable factor influencing treatment outcomes; non-adherence is associated with recurrence and mortality [1,4].

Contributors to AET non-adherence are well-established and include patient, treatment, and systems factors; several of which are modifiable. First, patient-related factors such as low perceived need for AET [5], self-efficacy for taking medication [6,7], and perceived risk of recurrence [6] are associated with low adherence. Patients with less social support [8–10] and more distress (e.g., depressive or anxiety symptoms) may be less likely to adhere to AET regimens [11]. In addition, treatment factors including AET toxicities, such as hot flashes/night sweats, joint pain, and fatigue, are major barriers [1,11–14]. Finally, systems factors such as higher cost of medication and poorer patient-physician relationships contribute to worse adherence to AET [10,15].

Despite identification of barriers to AET adherence through prior quantitative and qualitative work [10,12,13,16], reviews highlight the lack of efficacious, rigorous interventions, with only four completed randomized controlled trials [17] and no meaningful improvements in adherence [17–19]. Most studies employed retrospective or observational designs, tested interventions lacking a theoretical basis for behavior change, or failed to address known modifiable factors. For example, interventions generally have not focused on enhancing coping strategies to manage AET-related side effects, a major and modifiable barrier to AET adherence [8]. In addition, interventions thus far have largely employed psychoeducational content, reminder systems, and other atheoretical components that have not successfully improved adherence to AET [20,21]. Per the National Institutes of Health Stage Model for Behavioral Intervention Development [22], intervention development should be guided by formative work, including qualitative methods. Despite the qualitative work thus far in this area [16], it is possible that the limited intervention effects are due to a disconnect between the actual qualitative findings and the interventions developed, such that interventions developed for specific patient samples are not based on qualitative work done in that same

patient sample. In other words, most qualitative work conducted thus far has stopped short of leading to actual intervention development. Therefore, there is a pressing need to conduct a qualitative study that directly informs the development of a theoretically driven, efficacious intervention to optimize adherence to AET, in accordance with the NIH Stage Model for Behavioral Intervention Development [21,22]. Furthermore, there is a need to solicit feedback from patients during these qualitative explorations, in order to understand patient preferences for both practical and content-specific intervention components.

To address this need, a qualitative study was conducted with patients taking AET after breast cancer with the specific goal of developing an intervention. In addition to exploring experiences, perceptions, and attitudes towards AET, and barriers and motivators for adherence, this study examined individual preferences for a psychosocial intervention content and logistics in order to maximize feasibility, acceptability, and eventual efficacy. This is a novel contribution, given that most published qualitative work has not conducted this type of in-depth questioning to understand patients' intervention preferences [16]. In addition, above and beyond prior qualitative work, the current study explored differences in qualitative themes (e.g., adherence patterns) by patient characteristics, such as age, distress level, and the amount of time on AET.

Methods

Study Design

From 11/2017 to 11/2018, patients with a diagnosis of early-stage (0-IIIb), hormone receptor-positive breast cancer currently taking AET participated in a qualitative study to understand experiences on AET as part of a larger mixed-methods study design. Patients were recruited from the Massachusetts General Hospital (MGH) Cancer Center in Boston, Massachusetts. The Dana-Farber/Harvard Cancer Center Institutional Review Board approved the study (protocol:17–201).

Participants

Eligible patients were female, ≥ 21 years of age, fluent in English, had an Eastern Cooperative Oncology Group (ECOG) performance status ≤ 2, had completed adjuvant treatment, and were within three months to three years of initiating AET. Patients with a condition that would interfere with study procedures, such as a psychiatric or cognitive disorder, were not eligible. Patients who had discontinued AET were not eligible, due to the focus on non-adherence versus non-persistence. Twenty patients with poor adherence were purposefully recruited, followed by 10 patients with high adherence that simultaneously reported moderate to severe side effects. Given the potential for age, distress, and length of time on AET to influence adherence [23], equitable distribution of these factors across adherence levels was attempted throughout recruitment.

Procedure

Study staff consecutively identified potentially eligible patients by querying the electronic health record (EHR) for patients prescribed AET with upcoming appointments. With permission from the oncology clinician, staff described procedures to interested and eligible

patients, obtained informed consent, and administered screening measures. Patients who met criteria for low and high adherence were enrolled until these strata were filled. Patients of varying ages, distress levels, and time on AET were enrolled until balanced samples or thematic saturation was achieved. Enrolled participants were interviewed in-person in a clinic room or by telephone with trained study staff using a semi-structured interview guide (see supplemental materials) and were remunerated \$20. In addition to exploring experiences with AET, patients gave specific feedback on practical and content-focused aspects of a possible intervention. The guide was developed by a qualitative expert (EP), breast oncologists, and psychologists, based on existing literature, and pilot tested with research coordinators and the first three patients (these patients were included in the final sample). Slight modifications were made to the interview guide following testing with these three patients, including 1) incorporating a diagram to clearly illustrate the intervention and accompany our description, 2) asking specifically about past adherence barriers in addition to present adherence barriers, and 3) exploring perceptions of social support in more depth to understand and tailor the intervention to these needs.

Study Measures

Sociodemographic and clinical factors—Participants reported sociodemographic characteristics; disease and treatment information was collected from the EHR.

Brief adherence screen—Patients reported how much of their AET they had taken in the past 30 days on a Visual Analog Scale (VAS; 0–100%) and whether they had difficulties taking AET (yes vs. no) [24]. Patients who scored $\geq 90\%$ on the VAS and/or answered “yes” to the one-item adherence question were classified as low adherers. Patients reported their side effect intensity (none, mild, moderate, or severe) on a one-item question.

Distress—The nine-item Patient Health Questionnaire [25] (PHQ-9) and seven-item Generalized Anxiety Disorder [26] (GAD-7) questionnaire were used to assess distress and ensure balanced levels of distress across low and high adherers. Based on empirical cut-offs in oncology, patients with scores ≥ 8 on the PHQ-9 and/or ≥ 10 on the GAD-7 were categorized as high distress (vs. low distress).

