



How patients experience endocrine therapy for breast cancer: an online survey of side effects, adherence, and medical team support

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Abstract

Purpose Many patients with hormone receptor–positive (HR+) breast cancer do not adhere to endocrine therapy (ET), and treatment-related side effects are often discussed by participants in online breast cancer forums. Our aim was to survey this unique group of patients about their ET-related experiences.

Methods We partnered with patients active in breast cancer social media communities to develop a survey assessing ET-related side effects and medical team communication. Patients with a history of HR+ breast cancer who had received a recommendation to take ET were eligible to participate in the anonymous, online survey.

Results Respondents included 2353 women and 54 men. Aromatase inhibitors were the most commonly used medication. Side effects were reported by 91.2%, were more often experienced by women than men ($p < 0.001$), and were primarily related to medication type. Approximately one-third of respondents discontinued therapy early. While most felt supported by their medical team, 31.5% reported that their side effects were dismissed or minimized. Survey respondents most frequently reported that a healthy diet and exercise, yoga/acupuncture, and vitamins/supplements were helpful in managing ET-related side effects.

Conclusions ET-related side effects are very common, and one-third discontinued treatment early. Lifestyle changes and complementary therapies can be important tools for side effect management. One-third of patients did not feel that their side effects were taken seriously.

Implications for Cancer Survivors This is the largest survey of ET use by participants in online breast cancer communities. Further research is needed to identify strategies to improve treatment adherence and to better manage ET-related side effects.

Keywords Breast cancer · Endocrine therapy · Tamoxifen · Side effects · Aromatase inhibitors

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Introduction

The majority of invasive breast cancers are hormone receptor–positive (HR+) [1–5]. Endocrine therapy (ET), a key component of breast cancer treatment, reduces the risk of local and distant recurrence [2, 6–8]. The recommended duration of adjuvant ET for early-stage breast cancer (ES-BC, used in this paper to refer to stages 0–3) is 5 years, although it may be extended to 10 years in select high-risk patients [7, 8]. ET is also utilized as primary therapy for many patients diagnosed with HR+ metastatic breast cancer (Met-BC) [5, 8], a condition that requires some form of lifelong treatment.

Despite the known efficacy of ET, up to 30% of patients with invasive HR+ breast cancer who are prescribed ET never initiate therapy [9]. In addition, 18% to 73% of patients who initiate ET do not complete the prescribed course of treatment [2, 4, 6, 9–19]. Early discontinuation of therapy is associated

with increased recurrence and breast cancer–specific mortality rates, as well as higher medical costs [2, 9, 11, 18–21]. Therefore, it is crucial to understand barriers to ET adherence.

A growing number of patients participate in online support groups and discussion boards that focus on various aspects of medical care. Patients with breast cancer are more likely than those with other cancers to participate in such forums [22–29]. Common discussion topics include medication side effects and medical team interactions. Therefore, we sought to survey this unique group of patients about their experiences with ET. Our objectives were to characterize reasons for not initiating treatment, to describe patient-reported ET-related side effects and side effect management, and to investigate the impact of the patient-medical team relationship on medication adherence.

Methods

Survey development and administration

The motivation for this study came from conversations among patients who discuss ET and other aspects of their breast cancer care in online communities. Unique features of this work include the use of a survey designed with patient input and distribution of the survey using social media platforms, as well as the aims of evaluating self-reported side effect management strategies and effectiveness, and evaluating the patient experience in discussing side effects with their medical team.

Nine patient advocates (6 women and 3 men) were chosen based on their personal history of ES-BC or Met-BC, current or prior ET use, advocacy and research experience, and activity within breast cancer social media communities. Existing survey tools were reviewed, but as has been demonstrated in prior work [30], the advocates felt that no existing survey covered all pertinent issues. An original survey was therefore developed based in part on a conceptual framework of decisional support and decisional needs [31]. The patient advocates and eight medical experts contributed to survey development (Appendix Figure 1).

The Institutional Review Board of the University of California, Los Angeles granted approval to distribute a survey link to online breast cancer communities. The SurveyMonkey® tool was configured to be anonymous and to preclude repeat complete surveys from the same internet protocol address. All 33 questions required a response, and 13 questions allowed for open-ended comments. The survey was provided in English, and there was no financial or other type of incentive for participation. Four of the patient advocates pre-tested the survey prior to distribution. A link to the survey was posted on the senior author's (DJA) personal blog and Facebook and Twitter accounts, and it was shared by the Dr. Susan Love Research Foundation Army of Women (currently known as the Love Research Army) email newsletter and

social media accounts. We then relied on interested parties to share the survey within their social media networks. The survey was open from May 12 to July 14, 2019.

