ORIGINAL ARTICLE



Sociodemographic, clinical, psychosocial, and healthcare-related factors associated with beliefs about adjuvant endocrine therapy among breast cancer survivors

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Received: 24 September 2019 / Accepted: 11 December 2019 / Published online: 2 January 2020 © Springer-Verlag GmbH Germany, part of Springer Nature 2020

Abstract

Objective Adjuvant endocrine therapy (AET) reduces the risk of recurrence and mortality in women with hormone receptor– positive breast cancer. However, adherence to AET remains suboptimal. Women's beliefs about medication have been associated with medication adherence. The purpose of this study was to identify multilevel factors associated with women's beliefs about AET.

Methods Beliefs about AET, measured using the Belief about Medicines Questionnaire (BMQ), sociodemographic (e.g., age), psychosocial (e.g., religiosity), and healthcare factors (e.g., patient-provider communication), were collected via survey. Clinical data were abstracted from medical records. Two stepwise regression analyses models were performed to assess relationships between variables and necessity and concern beliefs.

Results In our sample of 572 women, mean BMQ concern score was 11.19 and mean necessity score was 13.85 (range 5–20). In the regression models, higher ratings of patient-provider communication were associated with lower concern and higher necessity beliefs. Higher concern beliefs were related to more AET-related symptoms (B = 0.08; 95% CI 0.06 to 0.10; p < 0.001), lower patient satisfaction (B = -0.07; 95% CI -0.09 to -0.04; p < 0.001), and higher religiosity (B = 0.05; 95% CI 0.01 to 0.08; p = 0.007). Higher necessity beliefs were associated with prior chemotherapy use (B = 0.11; 95% CI 0.06 to 0.16; p < 0.005) and less education (B = 1.00; 95% CI 0.27 to 1.73; p = 0.008).

Conclusions Modifiable factors are related to women's AET beliefs. Healthcare interactions may play a key role with regard to shaping women's beliefs about their AET medication.

Keywords Adjuvant endocrine therapy · Beliefs about Medicines · Breast cancer · Patient-provider communication

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Introduction

Breast cancer remains the most frequently diagnosed cancer in the United States [1]. Survival rates have improved over the years due to advances in screening, early detection, and treatment. Treatment modalities for breast cancer may include surgery, radiation therapy, chemotherapy, and, following primary treatment, adjuvant endocrine therapy (AET). AET, prescribed for women who are diagnosed with hormone receptor–positive breast cancer, has been shown to reduce the risk of recurrence and mortality by 40% and 31%, respectively [2, 3]. While this therapy results in favorable outcomes when taken for the full course of five or more years [4, 5], initiation and discontinuation rates remain less than satisfactory, with studies indicating that 17–25% of women do not initiate therapy following a provider recommendation [6, 7] and up to 50% discontinue AET by year five [8, 9]. Factors associated with non-initiation or premature discontinuation of AET vary from financial constraints, AET-related symptoms, sociodemographic characteristics, and ambivalence about AET [10–13].

Beliefs about medications play a role in medication adherence in several chronic illnesses. Medication adherence is the action of taking a medication as prescribed. Medication beliefs, i.e., one's thoughts about their medication, include necessity and concern beliefs. The former include the level to which one believes that there is a need to take the medication to improve their health, and the latter include feelings of worry or skepticism toward medications. While high necessity beliefs have been associated with better adherence, greater concern beliefs have been linked to lower adherence in several chronic conditions [14, 15]. Similar patterns have been observed for AET, wherein higher necessity beliefs have been associated with women's decisions to initiate and adhere to AET [16, 17]. Conversely, women with lower perceived necessity [18, 19] and greater concerns [20] were more likely to be non-adherent to AET. Understanding the role of women's beliefs becomes even more salient as many women are recommended for extended AET up to 10 years [21]. Prior studies emphasized the importance of women's necessity beliefs on the likelihood of pursuing extended therapy [16].

