Published in final edited form as:

Support Care Cancer. 2020 January ; 28(1): 271–278. doi:10.1007/s00520-019-04814-0.

Exploring the Role of Social Support and Adjuvant Endocrine Therapy use Among Breast Cancer Survivors

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Abstract

Background: Adjuvant endocrine therapy (AET) significantly reduces recurrence and mortality in women with estrogen receptor-positive breast cancer. Adherence to AET is about 50–60% for five-years and while numerous studies have identified barriers to AET adherence, few have identified the role of social support as a facilitator. Therefore, the objective of this study is to explore the role of social support during the on-going management of AET.

Methods: We conducted semi-structured in-depth interviews with breast cancer survivors (n=22) who filled a prescription for AET in the previous 12 months. Women were recruited from Los Angeles, California and Houston, Texas between 2014–2015. Interview questions prompted discussion about AET and how social support affects AET adherence. We analyzed interview transcripts with a grounded theory approach and grouped social support into four categories (emotional, informational, instrumental, and appraisal), then used a thematic content analysis to identify the sources and delivery of support.

Results: Women described that informational support was provided by medical providers who explained the purpose, benefits, and management of AET. Emotional support in the form of reassurance, communication, and empathy was provided by family, survivorship groups, medical providers, and spirituality/religiosity. Women identified several organizations and exercises that provided them with instrumental and appraisal support in the form of physical and emotional benefits, which was also provided by family, friends, and medical providers.

Conclusion: We identified that social support delivered to breast cancer survivors provided women with educational, physical, and emotional benefits that may play an important role in their continuation of AET.

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

Compliance with ethical standards: All procedures performed in this study involving human participants were in accordance with ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approvals were obtained from the University of Washington Institutional Review Board.

Disclaimer: The authors have full control of all primary data and agree to allow the journal to review the data if requested.

Keywords

Social support; AET adherence; emotional support; informational support; instrumental support; appraisal support

Introduction

Nearly two-thirds of breast cancer cases in the United States are diagnosed with estrogen receptor-positive breast cancer and are indicated for adjuvant endocrine therapy treatment (AET) for at least 5 years [1–3]. AET treatment reduces the risk of cancer recurrence and improves survival [4, 5]. Despite the benefits, adherence is suboptimal, where only 50–60% of patients adhere after the five-year recommended duration [6–8]. Poor adherence to AET is associated with many socio-demographic factors but the side-effects experienced from treatment are one of the main reasons why women discontinue therapy [8, 9]. Many studies have focused on direct reasons for discontinuing therapy, but few have identified treatment facilitators such as social support, which may be a modifiable factor to improve the management of AET-related side-effects and AET adherence.

Social support is an experience that involves voluntary associations in relationships with others. It is a measure of perception or realization of one being accepted, cared for, and provided with support from certain individuals or a specific group in their social network [10]. There are four dimensions of social support [11]. Emotional support is classified as expressions of empathy, love and caring. Instrumental support is tangible aid and service. Informational support is advice, suggestions, and information. Appraisal support is information that is useful for self-evaluation [12]. Social support serves as a protective factor against distress in ill patients [13] and may be beneficial to help women continue recommended AET treatment.

Social relationships can alleviate the course of AET treatment; however, patients often experience a decline in support from family and friends who lack an understanding of the purpose of AET or they lack informational support on the benefits of AET from their medical providers [13]. Social support could be beneficial in AET management whether it is having a spouse or caregiver present to follow-up and ask questions about treatment plans or reminding women to take their medications [14]. A study by Yamamoto and colleagues found that women felt a lack of support from their male partners because they did not understand their experiences of the side-effects [15].

Two theories have addressed the linkage between social support and physical and mental well-being: the buffering hypothesis and the direct effects hypothesis [10, 16–19] both postulate that high levels of social support lead to better health and fewer negative health outcomes. The buffering hypothesis suggests social support is protective during stressful events and individuals with lower levels of social support are more affected by stressful experiences [20, 21]. Whereas the direct effects hypothesis asserts individuals with high levels of social support have better health than individuals with low levels of social support, regardless of stress [20].