Data Analysis

All interviews were audio recorded and transcribed. Two study staff (JJ, EW) reviewed each transcript to develop a comprehensive thematic coding framework using inductive thematic content analysis with a six-step process including data familiarization, initial coding, generating themes, reviewing themes, defining and naming themes, and report writing [27]. Next, two study staff (EW, JB) and the lead investigator (JJ) independently coded each interview, continuously, using NVivo 11 software to validate the framework. Coders met to compare coding schemes, resolve discrepancies, and iteratively modify the framework. Data saturation was achieved when no new codes were identified. A coding comparison query showed a high level of coding reliability ($Kappa=.96$).

Results

Patient Characteristics

A total of 333 potentially eligible patients were approached; 61 patients asked study staff to follow-up later, 60 declined study participation, and 212 signed informed consent. After consenting, 34 reported low adherence and 187 patients reported high adherence to AET. Of the 34 patients reporting low adherence, seven were not included because thematic saturation was reached, five were lost to follow-up, one withdrew, one was deemed previously ineligible, and twenty completed the semi-structured interview. Subsequently, eleven women with high adherence to AET were enrolled, of which one was lost to follow-up. In total, 30 patients (low adherers=20; high adherers=10) completed interviews lasting approximately 27 minutes (range=12–43). Patients were an average of 55.13 years of age ($SD=12.37$); the majority was White (83.3%; 25/30), non-Hispanic (93.3%; 28/30), and partnered (76.7%; 23/30). See Table 1 for patient characteristics and Table 2 for representation of low and high adherers by age, distress, and time since initiation of AET.

Adherence Motivators and Patterns

Patients described high motivation for taking AET to reduce or block estrogen to prevent breast cancer recurrence. They did not convey an in-depth understanding of their medication (AI vs. tamoxifen) and how or why estrogen blockage or reduction would translate to a recurrence risk reduction. Patients described strategies for medication-taking, including reminder systems, visual cues, or pairing with food, beverage, or other medication. The following six major themes were identified (See Table 3 for exemplar quotes).

Side effects are distressing yet worth the protective benefit—Patients reported that side effects varied from relatively minimal to extremely severe. Regardless of severity, side effects were an ongoing concern, distressing, and debilitating. Patients with low adherence discussed side effects often and experienced a broad range of side effects. Almost all patients conveyed a strong commitment to preventing cancer recurrence with a willingness to tolerate side effects and tradeoff in quality of life (QOL) if necessary. Patients often attributed any symptoms to AET while acknowledging the uncertainty of the actual cause.

Generally, patients described three categories of side effects related to: 1) physical appearance and female identity (e.g., weight gain, hair thinning, body image, and vaginal dryness), 2) daily functioning (e.g., hot flashes, pain, fatigue, sleep difficulties, sexual functioning), and 3) emotional well-being (e.g., mood fluctuations, depressed mood, anxiety). Side effects related to functioning, such as hot flashes and pain, were often discussed in the context of a medication break, skipping doses intentionally, switching medications, or thoughts of discontinuing AET.

Emotional support from other cancer survivors is beneficial yet lacking, while informational support from clinicians is strong—Patients described receiving informational support from their breast oncologist or nurse practitioner, with some emotional support from family and friends. Patients frequently mentioned their own research

about AET with credible sources such as WebMD or the American Cancer Society. Only a few patients reported confiding in other survivors or support groups. However, those that did described receiving meaningful emotional and informational support that maintained adherence through connectedness and a sense of normalcy. Informational support from oncology clinicians was intact and maintained adherence, with patients citing exceptional trust in their doctor's recommendation. Although many questioned the necessity of AET, they were reassured by consistent messages from clinicians about the importance and benefits of AET. Patients described having helpful conversations with clinicians entailing problem-solving the time of day to take AET, taking a break for symptom relief, or switching medications. No differences in support emerged between low and high adherers.

Concerns, ambivalent attitudes, and negative beliefs about medication were ubiquitous—Patients often expressed negative attitudes towards medication-taking in general, citing concerns about use and ambivalence related to doubts about benefits versus belief in efficacy for preventing recurrence. They used strong or negative language to describe AET, questioning the therapeutic efficacy and necessity. Patients commonly cited having to gather motivation to stay adherent from hope or faith in the absence of objective feedback. Patients' concerns about AET centered on two broad themes: daily side effects (e.g., hot flashes or fatigue) and long-term health consequences (e.g., bone density or other cancer risk). While patients were concerned about the consequences of estrogen deprivation, they underscored their understanding and necessity of the tradeoff between reducing recurrence risk and QOL. Patients with low adherence described a broader range of concerns including medication cost, mood changes, side effects, long-term health consequences, doubts about efficacy, QOL impairments, and regimen length.

Non-adherence is both intentional and unintentional—Patients' self-reported adherence to AET was high overall. While some described a clinician-prescribed break or drug "holiday," few patients described an intentional break, such as skipping doses, due to side effects. Patients commonly cited forgetfulness as a barrier, describing a disruption in routine as a reason for missing doses, such as being away from home or caring for others. Patients did not have a backup plan to help with remembering in these situations. Usually, patients described missing one to two doses per month, with three missed doses at the most. Those who had unintentionally missed one or more doses were quick to express a strong commitment to adherence. Despite stratification by adherence level, no differences were found in how low and high adherers described taking medication.

Changes in mood emerged and are noticeable—A recurrent concern for patients was a noticeable shift in mood since initiating AET. Most were unaware of the potential for the medication to affect mood. Some described a more present worry, nervousness, or anxiety, often in the context of fears of recurrence. Others expressed feeling more down, sad, depressed, or being weepier. Patients described difficulties with mood management, such as mood swings or irritability. Low adherers endorsed more difficulties with mood than high adherers.

