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Understanding Breast Cancer Survivors' Beliefs and Concerns about Adjuvant Hormonal Therapy: Promoting Adherence

Alejandra Hurtado-de-Mendoza, Ph.D.¹, Roxanne E. Jensen, Ph.D.², Yvonne Jennings, BA¹, and Vanessa B. Sheppard, Ph.D.¹

¹Breast Cancer Program, Lombardi Comprehensive Cancer Center, Department of Oncology, 3300 Whitehaven St., NW Suite 4100 Washington, DC 20007

²Cancer Prevention and Control Program, Lombardi Comprehensive Cancer Center, Department of Oncology, 3300 Whitehaven St., NW Suite 4100 Washington, DC 20007

Abstract

Purpose—Adjuvant hormonal therapy is recommended for women with hormone receptor positive (HR) breast cancer. Though critical, many patients are non-adherent to this therapy. Few scales have been developed to specifically address beliefs about adjuvant hormonal therapy. This study explores the clarity and relevance of the Beliefs about Medicine Questionnaire (BMQ) in the context of adherence behaviors to hormonal therapy in Black and White breast cancer survivors

Methods—We recruited women diagnosed with HR positive cancer from the Washington, DC area. An interviewer administered a standardized survey and conducted a cognitive interview. Participants rated the BMQ across three areas: relevance, difficulty, and clarity. We coded whether the comments identified item level-issues: limited applicability, unclear reference, unclear perspective, or wording or tone. In-depth interviews were conducted with women who prematurely discontinued hormone therapy.

Results—The sample (n=30) was equally split between Black and White survivors. On average, women were 57.9 years old (SD = 9.0). Overall 77% rated scale as relevant. Cognitive interviews revealed areas of perceived limited acceptability such as the notion of becoming too dependent or the notion of becoming worse if not taking the medication. Women who discontinued hormonal therapy (n=2) felt ambivalent towards hormonal therapy as they reported having both positive and negative beliefs about the medication.

Conclusions—Our study findings suggest new areas for further research and instrument development to accurately measure self-reported beliefs about hormonal therapy by HR positive breast cancer survivors.

Corresponding Author: Dr. Alejandra Hurtado de Mendoza, 3300 Whitehaven St. NW, Suite 4100, Washington, DC 20007, Phone: 202-687-8916, Fax: 202-687-0305, ahd28@georgetown.edu.

Conflict of Interest

The authors declare that they do not have conflicts of interest and they do not have a financial relationship with the organization that sponsored the research. The authors have full control of all primary data and they agree to allow the journal to review their data if requested.

Keywords

breast cancer; cognitive interviews; survivors; medication beliefs

Introduction

Hormonal therapy has contributed to significant reductions in recurrence and mortality in breast cancer for women with hormone receptor (HR) positive breast cancer [1, 2]. However, studies show 30–50% of survivors fail to adhere to the treatment [2, 3]. Patients' beliefs about medications are important predictors of medication adherence [4]. Identifying medication beliefs measures that are relevant to adjuvant hormonal therapy is important since the characteristics of hormonal medication can differ from other medications. For instance, adjuvant hormonal therapy is taken when the signs of disease are no longer present but when side effects often persist. Additionally, the benefits of medication impact a future outcome: potential cancer recurrence.

Currently, there are no gold standard measures for assessing patients' beliefs about adjuvant hormonal therapy. Some authors have used Sillimans' scale [5] to assess the survivor's risk/benefit perceptions when deciding to take hormonal therapy [6, 7]. To assess current beliefs about hormonal therapy researchers have either developed items [8] or used validated scales such as the Beliefs about Medicine Questionnaire (BMQ) [9] in predominantly White samples. The BMQ is a well-validated measure developed with a sample of chronically ill patients, predominantly patients with diabetes, mental health problems, and cardiac problems, and a smaller sample of cancer patients [4]. Grunfeld and colleagues [9] used the BMQ with a sample of breast cancer patients and found an association between the BMQ necessity subscale and hormonal therapy adherence. The study also included open-ended questions that queried for the perceived benefits of taking hormonal therapy. Interestingly, the beliefs that were most commonly reported (e.g. hormonal therapy will stop me from getting cancer, hormonal therapy will decrease the risk of developing breast cancer) are not captured by the BMQ items. Thus, it is important to examine breast cancer survivors' perceptions on the applicability of BMQ to hormonal medication. This study aims to explore the clarity and relevance of the BMQ in the relation to hormonal therapy in a racially diverse sample of Black and White breast cancer survivors. Findings from this study can provide insights for developing new measures to capture breast cancer survivors' specific beliefs about hormonal therapy.

