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The Pain Experience of Hispanic Patients With Cancer in the U.S.

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Abstract

Background: Several plausible reasons for inadequate cancer pain management among Hispanic patients with cancer in the U.S. have been postulated; however, this issue is understudied.

Purpose: The purpose of the study was to explore Hispanic patients' cancer pain experience from a feminist perspective in order to find explanations for inadequate pain management for Hispanic patients with cancer.

Design: A qualitative online forum study.

Setting: Both Internet and community settings.

Participants: 15 Hispanic patients with cancer recruited using a convenience sampling method.

Methods: A 6-month online forum was conducted using nine discussion topics, and the data were processed using a thematic analysis.

Phenomenon of Interest: Cancer Pain Experience

Findings: Four major themes emerged: lack of communication with health care providers regarding undermedication; because of traditional gender roles guiding their behaviors, both women and men were enduring pain; participants placed the highest priority on family during the diagnosis and treatment process, thus setting aside their needs for pain management; finally, participants were enduring inconvenience and unfair treatment in the U.S. health care system while simultaneously appreciating what treatment they had been given.

Conclusions: Because of cultural factors and marginalized status in the U.S. as Hispanics and as immigrants, most of the participants could not adequately describe and manage their pain.

Implications: Findings suggest a need for further investigation of the influences of multiple factors, including financial issues, cultural norms, and gender stereotypes, on cancer pain experience among diverse subgroups of Hispanic patients with cancer.

Key Points:

- Because of their Hispanic identity or immigrant status in the U.S., financial difficulties, language barriers, and cultural values placing family as the highest priority, most of the Hispanic participants of this study could not adequately describe and manage their pain.
- Because of traditional gender roles emphasizing machismo, Hispanic men rarely complained about their pain.

- Due to cultural traditions emphasizing women's obedience and obligation to sacrifice for their families, Hispanic women were also enduring pain while fulfilling their multiple roles and responsibilities.
- Because of familism, Hispanic patients with cancer placed the highest priority on family while managing cancer pain.

Keywords

Hispanic; Cancer; Pain Experience

Juarez, Ferrell, and Borneman (1999) reported that Hispanics endured greater pain and poorer quality of life outcomes compared to Caucasians and African Americans. Anderson et al. (2002) indicated that Hispanic patients recounted severe pain and many concerns about pain management. Indeed, pain of Hispanic patients with cancer in the U.S., particularly Hispanic patients of lower socioeconomic status, seems to be undertreated (Delgado et al., 1995; Eley et al., 1994). Cleeland et al. (1997) found that Hispanic patients treated in ethnic minority settings were more likely to be undermedicated than patients seen in non-minority settings, and that they reported less pain relief and received inadequate analgesia dosages compared with patients from other ethnic groups. Anderson et al. (2004) also noted that physicians underestimated baseline pain intensity and provided inadequate analgesics for more than 50% of the Hispanic and African American patients with cancer in their study. In another study, Anderson et al. (2002) concluded that approximately 28% of Hispanic patients received analgesics insufficient in strength to manage their pain, and physicians underestimated pain severity for 64% of Hispanic patients.

Several possible reasons could explain why cancer pain management of Hispanic patients with cancer is inadequate. One factor could be Hispanic patients' concern about potential addiction to pain medications and development of tolerance (Anderson et al., 2002; Cleeland, 1991; Cleeland et al., 1997). Another issue could be fewer resources and greater difficulty in accessing care and filling analgesic prescriptions, especially for patients of low socioeconomic status (Cleeland, 1991; Cleeland et al., 1997). A third reason could be difficulty for health care providers in assessing pain because of differences in language proficiencies and cultural backgrounds (Cleeland, 1991; Cleeland et al., 1997). The most common reason cited for noncompliance with pharmacologic treatment by Hispanic patients with cancer was inability to understand instructions (Juarez, Ferrell, & Borneman, 1998). Finally, stoicism largely based in religious beliefs and fatalism among Hispanic patients with cancer has been considered as another factor in play (Juarez, Ferrell, & Borneman, 1998; Luquis, Villanueva Cruz, 2006; Rifkin, Doddi, Karagi, & Pollack, 1999). In other words, Hispanic patients with cancer tend to perceive cancer as their destiny, and accompanied by a sense of powerlessness or helplessness, approach pain with stoicism. Thus, their lack of verbal and behavioral expression of pain does not indicate a lack of pain itself (Juarez et al., 1998).

