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ORIGINAL ARTICLE

Hispanic breast cancer patients' symptom experience and patient-physician communication during chemotherapy

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Abstract

Objective Patient-clinician communication difficulties are a major barrier to effective symptom management during chemotherapy especially among non-English-speaking and minority patients. This study sought to examine how information is exchanged between patients and clinicians during chemotherapy treatment regarding pain, depression, fatigue, and nausea experienced among the most prevalent non-English-speaking group in the USA, Hispanic breast cancer survivors.

Methods Hispanic breast cancer patients and clinicians participated in focus groups to examine Hispanic breast cancer survivors' experience and patient-physician communication of symptoms during chemotherapy. Three separate focus groups (English language with patients, Spanish language with patients, and English language with clinicians) were conducted. All participants completed a demographic questionnaire.

Results Six breast cancer survivors participated in the English-language focus group, ten breast cancer survivors participated in the Spanish-language focus group, and five clinicians participated. Presence and communication of depressive symptoms between the English- and Spanish-language groups differed, with the majority of the English-language group sharing their experiences of depressive symptoms while those in the Spanish-language group did not report depressive symptoms. Results also indicated that most patients were unhappy with the response of clinicians regarding their reported symptoms. Several barriers to effective patient-clinician communication, including limited physician time, lack of patient knowledge, timidity, and language, were identified.

Conclusion The findings of this study underscore the need to improve patient-physician communication during chemotherapy to reduce the symptom burden among Hispanic breast cancer patients.

Keywords Hispanic · Breast cancer · Patient-physician communication · Symptoms · Chemotherapy

Introduction

Considerable progress has been made over the past two decades in the detection, prevention, and treatment of cancer. However, those improvements may not be observed equally among racial and ethnic groups, including Hispanics and Latinas (hereafter referred to as Hispanics). Among Hispanics living in the USA, breast cancer (BC) is the most common cancer type and leading cause of death. An estimated 19,800 Hispanic women were expected to be diagnosed in

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Douglas M. Post is deceased. This paper is dedicated to his memory.

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2015 [1], and even though Hispanic women are less likely to be diagnosed with BC than non-Hispanic white women, they are more likely to die of BC [1]. Hispanic women are also more likely to be diagnosed with advanced-stage BC and to have delays in starting chemotherapy compared to non-Hispanic counterparts [2, 3].

As advancements in treatment and early detection of BC improve, more attention has now focused on the symptoms experienced during and after cancer treatments. Fatigue, depression, pain, and nausea are among the most common symptoms that cancer patients experience during chemotherapy [4]. Fatigue has been found to be one of the most problematic side effects, with high and fluctuating prevalence rates [5]. Levels of emotional distress can also be high, and studies have suggested that depression may worsen during treatment [6]. Pain symptoms during chemotherapy, particularly stomach pain as well as muscular aches and pains, have been found to last 1 week or more during half the cycles [7]. Lastly, cancer patients experience significant chemotherapy-induced nausea/vomiting during 30–45% of the cycles [8]. Studies have indicated that the burden of experiencing these treatment-related side effects is pervasive, as indicated by the negative associations over time with patients' psychological adjustment and quality of life [7, 9, 10].

Previous research has identified ethnic disparities in symptom severity and management [11–14]. For example, Yoon et al. found that Spanish-speaking Hispanic BC survivors were significantly more likely than non-Hispanic white women to report an unmet need in symptom management [12]. In addition, when communicating distressing symptoms during chemotherapy treatment, Hispanic women received less information and experienced less communication from their physicians [15]. Thus, this study conducted focus groups to identify the symptoms experienced during chemotherapy, the patient-clinician communication regarding these symptoms, and barriers to patient-clinician communication among Hispanic BC patients and their clinicians.

Methods

Participants and recruitment

Three focus groups (two patient, one clinician) were conducted to collect information about themes of patient-physician symptom communication related to depression, pain, fatigue, and nausea. Potential patient and clinician participants were recruited from an oncology clinic in the southwest region of the USA. To be eligible for the focus groups, patient participants had to be female, age 18 and older, self-identified as Hispanic, fluent in either Spanish or English, and received chemotherapy treatment within the previous 3 years. Clinician participants, physicians or nurses, had to be age 18 and older, and care for Hispanic women undergoing chemotherapy for BC at the participating clinic.