Social support is recognized as an important facilitator of AET adherence. A study by Kroenke et al., found that those with moderate or low versus high social support were more likely to discontinue treatment and had higher levels of AET non-adherence [22]. Another study by Lambert and colleagues found family and friends was an important predictor of AET on-going use, and that women who reported higher levels of social support had greater adherence compared to women with lower levels of social support [23]. While these studies have identified the importance of social support for AET adherence, the purpose of this study is to explore how the different sources of support may help women manage AET-related side-effects among women actively taking AET.

Methods

Study Design

Semi-structured in-depth interviews were conducted with breast cancer survivors to understand their experiences, beliefs and perspectives while actively taking AET. This study design has been published in greater detail elsewhere [8]. The University of Washington's Institutional Review Board approved this study.

Recruitment

We interviewed breast cancer patients who filled at least one prescription for AET in the last 12 months from Los Angeles, California, and Houston, Texas, between September 2014–April 2015. Women were recruited from breast cancer survivorship groups with informational flyers sent via email to list serves and placed in oncologist's offices. Research staff also contacted survivorship groups, presented the purpose of the study, handed out flyers, and answered questions during a monthly meeting.

Study Procedure

Participants contacted research staff and were screened over the telephone to ensure that they met study inclusion criteria. Interviews were scheduled and conducted in study rooms at public libraries, and at the participant's workplace. We collected signed informed consent forms from each participant prior to the interview. Interviews lasted 35–60 minutes and women were given a \$25 gift card at the end of the interview. All interviews were done in English by the third author until saturation was reached.

Interview topics included the history of breast cancer diagnosis and treatment, experiences and management of AET related side-effects, relationships with physicians during AET treatment, and sources of social support during AET treatment. The full in-depth interview guide and demographic questionnaire has been published elsewhere [8]. In this paper, we focused our analysis on the participants' perspectives of their sources of social support during AET and how it helped them manage their side-effects.

Analysis

A total of 22 interviews were recorded using a digital audio device and professionally transcribed. Three interviews were inaudible due to poor sound quality and could not be transcribed. Transcripts (n=19) were uploaded into Dedoose qualitative data analysis

software, version 4.12. The first author developed an initial list of codes using data collection memos and overall study goals. We used a deductive approach to organize descriptions of social support into four constructs [11]. Then we used an inductive, constant comparison approach to identify additional concepts and themes from the interview data. The first two transcripts were double coded by the first and second author to check for reliability and consistency in coding. First and second authors then coded the remaining transcripts separately (n=17). The research team met weekly, in an iterative process, to revise the codebook by adding, removing, and refining codes to capture emerging themes. In this study, the emergent themes were explored and limited to any discussion regarding how social support helps women manage and adhere to AET.

Results

Participants

Table 1 provides participants characteristics. Most participants were white (52.6%) and under the age of 55 (52.6%), and interviewed in Los Angeles, California (68.4%).

Major Findings

Using the conceptual framework established by House, we explored the four domains of social (1) informational support, (2) emotional support, (3) appraisal support, and (4) tangible support (Table 2) [11]. We then identified who provided women with each type of support and the benefits provided to women actively taking AET (Table 3).

Informational support

Medical providers, online support, family, and survivorship groups provided informational support to survivors. These groups predominantly provided women with information about the benefits of taking AET, coping strategies to deal with the side-effects of treatment, and the pros and cons of initiating treatment.

Medical providers.—Medical providers recommended and explained the importance of AET and how to manage AET related side-effects.

Physicians offered women with the “latest information” and referred to “published studies” and “findings” that supported the prescription and continuation of AET. This information helped women’s decision-making as they felt their providers were very informed with the latest findings on AET success.

“When I first went to see [my doctor] she basically was giving me the latest information on the Arimidex treatment and the success it’s having...”