Strategies to manage symptoms, distress, or barriers to adherence are severely lacking—Patient strategies for managing AET-related difficulties were largely absent. Patients described “sticking it out,” and feeling lucky if side effects improved with time. Patients described managing mood and side effects by “pushing through” or “dealing with it.” There was a lack of action-oriented, behavioral strategies for managing side effects, concerns, barriers to adherence, and mood changes. Patients rarely mentioned physical activity, acupuncture, massage, or yoga. Although patients discussed side effects with clinicians, these conversations led to problem-solving the timing or type of medication. Conversations with clinicians did not result in discussion of specific strategies for side effect management or referrals to specialists for pain, fatigue, depression, etc. There were no differences in coping strategies by strata.

Preferences for a psychosocial intervention

Patients gave feedback on a possible intervention structure based on theoretical and empirical evidence. Regardless of adherence, patients underscored the need for support while taking AET and almost all were enthusiastic about the proposed skills-based program to enhance self-management of symptoms, reduce distress, and problem-solve barriers to adherence. Patients preferred group sessions, desiring support and the ability to share and learn from others’ experiences. Importantly, they recommended offering this intervention in the initial years of AET, as they perceived this period to be a difficult adjustment. Patients also preferred a virtual video platform from home rather than coming to the hospital.

Differences in age, distress, or time on AET

Differences within the themes based on patient age, distress level, or time on AET were explored. It was observed that younger patients described side effects with a greater intensity than older patients while older patients cited having difficulty parsing which symptoms were caused by AET versus natural aging. Patients who had been taking AET longer mentioned more concerns about the length of the regimen and expressed greater fear of recurrence than those who had started recently. Patients with higher distress described their mood with a greater intensity and were more likely to acknowledge a relationship between mood and AET.

Discussion

This qualitative study reinforced that patients with breast cancer experience challenges related to AET including side effects interfering with QOL, concerns and ambivalence about AET, distress about side effects and mood changes, and a lack of coping skills. Although mostly adherent to AET and motivated to reduce risk of recurrence, patients describe strong ambivalence, negative beliefs, and concerns regarding AET that likely serve as a barrier to adherence and are compounded by side effects and mood changes. Six themes emerged from the interviews related to: a) side effects, b) support, c) beliefs and concerns, d) adherence, e) mood, and f) coping. Those with low adherence endorsed greater challenges with side effects, more ambivalence towards AET, and more difficulties with mood. Notably, the in-depth questioning into patients’ preferences resulted in important information for intervention development over and above other qualitative studies conducted thus far.

Almost all patients were interested in a virtual psychosocial intervention with group support. Therefore, these findings highlight what might be most acceptable and feasible for patients, in turn, optimizing future intervention efficacy.

Patients' descriptions of AET-related side effects (e.g., hot flashes, pain, fatigue, weight gain, sleep difficulties, alopecia, and sexual dysfunction) as challenging and distressing are consistent with qualitative and quantitative literature [1,9,12–14,28]. Toxicities from both primary breast cancer treatment and AET can be specific to femininity and sexuality (e.g., breast deformation, vaginal dryness), which may be uniquely distressing relative to other cancers [14]. In addition, while medication is usually prescribed to provide relief from symptoms of a disease, AET is nuanced in that it *causes* side effects without relief of symptoms from the disease for which it is indicated (breast cancer), operating more so as a preventative medication versus a treatment [8]. While patients recognize the ambiguity of determining the source of specific side effects, they often attribute them to AET, promoting negative attitudes towards AET. Such perceptions are notable as AET-related side effects are associated with non-adherence [8]. However, skills-based counseling, such as cognitive behavioral therapy, can be effective in reducing menopausal symptoms for patients taking AET [29,30].

Patients in our study who received support from other cancer survivors found it to be exceptionally helpful, noting an ability to share challenges about adherence and side effects, while obtaining needed emotional and informational support. However, most patients did not have an established connection to another survivor and described minimal emotional support from friends and family. Most patients expressed a preference for a group-based intervention, demonstrating the need for connectedness and support from others taking AET. Patients in our study noted substantial informational support from their clinical oncology team, receiving a consistent message regarding the importance of the medication, and the ability to problem-solve medication changes or breaks with their clinician. This support is unique to our sample, as the improvement of patient-clinician communication is a priority in breast cancer care [1,31] based on evidence that poorer patient-clinician relationships predicts non-adherence [12]. Notably, social support plays an important role in adherence, either directly or indirectly through mood and psychological adjustment [8]. In breast cancer, low levels of social support are associated with nonadherence to AET [10,32,33], depression, and anxiety in patients [23]. However, support from clinicians may mitigate the risk of AET discontinuation for those with lower personal social support [33]. In addition, simply having a peer with breast cancer or social network [9] is related to better adherence to AET [34]. Incorporating support from fellow breast cancer survivors is an area of need and may be an important component to improve AET adherence [8].

The trade-off between side effects and survival was a recurrent theme that is consistent qualitative work [13,14]. In fact, studies show that patients who place higher priority on survival versus immediate QOL (i.e., viewing the efficacy of AET to be as or more important than downsides) are more likely to be adherent [12]. However, a significant and novel finding of the current study is that patients taking AET for a longer duration expressed greater concerns about fears of recurrence and about the regimen length, suggesting that fears of recurrence may not mitigate over time and that adherence support should be

longitudinal. Furthermore, patients in our study simultaneously conveyed ambivalence, negative attitudes, doubts about therapeutic efficacy, and concerns about the long-term consequences of AET [13,14]. Ambivalence was compounded patients' desires for reassurance in the form of an objective test that does not exist and other nuances of taking a medication for which there is no tangible disease-related symptom relief. While negative beliefs, low perceived need, distrust, and dissatisfaction with AET are associated with non-adherence [12], facilitation of positive self-talk and cognitions regarding the necessity for AET is associated with better adherence [8]. Within cognitive theory, patients may benefit from skills to modify unhelpful thought processes to promote a desired behavioral change in adherence as well as alleviate distress.

