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Provider Perspectives on Barriers and Facilitators to Adjuvant Endocrine Therapy-Related Symptom Management

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Abstract

Purpose—Adjuvant endocrine therapy (AET) utilization is linked to improved clinical outcomes among breast cancer survivors (BCS); yet, AET adherence rates remain suboptimal. Little is known about provider perspectives regarding barriers and facilitators to AET-related symptom management (SM). In this study, we examined provider perspectives on the barriers and facilitators to AET-related SM among BCS and opportunities for improvement.

Methods—We conducted three focus groups (FGs) with a multidisciplinary group of health care providers (n=13) experienced in caring for BCS undergoing AET. We utilized semi-structured discussion guides to elicit provider perspectives on AET-related SM. FGs were audiotaped, transcribed, and analyzed using qualitative software to identify key themes.

Results—Providers described patient-, provider-, and system- level barriers and facilitators to AET-related SM. At the patient-level, barriers included competing demands, limited time/resources, and possible misattribution of some symptoms to AET, while family/social relationships and insurance emerged as important facilitators. Discomfort with SM, limited time, and challenges

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distinguishing AET-related symptoms from other conditions were key provider-level barriers. Provider-level facilitators included routine symptom documentation and strong provider relationships. Care fragmentation and complexity of the cancer care delivery system were described as system-level barriers; however, survivor clinics were endorsed by providers.

Conclusions—Provider perspectives on AET-related SM can shed light on SM barriers and facilitators spanning multiple levels of the cancer care delivery system. Strategies for improving AET-related SM in BCS include increasing patients' knowledge and engagement in SM, equipping providers with efficient SM strategies, and improving coordination of symptom-related services through survivorship programs.

Keywords

symptom management; adjuvant endocrine therapy; provider perspectives; breast cancer; survivorship care

Introduction

Breast cancer (BC) is the most common cancer among women, with endocrine receptor positive (ER+) BC accounting for nearly 80% of breast cancers [1]. Despite evidence linking utilization of adjuvant endocrine therapy (AET) to reduced recurrence and improved survival outcomes among ER+ BC survivors who have completed primary treatment (e.g., surgery, chemotherapy, radiation) [2-5], studies indicate that nearly 59% of ER+ BC survivors are non-adherent to AET, and over 50% discontinue use prematurely [3,6-10]. Poor AET adherence may be partly attributed to AET-related side effects, including pain, hot flashes, fatigue, sexual dysfunction, and mood changes [11-15]. Because survival benefits accrue with long-term use of AET (i.e., recommended use over 5-10 years), managing AET-related symptoms is critical.

Prior studies suggest that cancer-related symptom management is less than adequate [16-18]; however, few studies have delineated facilitators and barriers to AET-related symptom management. Conceptual models of the cancer care continuum reveal that a range of factors at the patient-, provider-, and system-level impact care quality [19,20]. Still, no studies have applied a multi-level framework in examining barriers and facilitators to AET-related symptom management.

Moreover, although BC survivors often receive care from multidisciplinary healthcare providers (e.g., oncologists, nurses, psychologists), little is known about provider perspectives on barriers and facilitators to AET-related symptom management, as most previous studies have been limited to patient perspectives [21-23]. Given the shared role of patients and providers in the symptom management process, it is equally important to understand provider perspectives on factors influencing AET-related symptom management. Providers' insights may help inform interventions aimed at improving AET-related symptom management, AET adherence, and clinical outcomes among BC survivors.

The purpose of this exploratory qualitative study was to employ a multi-level framework (patient-, provider-, and system-level factors) to examine provider perspectives on the barriers and facilitators to AET-related symptom management among BC survivors and identify opportunities for care improvement.

Methods

Study Design and Participant Recruitment

We employed a focus group study design and recruited participants from the University of Pittsburgh Medical Center (UPMC) during 2012. Recruitment strategies included emails to UPMC providers, including a targeted list of providers with high exposure to BC survivors (e.g., breast medical oncologists). “High exposure” was defined as currently caring for five or more BC survivors. Eligible healthcare providers included physicians (e.g., medical oncologists, primary care physicians) and mid-level providers (e.g., nurses [including oncology nurses], psychologists, and social workers) with high exposure to BC survivors experiencing AET-related symptoms at the time of recruitment. Study participants received a $20 gift card incentive.