Statistical analyses

Characteristics and responses by survey participants were described using mean (\pm standard deviation), median (interquartile range [IQR]), and percentage according to the data distribution and type. Comparisons between respondents' sex and ES-BC versus Met-BC status were conducted using *t* test, Mann-Whitney *U*, and chi-square statistics or Fisher's exact test, as appropriate. Additional comparisons of question responses were conducted using a chi-square test for *p* values and logistic regression analysis for odds ratios. Effect modification of menopausal status on the age-adjusted association of tamoxifen-only versus aromatase inhibitor (AI)-only with reported side effects was evaluated with Wald's tests for interaction. All analyses were conducted in STATA version 13.0 (Stata Corporation, College Station, TX).

Results

Respondents and demographics

Of 2994 survey respondents, 95 were excluded for study criteria ineligibility, which included no history of breast cancer, HR-negative breast cancer, or no recommendation for ET from their medical team. An additional 381 were excluded due to incomplete surveys, discrepancies in responses, or inability to determine whether hormonal therapy for gender reassignment was administered. Of the remaining 2518 respondents, 4.4% (111/2518) reported that ET was recommended but they did not initiate treatment. These patients are characterized, but not included in the main analysis, leaving a final analytical cohort of 2407 respondents who initiated ET (Appendix Figure 2).

The final cohort of 2407 respondents included 54 men (2.2%) and 2353 women (97.8%). At the time of first breast cancer diagnosis, 25.6% (602/2353) of the women were premenopausal and 74.3% (1748/2353) were postmenopausal; three respondents did not remember their menopausal status. Respondents' ages ranged from 24 to 86 years. Age at diagnosis ranged from 23 to 82 years among female respondents, and from 24 to 73 years among male respondents. Most respondents (87.0%, 2093/2407) had been diagnosed with stage 1–3 disease. One hundred (4.2%, 100/2407) were diagnosed at stage 4, with de novo metastatic breast cancer. Of those initially diagnosed with ES-BC, 11.7% of patients (270/2307) developed Met-BC during the course of their treatment, 11.5% of women (260/2255), and 19.2% of men (10/52). Additional demographic information is provided in Table 1.

Treatment initiation and discontinuation

Among the 111 respondents who did not start ET as recommended (multiple selections permitted), concern about potential side effects was the most commonly expressed reason for not initiating therapy (92.8%, 103/111). Other reasons included concerns about impact on general health or other health conditions (80.2%, 89/111), perceived benefits not outweighing perceived risks (67.6%, 75/111), concerns about secondary cancers (49.5%, 55/111), desire to avoid taking a prescription medication (19.8%, 22/111), and cost (3.6%, 4/111). Two respondents (1.8%) did not initiate therapy because they anticipated becoming pregnant.

Among the entire cohort who initiated therapy, 8.8% (213/2407) reported that they took treatment breaks or discontinued therapy early either against the advice or without informing their medical team. Nine respondents took a treatment break or discontinued early because they intended to become pregnant.

Overall, 33.2% (799/2407) of patients discontinued therapy early, which included 32.8% (772/2353) of women and 50.0% (27/54) of men ($p = 0.008$). US residents were more

likely to discontinue ET early compared with non-US residents (34.7%, 663/1912 versus 27.5%, 136/495; $p = 0.002$). Those who did not have a college degree were more likely to discontinue early compared with those who had a college degree (37.3%, 218/585 versus 31.9%, 581/1822; $p = 0.016$). Respondents who discontinued early were fairly evenly distributed by stage at diagnosis (stage 0, 35.1%, 71/202; stages 1–3, 33.3%, 698/2093; stage 4, 26.0%, 26/100; did not remember stage, 33.3%, 4/12).

Medication type, duration, and side effects

Medication use and duration of therapy are shown in Table 2. Respondents were asked to select all ET agents they had used. Aromatase inhibitors (AIs) were the most commonly used medication, followed by tamoxifen; 26.6% (640/2407) took both tamoxifen and an AI at some point in their treatment. Most respondents (78.4%, 1888/2407) were current users of ET, and of this group, 15.7% (296/1888) reported currently living with Met-BC.