Medical providers also informed women of reliable resources available such as online sources, educational workshops, seminars, breast cancer newsletters and offered recommendations for alternative strategies that could help them mitigate the side-effects of AET. Recommendations included acupuncture, exercise, and other general health practices. One woman explained:

“... You could take different herbs for hot flashes, [the medical provider] recommended...Effexor. There’s some medicine that actually reduces hot flashes. And I forgot...I’m seeing an acupuncturist for the night sweats, and for the sleeping issues, and fatigue... so certain things I can do.”

Online support.—Women used online resources to connect with other breast cancer survivors to learn about their experiences with AET and the benefits of continuing treatment. Breast cancer blogs, WebMD, medical journals and recently published research provided women with an informational platform for making decisions to initiate and continue AET treatment. One woman explained why she used online sources:

“I went on different breast cancer blogs to read up on it [AET] and see what other women were saying about the drug...it seems to vary from person to person. Some people had really severe side effects to a point that they can’t tolerate it. Some people have no side effects at all. It was like just all to luck.”

Survivorship groups.—Survivorship groups provided women with a network of survivors where they could discuss their side-effects, coping mechanisms, and changes in treatment duration during the course of AET and to connect with others who understood their diagnosis and medical trajectory. The long-term survivors in the groups reminded women that there are benefits to continuing AET. One woman described the experiences of one member in her group:

“[Her] family doesn’t understand the symptoms she is experiencing, and they panic so she has to be with a group that’s strong and will help her walk through it and provides advice based on what they went through.”

Emotional support

Medical providers, online support, survivorship groups, spirituality/religiosity, and family provided women with emotional support. These groups supported women by lifting their spirits and encouraging them to think differently about AET and were a resource to women when they made decisions about AET initiation and retention.

Medical providers.—Medical providers encouraged women to think differently about their course of treatment by reminding them of their self-efficacy to continue taking AET. Doctors showed empathy by understanding that making decisions about AET is difficult and were willing to talk to women about their options, while emphasizing the benefits of treatment. One woman highlighted a positive experience with her provider when she felt hopeless about her AET adherence:

“I hate Tamoxifen. I hate this. And she [the oncologist] was like, how about you think about it as ‘oh, I’m lucky they invented this drug, that’s going to lower my chances of getting cancer.’ And so ever since that, that was in June, I’ve really tried to put a spin on it, that wow, I’m so fortunate this exists...”

Survivorship groups.—Survivorship groups provided women with open spaces to talk about any difficulties or embarrassments related to AET, and to console with others on how

to manage AET-related side-effects. Younger survivors did not find support groups and started their own. The majority of these groups were based in churches, cancer support communities, and clinics.

Some women found their support groups at churches and described their meetings as opportunities to listen to each other, cry, and show affection to one another. Some breast cancer support groups had prayer partners to support women when they felt emotionally distressed, and pairing was often between long-term survivors and first-time survivors. One woman described:

“I believe in the power of prayer. I’m not deeply religious, but I believe in the power of prayer and that, I think that helps people a lot.”

Spirituality/Religiosity—Women participated in spiritual exercises such as yoga, meditation, and relaxation techniques for emotional support during their treatments. They described these exercises as opportunities to “embrace their energy” and “transfer their energy” from something that is “bad to good”. One woman described her experience with qi gong classes as:

“You would sort of change the energy patterns in your body. And, believe it or not, I’m not usually a woo-woo kind of person. But I’ve physically noticed changes in my body with qigong. I have physically noticed things, and I think, like anything, you got to see it or feel it, or whatever, to believe it.”

Another woman described that meditation has physical and emotional benefits, and believed it played an important role in fighting cancer, she said:

“It’s meditative. Yeah, the breathing. It’s wonderful. And they’re finding out it’s a very positive thing for breast cancer patients. I think that and the hormone therapy are incredible ways to fight it.”

Religious practices were a significant source of emotional support, as women would pray to God who they trusted to support and protect them. Others engaged in long-term bible study as a way to focus on life lessons and an outlet to find motivation to adhere to AET. Faith was a foundation for women, and praying helped them find strength. One participant shared:

“I’m a very faithful person, so I just pray my way through it... And I believe God left me here, you know, for a reason, because there are other ladies that I know who didn’t survive, you know, friends and I just believe He has a plan for me.”