Focus Group Procedures and Data Collection

Three, one-hour focus group sessions were conducted at UPMC. Focus groups were kept small (≤6 participants per group) to ensure sufficient engagement and contribution from all participants [24,25]. All focus groups were held during lunch or dinner time in a private conference room within a few minutes walking distance of providers' practice facility at UPMC. All provider participants committed to participating for the full duration of the focus group and were instructed to maintain confidentiality of the focus group discussion. Sessions were led by a facilitator and co-facilitator. Both facilitators were doctoral-level researchers (1 MD and 1 PhD) who previously received formal training in qualitative methods (e.g., conducting interviews, facilitating focus groups, and analyzing qualitative data) and both possessed extensive experience conducting qualitative studies. Facilitators provided an overview of the study, obtained informed consent, and collected completed demographic surveys from all study participants

A semi-structured discussion guide was used to elicit provider perspectives on AET-related symptom management, barriers and facilitators to symptom management, and recommendations for improvement (Table 1). All focus group sessions were audio-recorded and transcribed verbatim. The University of Pittsburgh's Institutional Review Board approved this study.

Analysis

A thematic analysis approach was employed to identify patterns and themes from focus group transcripts [26]. Analysis began with careful review of the semi-structured discussion guide to develop topical codes summarizing key concepts. Next, three members of the study team read all three transcripts and generated a set of interpretive codes, using a data-driven inductive approach [27,28]. A preliminary codebook was developed and revised through an iterative process involving four team members. During the codebook development process, barrier and facilitator codes were further sorted into categories reflecting the level at which the facilitator or barrier operates (i.e., patient-, provider-, system-level).

After the codebook was finalized, two members of the study team coded one transcript and assessed inter-coder reliability. Because there was a high degree of consensus in the coding of the first transcript, one team member coded the remaining two transcripts and generated a summary report for each code. Four members of the study team reviewed the summary reports, discussed patterns in the coded text, and collectively derived themes.

All qualitative analyses were conducted using Dedoose qualitative analysis software, version 4.12.

Results

Participant Characteristics

The study sample (n=13) consisted of a multidisciplinary group of physician (n=7; n=3 in focus group 1, n=4 in focus group 2) and mid-level (n=6 in focus group 3) healthcare providers – including medical oncologists, primary care physicians, nurses, psychologists, and social workers – with high exposure to BC survivors experiencing AET-related symptoms. Most healthcare providers were female (93%), White (85%), and over 40 years of age (77%). On average, providers possessed 17.2 (SD=9.5) years of clinical experience and had a clinical load of 24.2 (SD=18.6) patients per week (Table 2).

Patient-, Provider-, and System-Level Barriers and Facilitators to AET-Related Symptom Management

Several patient-, provider-, and system-level barriers/facilitators emerged from the focus group data. Consistent with participants' exchangeable use of the terms “survivor” and “patient,” we use both terms interchangeably when referring to BC survivors receiving AET therapy. Results are described below.

Patient-Level Barriers—Providers collectively identified two patient-level barriers to AET-related symptom management: (1) competing demands and limited time/resources; and (2) patients misattribute symptoms to AET.

Competing Demands and Limited Time/Resources: Providers reported that survivors' life stressors and limited time/resources sometimes make it difficult for survivors to identify and pursue additional treatment to address symptoms. Younger women were identified as especially likely to struggle with these competing demands.

> “…‘these symptoms negatively impact quality of life,’ but at the same time to aggressively pursue all this treatment, it's a time commitment on their part. Sometimes a monetary commitment on their part.”

> “Especially for the younger women who are working and have children and have incredibly busy lives. And all of these [symptom management strategies], … take time and resources [that] sometimes, I think they don't have.”

Providers also mentioned that patients may sometimes prioritize their caregiver responsibilities over their own health, and in the process, neglect their symptom management needs.