Table 1 Survey respondent demographic characteristics

Characteristics	All respondents (<i>n</i> = 2407)	Women (<i>n</i> = 2353, 97.8%)	Men (<i>n</i> = 54, 2.2%)
Menopausal status of 2353 women (%)			
Premenopausal		602(25.6)	
Postmenopausal		1748(74.3)	
Does not remember		3(0.13)	
Current age (mean (SD))		56(10)	59(9)
Age at diagnosis (mean (SD))		50(10)	54(9)
Education (%)			
High school degree or less	171 (7.1)	167(7.1)	4(7.4)
Some college but no degree	414 (17.2)	402(17.1)	12(22.2)
Associate’s or bachelor’s degree	1011 (42.0)	982(41.7)	29(53.7)
Graduate degree	811 (33.7)	802(34.1)	9(16.7)
Nationality (%)			
USA	1912 (79.4)	1867(79.3)	45(83.3)
UK	215 (8.9)	215(9.1)	0
Canada	152 (6.3)	148(6.3)	4(7.4)
Other	128 (5.3)	123(5.3)	5(9.3)
Stage at diagnosis (%)			
0	202 (8.4)	199 (8.5)	3 (5.6)
I-III	2093 (87.0)	2044 (86.9)	49 (90.7)
IV	100 (4.2)	98 (4.2)	2 (3.7)
Does not remember	12 (0.5)	12 (0.5)	0
Currently living with metastatic disease	370 (15.4)	358 (15.2)	12 (22.2)

SD, standard deviation

Medication side effects are shown in Table 3. At least one class of side effects attributed to ET was reported by 91.2% (2194/2407) of respondents, including 91.5% (2152/2353) of women and 74.1% (40/54) of men ($p < 0.001$). Among patients with ES-BC, 91.6% (1866/2037) reported at least one class of side effect versus 88.6% (328/370) of those with Met-BC ($p = 0.065$).

Among women with both ES-BC and Met-BC, the most commonly reported side effects were musculoskeletal and general physical changes (such as weight gain and unhappiness with body image). Among men with ES-BC, sexual and cognitive/mood side effects were most commonly reported. Among men with Met-BC, sexual, cognitive/mood, and musculoskeletal side effects were noted with equal frequency.

Concerns about medication cost were reported by 5.4% (130/2407) of respondents (Table 3).

For women with ES-BC, odds of reporting side effects differed significantly according to the class of medication (tamoxifen-only versus AI-only) in age-adjusted models. Menopausal status did not independently influence this association (Fig. 1). Odds of reporting cardiac/vascular and musculoskeletal side effects, as well as concerns about medication cost, were higher in AI-only users than in tamoxifen-only users. Medication class was not associated with odds of reporting sexual, vasomotor, cognitive / mood, general physical, visual, gastrointestinal, or genitourinary side effects. We found no differences in odds of reporting side effects based on medication

Table 2 Medication use and duration

Variable	All patients (<i>n</i> = 2407)	W-ES (<i>n</i> = 1995)	W-Met (<i>n</i> = 358)	M-ES (<i>n</i> = 42)	M-Met (<i>n</i> = 12)
Type of endocrine therapy (%)					
Tamoxifen*	1277 (53.1)	1033 (51.8)	194 (54.2)	38 (90.5)	12 (100.0)
Tamoxifen-only	578 (24.0)	514 (25.8)	23 (6.4)	35 (83.3)	6 (50.0)
Tamoxifen + AI*	640 (26.6)	471 (23.6)	160 (44.7)	3 (7.1)	6 (50.0)
Raloxifene	14 (0.6)	11 (0.6)	3 (0.8)	0	0
Any type of AI					
Anastrozole*	1057 (43.9)	906 (45.4)	142 (39.7)	5 (11.9)	4 (25.0)
Exemestane*	488 (20.3)	388 (19.4)	99 (27.7)	1 (2.4)	0
Letrozole*	858 (35.7)	635 (31.8)	217 (60.6)	1 (2.4)	5 (41.7)
AI-only	949 (39.4)	855 (42.9)	90 (25.1)	4 (9.5)	0
Fulvestrant	127 (5.3)	118 (5.9)	7 (2.0)	0	2 (16.7)
Leuprolide	281 (11.7)	208 (10.4)	72 (20.1)	0	1 (8.3)
Current ET use (%)					
< 5 years	1464 (60.8)	1277 (64.0)	160 (44.7)	21 (50.0)	6 (50.0)
5 years	92 (3.8)	74 (3.7)	16 (4.5)	2 (4.8)	0
5 to 10 years	282 (11.7)	186 (9.3)	85 (23.7)	9 (21.4)	2 (16.7)
> 10 years	49 (2.0)	21 (1.1)	27 (7.5)	1 (2.4)	0
I do not remember	1 (0.04)	1 (0.05)	0	0	0
Prior ET use (%)					
< 5 years	287 (11.9)	248 (12.4)	31 (8.7)	4 (9.5)	4 (25.0)
5 years	118 (4.9)	103 (5.1)	11 (3.1)	4 (9.5)	0
5 to 10 years	93 (3.9)	72 (3.6)	21 (5.9)	0	0
> 10 years	21 (0.9)	13 (0.6)	7 (2.0)	1 (2.4)	0