Patients' descriptions of unintentional non-adherence in our study is consistent with the understanding that adherence comprises both intentional and unintentional behaviors [35]. Interestingly, while patients had reported low adherence on our screening measures, they often denied missing or skipping doses in the interview, suggesting underreporting of adherence problems. Consistent with prior qualitative work, medication-taking routines, reminder systems, visual cues, and storage strategies are techniques that maintain adherence [12], which patients mentioned in interviews, demonstrating some self-efficacy for taking AET. Self-efficacy for medication-taking is a robust predictor of adherence [36], and self-efficacy for coping with side effects may improve patients' well-being while taking AET [7]. Importantly, self-efficacy is a modifiable behavior in the context of the Theory of Planned Behavior [36] and may be a relevant intervention target.

Mood fluctuations, anxiety, and depressive symptoms were recurrent concerns and consistent with literature suggesting that approximately 33% of patients report depressive symptoms [37] and 18% report anxiety symptoms [38] after breast cancer. Depression, anxiety, and lower QOL are risk factors for poor adherence to AET [12,39]. It appears that patients may benefit from psychoeducation about the relationship between estrogen deprivation and mood. The lack of strategies to manage side effects, mood changes, or general distress related to adjustment to AET has been largely underexplored thus far. Some qualitative studies show that patients are dissatisfied with options to manage side effects, feel a loss of control over their bodies, describe minimal agency, and simply wait for side effects to improve with time [12,14]. The observed lack of coping strategies in the current study is striking, however, as emotional and physical symptoms can be alleviated with evidence-based pharmacological and non-pharmacological interventions and highlights the opportunity for intervention. For example, the acquisition of active strategies to cope with disease can reduce distress and promote positive adjustment [40,41], and management of depression may enhance adherence to AET and improve cancer outcomes [42].

Study Limitations

When interpreting these findings, it is important to consider that recruitment purposefully included a select number of patients who reported low or high adherence and only high adherers with moderate to severe side effects. Based on evidence that adherence to AET is most critical in the initial years following treatment [2], enrolled patients were within three years of initiating AET. A strength of the study is balanced representation across factors that

relate to adherence, including age, distress, and time on AET [23]. The patient sample was relatively homogenous, and the following should be noted: 1) self-reported adherence was seemingly higher than has been reported in the literature [3]; 2) the generally high socioeconomic status may explain why cost of medication was rarely discussed as a barrier, and also suggests an above average health literacy; 3) patients' expressed trust in clinicians may be unique to the culture at MGH and may not represent patient-clinician relationships across care settings; and 4) the sample is limited with respect to ethnic and racial diversity, which is known to relate to adherence and medication access [43]. Despite limitations, the themes highlight the experiences taking AET that can serve as modifiable targets and inform a patient-centered intervention. Moreover, this study extends prior literature by specifically identifying patient preferences and incorporating these into actual intervention development to be implemented in this clinical setting, per the NIH Stage Model for Behavioral Intervention Development [21,22]. An additional strength of the study is the focus on identifying differences in qualitative themes based on patient characteristics in order to further individualize the intervention.

Clinical Implications

Patients taking AET may benefit from referral to supportive and skills-based services (e.g., social work, psychology, psychiatry) to discuss their needs after breast cancer and adjustment to AET. Patients expressing difficulties with adherence, distress related to side effects, or concerns about AET have the potential to benefit most. On a larger scale, there is an urgent clinical need to develop, test, and implement effective, theoretically-based interventions to promote adherence, reduce distress, and enhance self-management of side effects for patients taking AET after breast cancer treatment [10,12,18]. Patients in our study expressed enthusiasm and interest in a skills-based program, preferring a virtual and small-group intervention. The themes identified can inform intervention targets, such as coping self-efficacy, side effect management, relaxation skills, and uncertainty management. In addition, a recent meta-analysis suggests that bi-directional communication may be an important intervention component for AET adherence [19]. Accessible interventions that incorporate theoretical approaches for behavior change, consider bidirectional communication, apply knowledge from adherence interventions with other chronic conditions [44] and offer a connection with a fellow breast cancer patient [8,34] will likely be most successful [17,19].

Conclusions

In summary, patients taking AET after breast cancer express high and unwavering motivation to take AET to prevent recurrence and improve survival; however, they experience substantial challenges regarding side effects and QOL, psychological distress and mood fluctuations, and ambivalence and concerns about medications. These concerns are compounded by patients' limited coping skills and low self-efficacy for managing side effects and distress. While patients describe strong support from their oncology team, social support and connection to other patients prescribed AET are limited. An evidence-based intervention that targets adherence, symptom management, and distress while incorporating patient preferences and social support from others on AET may be feasible and acceptable, with the potential to improve long-term outcomes after breast cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

We would like to thank the study participants for their time and effort, as well as the breast oncology clinicians for referring their patients to the study.

Funding: This study was funded by the National Cancer Institute: K07CA211107 (Jacobs).