> "But some women have said that their husband is also sick and so their priority is making sure the husband has all his medications and [their symptoms] sort of [go] by the wayside."

Patients' Misattribute Symptoms to AET: Participants also reported that patients are often unsure about the origins of their symptoms, and perceived that patients sometimes misattribute their symptoms to AET. Providers indicated that potential misattribution of symptoms can create a psychological barrier that shifts focus from managing actual AET-related symptoms, often leading to additional patient suffering.

> "A woman who I think psychosocially within the frame of mind of wanting her cancer to be behind her… [mis] attributed a lot of her symptoms… to her tamoxifen and I think she suffered more with those symptoms because she made that attribution to the tamoxifen and felt like this was something that was keeping her from kind of moving on."

Patient-Level Facilitators—Two factors emerged as patient-level facilitators to AET-related symptom management: (1) social relationships; and (2) insurance coverage.

Social Relationships and Support: Participants described how having a spouse or caregiver to follow up and ask questions about symptoms can help support AET-related symptom management. Additionally, providers reported that survivors' may also be more inclined to seek symptom management services when their family (e.g., spouses, dependent children) or other social relationships are negatively impacted by their AET-related symptoms. As one nurse put it,

> "I think some women do things to keep living or keep being in good shape for their family… Like in order for my husband to stop yelling at me I will ask the doctor about x because it's affecting both of us, as an example."

Insurance Coverage: Providers also acknowledged that having insurance coverage, particularly Medicare, is especially helpful to patients' access to symptom management services.

> "… things can get much better when they turn 65 because they get Medicare. Because you know, it's really [easy] then to prescribe medication. It's helpful."

Additionally, providers discussed how access to some complementary/alternative therapies for symptom management improved under one particular "health plan [which] covers [acupuncture] for chemotherapy-induced nausea and vomiting…"

Provider-Level Barriers—Four provider-level barriers to AET-related symptom management were identified: (1) symptom management is time consuming; (2) challenge of distinguishing between AET-related symptoms and symptoms stemming from other conditions; (3) limited knowledge of available complementary/integrative medicine services; and (4) primary care providers' discomfort with AET-related symptom management in BC survivors.

Symptom Management is Time Consuming: Providers reported that a key barrier to symptom management is the substantial amount of time that goes into assessing and addressing symptoms.

> "We don't really understand what's going on [in] like one 20 minute visit, I know we're not going to get to the root of what's going on… [it] just takes more time to truly try to figure it out."

> "…I find when it is not a clear mood disorder, it's much harder… You search for somatic things, there's nothing… They're moody, but they're not diagnosable…"

Challenge of Distinguishing between AET-Related Symptoms and Symptoms Stemming from Other Conditions: Providers described the difficulty of determining whether patient symptoms are due to AET or other co-morbid conditions (e.g., mental illness, menopause). This clinical uncertainty can make it challenging for providers to offer adequate explanations and manage patients' symptoms.

> "Another patient, [who] is also in therapy, has a lot of depression symptoms, poor compliance, and really low [medication] adherence,… but I don't know if [her depressive symptoms are] related to major depression or related to her [AET]."

> "…it's difficult to know what might be natural age- related changes versus what could be late effects of earlier treatment or side effects of their hormonal therapy."

Limited Knowledge of Available Complementary/Integrative Medicine Services: Providers acknowledged the existence of complementary/integrative medicine approaches that may help manage AET-related symptoms and a willingness to suggest these approaches to survivors. However, many providers expressed a lack of awareness of locally available complementary/integrative symptom management approaches, such as acupuncture and mind-body therapy. Limited awareness lessened their likelihood of referring patients to these services.

> "…It seems like one of the barriers is lack of physician options, like you didn't know about acupuncture… [and] different mind-body approaches [for] hot flashes…"

> "… because you get so specialized and so focused on your own little world that [you forget] there are so many other little groups out there [like acupuncture] that could be helpful."