AI aromatase inhibitor, ET endocrine therapy

*Multiple selections permitted

W-ES women, early stage

W-Met women, metastatic

M-ES men, early stage

M-Met men, metastatic

Table 3 Medication side effects

Variable	All patients (n = 2407)	W-ES (n = 1995)	W-Met (n = 358)	M-ES (n = 42)	M-Met (n = 12)	Chi-square p value: M-ES versus W-ES	Chi-square p value: W-ES versus W-Met	Chi-square p value: M-Met versus W-Met
Reported side effects (%)*								
Any	2194 (91.2)	1835 (92.0)	319 (89.1)	31 (73.8)	9 (75.0)	<0.001	0.072	0.130
Cardiovascular	309 (12.8)	262 (13.1)	41 (11.5)	3 (7.1)	3 (25.0)	0.253	0.382	0.154
Cognitive/mood	1515 (62.9)	1282 (64.3)	205 (57.3)	21 (50.0)	7 (58.3)	0.057	0.011	0.941
Eyes	798 (33.2)	654 (32.8)	132 (36.9)	10 (23.8)	2 (16.7)	0.22	0.131	0.152
General physical changes	1652 (68.6)	1381 (69.2)	248 (69.3)	17 (40.5)	6 (50.0)	<0.001	0.985	0.157
Gastrointestinal	629 (26.1)	514 (25.8)	109 (30.4)	3 (7.1)	3 (25.0)	0.006	0.064	0.686
Genitourinary	945 (39.3)	812 (40.7)	128 (35.8)	4 (9.5)	1 (8.3)	0.05	0.078	<0.001
Musculoskeletal	1788 (74.3)	1488 (74.6)	278 (77.7)	15 (35.7)	7 (58.3)	<0.001	0.217	0.118
Sexual	1314 (54.6)	1087 (54.5)	199 (55.6)	21 (50.0)	7 (58.3)	0.563	0.700	0.035
Vasomotor	1461 (60.7)	1231 (61.7)	207 (57.8)	17 (40.5)	6 (50.0)	0.005	0.165	0.590
High cost of medication	129 (5.4)	95 (4.8)	34 (9.5)	0	0	0.148	<0.001	0.263

AI aromatase inhibitor, ET endocrine therapy

*Multiple selections permitted

W-ES women, early stage

W-Met women, metastatic

M-ES men, early stage

M-Met men, metastatic

class in respondents with ES-BC versus Met-BC (Appendix Table 1).

Side effect management

Survey respondents most frequently reported that three groups of management strategies were helpful for ET-related side effects: a healthy diet, exercise, and physical therapy; complementary therapy such as yoga, acupuncture, and meditation; and vitamins, supplements, and herbs including medical marijuana. Some respondents felt that peer-to-peer support (19.9%, 478/2407) or websites with information about endocrine therapy (9.6%, 230/2407) were helpful, but the medical team was less likely to recommend these resources. For patients with ES-BC and Met-BC, there were only a few significant differences in suggestions for side effect management received by the medical team versus family/friends/internet. ES-BC and Met-BC patients experienced the same rates of side effect relief from the different management recommendations (Appendix Table 2). Among both ES-BC and Met-BC patients, those who felt supported by their medical team were more likely to receive a higher median number of side effect management recommendations from their medical team compared with patients who did not feel supported (2 [IQR 1,4] versus 0 [IQR 0,1], $p < 0.001$).