References

- Burstein HJ, Lacchetti C, Griggs JJ. Adjuvant Endocrine Therapy for Women With Hormone Receptor-Positive Breast Cancer: ASCO Clinical Practice Guideline Focused Update. *J Oncol Pract.* 2018;15(2):106–7. Epub 2018/12/05. doi: 10.1200/JOP.18.00617. [PubMed: 30523754]
- Davies C, Godwin J, Gray R, Clarke M, Cutter D, Darby S, et al. Relevance of breast cancer hormone receptors and other factors to the efficacy of adjuvant tamoxifen: patient-level meta-analysis of randomised trials. *Lancet.* 2011;378(9793):771–84. doi: 10.1016/S0140-6736(11)60993-8. [PubMed: 21802721]
- 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(2):459–78. doi: 10.1007/s10549-012-2114-5. [PubMed: 22689091]
- Yood MU, Owusu C, Buist DS, Geiger AM, Field TS, Thwin SS, et al. Mortality impact of less-than-standard therapy in older breast cancer patients. *J Am Coll Surg.* 2008;206(1):66–75. doi: 10.1016/j.jamcollsurg.2007.07.015. [PubMed: 18155570]
- Fink AK, Gurwitz J, Rakowski W, Guadagnoli E, Silliman RA. Patient beliefs and tamoxifen discontinuance in older women with estrogen receptor--positive breast cancer. *J Clin Oncol.* 2004;22(16):3309–15. doi: 10.1200/JCO.2004.11.064. [PubMed: 15310774]
- Stanton AL, Petrie KJ, Partridge AH. Contributors to nonadherence and nonpersistence with endocrine therapy in breast cancer survivors recruited from an online research registry. *Breast Cancer Res Treat.* 2014;145(2):525–34. doi: 10.1007/s10549-014-2961-3. [PubMed: 24781972]
- Shelby RA, Edmond SN, Wren AA, Keefe FJ, Peppercorn JM, Marcom PK, et al. Self-efficacy for coping with symptoms moderates the relationship between physical symptoms and well-being in breast cancer survivors taking adjuvant endocrine therapy. *Support Care Cancer.* 2014;22(10):2851–9. doi: 10.1007/s00520-014-2269-1. [PubMed: 24821365]
- Bright EE, Stanton AL. Prospective investigation of social support, coping, and depressive symptoms: A model of adherence to endocrine therapy among women with breast cancer. *J Consult Clin Psychol.* 2018;86(3):242–53. Epub 2017/12/21. doi: 10.1037/ccp0000272. [PubMed: 29265835]
- Wells KJ, Pan TM, Vazquez-Otero C, Ung D, Ustjanauskas AE, Munoz D, et al. Barriers and facilitators to endocrine therapy adherence among underserved hormone-receptor-positive breast cancer survivors: a qualitative study. *Support Care Cancer.* 2016;24(10):4123–30. doi: 10.1007/s00520-016-3229-8. [PubMed: 27146492]
- Moon Z, Moss-Morris R, Hunter MS, Carlisle S, Hughes LD. Barriers and facilitators of adjuvant hormone therapy adherence and persistence in women with breast cancer: a systematic review. *Patient Prefer Adherence.* 2017;11:305–22. doi: 10.2147/PPA.S126651. [PubMed: 28260867]
- Bender CM, Gentry AL, Brufsky AM, Casillo FE, Cohen SM, Dailey MM, et al. Influence of patient and treatment factors on adherence to adjuvant endocrine therapy in breast cancer. *Oncol Nurs Forum.* 2014;41(3):274–85. doi: 10.1188/14.ONF.274-285. [PubMed: 24769592]
- Lambert LK, Balneaves LG, Howard AF, Gotay CC. Patient-reported factors associated with adherence to adjuvant endocrine therapy after breast cancer: an integrative review. *Breast Cancer Res Treat.* 2018;167(3):615–33. Epub 2017/11/06. doi: 10.1007/s10549-017-4561-5. [PubMed: 29110151]

13. Cahir C, Dombrowski SU, Kelly CM, Kennedy MJ, Bennett K, Sharp L. Women's experiences of hormonal therapy for breast cancer: exploring influences on medication-taking behaviour. *Support Care Cancer*. 2015;23(11):3115–30. doi: 10.1007/s00520-015-2685-x. [PubMed: 25744290]
14. Pellegrini I, Sarradon-Eck A, Soussan PB, Lacour AC, Largillier R, Tallet A, et al. Women's perceptions and experience of adjuvant tamoxifen therapy account for their adherence: breast cancer patients' point of view. *Psychooncology*. 2010;19(5):472–9. doi: 10.1002/pon.1593. [PubMed: 19507263]
15. Given BA, Spoelstra SL, Grant M. The challenges of oral agents as antineoplastic treatments. *Semin Oncol Nurs*. 2011;27(2):93–103. doi: 10.1016/j.soncn.2011.02.003. [PubMed: 21514479]
16. Xu H, Zhang XJ, Wang DQ, Xu L, Wang AP. Factors influencing medication-taking behaviour with adjuvant endocrine therapy in women with breast cancer: A qualitative systematic review. *J Adv Nurs*. 2020;76(2):445–58. doi: 10.1111/jan.14253.
17. Heiney SP, Parker PD, Felder TM, Adams SA, Omofuma OO, Hulett JM. A systematic review of interventions to improve adherence to endocrine therapy. *Breast Cancer Res Treat*. 2019;173(3):499–510. Epub 2018/11/01. doi: 10.1007/s10549-018-5012-7. [PubMed: 30387003]
18. Ekinci E, Nathoo S, Korattiyil T, Vadhariya A, Zaghoul HA, Niravath PA, et al. Interventions to improve endocrine therapy adherence in breast cancer survivors: what is the evidence? *Journal of Cancer Survivorship*. 2018:1–9.
19. Finitis DJ, Vose BA, Mahalak JG, Salner AL. Interventions to promote adherence to Endocrine Therapy among breast cancer survivors: A meta-analysis. *Psycho-Oncology*. 2018.
20. Greer JA, Amoyal N, Nisotel L, Fishbein JN, MacDonald J, Stagl J, et al. A systematic review of adherence to oral antineoplastic therapies. *Oncologist*. 2016;21(3):354–76. doi: 10.1634/theoncologist.2015-0405. [PubMed: 26921292]
21. Rounsaville BJ, Carroll KM, Onken LS. A Stage Model of Behavioral Therapies Research: Getting Started and Moving on From Stage I. *Clinical Psychology: Science and Practice*. 2001;8(2):133–42. doi: 10.1093/clipsy.8.2.133.
22. Onken LS, Carroll KM, Shoham V, Cuthbert BN, Riddle M. Reenvisioning Clinical Science: Unifying the Discipline to Improve the Public Health. *Clin Psychol Sci*. 2014;2(1):22–34. doi: 10.1177/2167702613497932. [PubMed: 25821658]
23. Kus T, Aktas G, Ekici H, Elboga G. Comparison of distress in breast cancer survivors treated with different adjuvant endocrine therapies: a single-centre cross-sectional study. *Psychiatry and Clinical Psychopharmacology*. 2017 Epub 26 Jun 2017. doi: 10.1080/24750573.2017.1342316.
24. Kalichman SC, Amaral CM, Swetzes C, Jones M, Macy R, Kalichman MO, et al. A simple single-item rating scale to measure medication adherence: further evidence for convergent validity. *J Int Assoc Physicians AIDS Care (Chic)*. 2009;8(6):367–74. doi: 10.1177/1545109709352884. [PubMed: 19952289]
25. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606–13. [PubMed: 11556941]
26. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006;166(10):1092–7. doi: 10.1001/archinte.166.10.1092. [PubMed: 16717171]
27. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
28. Blok EJ, Kroep JR, Meershoek-Klein Kranenbarg E, Duijm-de Carpentier M, Putter H, Liefers GJ, et al. Treatment decisions and the impact of adverse events before and during extended endocrine therapy in postmenopausal early breast cancer. *Eur J Cancer*. 2018;95:59–67. Epub 2018/04/07. doi: 10.1016/j.ejca.2018.03.014. [PubMed: 29635145]
29. Atema V, van Leeuwen M, Kieffer JM, Oldenburg HSA, van Beurden M, Gerritsma MA, et al. Efficacy of Internet-Based Cognitive Behavioral Therapy for Treatment-Induced Menopausal Symptoms in Breast Cancer Survivors: Results of a Randomized Controlled Trial. *J Clin Oncol*. 2019;37(10):809–22. Epub 2019/02/14. doi: 10.1200/JCO.18.00655. [PubMed: 30763176]
30. Taylor CE, Meisel JL. Management of Breast Cancer Therapy-Related Sexual Dysfunction. *Oncology (Williston Park)*. 2017;31(10):726–9. [PubMed: 29083465]