Methods

Setting and Sample

Participants were recruited via oncology clinics and community outreach in Washington DC. Women were eligible if they had an HR positive breast cancer diagnosis and had completed primary therapy, had been prescribed hormonal therapy, self-identified as Black or White, were ≥ 21 years old, and spoke English. Not having the cognitive ability to provide consent was an exclusion criterion. Identified participants were first contacted by phone to confirm eligibility, obtain consent, and schedule a time for the interview. The interviews were

completed on a second call. In-depth interviews were conducted with two women who reported discontinuing hormonal treatment prematurely. Participants received a \$15 gift card by mail. Study procedures were approved by Georgetown University Institutional Review Board.

Measures

Demographic information

Demographic factors included age, income, marital status, education, and race.

Beliefs about Medicine

The BMQ assesses general and specific beliefs about medicine using a cost-benefit framework in which beliefs about the necessity of taking the medication are weighted against the concerns. We used the ten-item subscale from the BMQ (*BMQ-specific*) that captures beliefs about a specific prescribed medication that can be adapted to any medication [4]. The BMQ includes two 5-item subscales on a 5-point Likert response option (ranging from strongly agree to strongly disagree): perceived necessity of medication and perceived concerns of taking the medication.

Scale Clarity and Relevance

We used cognitive interviews [10–12] to query whether participants thought the scale was (1) relevant, (2) difficult to answer, (3) and clear (yes vs. no) and to comment on items if they found them to be problematic. We calculated the frequency for the binary responses for relevance, difficulty, and clarity for the scale (yes vs. no). We used the problem types classification suggested by Knafl [13] to categorize the open-ended responses that pertained to the scale or to specific items as: Limited Applicability: comments that suggest that the item is not applicable to certain situations. Unclear Reference: lack of clarity regarding the aspects that items address. Unclear Perspective: lack of clarity in the perspective from which an item should be answered. Wording or Tone: words perceived to be confusing, offensive, or that prime a negative tone. Open-ended questions were included to understand adherence challenges for women who spontaneously reported discontinuing therapy. Responses were coded to capture the experiences taking medication and reasons for discontinuation.

Analysis

Descriptive statistics were computed for the demographic characteristics. We calculated the frequencies of the BMQ binary responses (whether the scale was considered to be relevant, difficult, and clear; yes vs. no) and conducted a content analysis of open-ended responses and in-depth interviews using Knafl and colleagues' problem types classification.

Results

Sample Characteristics and BMQ Reliability

On average, women were 57.9 years old ($SD = 9.0$). Around half (43.3%) had an annual household income \$60,000, and 60% had completed a college degree or more. Half self-

identified as Black and half as Whites. Two women self-identified as Latina (one Black and one White). Black women were significantly less likely to be married (see Table 1).

Clarity and Relevance

Most participants perceived the BMQ to be relevant (77%), not difficult to answer (83.3%), and clear (100%). There were no significant differences by race. However, some participants felt that some items were not applicable for hormonal therapy medication: *“some questions are confusing. Seem more appropriate for allergy type meds,” “seems like these may be for a different med like blood pressure.”* Other items raised issues about unclear reference. The meaning of the word “mystery” was unclear as well as the notion of “becoming worse.” Other comments suggested a problem of unclear perspective. For instance, questions related to the future or to hypothetical situations were harder to answer and they felt their answers were speculative. In relation to wording and tone, the notion of *“becoming worse”* was challenged by some participants since they did not feel they were currently sick (see Table 2).

Two of the White survivors spontaneously reported that they had discontinued their medication, for eight months and three months respectively, but both were open to reconsidering that decision. When probed regarding their reasons for early discontinuation, both pointed to the side effects and impact on quality of life as main reasons for stopping treatment. They expressed ambivalence in knowing that the hormonal therapy could increase survival but also having trouble dealing with the side effects and how they impacted their everyday life.