Medical team communication

The majority of patients reported that they understood the goals of therapy, concordant with their stage of disease. For example, respondents with Met-BC at diagnosis had increased odds of reporting the goal of therapy as “controlling spread,” compared with those with ES-BC (OR 107, 95% CI [47, 247] $p < 0.001$). Patients who stopped treatment early and those who took the full course of therapy were similar in their understanding of the goals of therapy (Appendix Table 3).

The majority of patients who experienced side effects reported discussing or attempting to discuss them with their medical team (ES-BC 92.8%, 1732/1866 and Met-BC 91.8%, 301/328). Respondents were most likely to discuss management of side effects with their oncology physicians (79.0%, 1902/2407) versus (multiple selections permitted) other oncology team members such as nurse practitioners (33.6%, 809/2407), primary care providers (36.8%, 885/2407), or other medical specialists (12.3%, 296/2407). Additional information regarding support and side effect management recommendations by medical team category is provided in Appendix Table 4.

In characterizing medical team discussions (multiple selections permitted, and 2 patients characterized discussions without indicating a side effect), 70.0% (68.8%, 1193/1734 with ES-BC compared with 77.4%, 233/301 with Met-BC) felt supported by their medical team ($p = 0.003$). However,

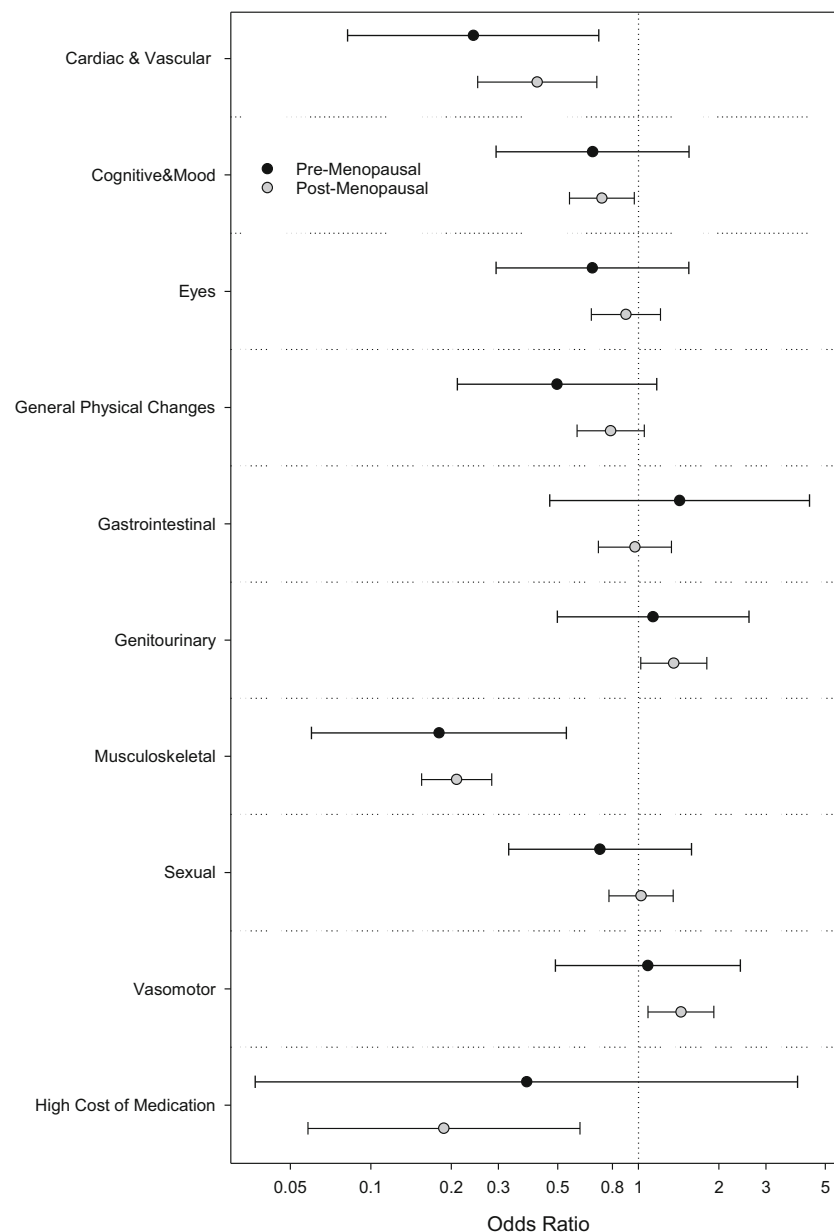


Fig. 1 Age-adjusted odds of side effects in women who received tamoxifen-only compared with AI-only

31.5% (33.2%, 575/1734 with ES-BC and 22.3%, 67/301 with Met-BC) stated that they were made to feel as though they should be better able to handle side effects on their own, or that their side effects were not related to treatment, or both ($p < 0.001$). A small number of patients, 6.6% (6.4%, 120/1866 with ES-BC and 7.6%, 25/328 with Met-BC, $p = 0.424$), did not discuss or attempt to discuss side effects with their medical team, noting that there were more important issues to discuss, that there was not enough time, or that they did not feel comfortable.

