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Patient-Provider Communication and Hormonal Therapy Side Effects in Breast Cancer Survivors

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Abstract

Side effects from hormonal therapy (HT) for breast cancer treatment occur frequently and are associated with worse quality of life and HT non-adherence. Whether improved patient-physician communication is associated patients' reporting of side effects is unknown. We undertook this study to assess factors associated with women's reports of HT side effects. Between December 2012 and April 2013, we conducted a cross-sectional survey of breast cancer patients undergoing HT in an urban medical center. Descriptive statistics, univariate and multivariate analyses were used to evaluate associations. Of the 100 participants, 67% reported having HT side effects. However, when prompted, an additional 9% reported experiencing specific HT-related symptoms. Despite very high communication scores, one third of participants reported they had not discussed side effects with providers. Multivariate analysis showed that after controlling for age, education, race and medication beliefs, women who had difficulty asking providers for more information were more likely to report side effects (odds ratio 8.27, 95% confidence interval 1.01–69.88). Although HT side effects often occur and are bothersome, patient-provider discussions about side effects remain suboptimal. Providers should actively ask patients about medication side effects so that they can be addressed to improve quality of life and potentially, medication adherence.

Keywords

breast cancer; hormonal therapy; side effects; patient-provider communication

Introduction

In women with estrogen receptor-positive (ER+) breast cancer, adjuvant hormonal therapy (HT) with tamoxifen or an aromatase inhibitor has been shown to reduce breast cancer recurrence and mortality rates by 30% and is currently considered the standard of care

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(Network 2015) However, despite proven survival benefits, many studies have demonstrated that early discontinuation and/or non-adherence to HT often occur, often due to side effects or negative beliefs about medication (Osterberg and Blaschke 2005; Hershman, Kushi et al. 2010; Cluze, Rey et al. 2012). The ATAC Trialist Group showed that treatment-related adverse events occurred among 61% of patients on anastrazole and 68% of patients on tamoxifen (Howell, Cuzick et al. 2005; Buzdar, Howell et al. 2006). At the five-year follow up, HT withdrawals due to adverse effects occurred among 11% of patients treated with anastrazole and 14% of those treated with tamoxifen. Several other studies also demonstrated that patients who experienced side effects were more likely to stop taking HT (Buzdar, Howell et al. 2006; Lash, Fox et al. 2006; Cella and Fallowfield 2008).

In addition to adherence, side effects can significantly affect patients' quality of life (QoL) (Whelan, Goss et al. 2005; Cella, Fallowfield et al. 2006). Some studies have investigated the QoL of women participating in the ATAC study by using the Functional Assessment of Cancer Therapy-Breast (FACT-B) questionnaire plus an additional endocrine symptoms subscale at the 2-year and 5-year treatment period of treatment. They assessed physical, social, emotional and functional well-being in women taking HT and found significant decreases in physical and functional well-being in the first three months on therapy. These QoL measures steadily improved throughout the treatment period, but did not return to baseline levels. In addition, most patients experienced a worsening of endocrine-related symptoms at the 3-month assessment that did not improve.

Physician communication and shared decision-making have been positively related to breast cancer patient outcomes, decreased psychological distress and depression, and improved quality of life (Morris and Royle 1988; Street and Voigt 1997; Vogel, Leonhart et al. 2009; Budden, Hayes et al. 2014). Successful information exchange allows patient concerns to be elicited and ensures that explanations about treatment options are understood. This collaborative provider communication model lays a foundation for shared decision-making and has been associated with increased adherence to provider recommendations including prescribed medications for chronic diseases (Schneider, Kaplan et al. 2004; Schoenthaler, Chaplin et al. 2009; Stavropoulou 2011). In particular, because medication concerns have been shown to be associated with HT medication adherence (Pellegrini, Sarradon-Eck et al. 2010; Wells, Pan et al. 2016), physician communication about medication concerns (including side effects) is likely to be important for improving medication adherence. However, little literature has addressed whether improved communication affects patients' reporting of side effects, a pre-requisite to addressing them.

In this study, we conducted a survey of women with ER+ breast cancer who were prescribed HT to assess factors associated with reports of side effects.

Methods

Study Location and Participants

Women with ER+ breast cancer receiving HT were recruited between December 2012 and April 2013 from an outpatient breast center practice at Mount Sinai Hospital, a tertiary-care facility in New York City. Potential participants were identified via review of appointment

logs of medical oncologists and breast surgeons at this practice. Eligibility for the study was confined to patients who were English- or Spanish-speaking, ≥18 years, diagnosed with ER+ breast cancer, and were taking HT. Patients were excluded if they were on HT for other medical reasons, if they did not have the capacity to consent, or if their physician did not authorize participation.