Previous research identified sociodemographic and clinical characteristics associated with women's necessity and concern beliefs about AET [22]. However, to our knowledge, no studies to date have sought to understand how psychosocial factors, including religiosity, distress, and gender discrimination, as well as healthcare factors, such as patient-provider communication, healthcare satisfaction, and trust in healthcare providers, impact women's beliefs about AET. These factors have been explored within the context of other chronic illnesses, with studies in the area of inflammatory bowel disease showing that disease beliefs served as mediators between satisfaction with provider communication and adherence, and studies in rheumatoid arthritis identifying unsatisfactory patientprovider communication as a negative influencer of necessity beliefs about medicines [23]. Within the context of AET, it is evident that more information is needed to understand drivers of beliefs toward AET. Therefore, the aim of this study was to identify sociodemographic, clinical, psychosocial, and healthcare-related factors associated with necessity and concern beliefs about AET among breast cancer survivors.

Methods

Study design

These analyses were part of a large longitudinal cohort study (n = 592) conducted between 2012 and 2017 that sought to understand factors related to women's AET adherence and discontinuation. The analysis presented in this paper is

cross-sectional. Women completed a survey either online or over the phone with trained clinical research assistants to collect sociodemographic and clinical characteristics, and psychosocial and healthcare-related factors. Medical records information was abstracted and pharmacy refill data were obtained to estimate adherence to AET. Women also had an opportunity to provide a biospecimen. Additional details, including sample size calculation, are provided elsewhere [24]. This secondary analysis study procedures were approved by the Georgetown University Institutional Review Board (IRB).

Subjects and setting

Women diagnosed with hormone receptor–positive nonmetastatic invasive breast cancer were recruited from three healthcare centers in Washington, D.C., Atlanta, GA, and Detroit, MI, following AET initiation. Eligible women were \geq 18 years of age and filled a prescription for AET. All participants provided informed consent prior to study initiation. For the purpose of this analysis, only Black/African American or White women were included (*n* = 572).

Data collection

Baseline and annual follow-up telephone or online surveys were conducted to collect information about women's medication beliefs, sociodemographic and clinical characteristics, psychosocial factors, and experience with the healthcare system. Telephone surveys were completed by trained clinical research assistants and participants were encouraged to complete the entire survey during one phone call. Surveys took approximately one hour to complete. Constructs were assessed using previously validated scales, as detailed below.

Medication beliefs We adapted the Beliefs about Medicines Questionnaire (BMQ) to measure women's beliefs about AET [25]. The BMQ consists of 10-items scored on a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree). Five items assess concerns with AET (e.g., "I sometimes worry about the long-term effects of my endocrine therapy medication") whereas the other five measure AET necessity beliefs (e.g., "My life would be very hard without my endocrine therapy medication"). Scores on each subscale range from 5 to 20, with higher scores indicating higher concern or necessity beliefs. The instrument presented strong internal consistency (Cronbach's alpha concern subscale = 0.75; Cronbach's alpha necessity subscale =0.84).

Sociodemographic and clinical characteristics Sociodemographic variables collected included age, race, education, marital status, and household income. Clinical variables included type of AET received (tamoxifen or aromatase inhibitor), tumor stage, surgery type (e.g., lumpectomy, mastectomy), prior chemotherapy or radiation treatment, and experience of side effects from AET assessed with the Functional Assessment of Cancer Therapy Endocrine Subscale (FACT-ES) [26]. The FACT-ES includes 24 items related to commonly reported AET symptoms (e.g., "I have hot flashes"), and responses are provided on a 5-point Likert scale. Scores range from 0 to 96, with higher scores indicating higher symptom burden. The scale has strong internal reliability (Cronbach's alpha = 0.79).