When respondents were asked to offer advice or suggestions for how the medical team could help a patient feel more supported or could assist with side effect management

(multiple selections permitted), the most-selected option was referral to a website with information about side effects and how to manage them, followed by a specific office visit (in-person or virtual) to discuss medication side effects. Other recommendations included access to an oncology social worker, peer support (in-person or virtual), an app to track and report side effects to the medical team, and access to a financial counselor (Appendix Table 5). Survey respondents expressed frustration about side effects not being taken seriously and about a lack of effective side effect management strategies. Some representative comments include: “Yes, these are COMMON side effects — can you handle it?”; “I felt dismissed, I don’t think they felt my complaints were that big a deal”; and “I felt comfortable discussing with doctors,

but at the end I felt like there's nothing that can be done to help my symptoms.”

Discussion

This is the largest survey of ET use by patients who participate in online breast cancer communities. We demonstrate that social media can be effective in rapidly obtaining large numbers of patient responses regarding care issues. Similar to previous studies [1, 7, 10, 17–19, 34–39], our results demonstrate that most patients (91%) who take ET experience related side effects, and one-third discontinue treatment early. Our findings suggest that online patient communities can be a valuable tool for identifying variables that influence breast cancer patients' adherence to ET.

We found that most patients understood the goals of therapy; however, this understanding was not associated with a higher likelihood of completing treatment. This suggests that understanding of the importance of therapy may not be sufficient for adherence when patients face medication-related side effects that significantly interfere with quality of life. While medical team support and communication are important factors influencing ET adherence [6, 9, 14, 40–45], we did not find that feeling “supported” by the medical team was associated with improved medication adherence. A very low number of survey respondents reported financial concerns related to ET or as a reason for discontinuing therapy. In contrast, previous studies have found associations between socioeconomic status, out-of-pocket medication costs, and ET adherence [46, 47]. Our finding may be related to the widespread availability of generic formulations or that participants in online patient communities are more likely to be of higher socioeconomic status compared with the general population [48–51]. Despite low reported concerns about medication cost, we found similar rates of early discontinuation as have studies evaluating adherence based on socioeconomic status [47].

The responses to our survey demonstrate the many nuances of ET-related side effects and challenges with adherence faced by patients. Respondents to our survey provided many suggestions that would make them feel more supported or would help them to better manage side effects. Most of these centered on communication including dedicated office visits and the ability to report side effects, as well as peer support. It is important that one-third of our survey respondents felt that their medical team did not take their side effects seriously. Patients and their medical team members might have differing perspectives on the definition of a “well-tolerated” medication and on measures of quality of life [52, 53], but efforts must be made to better understand the patient's point of view. There are a variety of conceptual framework models such as decision support and needs, symptom management, symptom experience, self-management, and patient activation [31, 53–56] that

can be applied to improve adherence [57, 58]. For example, a recent pilot program demonstrated that patient activation did not improve oral oncolytic adherence; however, patients who completed the program did report increased confidence in their ability to self-manage symptoms and seek help when experiencing side effects [55]. Although these conceptual framework models may be used to guide interventions, our study provides patient-driven recommendations about improving medical team support of patients who experience medication-related side effects and can serve as areas of future study.

In a recent nationwide survey of oncology patients, respondents reported being more likely to stop therapy if they experienced unexpected side effects, and approximately one-third said they wished they had known more about treatment toxicities [59]. This demonstrates the importance of continued and serial communication between the medical team and the patient. Overcoming the burden of numerous in-office visits, the increase in successful telehealth visits during the COVID-19 pandemic [60] has demonstrated that virtual platforms can be a means for these discussions. An in-person or virtual visit just prior to treatment initiation could overcome the finding that many patients do not remember having detailed discussions about potential ET-related side effects and may serve to reinforce that ET is just as important a component of treatment as surgery, chemotherapy, or radiation therapy [20, 30, 61]. Intermittent telehealth visits could also address patient decision resolve, as many patients re-visit their commitment to continue ET multiple times throughout the course of treatment [2]. Patients may benefit from repeated review of both medication benefits, focusing on absolute, rather than relative benefit, as well as the impact on quality of life during the course of therapy [2, 5, 18, 19, 34, 37, 42, 43, 62, 63], in a way that more passive reminders do not address.