Women were approached at the time of their outpatient appointment and invited to participate in a survey. In total, we screened over 300 women for eligibility between December 2012 and April 2013; of these, most were not eligible because they did not have ER+ breast cancer or were no longer/not currently prescribed HT. A few patients were not eligible due to language issues. Of those remaining, 112 eligible women invited to participate in the survey. Twelve women (10.7%) refused to participate; the remaining 100 were enrolled in the study. While the sample size was determined based on feasibility issues given the scope and budget for the project, we had calculated that this sample size would have 80% power with a two-sided alpha=0.05 to detect a 25% difference in report of HT side effects between women who were adherent vs. non-adherent to HT. Signed written informed consent was obtained, and patients underwent a standardized, face-to-face interview administered by trained research staff. The study protocol was approved by the Institutional Review Board of the Mount Sinai Medical Center.

Measures

Sociodemographic data, including age, race, ethnicity, educational achievement, marital status, and household income were collected by self-report. We also asked about level of social support and participants' reason for taking HT (to prevent cancer from coming back, to treat breast cancer, both or neither). To evaluate the presence of side effects from hormonal therapy, we first asked participants if they were currently having any side effects from HT. Then, we questioned them about specific HT side effects based on the FACT-B endocrine subscale (Fallowfield, Leaity et al. 1999), including hot flashes, sweats, weight gain, nausea, low energy, fluid retention, irritability, decreased sexual interest, vaginal dryness, vaginal bleeding, vaginal discharge, skin rash, bone pain, joint pain or muscle pain (Vogel, Costantino et al. 2006; Amir, Seruga et al. 2011). Participants rated severity of side effects on a 4-point Likert scale: "not at all bothersome," "a little bothersome," "somewhat bothersome," or "extremely bothersome." Severity of side effects was summed for the total number of side effects experienced to create an overall side effect severity score with higher scores indicating great bothersome-ness of side effects. If the participant reported having HT-related side effects or any of these symptoms, we then asked if she had discussed these problems with any medical provider.

Participants rated patient-physician communication with their primary oncologist using the Patient Reactions Assessment (PRA) tool, which has three sub-scales including a Patient Information Index (PII), measuring quality of information provided by the physician; a Patient Affective Index (PAI), measuring affective behaviors of health care providers; and a Patient Communication Index (PCI), measuring patient's perceived ability to initiate communication with their providers. The PRA possesses high internal consistency and is a valid measurement of patient-perceived quality of the patient-provider relationship.

Cronbach alpha coefficients for the PII, PAI and PCI subscales are 0.85, 0.85, and 0.82, respectively (Galassi 1992). PRA items are scored on a 4-point Likert scale from “strongly agree” to “strongly disagree,” with higher scores (range 0 to 45) indicating more positive physician communicative behaviors. This tool has been used to evaluate patient-provider communication in chronic diseases including cancer, diabetes and HIV (Ciechanowski, Katon et al. 2001; Arora 2003; Marelich and Murphy 2003).

Self-reported medication adherence was assessed with the 4-item Morisky medication adherence scale. The four items are: “Do you ever forget to take your hormone medication?” “Are you careless at times about taking your hormone medication?” “When you feel better do you sometimes stop taking your hormone medication?” and “Sometimes if you feel worse when you take your hormone medicine, do you stop taking it?” The scale has been validated against a clinical measure of blood pressure control in patients with hypertension and has been also used in studies of patients with hypertension and diabetes (Morisky, Green et al. 1986; Morisky, Ang et al. 2008). The scale is composed of four yes/no questions about past patterns of medication use. Medication non-adherence was defined as a positive answer to ≥2 questions on the Morisky scale (Morisky, Green et al. 1986).

We used the Beliefs about Medicines Questionnaire (BMQ) to evaluate participants’ medication beliefs. The BMQ consists of two 5-item sub-scales assessing necessity and concerns about medications (Horne, Weinman et al. 1999). The necessity scale includes items such as “My health, at present, depends on my hormonal treatment” or “My life would be impossible without my hormonal treatment,” and the concern scale items include “Having to take my hormonal treatment worries me” or “My hormonal treatment disrupts my life.” BMQ responses were coded on a 5-point Likert scale from “strongly agree” to “neutral” to “strongly disagree,” with total scores for the necessity and concern scales ranging from 0 to 20 (higher scores indicate increased necessity or concerns beliefs). The BMQ has been associated with medication adherence across a range of illnesses, including breast cancer, hypertension, and rheumatoid arthritis (Ross, Walker et al. 2004; Grunfeld, Hunter et al. 2005; Neame and Hammond 2005).