Psychosocial factors The Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer) is a 12-item 4point Likert scale (1 = strongly disagree, 4 = strongly agree) with strong reliability (Cronbach's alpha = 0.87) developed to assess individuals' beliefs that they can effectively communicate to gather information (e.g., "If I don't understand something, it is easy for me to ask for help") [27]. Scores range between 12 and 48 and higher scores indicate greater selfefficacy. The CASE-cancer scale is composed of three subscales with scores ranging from 4 to 20 for each - positive attitude (Cronbach's alpha = 0.85), obtaining information (Cronbach's alpha = 0.79), and understanding and participating in care (Cronbach's alpha = 0.72). Religiosity was assessed with a previously validated (Cronbach's alpha = 0.95) 9-item 5-point Likert scale (e.g., "I rely on God to keep me in good health"), where higher scores indicate higher religiosity [28]. The Bird and Bogart's discrimination scale was adapted to measure women's experiences with racial (Cronbach's alpha = 0.90) and gender discrimination (Cronbach's alpha = 0.86) in the medical system [29]. Women responded to seven yes/no questions for each of the two scales (e.g., "Have you ever been treated with less courtesy than other people because of your race", "Have you ever had a doctor or nurse not listen to what you were saying because of your gender"). Scores range from 0 to 7 with higher scores indicating stronger experiences with discrimination. Emotional (Cronbach's alpha = 0.94) and tangible support (Cronbach's alpha = 0.92) was measured using the Medical Outcome Survey; higher scores on each scale indicate more support [30]. Lastly, women's levels of distress in the past week (including the day of the survey) were assessed using the distress thermometer, a visual analogue scale where 0 denotes "no distress" and 10 "extreme distress" [31]. Scores were categorized as low (0-4), medium (5-7), and high (8-10) distress.

Healthcare factors Satisfaction with the medical care received was assessed with the patient satisfaction questionnaire (PSQ-18). The PSQ-18 is comprised of 18 items (e.g., "The medical care I have been receiving is just about perfect"), with responses provided on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree) [32]. Scores range between 18 and 90 where higher scores indicate greater satisfaction

(Cronbach's alpha = 0.88). Patient-clinician communication was assessed with Makoul's 8-item communication scale (e.g., "The doctor fully explained the benefits of endocrine therapy"), where higher scores indicate better communication (Cronbach's alpha = 0.80) [33]. The Primary Care Assessment Survey (PCAS) was used to measure women's trust in the clinicians who provided care during cancer diagnosis and treatment (Cronbach's alpha = 0.81) [34]. It consists of seven items (e.g., "I completely trust my doctor's judgment about my medical care") and responses are provided on a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree).Transformed scores range between 0 and 100 and higher scores indicate greater trust in the clinician. Medical mistrust was assessed with LaVeist's 7-item scale (e.g., "Mistakes are common in healthcare organizations"). Responses are provided on a 5-point Likert scale, with resulting scores ranging between 7 and 35 and higher scores denoting greater medical mistrust (Cronbach's alpha = 0.80) [35].

Data analyses

Analysis was performed with baseline data from the large longitudinal cohort study [24]. Descriptive statistics were calculated to summarize sociodemographic, clinical, psychosocial, and healthcare-related variables, with means and standard deviations (SD) presented for continuous variables and frequencies and percentages for categorical variables. Multivariable linear regression analyses were performed to examine the association between necessity/concern beliefs (dependent variables) and sociodemographic/clinical characteristics, psychosocial, and healthcare-related factors (independent variables). A stepwise selection method was applied to the linear regression models, while race and age were constrained. All tests were two-sided with a type I error α = 0.05. P values were obtained through F tests. Statistical analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, NC).

Results

Of the 572 women included in the analysis, most were over 50-years-old (76.9%), white (71.7%), had at least some college education (85.8%), were married (64.4%), and were taking an aromatase inhibitor (61.8%) (Table 1). Two thirds of women had prior radiation therapy, and slightly over half (60.5%) did not receive prior chemotherapy. Mean BMQ concern and necessity scores were 11.2 (SD = 2.9) and 13.8 (SD = 3.0), respectively. Women were relatively satisfied with their care (mean (SD) = 73.0 (9.3)) and over half (56.6%) reported low levels of distress (Table 2).