31. Turner K, Samuel CA, Donovan HA, Beckjord E, Cardy A, Dew MA, et al. Provider perspectives on patient-provider communication for adjuvant endocrine therapy symptom management. *Support Care Cancer*. 2017;25(4):1055–61. Epub 2016/11/18. doi: 10.1007/s00520-016-3491-9. [PubMed: 27864628]
32. Wassermann J, Gelber SI, Rosenberg SM, Ruddy KJ, Tamimi RM, Schapira L, et al. Nonadherent behaviors among young women on adjuvant endocrine therapy for breast cancer. *Cancer*. 2019 Epub 2019/05/23. doi: 10.1002/encr.32192.
33. Kroenke CH, Hershman DL, Gomez SL, Adams SR, Eldridge EH, Kwan ML, et al. Personal and clinical social support and adherence to adjuvant endocrine therapy among hormone receptor-positive breast cancer patients in an integrated health care system. *Breast Cancer Res Treat*. 2018;170(3):623–31. Epub 2018/04/18. doi: 10.1007/s10549-018-4774-2. [PubMed: 29671113]
34. Simon R, Latreille J, Matte C, Desjardins P, Bergeron E. Adherence to adjuvant endocrine therapy in estrogen receptor-positive breast cancer patients with regular follow-up. *Can J Surg*. 2014;57(1):26–32. [PubMed: 24461223]
35. Lehane E, McCarthy G. Intentional and unintentional medication non-adherence: a comprehensive framework for clinical research and practice? A discussion paper. *Int J Nurs Stud*. 2007;44(8):1468–77. Epub 2006/09/12. doi: 10.1016/j.ijnurstu.2006.07.010. [PubMed: 16973166]
36. Hurtado-de-Mendoza A, Carrera P, Parrott WG, Gomez-Trillos S, Perera RA, Sheppard VB. Applying the theory of planned behavior to examine adjuvant endocrine therapy adherence intentions. *Psychooncology*. 2019;28(1):187–94. doi: 10.1002/pon.4931. [PubMed: 30353610]
37. Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. *BMJ*. 2005;330(7493):702. doi: 10.1136/bmj.38343.670868.D3. [PubMed: 15695497]
38. Stafford L, Judd F, Gibson P, Komiti A, Mann GB, Quinn M. Screening for depression and anxiety in women with breast and gynaecologic cancer: course and prevalence of morbidity over 12 months. *Psychooncology*. 2013;22(9):2071–8. Epub 2013/02/12. doi: 10.1002/pon.3253. [PubMed: 23401315]
39. Haskins CB, McDowell BD, Carnahan RM, Fiedorowicz JG, Wallace RB, Smith BJ, et al. Impact of preexisting mental illness on breast cancer endocrine therapy adherence. *Breast Cancer Res Treat*. 2019;174(1):197–208. Epub 2018/11/21. doi: 10.1007/s10549-018-5050-1. [PubMed: 30465157]
40. Carver CS, Pozo C, Harris SD, Noriega V, Scheier MF, Robinson DS, et al. How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *J Pers Soc Psychol*. 1993;65(2):375–90. [PubMed: 8366426]
41. Stanton AL, Danoff-Burg S, Huggins ME. The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psychooncology*. 2002;11(2):93–102. [PubMed: 11921325]
42. Mausbach BT, Schwab RB, Irwin SA. Depression as a predictor of adherence to adjuvant endocrine therapy (AET) in women with breast cancer: a systematic review and meta-analysis. *Breast Cancer Res Treat*. 2015;152(2):239–46. doi: 10.1007/s10549-015-3471-7. [PubMed: 26077640]
43. Farias AJ, Wu WH, Du XL. Racial differences in long-term adjuvant endocrine therapy adherence and mortality among Medicaid-insured breast cancer patients in Texas: Findings from TCR-Medicaid linked data. *BMC Cancer*. 2018;18(1):1214 Epub 2018/12/04. doi: 10.1186/s12885-018-5121-z. [PubMed: 30514270]
44. Safren SA, Bedoya CA, O’Cleirigh C, Biello KB, Pinkston MM, Stein MD, et al. Cognitive behavioural therapy for adherence and depression in patients with HIV: a three-arm randomised controlled trial. *Lancet HIV*. 2016;3(11):e529–e38. Epub 2016/09/19. doi: 10.1016/S2352-3018(16)30053-4 PubMed PMID: 27658881; PubMed Central PMCID: PMC5321546. [PubMed: 27658881]

Table 1.