Statistical analyses

We used descriptive statistics to assess overall rates of HT side effects, HT adherence, discussion of side effects with providers and illustrate the distribution of communication scores and medication beliefs. Bivariate analysis using the chi-square test was used to examine associations between medication adherence and HT side effects. We used Wilcoxon rank-sum test to compare report of HT side effects and provider communication because the distribution of the communication subscale values (PRA scores) was not normally distributed.

To control for confounding variables that might affect the association between report of HT side effects and physician communication, we adjusted for age, race (White vs. Non-White), education (greater than high school vs. high school or less) and medication beliefs (BMQ necessity scores and BMQ concerns scores) in the multivariate logistic regression analysis, based on prior literature showing associations between age, race, education and physician communication (Roter 2000; Williams, Davis et al. 2002; Cooper, Roter et al. 2003) and the

association between side effect attribution and beliefs about medications (Heller, Chapman et al. 2015). The parameters in the model were estimated using maximum likelihood estimation, and we used the Likelihood Ratio Test assess overall significance of the model. The goodness of fit was assessed through R^2 statistics. We did not examine interactions between confounding variables because none of the other variables included in the model were significantly associated with report of HT side effects. In post-hoc exploratory analyses, we evaluated whether individual PRA items were associated with report of HT side effects. All analyses were conducted using SAS 9.2 (Cary, NC) using two-tailed p-values.

Results

The mean age of participants was 59 years (range 30–83 years (Table 1). Sixty-eight percent of the participants were white, 12% were black and 17% Hispanic. Most had commercial insurance (61%), and 75% had a college or greater level of educational attainment. Sixty-nine women (69%) were taking an aromatase inhibitor, and 31% were taking tamoxifen.

Sixty-seven (67%) patients initially reported having side effects due to HT. However, when participants were asked specifically about presence or absence of specific HT-related symptoms, an additional 9 patients (or 76 patients total) reported experiencing at least one side effect. The most frequently reported HT side effects included: hot flashes (50%), sweats (40%), joint pain (33%), weight gain (25%), decreased libido (24%), and decreased energy (23%). Thirty-eight patients (38%) reported having two or more side effects when asked about specific HT-related side effects. A total of 52 patients (52%) reported being “somewhat to extremely” bothered by their side effects. Of the initial 67 participants who reported side effects from HT, only 43 (64%) reported that they had discussed side effects with a healthcare provider. Of those who did discuss side effects with a medical provider, 87% reported that they initiated the conversation, with only 13% reporting that their medical provider introduced the topic. Reports of side effects were not associated with age, education, race/ethnicity, level of social support, overall severity of side effects, or reasons for taking HT ($p>0.05$ for all comparisons, Table 2).

The mean for the BMQ necessity and concerns scores were 10.8 and 8.0, respectively. Overall, participants felt that HT was important, although worries were expressed about HT or its long-term effects. BMQ necessity; concern scores were not associated with report of HT-related side effects ($p>0.05$ for all comparisons).

Overall, physician communication scores were very high. The median for the total PRA score was 41.0 (maximum score 45), and the medians for the PRA subscales were: PCI 12.5, PAI 15.0, and PII 15.0 (maximum score 15 for each subscale). The distribution curve for each subscale was very right-skewed, indicating that most participants felt their providers provided excellent communication. Neither the total PRA score nor the individual subscale scores were associated with reporting side effects ($p >0.05$ for all comparisons). However, those who agreed with the statement “If I don’t understand something the medical provider says, I have difficulty asking for more information” had a higher likelihood of having HT side effects (93% vs. 64%, $p=0.03$). Multivariate analysis controlling for age, education, race and medication beliefs revealed that participants who reported difficulty asking providers for

more information were more likely to report having HT side effects (odds ratio 8.27, confidence interval 1.01–69.88, Table 3). None of the other covariates were significantly associated with having HT-related side effects.

Lastly, a total of 77 (77%) women were considered to be adherent with their HT regimen by the Morisky scale; 88% reported that they had taken HT every day over the past 7 days. The median duration of HT therapy for the entire cohort was 24 months. HT adherence varied with duration of HT treatment: among those who were on HT for ≤12 months, 76% were adherent compared with 83% for those on HT for 12 to 36 months and 68% for women on HT for >36 months, but these differences in adherence were not statistically significant (p=0.35). HT adherence was also not associated with report of side effects, BMQ scores or PRA scores (p>0.05 for all comparisons). Furthermore, neither report of HT-related side effects, BMQ scores or PRA scores were associated with HT adherence over the past week.