Primary Care Providers' Discomfort with AET-related Symptom Management in BC Survivors: Primary care providers expressed some uncertainty and ambivalence toward managing symptoms among BC survivors, which can impact patients' receipt of adequate AET-related symptom management. Additionally, some providers mentioned that AET-related symptom management might be beyond the scope of a primary care provider's role, suggesting that this responsibility should be left to the prescribing provider (i.e., medical oncologist).

> “ [An] aromatase inhibitor is a drug that I never prescribe… I think that's sort [of] … like a line [in] the sand that I [don't] cross as a [primary care provider].”

> “I guess I never expected the primary care doctors to manage these symptoms… I kind of thought if you're giving the medicine that's making the person have the side effect, then you should be the one to help them with the side effects.”

Provider-Level Facilitators—Providers mentioned two provider-level facilitators: (1) strong relationships among providers; and (2) symptom documentation and tracking using electronic health records (EHRs).

Strong Relationships among Providers: Providers explained how strong provider-to-provider relationships are important to the AET-related symptom management process by facilitating better provider-to-provider communication and care coordination for patients on AET.

> “I think [my likelihood of contacting another physician] depends in part on what my relationship is with that particular physician and how distressed the patient is and if I think it's something that really needs to be addressed quickly.”

Similarly, in describing her likelihood of consulting other providers for input on managing patients' symptoms, one nurse reported that,

> “It makes a difference who the particular physician is and [the] nurse working with that physician. Some of them, I'm comfortable with calling them on the phone with the patient in the room so they can hear what I'm saying and correct me.”

Symptom Documentation and Tracking using EHRs: Providers also indicated that regularly using the physician notes feature in the EHR facilitates ongoing conversations with patients regarding their symptoms.

> “For the patient who needs to talk about [their symptoms], … I'll sort of remind her about what her oncologist said. One thing that's really nice in [the EHR] is I can open the note from the oncologist and be like, ‘look, this is what we agreed… ’ ”

Additionally, providers described how EHRs facilitate patient tracking, symptom follow-up, and provider-to-provider communication regarding patients' symptoms.

> “One of the advantages of [our EHR] is I have patients with breast cancer and I know the patient's oncologist… I communicated that I refer this issue to [the] oncologist so his fellow looks through my note and then they kind of follow-up.”

System-Level Barriers—Providers identified two interrelated system-level barriers: (1) complexity of the cancer care delivery system; and (2) inadequate care coordination across the system.

Complexity of the Cancer Care Delivery System: Providers explained that the complexity of the system partly contributes to confusion and frustration among patients in knowing where to seek symptom management services. Specifically, providers described how the multidisciplinary nature of cancer care can sometimes make it difficult for BC survivors to know whom to contact regarding AET-related symptoms.

> “I can understand a patient not knowing who to call. For joint pain, is it their [primary care provider], their oncologist? Should they be seeing a rheumatologist? Do they need an orthopedic surgeon?”

Inadequate Care Coordination throughout the System: Lack of care coordination across numerous providers emerged as a key system-level challenge to AET-related symptom management.

> “I do have a couple people [who] have gone back to the primary care, haven't seen the oncologist for 3 [or] 5 years, and they have symptoms [that] primary care didn't pick up.”

Providers expressed that these coordination challenges are not limited to AET nor rooted in individual provider practices, but instead reflect a broader systemic issue when “multiple layers of providers” are involved in patient care.

> “ [The] problem … is not unique just to this situation, when you have multiple layers of providers associated with it… I think it really just doesn't speak only to the problems with the [AET]…. I think that's just an overall medicine issue.”

Additionally, providers suggested that the role of the primary care provider as the “gatekeeper” and manager/coordinator of patients' care, including symptoms, diminishes when several providers are involved in care delivery.

> “I think the more layers you have providing care, that concept of gatekeeper has just gotten washed and unfortunately, [primary care providers] are not [providing care] as they thought.”

System-Level Facilitators—Providers described one system-level facilitator: (1) clinics focused on post-treatment survivorship care.

Survivor Clinic: Providers were very supportive of survivor clinics and “one-stop shops” that centralize symptom management for patients, thereby mitigating system navigation and care coordination challenges to symptom management.