Patient demographic and clinical characteristics (N=30)

	M (SD)	Range	N (%)
Age (years)	55.13 (12.37)	27–76	–
Gender			
Women	–	–	100 (30)
Race			
White	–	–	25 (83.3)
Asian	–	–	3 (10)
Black or African American	–	–	1 (3.3)
Other	–	–	1 (3.3)
Ethnicity			
Hispanic or Latino/a	–	–	2 (6.7)
Education			
Doctoral/medical/law degree	–	–	2 (6.7)
Master's degree	–	–	10 (33.3)
College graduate	–	–	11 (36.7)
2 years of college/associates degree	–	–	6 (20.)
High school graduate/GED	–	–	1 (3.3)
Relationship Status			
Married/living as if married	–	–	21 (70)
Single, never married	–	–	4 (13.3)
Non-cohabitating relationship	–	–	2 (6.7)
Divorced/separated	–	–	3 (10)
Employment Status			
Full-time or part-time	–	–	21 (70)
Caring for home or family	–	–	1 (3.3)
Unable to work due to illness/disability	–	–	1 (3.3)
Retired	–	–	7 (23.3)
Income			
\$25,000–\$49,999	–	–	3 (10)
\$50,000–\$99,999	–	–	5 (16.7)
\$100,000–\$149,999	–	–	14 (46.7)
> \$150,000	–	–	6 (20)
Missing	–	–	2 (6.7)
Type of AET			
Anastrozole	–	–	8 (26.7)
Exemestane	–	–	4 (13.3)
Letrozole	–	–	6 (20)
Tamoxifen	–	–	12 (40)
Breast Cancer Stage			
I	–	–	17 (56.7)

	M (SD)	Range	N (%)
II			10 (33.3)
III			3 (10.0)
Time from AET start date to enrollment (years)	1.76 (.75)	.28–2.9	–
Self-reported adherence to AET on VAS (% taken)	89.27 (17.71)	5–100	–
Total PHQ-9 (Sum)	4.47 (4.64)	0–16	–
PHQ- 9 Depression Severity			
None or mild	–	–	16 (53.3)
Moderate, moderately severe, or severe	–	–	14 (46.7)
Total GAD-7 (Sum)	4.40 (4.19)	0–16	–
GAD-7 Anxiety Severity			
None or mild (0–4)	–	–	20 (66.7)
Moderate, moderately severe, or severe (5–9)	–	–	10 (33.3)

Note: AET= Adjuvant Endocrine Therapy; VAS=Visual Analog Scale; PHQ-9=Nine-item Patient Family Health Questionnaire; GAD-7= Seven-item General Anxiety Disorder questionnaire; Clinical severity for PHQ-9 and GAD-7 based on empirical cutoffs:[25,26] Self-reported adherence to AET on the VAS is the percentage of medication taken from 0–100% over the past 30 days.

Table 2.

Representation of low and high adherers by age, distress, and time since initiation of adjuvant endocrine therapy

	Low Adherers (n=20)	High Adherers (n=10)
Age		
50 years old	10 (50%)	6 (60%)
> 50 years old	10 (50%)	4 (40%)
Distress		
Low	14 (70%)	7 (70%)
High	6 (30%)	3 (30%)
Time on AET		
3–19 months	7 (35%)	6 (60%)
20–36 months	13 (65%)	4 (40%)

Note: High distress = Nine-item Patient Health Questionnaire (PHQ-9) ≥ 8 and/or Seven-item Generalized Anxiety Disorder (GAD-7) ≥ 10

Table 3.