BC patients who met the eligibility criteria were recruited during clinic visits or through a phone call by clinicians. Clinicians introduced the study to the BC patients who had experienced difficulties in the past 3 years with depression, pain, fatigue, and/or nausea during chemotherapy treatment. If the patient expressed interest, the focus group coordinator then contacted the potential patient participant by phone, explained the study in detail, answered questions, and assessed willingness to participate.

Clinicians who met the eligibility criteria were approached in person or through a phone call or email message by the focus group coordinator. During the correspondence, the focus group coordinator screened prospective participants, verified their eligibility, explained the study, answered questions, and assessed willingness to participate. If the oncologist or nurse was eligible and expressed interest, he/she was provided information regarding the date, time, and location for the focus group session.

Focus groups

Three separate focus groups (English language with patients, Spanish language with patients, and English language with clinicians) took place at the participating clinic. Written, informed consent as well as a brief demographic questionnaire was obtained from all participants. Once the focus groups began, the conversation followed a discussion guide that covered the patient's experience with chemotherapy and communication about their symptoms with their clinicians. In addition, patients were asked to reflect on barriers to communicating with their clinicians about these symptoms. The same process occurred with clinicians for their focus group, guided by discussion questions regarding patient-clinician communication of symptoms during chemotherapy.

All focus groups took part at the participating clinical site, were audio recorded, and lasted approximately 90 min. All patient participants received a $25 gift card for their time. Informed consent procedures and study protocols were approved by the Institutional Review Boards of the participating clinics and universities.

Analysis

Descriptive statistics and frequency distributions were used to characterize research participants' demographics. Cross-tabulations, utilizing Fisher's exact test and Chi-square tests, were used to test for differences in categorical variables, whereas an independent samples *t* test was used to test for mean differences in age and household size between English- and Spanish-language focus groups. All analyses were conducted using IBM SPSS Statistics 23.

Audio recordings, both in English and Spanish, were transcribed verbatim and translated, if necessary, by the bilingual focus group facilitator. Transcripts were reviewed for accuracy. Two research staff members trained in qualitative analysis read the focus group transcripts and generated a list of themes that categorized the experiences shared by participants. All transcripts were coded using NVivo qualitative software and coded independently. Both staff members then reviewed codes and discrepancies were resolved through consensus.

Results

Sample demographics

Twenty-two participants took part in the three focus groups and twenty-one (95.5%) completed the demographic questionnaire. Six BC survivors participated in the English-language focus group, five BC survivors participated in the Spanish-language focus group, and five clinicians participated in their focus group. Participant characteristics of patients and clinicians are reported in Tables 1 and 2, respectively.

Focus group themes

Two themes emerged from the three focus groups. The first was that the experience and communication of reported fatigue, pain, depression, and nausea differed among patient groups and between patients and clinicians, often resulting in frustration. The second was that there were numerous barriers to patient-physician communication.

Experience and communication of reported symptoms

Fatigue

Several patients identified fatigue as a severe and pervasive symptom they experienced during and after chemotherapy. One patient said, “That was the biggest thing, fatigue, even

Table 1 Patient characteristics, (*n* = 16)*

	English-speaking (*n* = 6) *n* (%)	Spanish-speaking (*n* = 10) *n* (%)	**Total** (*n* = 16) *n* (%)
Age, mean (SD)	54 (10.4)	59.4 (10.2)	57.4 (10.2)
Hispanic identification			
Mexican	2 (33.3)	9 (90.0)	11 (68.8)
Other Hispanic/Latino group	4 (66.7)	1 (10.0)	5 (31.2)
Race			
White	5 (83.3)	10 (100)	15 (93.8)
Other	1 (16.7)	0 (0)	1 (6.2)
Marital status			
Married	3 (50.0)	5 (50.0)	8 (50.0)
Divorced/separated/widowed/never been married	3 (50.0)	5 (50.0)	8 (50.0)
Education level			
Grade school	0 (0)	3 (37.5)	3 (21.4)
High school diploma/GED	1 (16.7)	2 (25.0)	3 (21.4)
Some college/college degree	5 (83.3)	3 (37.5)	8 (57.2)
Employment status			
Work full-time/part-time	5 (83.3)	4 (40.0)	9 (56.3)
Disabled/retired	1 (16.7)	6 (60.0)	7 (43.7)
Income			
≤ $29,999	2 (33.3)	4 (40.0)	6 (37.5)
≥ $30,000	4 (66.7)	1 (10.0)	5 (31.2)
Household size, mean (SD)	2.8 (2.1)	3.7 (2.6)	3.3 (2.3)
Health insurance			
Private	2 (33.3)	3 (10.0)	5 (31.2)
Medicare/Medicaid/state plan	2 (33.3)	6 (60.0)	8 (50.0)
Reported depression	4 (75.0)	0 (0)	4 (25.0)