In addition to these possible explanations, studies have supported the idea that inadequate cancer pain management in Hispanic patients could be linked to the cultural attitude of familism (Blackhall et al., 1995; Orono et al., 1994; Marshall et al., 1998; Salazar, 1996). Familism, the (often Hispanic) cultural tradition of responsibility toward family at the expense of one's own needs, has been frequently discussed (Marshall et al., 1998; Salazar, 1996). Blackhall et al. (1995) reported that Mexican patients with cancer are less likely to be told (at the behest of the family) that their condition is terminal and that they tended to have family-centered models of decision making (Orono et al., 1994). Marshall et al. (1998) wrote of a similar finding among Latinos: families protected patients with cancer from a terminal diagnosis because the families did not want to "harm" the patients with the knowledge of their short life expectancy, believing

that it was more merciful to withhold painful information (Marshall et al., 1998). While Caucasian patients with cancer tended to place the highest priority on their own individual experiences and interests and wanted to have control of their bodies and lives, Hispanic patients with cancer tended to emphasize the welfare of one's family over individual welfare (Pinquart & Sörensen, 2005). Consequently, Hispanic patients with cancer were more likely to seek support from family members, friends, and health professionals in the diagnosis and treatment process, which includes the management of cancer pain (Gonzales, Gallardo, & Bastani, 2005). Family thus plays a powerful role in treatment decision making (Maly, Umezawa, Ratliff, & Leake, 2006). Within this context of inattention to cultural/ethnic identity, coupled with a familism-style approach to managing cancer diagnoses, Hispanic patients' pain could not be adequately assessed and managed.

Purpose of the Study

The study reported in this paper aimed to explore Hispanic patients' cancer pain experience using an online forum. The online format was chosen for the study because it has been reported to provide a more comfortable forum to discuss sensitive personal health issues (Kramish et al., 2001). In addition, an online forum allows patients with cancer in different geographical areas to communicate and exchange their experiences and opinions (Fawcett & Buhle, 1995).

Theoretical Basis

By using a feminist perspective, we explored how gender and ethnicity influenced the cancer pain experience while respecting research participants' own views, perspectives, opinions, and experiences, rather than prioritizing the researchers' interests. We assumed that Hispanic patients' inadequate cancer pain management would come from their interactions with their environments rather than from any supposed biological differences from other ethnic groups. For example, a Hispanic woman who has been raised within a culture of familism may not report pain until it becomes very serious and intolerable, in the interests of not wanting her family to worry about her and not wanting to disturb her family's already busy life. Her health care provider in the current U.S. system might think that the woman does not need pain medication, and might make a decision about cancer pain management based on current standardized practice guidelines that exclude considerations of cultural factors like familism. Thus, undermedication of Hispanic patients' cancer pain might come from cultural differences between Hispanic patients with cancer and their health care providers who have been trained in modern medicine based on Western culture. It might also have resulted from not considering the patient's own views and attitudes toward cancer pain. In this study, the patients' own views and attitudes toward cancer pain were highlighted, and gender and ethnicity were considered significant factors that might influence Hispanic patients' cancer pain experience.

Methods

This was an online forum study among 15 Hispanic patients with cancer, conducted as part of a larger study on cancer pain experience among four different ethnic groups. The findings on the cancer pain experiences of other ethnic groups (Whites, Asians, and African Americans) are available elsewhere (the authors, in press; the authors, in review). The quantitative findings comparing the cancer pain experiences of the four major ethnic groups studied can be found elsewhere as well (the authors, in review).

Settings and Samples

Fifteen self-identified Hispanic patients with cancer were recruited from the sample of 105 Hispanic Internet survey participants in the larger study. The participants were recruited using a convenience sampling method through both the Internet and community settings. Data

collection was done only through the Internet. Forty-four Hispanic Internet survey participants were invited to participate in the additional online forum; 15 actually participated and remained in the online forum by the end of the 6-month period. Stevens (1996) suggested that 6 to 10 participants are adequate for a focus group discussion. Thus, 15 participants were considered more than adequate for the online forum discussion.

The Internet survey data were used to compile information on the participants' sociodemographic characteristics. The participants included only patients with cancer who were at least 18 years of age, who could read and write English or Spanish, whose self-reported ethnic identity was Hispanic, who had access to a computer and the Internet and were able to use them, and who had experienced pain from cancer. Mean age was 49.40 years ($SD=13.07$). Eighty percent of participants were women and 80.0 % were Catholic. About 47% of the participants were middle-school graduates; 93.3% were employed; the median annual family income was \$1,200 (range: \$0-33,600); and 80.0 % reported that their family incomes were totally insufficient for their basic needs. About 47 % of the participants were born in the U.S.; 60% reported their ethnic identity as Mexican; 12.6% reported their ethnic identity as Hispanic American; and the mean months residing in the U.S. was 112.56 months ($SD=109.47$). More details on sociodemographic characteristics are provided in Table 1.