Family.—Few women sought emotional support from family members or significant others, but those who did, explained that they provided help in making decisions about treatment options and duration. Family members shared positive energy and would accompany women to medical and support services such as counseling, exercise classes and screenings while significant others showed empathy towards the anxiety and frustration women felt during AET treatment.

Instrumental/tangible support.

Medical providers, friends, family and external organizations provided women with instrumental/tangible support. Friends and family provided assistance with financial burdens, and family commitments. Medical providers and external organizations offered recommendations and outlets to overcome AET related side-effects.

Medical provider.—Providers offered recommendations on how to adhere to AET by prescribing medications for AET-related side-effects and giving them referrals for cancer-related services such as genetic testing, mindfulness training, and wellness training.

Family and Friends.—Friends provided financial support that would help with purchasing necessities and would arrange social and outdoor activities. They also assisted women with their medication schedule by setting cell phone reminders every night. Women with children explained that family provided tangible aid by helping take care of children.

External organizations.—Several external organizations played a prominent role in providing women with wellness services such as therapy, acupuncture, art classes, and exercises classes such as Tai Chai, Qi gong, and yoga.

Appraisal support

Religiosity and spirituality played a role in women's self-affirmation and belief that they could overcome AET.

Religiosity.—Religion helped instill in women the importance of their faith and trust in God during AET treatment, and many women explained that their strength and confidence was rooted in God. Other women explained that their family and friends were not empathetic or understanding of their diagnosis, and found that their confidence was in their prayers to God that their AET would be successful. One woman said:

“So, for me, my faith is my rock. That's my center, what helps me...”

Spirituality.—Spirituality played an important role in women's positive energy, self-efficacy and belief that they could overcome AET side effects and cancer.

Patient self-support

Women were identified as resilient in self-managing their AET treatment. Several women used pillboxes to remind them to take their pills every day, ice packs for hot flashes, medicinal marijuana, and exercise/exercise classes. Women took the initiative and sought out many of the sources of social support. For instance, women were often harnessing technology to access online resources of informational support and found social support groups and online communities on their own. While we focused this analysis on social support, we recognize and found that self-encouragement and motivation played a key role in the continued use of AET.

Discussion

In this qualitative study exploring the role of social support among women actively taking AET, we found that informational support provided mainly by medical providers and online support was widely used by women to inform them of the AET benefits, treatment and duration and common side-effects. Emotional support delivered by medical providers, online support and survivorship groups played a role in encouraging women to think differently about AET and to have a positive outlook for the future. Instrumental/tangible support offered mainly by family and friends provided assistance with responsibilities and commitments, while medical providers and external organizations offered recommendations to overcome AET-related side-effects. Appraisal support founded in religious and spiritual practices supported women's self-affirmation and beliefs.

In our study, informational support helped women understand the benefits of AET and connected women with an online network of breast cancer survivors with similar experiences regarding AET. Similarly, others have found that informational support impedes a patient's adherence to AET because of inaccurate information collected from the Internet [13]. Informational support was a positive facilitator in our study and women did not get negative information from the Internet or from other sources. Social support from family is an important facilitator of ongoing AET use [24], with women reporting higher levels of social support also having higher levels of AET adherence [25]; however we found that family members lacked a role in providing informational support, which as previously described, might be due to a lack of understanding about side-effects and how to improve symptom management [15].

Our findings show emotional support can be leveraged to improve AET use. We found that medical providers were helpful for women who needed to be reminded of the long-term benefits of AET and encouraged them to perceive their treatment as a positive opportunity. This compliments findings that show physicians help patients emotionally by interacting with them in a way that instills a sense of trust and care for them [8]. Interestingly, we also found other sources of emotional support such as religiosity, survivorship groups and spirituality played a prominent role in women's self-efficacy and management of AET-related side-effects. This finding is consistent with previous research that show how social relationships and support facilitate symptom management [14, 26].