In the multivariable regression model, neither age nor race was a predictor of women's concern (p = 0.103 and p = 0.115,

	n (%) or n (mean ± SD)
Age	
> 50 years	440 (76.9)
\leq 50 years	132 (23.1)
Race	
Black	162 (28.3)
White	410 (71.7)
Education	
Less than college	80 (14.2)
College or above	485 (85.8)
Marital status	
Married	367 (64.4)
Single	203 (35.6)
Household income	
<usd100,000 td="" year<=""><td>268 (50.0)</td></usd100,000>	268 (50.0)
\geq USD100,000/year	269 (50.0)
AET therapy	
Aromatase inhibitor	352 (61.8)
Tamoxifen	216 (38.2)
Tumor stage	
Stage I	304 (61.0)
Stage II	152 (30.5)
Stage III	42 (8.5)
Surgery type	
Lumpectomy	238 (51.2)
Mastectomy	198 (42.6)
Both	25 (5.4)
No surgery	4 (0.8)
Chemotherapy	
Yes	212 (39.5)
No	325 (60.5)
Radiation therapy	
Yes	341 (67.1)
No	167 (32.9)
Distress level	
Low	321 (56.6)
Medium	169 (29.8)
High	77 (13.6)
Symptom burden (FACT-ES) (range = $0-92$)	$538(18.2 \pm 11.3)$
BMO concern score (range = $5-20$)	567 (11.2 ± 2.9)
BMO necessity score (range = $5-20$)	546 (13.8 ± 3.0)
Medical mistrust (range = $7-35$)	565 (20.4 ± 4.9)
Emotional support (range = $0-100$)	570 (82.5 ± 18.4)
Tangible support (range = $0-100$)	561 (80.4 ± 23.6)
Trust in provider (range = $0-100$)	$569(78.6 \pm 15.1)$
Communication (range = $8-48$)	572 (33.9 ± 4.9)
Patient satisfaction (PSO-18) (range = $18-90$)	543 (73.0±9.3)
Self-efficacy (total) (range = $12-48$)	572 (44.7 ± 4.0)
Understand and participation (range = $4-16$)	572 (15.1 ± 1.4)

Table 1Sociodemographic, clinical, psychosocial, and healthcare-related factors (N = 572)

 Table 1 (continued)

	n (%) or n (mean ± SD)
Positive attitude (range = $4-16$)	571 (14.4±2.0)
Obtaining information (range = $4-16$)	572 (15.2±1.4)
Religiosity (range = $9-36$)	571 (26.7±7.5)
Gender discrimination (range = $0-7$)	$536~(0.5 \pm 1.3)$
Racial discrimination (range = $0-7$)	566 (0.4±1.3)

SD, standard deviation

respectively) or necessity beliefs (p = 0.135 and p = 0.471, respectively). Greater concern beliefs were associated with household income higher than USD100,000 (B = 0.75; 95% CI 0.27 to 1.23; p = 0.002), more AET-related symptoms (B = 0.08; 95% CI 0.06 to 0.10; p < 0.001), poorer provider communication (B = -0.10; 95% CI -0.15 to -0.14; p = 0.001), lower patient satisfaction (B = -0.07; 95% CI -0.09 to -0.04; p < 0.001), and higher religiosity scores (B = 0.05; 95% CI 0.01 to 0.08; p = 0.007). Greater necessity beliefs were associated with having less than college education (B = 1.00; 95% CI 0.27 to 1.73; p = 0.008), prior chemotherapy use (B = 0.62; 95% CI 0.09 to 1.15; p = 0.023), and higher ratings of provider communication (B = 0.11; 95% CI 0.06 to 0.16; p < 0.005).