> “But I think the [survivor] clinic… is a great step, too, because I think it's sort of like for any condition [there is] a clinic to help symptoms in survivors… a survivor clinic is very helpful.”

Discussion

Improving the management of AET-related symptoms is critical to maximizing survival and quality of life outcomes for BC survivors. Findings from this study shed light on provider perspectives regarding the barriers and facilitators to AET-related symptom management, as well as opportunities for enhancing care. In employing a multi-level framework, we found that providers identified more barriers than facilitators, and that most of these barriers were interrelated and operated at the provider- level. We focus our discussion below on the barriers and facilitators that we found to be most critical and immediately actionable for improving AET-related symptom management.

Limited time and other resource constraints, at both the patient- and provider-level, emerged as key barriers to AET-related symptom management. At the patient-level, time commitments and competing demands may result in neglect of troublesome AET-related symptoms. Thus, symptom management approaches that prioritize convenience and efficiency can help ensure more patient-centered care. At the provider-level, the time consuming process of assessing and managing symptoms during a single clinical visit, where multiple other cancer-related issues need to be addressed, emerged as a key challenge. As growth in the number of cancer survivors continues to outpace growth in the number of oncology providers [29], it will be especially important for future research to identify best practices for streamlining and improving the symptom management process [30,31]. Furthermore, given that providers are not compensated for time spent assessing and managing AET-related symptoms, reimbursement and value-based payment strategies that incentivize providers to engage in symptom management should also be considered.

Providers also pointed to barriers related to uncertainty and limited knowledge regarding AET-related symptoms and their management. Previous studies have also documented gaps in patients' recognition and providers' assessment of treatment-related symptoms [17,32-34]. These findings suggest that better educating patients and providers regarding AET-related symptoms may help improve the symptom management process. For example, provider-initiated discussions of AET-related symptoms at the point of prescribing, with routine follow-up discussions at each clinical encounter, can facilitate patient education. Furthermore, equipping providers, especially non-oncology specialists, with pocket/desk references describing common AET-related symptoms and symptom management strategies can help educate and empower providers in assessing, monitoring, and managing AET-related symptoms.

Consistent with previous research [35,36], inadequate care coordination and the complexity of navigating the cancer care system were identified as a key system-level barriers to AET-related symptom management. These findings indicate potential communication breakdowns and care fragmentation during the cancer survivorship phase [37,38], and highlight the need for patient navigators to guide, support, and advocate for BC survivors regarding symptom concerns and symptom management options [39]. Although the cancer patient navigation movement has grown in recent years [35,36,40,41], with patient navigators becoming increasingly available to cancer patients during the earlier phases of cancer care (e.g., diagnosis, treatment), there are fewer examples of patient navigator engagement during the cancer survivorship phase [39]. Thus, additional research is needed to inform best practices for designing and implementing patient navigator programs that support BC survivors' AET-related symptom management needs. Moreover, survivor clinics that centralize symptom management services and survivorship care plans that include strategies for managing AET-related symptoms are promising approaches for enhancing symptom management quality [37,42-44]. Such clinics and care plans could help expose survivors and providers to a range of symptom management services, including novel complementary and integrative medicine approaches.

Findings from this provider-perspective study help to broaden knowledge regarding AET-related symptom management challenges. Prior studies have largely focused on patient perspectives, highlighting issues such as patient uncertainty in determining symptom origins, dissatisfaction with symptom management information received from providers, communication challenges, and unmet preferences for non-pharmacological symptom management approaches [21-23,45]. Our findings are consistent with and complement results from patient-focused studies. For example, similar to patients, providers described provider difficulty and uncertainty in distinguishing the sources of patients' symptoms. This uncertainty may contribute to patient-provider communication challenges and patients' dissatisfaction with the symptom management information they receive from providers. Additionally, providers in this study reported limited knowledge of available complementary/integrative medicine services, which likely accounts for unmet patient preferences for non-pharmacological symptom management. Moreover, obtaining provider perspectives also helped to shed light on other barriers that patients may be less aware of, including providers' discomfort with symptom management, time constraints, and care system complexity and fragmentation. Targeting these provider-identified factors through multi-level strategies will be important to improving the quality of AET-related symptom management.