* Some variables do not total 16 because of incomplete data

Table 2 Clinician characteristics ($n = 5$)

	n (%)
Age, mean (SD)	48.4 (11.5)
Gender	
Female	3 (60.0)
Male	2 (40.0)
Ethnicity	
Hispanic/Latino	5 (100.0)
Marital status	
Married	3 (60.0)
Not married	1 (20.0)
Widowed	1 (20.0)
Professional role	
Physician	1 (20.0)
Nurse/nurse practitioner	4 (80.0)
Years in practice, mean (SD)	22.0 (11.2)
Years at current hospital, mean (SD)	18.0 (12.2)

now, I don't feel normal yet. I'm very tired." Another patient said, "I became a couch potato." However, the majority of the patients acknowledged that it did not interfere with their responsibilities, especially work. One patient said, "…I was too busy, I never stopped working. I have kids, sports, and everything, so I really didn't pay attention to the fatigue." Similarly, another patient said, "I did feel tired, but I also, I didn't stop moving I had to go to work." Clinicians acknowledged that fatigue is a common symptom in their practice and instructed patients to "engage in regular activities as much as possible to avoid worsening the symptom."

When asked about the communication of fatigue, patients felt that they did not experience barriers in discussing fatigue with their clinicians and clinicians felt that fatigue, of all symptoms, is most easily communicated. One clinician said, "… it's easier for them to talk about their fatigue because it's part of their day…" Another clinician mentioned he told his patients that "the fatigue they feel is not the same fatigue that you feel when you go and work out."

Patients did express frustration in the clinicians' responses to their complaints about fatigue. This led patients to reduce efforts to communicate their fatigue. One patient noted, "I'm tired, but unfortunately that's not important to them." Another said, "…I would tell him my symptom but eventually they're going to say, 'It's because of the medicine,' nothing else… why tell them in the first place?"

Depression

Several patients in the English-language focus group discussed experiences with depression as a side effect of their diagnosis and treatment. One patient shared, "…you do get depressed, and you do get depressed a lot. I got depressed a lot." Another mentioned that depression is still present even after the completion of chemotherapy by saying, "And also the depression is still going on." Similar to the questionnaire results, participants in the Spanish-language group did not report any symptoms of depression. The Spanish-language patients said that, "… I still felt sick but not to the point of depression" and that "…everyone was surprised that I was never sad or crying a lot."

When asked about depression among their patients, clinicians argued that patients experienced anxiety or fear about initiating treatment but that patients do not report symptoms of depression throughout the course of treatment. One clinician said, "They were more anxious or scared, that, more than depression." Another clinician explained a patient's emotional distress about chemotherapy stating, "She was crying because she didn't know what to expect, so we explained everything to her, and she went through the first course of treatment, and the more she came, the easier, the more at ease she felt."

One patient mentioned that she discussed her depressive symptoms with her clinician but the woman, like the other patients, ultimately felt a self-sufficiency in managing her own symptoms. She said, "I asked my doctor for pills, and I told him I wasn't taking this treatment well, and he did give me the pills and I did buy them, and then I said, 'Well, why am I going to take these pills? Get over yourself.' I kind of talked myself out of it." Another patient has a similar mindset regarding her depressive symptoms saying, "I was like, 'No, no, no, I'm not going to let this [depression] get in the way of living a normal life.'"

Pain

The majority of patients from both focus groups did not report pain. Several utterances about their lack of pain included "no pain, I never felt pain," "I really didn't have pain," and "I did not feel much pain. It did not hit me like I had heard about." Two patients reported minor bone pain though it did not interfere with daily life. One patient explained it as, "my joints hurt and I felt achy like if I exercised a lot." However, patients in both groups discussed the specific pain associated with hair loss during chemotherapy. They emphasized that this pain was intense and unanticipated. Another patient chimed in saying, "It hurt a lot when my hair was falling out. It felt like thorns." One patient agreed saying, "yeah, it [hair] hurts so I shaved it off."

When asked if they communicated this pain to their clinicians, all of the patients affirmed that they had spoken with their clinicians directly but were frustrated at their response. One patient said, "But they [clinicians] tell you it's normal… I would wonder, 'Should I even tell him?' There were times I didn't say anything. Why bother if everything is normal?"