Discussion

Effective patient-provider communication is a modifiable factor that may help improve patient's self-management behaviors for chronic illnesses. Early discontinuation and non-adherence to HT occur frequently among ER+ breast cancer patients, often at the cost of increased risk of recurrent and mortality. Similar to other studies, we found that the majority (68%) of our participants reported having side effects due to HT. Yet, over one-third of these women did not discuss their symptoms with a health care provider, despite high physician communication scores. Moreover, most discussions about side effects (87%) were initiated by patients, despite reported difficulty with asking providers for more information. Thus, patient-provider communication about medication treatment side effects remains suboptimal.

With improved screening, diagnosis, and treatment options for breast cancer, overall prognosis for most patients is excellent, and quality of life has become an important patient-centered outcome. In the MA.17 randomized trial of letrozole vs. placebo after tamoxifen, Whelan et al. found a small but statistically significant impairment in physical function, body pain, sexual function and stamina dimensions among patients taking HT vs. placebo (Whelan, Goss et al. 2005). Several other studies have confirmed impairment in quality of life domains in patients undergoing adjuvant HT and demonstrated that the adverse effects of HT may reduce patients' adherence with cancer treatment recommendations (Sloan, Cella et al. 2002; Biglia, Moggio et al. 2010; Lemieux, Goodwin et al. 2011). If providers fail to ask about and address HT side effects, patients' side effects will be underestimated, and patients may suffer from worse QoL and a higher risk of HT nonadherence.

It is important to note that almost 10% of our participants did not report having HT side effects, until prompted about specific symptoms known to be associated with HT. Patients who reported difficulty asking for clarification about medical care and treatment had a higher likelihood of having side effects. Patients may not ask questions for a variety of reasons, including not wanting to appear ignorant, lack of knowledge about their illness and not knowing which questions to ask, or their belief in the provider as an expert authority (Roter 1977). Similarly, patients may be reluctant to bring up side effects for fear that

providers will prescribe more medications to treat side effects, switch them to a different HT regimen that they will tolerate less well, or perhaps even stop HT altogether. Investigators have used question prompt lists in cancer consultations to encourage question-asking behaviors and to improve patient-physician communication (Butow, Dunn et al. 1994; Brown, Butow et al. 2001; Dimoska, Butow et al. 2012). However, these lists are often used for initial consultations and do not specifically address methods to bring up side effects during cancer treatment. Thus, additional research is needed to develop tools or processes to improve patient-provider communication about HT side effects throughout the course of HT treatment.

As cancer discussions shift away from a paternalistic model to a more shared decision-making and relationship-centered model of communication, it is important to create an open environment for patients to express doubt and confusion and to ask questions comfortably. Providers frequently fail to ask breast cancer patients about potential side effects of HT, possibly due to time constraints during an office visit or because providers may assume that patients who have been on HT for a few years are tolerating the medication well. Perhaps providers have already discussed side effects in previous visits and so do not feel a need to revisit this issue or may have independently acknowledged a “symptoms check-list” filled out by the patient prior to the encounter without discussing it with the patient. Failure to ask specifically about side effects represents a missed opportunity for providers to address patient concerns and to help women better understand and tolerate their treatment.

While we did not observe a relationship between side effects and HT adherence, we noted a trend toward decreased adherence over time. It is unclear if greater side effect burden over time affects HT adherence. Certainly, other studies have shown that women who report severe side effects, including depression, nausea, vision problems, and vaginal bleeding are less likely to be adherent (Demissie, Silliman et al. 2001; Lash, Fox et al. 2006). Thus, addressing side effects may also improve medication adherence in the long-term.

This study had several limitations. First, participants were recruited from a single urban teaching hospital; so, the results may not be generalizable to other populations or settings. Second, as the sample size was modest, we may not have had adequate statistical power to detect an association between reporting of side effects with communication scores, medication beliefs or HT adherence, if these associations were weak. Additionally, medication adherence was assessed through self-report, which may have resulted in an overestimation due to reporting bias. However, we used a well-validated instrument to measure adherence, although this scale predominantly measures trait adherence, rather than current adherence. Moreover, we found no association between current adherence and report of side effects. Further, this was a cross-sectional study; thus, we were unable to assess the effect of side effect burden on quality of life, perceived disability or HT adherence over time. In addition, social support was assessed with a single item question, rather than a standard instrument, so we may not be able to compare directly the results concerning social support with other studies which have used standard instruments. Lastly, the assessment of patient-provider communication relied on participants’ self-reported perception of the interaction and recollection of whether they had discussed side effects with their provider rather than objective assessment of the communication through recorded patient-physician

interviews. The responses may also have reflected social desirability among patients who favorably rated physicians they liked. Yet, patients' perception of the how their providers communicate may often affect their medical decision-making and self-management behaviors (Epstein 2006; Schoenthaler, Chaplin et al. 2009).