Strengths of this study include our focus on provider perspectives on AET-related symptom management, inclusion of both physician and mid-level providers, and novel use of a multi-level framework to examine barriers and facilitators to AET-related symptom management. Limitations of this exploratory study include the sample composition. Most providers were female and White and none specialized in complementary/integrative medicine, thereby limiting generalizability to other provider groups. We were also unable to compute a response rate due to our recruitment approach which involved sending recruitment emails to multiple provider email list serves. As such, it was not possible to ascertain whether respondents differ in meaningful ways from non-respondents. Secondly, our findings may not generalize to other settings, as this study was limited to providers at a single high-volume academic medical center in an urban setting. Future research should explore and compare barriers and facilitators to AET-related symptoms in other settings, including community hospitals and rural facilities.

Conclusions

Findings from this study suggest that efforts to improve AET-related symptom management should span multiple levels, in order to address patient-, provider-, and system-level barriers to AET-related symptom management. Future research should examine the effectiveness of interventions that target multiple levels of influence simultaneously to determine whether there are synergistic effects across multi-level strategies. Such multi-level symptom management interventions can potentially lead to improved quality of life, AET adherence, and survival outcomes for the growing number of BC survivors.

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Table 1

Focus Group Discussion Guide Questions

Topic	Questions
Perspective on survivors' symptoms	First, we'd like to ask you about your perspective of breast cancer survivors who suffer symptoms. • Do you find it challenging to manage symptoms in breast cancer survivors? What are the challenges? • Do you find it time-consuming to manage symptoms in breast cancer survivors? What takes the most time?
Treatment preferences	What treatment approaches do you tend to follow for symptoms (in breast cancer survivors on adjuvant hormonal therapy), given that we often have multiple treatments available and little evidence guiding us about the best first/second/third line treatment? • Do you tend to prescribe pharmacological versus non-pharmacological treatments? • Do you try to involve your survivor in the decision making process? How do patients react to this? • How much time do you allow passing prior to reevaluating its effectiveness? • Do you usually add a next line of treatment or replace it for the first?
Barriers to treatment	What barriers have you or your breast cancer survivors experienced when pursuing treatment for symptoms? • What barriers have you encountered in pursuing this treatment? Cost? Non-compliance? Logistic barriers? • How closely do you follow survivors with symptoms? Do you follow them more closely if their symptoms are more severe?
Non-adherence to hormonal therapy	We'd like to ask you about your perspective on adherence to adjuvant hormonal treatment. This may include medication called tamoxifen (Nolvadex®), letrozole (Femara®), anastrazole (Arimidex®), or exemestane (Aromasin®). • Do you think you have sufficient time for a complete explanation of the risks and benefits when prescribing adjuvant hormonal therapy? • Do you reinforce the importance of complying to derive the most survival benefit at each visit? • Do you probe for side effects? • Do you explore affordability issues? • Do you ask your breast cancer survivors if they adhere to adjuvant hormonal therapy? • Generally, how well do you think survivors adhere to adjuvant hormonal therapy?
Recommendations	We've covered all of the topics that we hoped to talk with you about but have two last questions before we end. Let's go around the room and hear from each of you about: • What is the one thing that could be done to help you help women successfully and consistently take their adjuvant hormonal treatment? We are looking for answers that can really be acted on, things that could improve the care women receive or other ways that you think women could be best supported. • Similarly, thinking about the barriers we discussed earlier, what is the one thing that could be done to help you help women manage side-effects of hormonal therapy, either on their own or with help from a health care provider? • Is there anything else that you would like to say about this topic before we finish?

Table 2
Focus Group Participant Characteristics

Number of Health Care Providers	13
Mean Age (SD)	47.4 (9.1)
Mean Years in Practice (SD)	17.2 (9.5)
Mean Number of Patients per Week (SD)	24.2 (18.6)
Sex - % (N)	
Female	92.3 (12)
Male	7.7 (1)
Provider Type - % (N)	
Physician	53.8 (7)
Non-Physician	46.2 (6)