Another said her clinician did not listen to their complaints of pain and only replied, "Give it time!"

Nausea

Both patients and clinicians emphasized that nausea was the most severe and pervasive side effect associated with chemotherapy. A patient shared, "For me, it went really bad, a lot of nausea, no vomiting but constant nausea." Another said, "I used to get nauseous and the only thing that helped was fresh things." Another patient mentioned nausea along with other symptoms: "… but there was being tired and of course nausea and vomiting and diarrhea."

Clinicians specifically discussed the association between pain and nausea and how it related to their patients' communication of their symptoms. One clinician said,

"We see more of the nausea, and if you ask a patient, 'Do you have pain? They'll probably tell you, 'No.' but if you ask them if they have nausea, 'Oh yeah and really bad, and I was throwing up for three days, like six times a day,' and I think that's pain, having nausea and vomiting and feeling ill. That is pain for the patient, but if you ask them specifically, 'Did you have pain? 'No, but the discomfort and the nausea and the vomiting, yes.'"

Patients reported their experiences of nausea to their clinicians. However, the clinicians' response was often a prescription medication, and patients were uninterested in adding another medication to their already-complicated regimen. One patient stated, "but they tell you it's normal. 'It's normal. Do you want a pill?" Another patient mentioned, "I didn't want to take anything extra. Chemo's enough, thank you." Similarly, one patient said, "There's enough that we have to take without something that's optional!"

Barriers to patient-physician communication

Patients generally reported effective patient-clinician communication regarding their experiences during chemotherapy. However, several barriers including time, lack of knowledge, timidity, and language were identified through the focus groups.

Time

Patients identified limited time with their clinicians as the most significant barrier to effective communication. Patients perceived their nurses as having more time to devote to their care than oncologists. For example, one patient said, "…you have him [the oncologist] for a little while. I was with the nurses pretty much all day long… they were more available to me and more comfortable." Clinicians also agreed that limited time was a barrier to patient-physician communication. One clinician mentioned that patients "don't get that one-on-one time with the doctor" due to their hurried schedule. Another clinician stressed the importance of recording symptoms as "it'll save time during the visit."

Lack of knowledge

Many patients explained that they knew little of what to expect regarding their diagnosis and treatment and this lack of knowledge was a barrier to understanding and communicating their symptoms. One woman stated, "They don't tell you before, 'You are going to suffer from this. This will happen. This can happen. This will happen next.' It is very rare that they will mention it." A second patient declared "…I went in blind… it's an important barrier [to communication] because you never have the information until you are going through it." Clinicians also agreed that patients are often unaware of what chemotherapy entailed as well as the associated side effects and that this lack of knowledge fostered fear and anxiety in their patients. One clinician explained, "They're scared more than anything initially, and then once they get the first treatment, the more at ease they are."

Timidity

Clinicians felt that Hispanic women are generally shy and may not openly discuss their symptoms. Clinicians stated, "… women are more shy in the Hispanic population when it comes to communicating with a male nurse or about something so intimate" and that this timidity reduced among younger patients because they were "…I guess more educated and want to be heard." Patients disagreed with this characterization and argued that Hispanic women are a very open and talkative culture saying, "we are very loud and very strong," "…as Hispanics we are just a little more talkative," and "I wasn't embarrassed or shy about asking him about anything and everything."

Language

Patients in the Spanish-language focus group stressed that language was a barrier to symptom communication with their clinicians. One patient said, "I had an easier time communicating with the nurses that with the doctor. The doctor was very short when he talked, and talking with the nurses came easier. It was because of the language." Another patient mentioned discussing her symptoms with nurses was easier by saying, "The nurse spoke Spanish to me so I would tell her, 'Look, the doctor told me this, I am experiencing this."

Discussion

This study sought to identify the symptoms experienced during chemotherapy, the patient-clinician communication regarding these symptoms, and barriers to patient-clinician communication between Hispanic BC patients and clinicians. Corresponding with the previous literature [13, 16–18], patients in both groups reported high levels of fatigue and nausea associated with chemotherapy. Fu and colleagues [13] noted that in addition to high levels of fatigue and nausea, Hispanics reported higher overall chemotherapy-related symptoms than non-Hispanics. In addition, Hispanic BC survivors suffered worse post-treatment health-related quality of life and more pain, fatigue, depressive symptoms, and distress than their non-Hispanic white counterparts [19–22]. As noted in this study and in the literature, symptoms experienced during chemotherapy also extended into a post-treatment, survivorship phase for Hispanic BC patients.