In summary, we found that most breast cancer patients in our sample who were on HT experienced side effects, and despite reporting excellent communication with their providers, many still did not discuss medication side effects, even though they were quite bothered by them. We did not find report of side effects to be associated with HT adherence, medication beliefs or communication scores. To provide the best care to breast cancer patients and promote adherence to provider recommendations, health care professionals should actively ask patients specifically about medication side effects on a regular basis and encourage patients to speak freely about their treatment concerns and questions. Further research should evaluate specific barriers preventing breast cancer patients from fully discussing medication concerns with their providers and to evaluate the role of side effect burden on HT adherence over time.

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TABLE 1.

Characteristics of study participants

Characteristic	Number (%)
Mean Age, years (range)s	59 (30-83)
Race/Ethnicity	
White	68 (68%)
Black	12 (12%)
Hispanic	17 (17%)
Other	3 (3%)
Insurance	
Commercial	61 (61%)
Any Medicare	25 (25%)
Any Medicaid	14 (14%)
Education	
Less than high school	9 (9%)
High school or GED	16 (16%)
College	22 (22%)
Graduate Degree	53 (53%)
Type of Hormonal Therapy	
Selective ER modulator	31 (31%)
Aromatase inhibitor	69 (69%)
Primary Language	
English	73 (73%)
Spanish	18 (18%)
Other	9 (9%)
Place of birth	
United States	65 (65%)
Other country	35 (35%)
Marital Status	
Married	63 (63%)
Divorced	7 (7%)
Separated	1 (1%)
Widowed	11 (11%)
Single (never married)	18 (18%)
Health Status	
Excellent	39 (39%)
Very Good	33 (33%)
Good	27 (27%)
Fair	1 (1%)
Underwent surgery	96 (96%)
Received radiation	74 (74%)
Received chemotherapy	59 (59%)

Characteristic	Number (%)
Taking medications for side effects	21 (22%)

ER=estrogen receptor, GED=graduate education degree

TABLE 2.

Participant Characteristics by Report of HT Side Effects

	Reported side effects (N=67)	No side effects reported (N=31)	*P*-value
Age, years, mean (SD)	58 (10.2)	60 (12.1)	0.31
Race			0.06
Non-white	26 (81%)	6 (19%)	
White	41 (62%)	25 (38%)	
Education			0.96
High school or below	17 (25%)	8 (25%)	
College or above	50 (75%)	23 (75%)	
Social Support			0.54
A Lot	59 (88%)	26 (84%)	
Somewhat or less	8 (12%)	5 (16%)	
Median HT duration (months)	20	36	0.58
HT duration			0.20
≤12 months	30 (45%)	8 (26%)	
12-36 months	22 (33%)	13 (42%)	
> 36 months	15 (22%)	10 (32%)	
HT necessity score, mean (range)	10.8 (0-20)	10.9 (4-16)	0.91
HT concern score, mean (range)	8.0 (0-16)	6.8 (0-12)	0.12
HT purpose			0.90
Prevent	27 (42%)	13 (42%)	
Treat	10 (15%)	4 (13%)	
Prevent and Treat	25 (39%)	11 (36%)	
Neither	2 (2%)	2 (3%)	
HT adherence	50 (75%)	25 (81%)	0.51
Reported discussion of side effects with a provider	43 (88%)	6 (12%)	0.03
Patient-Provider Communication			
Total score, mean (range)	39.7 (24-45)	40.1 (34-45)	0.73
Information subscale, mean (range)	13.2 (5-15)	13.2 (3-15)	0.94
Affective subscale, mean (range)	14.1 (7-15)	14.1 (9-15)	0.95
Communication subscale, mean (range)	12.0 (3-15)	12.8 (7-15)	0.25

HT=hormonal therapy

TABLE 3.

Results of Multivariable Analyses of Factors Associated with Report of HT-Related Side Effects

Variable	Estimate	Odds Ratio	95% CI
Age	−0.006	0.99	0.95-1.04
HS Education	0.937	2.55	0.58-11.25
Race*			
Black	1.677	5.35	0.89-32.04
Hispanic	1.253	3.50	0.62-19.89
Medication Beliefs			
HT necessity	0.035	1.04	0.90-1.19
HT concern	0.126	1.13	0.99-1.31
Difficulty asking provider for information	2.189	8.92	1.08-73.5

*compared to White race; HS: high school; CI: confidence interval