Discussion

To the best of our knowledge, this is the first study to identify psychosocial and healthcare-related factors associated with beliefs about AET, in addition to sociodemographic and clinical characteristics. In our sample, higher necessity beliefs were associated with less than college education, poorer provider communication, and prior chemotherapy use, and greater concern beliefs were found in women who experienced more AET-related symptoms, those with higher religiosity scores, and those who reported lower ratings of patientprovider communication and patient satisfaction. Participants reported moderate levels of concern and necessity beliefs, consistent with those of a similar study [22].

Patient-provider communication was simultaneously associated with women's concern and necessity beliefs, with good communication resulting in higher necessity and lower concern beliefs. Given the relationship between medication beliefs and adherence [16–19], it could be hypothesized that effective communication improves adherence to AET [36] via modification of beliefs, although further studies are required to test this hypothesis. Communication is critical for clinicians to elicit women's beliefs and preconceived notions about AET and tailor their approach to reinforcing adherence to AET to each individual patient. For example, if a patient voices concerns about the side effects associated with AET,

Tabl	e 2	Mu	ltipl	e regression	models	s of BMQ	concern	and BMQ) necessity
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	BMQ Conce	rn	BMQ Necessity		
	β (95% CI)	p-value	β (95% CI)	p-value	
Age (>50 vs. \leq 50)	0.46 (-0.09, 1.01)	0.103	0.47 (-0.15, 1.09)	0.135	
Race (black vs. white)	0.47 (-0.11, 1.04)	0.115	0.21 (-0.36, 0.78)	0.471	
Education (< college vs. \geq college)			1.00 (0.27, 1.73)	0.008*	
Household Income (≥USD100k vs. <usd100k)< th=""><th>0.75 (0.27, 1.23)</th><th>0.002*</th><th></th><th></th></usd100k)<>	0.75 (0.27, 1.23)	0.002*			
Chemotherapy (yes vs. no)			0.62 (0.09, 1.15)	0.023*	
FACT-ES total Score	0.08 (0.06, 0.10)	< 0.001**			
Provider Communication	-0.10 (-0.15, -0.14)	0.001*	0.11 (0.06, 0.16)	< 0.001**	
Patient Satisfaction (PSQ-18)	-0.07 (-0.09, -0.04)	< 0.001**			
Religiosity	0.05 (0.01, 0.08)	0.007*			

The *p* values were obtained through F tests. Gray-shaded fields indicate that a variable was only selected in one of the two models during the stepwise selection method (e.g., prior chemotherapy). " β " represents beta coefficient estimate

CI confidence interval

**p* < 0.01

***p* < 0.001

potentially compromising adherence, clinicians may offer opportunities for the patient to communicate with the team on a more frequent basis, rather than during office visits only. There may be opportunities to educate patients about selfadvocacy by asking their provider pertinent questions about their AET. Ideally, communication should occur on both sides of the patient-provider dyad. Patient education about AET may require a multidisciplinary approach by engaging all professionals (e.g., physicians, nurses, pharmacists) to address women's beliefs about AET.

Higher necessity beliefs were identified in women with lower educational attainment. Similar findings were noted in a study seeking to understand factors associated with beliefs of patients with human immunodeficiency virus (HIV) [37]. Less educated women may be more likely to listen to their providers while women with more education may question their doctors' assertions. Qualitative methods that explore how women of varying educational backgrounds interact with their providers may provide insight into this relationship.

Women who had prior chemotherapy reported significantly higher necessity beliefs than those who had not received chemotherapy. To our knowledge, this finding has not been reported in the literature. A potential explanation could be that women who had prior chemotherapy exhibit greater perceived severity of their disease than women who did not have prior chemotherapy. This heightened perceived severity may enhance their understanding of the need for recommended therapies. Additionally, as a result of receiving additional treatment, these women may have more interactions with providers who may, in turn, further explain the need for AET during discussions about chemotherapy. Experience of AET-related symptoms was associated with greater concerns with medication. Side-effect experience is one of the most frequently reported reasons for non-adherence to and discontinuation of AET [38]. However, studies show that, even when women experience symptoms, they have better adherence when there is a good patient-provider communication [36, 39].