The focus group data indicated that English-speaking Hispanic BC survivors spoke to their clinicians about their depressive symptoms at a notably higher rate than Spanish-speaking survivors. There were no significant differences in the demographics characteristics between the English-speaking and Spanish-speaking Hispanic BC survivors, other than language preference. Corresponding with the previous literature [23, 24], patients also listed language as a barrier to effective communication with their clinicians.

Language usage is a major component of acculturation and researchers often rely on English-language proficiency as a proxy for acculturation to U.S. society [25, 26]. Yanez and colleagues found that lower English language use was associated with more cancer-specific distress than higher English use [27]. Regarding depression, Maly et al. [18] found that more acculturated Hispanic BC patients were more likely to achieve resolution of their depression compared to less acculturated Hispanics. In order for the more acculturated Hispanic BC patients to evaluate their depression, it can be inferred that they communicated and characterized depressive symptoms to their clinicians. Hispanic BC survivors in the English-language focus group of the current study, who may be considered more acculturated, showed a similar behavior in communicating and characterizing depressive symptoms. However, less acculturated Hispanic BC patients in the Spanish-language focus group in the current study may have been reluctant to report their depressive symptoms because of culturally based factors such as stigma about depression and fatalism [11, 18, 28]. These findings accentuate the importance of timely, appropriate assessment of depressive symptoms within a culturally appropriate context to reduce the depressive symptom burden among Hispanic BC patients [29].

Another main finding was that patients often expressed frustration to the clinicians' response to their symptom reporting. The study's findings correspond with previous studies that found Hispanic cancer survivors had negative experiences with physicians [23, 30, 31]. Ashing-Giwa and colleagues found that female Hispanic cancer survivors perceived that their physicians did not listen to them or take their concerns seriously [31]. Yet, those survivors reported communication with clinicians as a key factor in their quality of care [31]. A recent study by Katz et al. [32] also found that Latinas reported a lower appraisal of surgeons' and medical oncologists' quality of communication, suggesting that they did not believe that their providers were responding to their needs.

Despite the high incidence of adverse symptoms during chemotherapy, patient-clinician symptom communication is deficient [33, 34]. Effective patient-physician communication can greatly influence symptom management as well as satisfaction with care and quality of life [35]. Efforts to improve patient autonomy and patient self-efficacy in communicating with physicians have been identified to be effective [36, 37]. On the clinician side, patient-centered communication, which involves exploring patients' concerns and assessing and responding to their emotions, has been associated with better patient outcomes [34, 38]. Thus, enhanced symptom monitoring and implementation of communication strategies for both patients and clinicians need to be utilized regularly within the healthcare system.

Recent interventions have incorporated patient and clinician education with electronic resources to facilitate better symptom communication and patient outcomes [39–42]. Basch and colleagues [40] found that a web-based collection of patient-reported symptoms during chemotherapy treatment, with automated alerts to clinicians for severe or worsening symptoms, did improve health-related quality of life and engaged patients as active participants in their symptom management. Despite the growing research field, there is a lack of culturally appropriate, evidence-based interventions for Hispanic BC survivors and their clinicians. Future interventions to improve patient-clinician communication should not promote change in culturally held beliefs but rather systematically ensure that intervention elements are culturally relevant to Hispanic patients [27].

Limitations

Some limitations of this study are worth noting. The first limitation is the small sample size of the focus group participants. In addition, this study was conducted in one geographic location and may not be generalizable to other Hispanic women with BC. Second, more than two thirds of the patient participants identified as Mexican. In addition, the measure of language preference was used as a proxy for acculturation and further work assessing the role of symptom management is needed in this population. Third, this study relied on self-report measures during focus groups and it may contain possible biases.

Conclusion

This study examined the experiences of pain, depression, fatigue, and nausea of Hispanic BC patients, patient-clinician communication regarding these symptoms, and barriers to effective patient-clinician communication. Results indicated that the presence and communication of depressive symptoms between the English- and Spanish-language groups differed, with the majority of the English-language group sharing their experiences of depressive symptoms. Patients were unhappy with the response of clinicians regarding their reported symptoms and mentioned several barriers, including language and time, to effective patient-clinician communication. The findings of this study emphasize the need to improve patient-physician communication during chemotherapy to reduce the symptom burden among Hispanic BC patients.

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Compliance with ethical standards

Informed consent procedures and study protocols were approved by the Institutional Review Boards of the participating clinics and universities.

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

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