Discussion

To our knowledge, this was the first descriptive study to examine the clarity and relevance of BMQ in the context of hormonal therapy adherence in breast cancer survivors. Participants noted some instances of perceived limited applicability (e.g. seemed to be developed for other medications), unclear reference (medicines protective from becoming worse), unclear perspective (uncertainty about hypothetical and future-oriented questions), and wording/tone (the word “worse” assuming they were currently sick) that deserve further exploration.

Prior studies have found that high scores on BMQ necessity are associated with medication adherence while high scores on concerns are related to non-adherence [4]. Likewise, the BMQ necessity-concerns differential (i.e. positive score-benefits outweigh costs and vice versa) has also been associated with adherence [4]. However, this scoring may fail to identify a subset of patients like the participants who discontinued in our study who understood the necessity of taking hormonal therapy but also raised several concerns at the same time. The ambivalent perception of hormonal treatment has also been described [14] in a qualitative study with breast cancer survivors. Identifying patients who score high on both necessities and concerns (ambivalent patients) would be important, since the association between beliefs and intentions/behavior is weaker in individuals who are ambivalent [15] and there are unique intervention strategies (e.g. motivational interviewing) that may be more effective to enhance adherence for this subgroup. Thus, designing surveys that capture relevant beliefs (uncertainty about recurrence) and ambivalent attitudes is warranted.

The study had certain limitations. The sample was a small convenience sample of women with a high level of education, so the generalizability of the results is limited. Two participants spontaneously reported that they had discontinued treatment, but we did not explicitly ask about discontinuation. Thus, we cannot know how many women had actually stopped taking the medication. We did not find race differences, but future larger studies should examine whether race and other socio-demographic factors impact the perceptions of relevance and clarity of the BMQ. Future studies should also explore further survivor's experiences taking hormonal therapy to develop specific measures to assess beliefs about hormonal therapy in HR positive breast cancer survivors.

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Table 1

Sample Demographic Characteristics, N=30

	Black (n=15)	White (n=15)	<i>p</i>
Age (range) Mean (sd)	58.3(9.8)	57.3(8.4)	.78
Education <i>n</i>(%)			
High school	3 (21.4)	1 (6.7)	
Some college	5 (35.7)	2 (13.3)	.11
College degree or more	6 (42.9)	12 (80)	
Marital Status <i>n</i>(%)			
Married/Living with partner	5(33.3)	10 (71.4)	.04
Divorced/widowed/single	10(66.7)	4 (28.6)	
Household Income <i>n</i>(%)			
<60,000	6 (46.2)	7 (53.8)	.69
60,000	7 (53.8)	6 (46.2)	
Employment Status <i>n</i>(%)			
Full-time	7(53.8)	4(28.6)	.18
Part-time/retired	6 (46.2)	10 (71.4)	

Table 2

Problem Types and Quotes in BMQ Items

BMQ-Items	Problem Types	Quotes
Perceived Necessity Subscale		
My current health depends on hormonal therapy medications	Limited applicability	<i>"it is more long term"</i>
My life would be very hard without hormonal therapy medication	Unclear perspective	<i>"very speculative"</i>
Without hormonal therapy medications, I would become very ill	Unclear reference	<i>"some people get extremely ill, define extremely ill"</i>
My health in the future will depend on hormonal therapy medications	Unclear perspective	<i>"I had to really give them some thought. I was not sure about future questions, can only go on the now"</i>
Hormonal therapy medications will protect me from becoming worse	Unclear reference Wording or tone	<i>"what is worse?" "the meaning of becoming worse is not clear, worse than now, worse than when I had the treatment?" "becoming worse could be better" "don't like the becoming worse, it assumes you are currently sick," "I don't have strong feeling about my meds, I feel that the cancer is gone, the meds help ensure that the cancer won't come back."</i>
Perceived Concerns Subscale		
Having to take hormonal therapy medications worries me	None	
I sometimes worry about the long-term effects of hormonal therapy medications	None	
Hormonal therapy medications are a mystery to me	Unclear reference	<i>"mystery, what does that mean?", "the word mystery threw me. Should be more specific"</i>
Hormonal therapy medications disrupt my life	None	
I sometimes worry about becoming too dependent on hormonal therapy medications	Limited applicability	<i>"wording did not pertain to my situation"</i>