Women who had household incomes of at least USD100,000 reported higher concern beliefs than women with lower household incomes. Although education did not show a relationship with concern beliefs, ad hoc analysis showed that a greater proportion of women with an income of at least USD100,000 had a college education or higher compared with those with an income of less than USD100,000 (95.1% vs. 78.1%, respectively; p < 0.0001). Thus, these women may be more prone to conducting more extensive research about cancer and treatments.

Higher concern beliefs were identified in women who reported lower patient satisfaction. The PSQ-18 assessed women's satisfaction with communication with their providers, but it also measures women's satisfaction with accessibility to healthcare, affordability, and the technical ability of their providers [32]. This suggests that the healthcare experience as a whole, not just the patient-provider interaction, may contribute to shaping beliefs about medication. Future work should explore the role of patient satisfaction as a mediator between beliefs about medicines and adherence.

A new contribution to the literature is the finding that women with higher religiosity scores hold higher concern beliefs. A number of studies have explored the relationship between religiosity and medication adherence, but results were mixed [40]. One study from the HIV literature found that individuals who were less likely to be adherent to their antiretroviral therapy reported high levels of religiosity. Individuals relied on scriptures, prophetic messages from spiritual leaders, and testimonies from others instead of their medication [41]. This finding may suggest the need to develop interventions to address concern beliefs by engaging religious leaders to integrate religion and medicine.

Study limitations

Although this study has notable strengths, such as demographic diversity of the sample and the inclusion of understudied factors (e.g., psychosocial and healthcare factors), there are limitations to note. All women in our sample were insured; therefore, findings are not generalizable to underinsured and uninsured women. Our sample was limited to women who initiated AET, so we cannot generalize findings to all women who are prescribed AET, particularly those who elect not to initiate therapy. The cross-sectional design of this study limited our ability to illustrate causation or to observe changes in women's beliefs over time.

Clinical implications

Providers play a critical role in shaping women's beliefs about their AET medicines. An ideal approach to understanding patient beliefs about their medicines should involve tailored or individualized communication that affords patients with an opportunity to discuss how they feel about their medicines and any associated symptoms [42]. Given the differences in beliefs among women with varying education levels and household income, providers may consider offering additional resources or materials to these women with the goal to foster more positive beliefs about AET, which may ultimately improve adherence.

Conclusion

Several sociodemographic and clinical characteristics, and healthcare and psychosocial factors were associated with women's necessity and concern beliefs about AET. Findings from this study offer educational and behavioral intervention targets for healthcare providers seeking to improve attitudes toward and adherence to AET. Future research should focus on exploring how healthcare factors, including patientprovider communication and patients' experiences with healthcare, impact perceptions and beliefs about medication and adherence to AET. Acknowledgements The authors would like to thank the women who participated in this study by sharing invaluable information. The authors would also like to thank Ms. Mishaal Khan for technical support.

Funding information This research was funded by the National Cancer Institute R01CA154848. It was also supported in part by the NIH-NCI Cancer Center Support Grant P30 CA016059 the CTSA Award No. UL1TR002649 from the National Center for Advancing Translational Sciences, NIH-NCI 2T32CA093423, and NCI Center to Reduce Cancer Health Disparities, Award No. P30CA177558-05S3. This project was also supported by Georgetown-Howard Universities Center for Clinical and Translational Science (GHUCCTS) by Federal Funds; the National Center for Advancing Translational Sciences (NCATS); and the National Institutes of Health (NIH), through the Clinical and Translational Science Awards Program (CTSA) (KL2TR001432).

Compliance with ethical standards

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

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