As our survey respondents reported that diet, exercise, and physical therapy were among the most helpful side effect management strategies, providing nutrition and exercise counseling prior to ET initiation may help improve a patient's treatment experience. However, less than half of the respondents felt that any interventions were helpful. This suggests that offering varied and more personalized suggestions for side effect management could improve patients' experience with ET. Areas for future study may include medical team education on non-prescription resources including interactive educational and side effect reporting and management tools, peer support, and complementary therapies.

We found that patients with ES-BC and Met-BC experience similar side effects and have comparable side effect management experiences. Despite their similarity in responses to this survey, patients with Met-BC clearly have a different experience with different supportive needs compared with those with ES-BC [64–66]. Patients with Met-BC may be on some

form of endocrine therapy for life, often in combination with other agents. Frequency and severity of side effects that impact quality of life may go under-reported and therefore under-treated in this patient population [67]. One respondent noted “When I was early stage I stopped anastrozole after nine months due to severe arthralgia that interfered with my career. Now that I am metastatic I take my exemestane every day, regardless of symptoms” and another stated that “Side effects mean nothing if it is saving my life.” Attention to quality of life either through the expanded use of specific patient-reported outcomes or other measures [66–68] on a regular basis is especially important in this patient population.

Our study adds to what is known about the experience of men with breast cancer who are prescribed ET [15, 69–73]. Compared with women, men in our study were less likely to report side effects but more likely to discontinue therapy. Interestingly, prior work has demonstrated that men are more likely compared with women to adhere to medications for myocardial infarction, hypertension, and other chronic conditions [74–76]. More work is needed to better understand ET-related side effects and factors associated with medication adherence in men. There remains a lack of peer and emotional support specific to men, with one male respondent commenting, “I am a male going through this. I sometimes feel very alone in my situation.” The ongoing International Male Breast Cancer Program [70, 77] is expected to provide additional information on male breast cancer biology, outcomes, and quality of life, as well as recommendations for optimal treatment and supportive care.

Our study has several limitations. As with any survey distributed over social media, the results are biased by the scope of survey respondents, and we cannot estimate the extent to which this respondent pool represents the experience of all patients taking endocrine therapy. Participants in online patient communities are more likely to be white, younger, college-educated, and of higher socioeconomic status than the general patient population [52, 54, 55, 78], so our findings may not apply to a more diverse population, and this should be a focus of future work [79]. We did not ask about baseline symptoms or prior/ concomitant therapy, which could impact how patients with both ES-BC and Met-BC experience ET [36, 37, 68]. We do not know if participants stopped treatment early due to severity of side effects, ability to manage side effects, or other reasons. We did not have the ability to access medical records to confirm patient-reported stage, medication use, and other factors. Finally, we did not use a validated survey tool, although not all validated patient-reported outcome survey tools accurately reflect the patient experience [80]. We designed our survey with the input of breast cancer patient advocates, including men and women with different disease stages and care experiences, in an attempt to address issues that were important to them.

Strengths of our study include a large number of respondents, most of whom were within their first 5 years of treatment, reflecting contemporary ET use and a low likelihood of recall bias. This unique online patient population is engaged in their healthcare and is comfortable using their own treatment experiences to help others. These patients are also experienced in interacting with the medical community as partners in education and research, as evident from their engagement with survey design and distribution.

Conclusions

Most breast cancer patients who initiated ET reported treatment-related side effects. Concern about side effects was the most common reason for not initiating therapy, and approximately one-third of those who initiated therapy did not complete the full treatment course. Approximately one-third reported feeling dismissed or not taken seriously when trying to discuss side effects and the impact of ET on quality of life with their healthcare team.

At most, only 41% of patients experienced side effect relief, demonstrating that more effective strategies for managing ET-related side effects are needed. In addition, while we have shown that social media is effective for obtaining information on the patient experience, further studies must identify the optimal ways to solicit and interpret patient-reported outcomes from this rapidly growing patient population.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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