Instrumental support was offered from variety of sources including medical providers, friends, family, and external organizations. In our study, religiosity, and spirituality appeared to play a major role in appraisal support as it served as an encouragement to the continuation of treatment and as an informal social support network. Lotzke and colleagues found that among women with stage I–III breast cancer undergoing endocrine therapy, practicing yoga had a beneficial effect on several aspects of quality of life [27]. Our findings suggest that incorporating aspects of spirituality or religiosity may help women have more positive attitudes about AET. Interventions that focus on educational information have not shown to have a significant improvement on adherence [28]. Using different avenues that reinforce the value of AET, such as religiosity and spirituality, can help women have more positive self-affirmation about control over their side effects.

Our results are consistent with the direct hypothesis that asserts people with high levels of social support have better health than people with low social support, irrespective of stress [10]. In our study, we found this hypothesis relates to informational support from medical providers, online support, and survivorship groups. These groups provided women with information concerning AET-related side-effects and management, which women perceived as important for making decisions. Other results are consistent with the buffering hypothesis, that states social support is protective during stressful events. Women experienced the stress of being a cancer survivor, and received emotional, appraisal, and tangible support to manage this from medical providers, family, church, and religion/spirituality, which were considered constructive for a women's course of treatment.

Strengths of this study include our focus on patient perspectives on AET-related symptom management and barriers to continuing AET treatment. It allowed for a greater understanding of the attitudes, opinions, and behaviors of women that are important to women on active treatment. Given the demographics of women in our study, who were highly educated with an income at or above the U.S. median household income, we may not have recognized other aspects that are important drivers or barriers to taking AET. The results from our study do however provide insight into the different sources of social support and how they help women better manage their AET side-effects and understand the importance continuing treatment. Our findings are supported by literature that demonstrates the importance of social support in health-related outcomes [10].

Conclusion

Our study identified the types and sources of social support delivered to breast cancer survivors on active AET. The most prominent sources all types of social support were medical providers, online support, religiosity/spirituality, and survivorship groups. Since AET side-effects are associated with AET non-adherence [29, 30], this study stresses that it is imperative for medical providers to offer patient-centered symptom management schemes and to provide adequate information and communication about AET side-effects that can help women cope with the physical and psychosocial challenges of AET. The clinical implications of this research highlight the importance for primary care providers to have an enhanced understanding of AET, including the barriers and facilitators that influence adherence, and the symptom management strategies available for AET side-effects. Information from this study can be useful for the provision of developing interventions that work to increase social support and enhance facilitation of the specific supportive needs of breast cancer survivors using AET.

Acknowledgements

The authors would like to extend our gratitude to the study participants who provided insight and perspective, and without whom this work would not be possible. This research was supported by a Ruth L. Kirschstein National Research Service Award for Individual Predoctoral Training grant from the National Cancer Institute F31 CA174338 (A Farias, Principal Investigator). This work was also supported in part by a Postdoctoral Fellowship, University of Texas School of Public Health Cancer Education and Career Development Program- National Cancer Institute/NIH Grant R25 CA57712. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Cancer Institute or the National Institutes of Health.

Funding information: This research was supported by a Ruth L. Kirschstein National Research Service Award for Individual Pre-doctoral Training grant from the National Cancer Institute F31 CA174338 (A Farias, Principal Investigator).

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Table 1.

Summary of women's characteristics (n=19).

Characteristic	N (%)
Age	
<45	5 (26.3)
45–54	5 (26.3)
55–65	5 (26.3)
>65	4 (21.1)
Race/Ethnicity	
White	10 (52.6)
African American	6 (31.6)
Asian	2 (10.5)
Hispanic	1 (5.3)
Adjuvant Endocrine Therapy	
Aromatase Inhibitor	8 (4.2)
Tamoxifen	11 (5.8)
Marital Status	
Single	4 (21.1)
Married	10 (52.6)
Divorced	4 (21.1)
Widowed	1 (5.3)
Geographic Region	
Houston, TX	6 (31.6)
Los Angeles, CA	13 (68.4)
Educational Attainment	
High school or lower	1 (5.3)
Some college, technical school	5 (26.3)
Bachelor's degree	9 (50.0)
Master's degree	3 (15.8)
Doctorate degree	1 (5.3)

Table 2.