Exemplar quotes from patient interviews illustrating themes

<p>Theme: Side effects are distressing yet worth the protective benefit</p>
<ul style="list-style-type: none"> • <i>I hate it ...everything the Tamoxifen's supposed to give [you]... I actually counted them all [the side effects], insomnia, mood changes, everything...dryness, hot flashes, headaches, joint pain, muscle pain, what else?</i> [Pt 02, Low] • <i>I'm very fortunate that I haven't had big issues with the letrozole and I feel very lucky about that.</i> [Pt 16, Low] • <i>If I take this medication, it keeps the cancer coming back. But then I also may lose [my] quality of life.</i> [Pt 22, High] • <i>Overall, what's to be gained is greater than the side effects that I kind of just muddle through, really.</i> [Pt 28, Low]
<p>Theme: Emotional support from other breast cancer survivors is beneficial yet lacking, while informational support from clinicians is strong.</p>
<ul style="list-style-type: none"> • <i>...and I discussed it with [doctor] and she said. "No. I think you're making a mistake. I really think you should go back on it." And she kind of talked me back into it.</i> [Pt 07, Low] • <i>I've had a sister that has gone through it and taken the Tamoxifen, and I've asked [her] ... just sometimes you want to see that it's normal, or so-called normal, [and] you feel better.</i> [Pt 23, High] • <i>Whatever they suggest... I will take it as long as they feel that it's going to benefit my chances of recurrence ... because I don't want to get cancer again. Basically, I would do anything [doctor] tells me to do if I thought it was going to help.</i> [Pt 26, Low] • <i>I think I was very fortunate that [doctor] took the opportunity to set me up with a time that I should take the medication.</i> [Pt 27, High] • <i>I have a friend who went through treatment five years ago...she can relate to the challenges of post-breast cancer treatment...she is a sounding board for me... online, I'm a member of the Young Survivor Coalition...that's huge. When I meet with [nurse] she always asks how I'm doing, whether I'm having any difficulties. So, I feel like that's quite supportive.</i> [Pt 29, High]
<p>Theme: Concerns, ambivalent attitudes, and negative beliefs about medication were ubiquitous</p>
<ul style="list-style-type: none"> • <i>I'd have to say I'm opposed to taking it, but I feel like I don't want to take a chance not taking it. And I often wonder am I making the right choice or - because the potential side effects - am I just looking down the road with getting a different type of cancer, maybe ovarian, cervical, whatever. So, it makes me worry.</i> [Pt 07, Low] • <i>I find it's something that's very easy to do, very easy to take... I mean, it made me wonder. "Is this working? Is it blocking enough estrogen? Or am I producing too much and is that still something to worry about?"</i> [Pt 09, High] • <i>I'm giving it the benefit of the doubt that it's beneficial...</i> [Pt 10, Low] • <i>It's horrible [laughter]. It's terrible...it's very nasty...I don't like it one bit, but I don't feel like I have a choice, so on we go.</i> [Pt 19, High] • <i>Oh, I have so many concerns [laughter]. Well, first of all, it can kill you, so that's obviously a concern.</i> [Pt 30, High] • <i>The only other concern is... I have three years left... what's going to happen after? What's it going to cause my body to do or not do? What are the effects of the medication going to leave behind after I'm done?</i> [Pt 32, Low] • <i>The question I have my mind [is] does it really make any difference? Couldn't I stop now?</i> [Pt 34, Low]
<p>Theme: Non-adherence is both intentional and unintentional</p>
<ul style="list-style-type: none"> • <i>I don't know if I can handle it for 10 years. I cannot even handle it really for one more year.</i> [Pt 02, Low] • <i>I used to skip for, continuously, two, three days, depending on the level of headaches I had... I know it is helping preventing cancer [from] coming back, so that's the only reason I don't skip.</i> [Pt 03, Low] • <i>I stopped it for a week because I was just tired of how it made me feel.</i> [Pt 07, Low] • <i>I take it in the morning with my vitamin D and my blood pressure medicine. And I usually have either water or juice or coffee with it...so it's just so routine that it's really not an option, unless something came up and I had to run off and do something.</i> [Pt 04, Low] • <i>I keep it in my bedroom near jewelry and stuff, but tucked away so I don't have to look at it, so it's not a constant reminder of death</i> [Pt 15, Low] • <i>The first year it was a huge problem. I would go maybe four or five days, but now I might go a couple of days. Sometimes the weekends [forgets], because the weekends get so busy.</i> [Pt 18, Low]
<p>Theme: Changes in mood emerged and are noticeable</p>
<ul style="list-style-type: none"> • <i>You've just recovered and you feel happy that you've recovered... and then you notice in your mirror... this hair loss and all, it's pretty depressing.</i> [Pt 03, Low] • <i>I'm afraid that it does affect my mood...I've become more weepy at times...and I wonder if this is a side effect, because I never had that experience before.</i> [Pt 05, Low] • <i>I think it's increased my anxiety level.</i> [Pt 33, High] • <i>...the whole thing, the depression part, the memory part, my anxiety, my-- I don't sleep well...</i> [Pt 32, Low] • <i>I'm moody. I am moodier and crankier. I don't know why.</i> [Pt 34, Low] • <i>I think I'm paranoid to get cancer back... I think in my psyche maybe just because I'm scared...maybe I'm so diligent about it because I'm just petrified.</i> [Pt 11, High]
<p>Theme: Strategies to manage symptoms, distress, or barriers to adherence are severely lacking</p>
<ul style="list-style-type: none"> • <i>Cope? I haven't thought about it at all. Because my only hope is that I shouldn't get it back again, that's all... initially, I felt it a lot more...I think [my] body has gotten used to it</i> [Pt 03, High] • <i>I like to push through it and see if I will be fine.</i> [Pt 05, Low] • <i>I found that with a few things and being able to alter some things in my diet I've got that under better control.</i> [Pt 09, High] • <i>...there were a couple of days I'd forget at night and I'd take it in the morning when I got up and then if I was around other people, I'd be sweating, blushing. And I thought, "It's just easier if I take it at night and I sleep through any side effects."</i> [Pt 15, Low] • <i>I mean, they're a little bit better...and I don't know if that's just that the medication side effects kind of diminish over time...and [doctor] did</i>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

try switching to exemestane, and that wasn't any better. As a matter of fact, probably worse. [Pt 19, High]

- *Well, actually, honestly, I didn't do anything special. I just kind of had to hang in there...just stick around and just make it work. [Pt 31, Low]*

Preferences for a psychosocial intervention

- *I think the video conferencing would be best not having to drive...that you could do this in the privacy of your own home would be really good... if there were some video conference, face-to-face, where you can talk with another person that has gone through this, I think that it's just so helpful. I think for most patients, especially if you don't have somebody that has been through breast cancer, I would absolutely encourage [them to do the intervention]. [Pt 09, High]*
- *I think that it's nice to share your experiences with other women who are going through the same thing. And you can kind of draw support from each other... and when you have similar experiences you feel that support because you're not alone. And so, I think that would be valuable. [Pt 10, Low]*
- *I think all the support that you can offer for women in this position is great. All along it was always good for me to hear from somebody either who was currently where I was, and better yet, somebody who was past where I was. Somebody who was like, "Oh yeah, I was there. It was awful, but you'll be fine." That is always very comforting. [Pt 26, Low]*
- *I think that's a good idea. I do believe that more attention should be spent on talking about the medication... [Pt 30, High]*
- *I think it would have helped at the beginning...I know physicians don't like to mention side-effects unless you bring them up ...so nobody seems to mention side-effects. [Pt 34, Low]*

Note: Low = Low Adherence Strata [02, 03, 04, 05, 07, 10, 15, 16, 18, 26, 28, 31, 32, 34]; High = High Adherence strata [09, 11, 19, 22, 23, 27, 29, 30, 33].