Themes and definitions pertaining to patient report of their social support during active adjuvant endocrine therapy.

Emergent themes	Definitions
1. Informational support	General statements that exemplify advice, guidance, suggestions or useful information from a medical provider, family member, friend, Internet or other cancer survivors
2. Emotional support	General statements that exemplify emotional support such as empathy, compassion, and genuine concern from others
3. Instrumental support/tangible aid	General statements that exemplify instrumental support, which involves the provision of tangible aid and services that directly assist a person in need
4. Appraisal support	General statements that exemplify appraisal support such as information that is useful for constructive feedback, affirmation and self-evaluation purposes

Table 3.

Types and delivery of social support regarding active adjuvant endocrine therapy.

Type of support	Sources of support	Example of support given
Informational support	MP	<ul style="list-style-type: none"> Information on AET benefits, guidelines for following treatment regimens, duration of treatment, AET side-effects, and the management of AET side-effects Information about resources including: reliable online sources, educational workshops and seminars, breast cancer newsletter, diet, acupuncture, exercise and general health practices
	OS	<ul style="list-style-type: none"> Resources including breast cancer blogs, medical journals, and WebMD articles about AET treatment
	SG	<ul style="list-style-type: none"> Information on the types of side-effects, coping mechanisms, and changes in treatment durations (5 years versus 10 years) from other survivors
	F	<ul style="list-style-type: none"> Information about benefits of AET from family members with a history of breast cancer
Emotional support	OS	<ul style="list-style-type: none"> Facebook and online support group chats Connecting with other survivors via online platforms
	R	<ul style="list-style-type: none"> Engaging in religious practices such as service attendance, praying and reading religious literature Praying partners Family and friends praying for their well-being Breast cancer support groups at church
	S	<ul style="list-style-type: none"> Participating in spiritual exercises such as yoga, meditation, and relaxation techniques
	SG	<ul style="list-style-type: none"> Sharing with members of support groups their experiences with new symptoms/side-effects
	MP	<ul style="list-style-type: none"> Encouraging women on how to think differently about AET to help them better adhere to their treatment
	F	<ul style="list-style-type: none"> Providing help in making decisions about treatment options and duration of treatment Accompanying women to medical and support services such as counseling, exercise classes and mammogram screenings
	SO	<ul style="list-style-type: none"> Helping in decision-making of AET initiation Showed empathy and understanding of the anxiety and frustration the patient feels
Instrumental/Tangible aid	MP	<ul style="list-style-type: none"> Providing medication for AET side-effects and referrals for cancer-related services such as genetic testing, mindfulness training, and wellness centers.
	FR	<ul style="list-style-type: none"> Offers financial support by purchasing necessities such as a refrigerator Invites for social and outdoor activities Assistance with medication schedule by setting cellphone reminders every night
	FA	<ul style="list-style-type: none"> Helping take care of children

Type of support	Sources of support	Example of support given
		<ul style="list-style-type: none"> Helping physically address the side-effects of the patient's treatment such as cutting her hair
	EO	<ul style="list-style-type: none"> Providing wellness services such as therapy, support group resources, acupuncture, and art classes Providing exercise classes such as Tai Chai, Qi gong, gym and yoga
Appraisal support	R	<ul style="list-style-type: none"> Instilling the importance of their faith and trust in God during treatment
	S	<ul style="list-style-type: none"> Providing positive energy and self-efficacy that they can overcome the disease Providing emotional and physical benefits

Abbreviations: MP, medical providers; OS, online support; SG, survivorship groups; FA, family; R, religion; S, spirituality; SO, significant other; FR, friends; EO, external organizations