During the six-month period when the online forum was administered, a total of 227 messages were posted. In other words, each participant posted an average of 2.5 messages per month, which was a higher number of messages than that requested by the researchers (one message per topic was mandatory for reimbursement of participation). To motivate participants to contribute for the entire six-month period, the research staff worked on having respectful and trustworthy Internet interactions with participants. Two Hispanic research staff members consistently communicated with the participants for the six months. In addition, \$50 gift certificates were provided participants at the completion of the online forum, and bimonthly newsletters describing the study in both English and Spanish were sent to participants.

Online Forum Topics

For the six-month online forum, a total of 10 topics related to cancer pain experience were discussed (see Table 2). Of the topics, nine were the original topics that researchers posted; one topic was added at the end of the fifth month based on participants' feedback. Each topic included several related prompts. For example, Topic One, on terms used to describe cancer pain and their meanings, included the following prompts: (a) "when you have pain, what language are you using to express your pain?"; (b) "when you have pain, how do you express your pain?"; (c) "how do you call pain?"; (d) "any other names that you are using to call pain?"; and (e) "what are the meanings of the names?". The original nine topics and related prompts were developed by the researchers, revised based on feedback from a panel of oncology experts, and pilot-tested among nine patients with cancer (the authors, 2004). The topics were posted serially (one to three topics per month, depending on the progress of the forum discussion); several prompts per topic were posted and explained to participants to ensure they understood the topics before responding.

Data Collection Procedures

Although 44 potential participants originally agreed to participate in the forum, only 15 participants were retained for the forum. The forum was initiated by sending out e-mails to inform invited participants that the forum was starting. When each participant logged in at the forum site for the first time, she/he was asked to introduce herself/himself to other participants. Then, participants were asked to read and discuss the discussion topics one by one, and were required to visit the online forum site at least two times per month. The messages that the participants could post on the forum site were in several forms, such as stories, conversations,

and responses to others' messages, and participants could post messages at their convenience. Prompts related to the topics were used as needed. The content and flow of discussion were monitored in the administration of the forum. The researchers tried not to interrupt the interactions among participants. Only when an intervention was needed (e.g., when participants posed a question to the researchers) were researchers involved in the interactions.

Data Analysis

First, the data were saved in ASCII format in the database. Then, data were printed out directly from the online forum site for close reading (since this was non-face-to-face discussion, we needed to note any visual cues in the messages such as emoticons, periods, commas, or other written symbols). The data collected in Spanish were translated into English and then back-translated by two bilingual research team members, respectively. Analysis of the data began as soon as the data from the first week of the online forum were gathered. Using thematic analysis, the data were thoroughly read and re-read for line-by-line coding. The codes were recorded as a coding book and were categorized through internal cognitive processing and reflexively analyzing content and context. Categories were linked to each other, and themes representing the linkages among the categories were extracted. Throughout the analysis process, we looked at what was culturally unique cancer pain experience of Hispanic patients. Potential impacts of contextual factors (e.g., patients' health status, financial status, families' responses and roles, stability of their daily lives, and social support networks) on the participants' pain experiences were also explored during analysis. The transcripts were continuously read and re-read in order to get more extract more ideas and more refined ideas about the cancer pain experience of these Hispanic patients; researchers regularly checked their interpretations against the original transcripts.

Rigor of the Study

As mentioned above, a feminist perspective was taken for this study, and the standards of rigor in feminist research by Hall and Stevens (1991) were used to guide the study. *Dependability* was ensured through examining the methodological and analytical decision trails that were created throughout the online forum process. For *reflexivity*, a chronological research diary, memos, and field notes were kept. *Credibility* and *relevance* were ensured by asking participants to provide feedback on the study through a message board available on the project website or in person if needed. Finally, *adequacy* of the study was sought through continuously re-examining research methods, goals, research questions, design, scope, analysis, conclusions, and impact within the social and political environment, throughout the data collection and analysis process.

Human Subjects Protection

The Institutional Review Board where the authors are affiliated approved the study. Recruits were asked to consent to participate in the study by clicking a hyperlink button saying "I agree to participate" at the Internet website. Then, they were asked to register for the online forum, and given initial usernames and passwords during the registration process, which they could later change at their convenience. The participants were asked to choose and use pseudonyms in the forum. In order to ensure confidentiality and protect privacy in the forum discussion, interactions at the forum site were recorded, monitored, and controlled. Only those with usernames and passwords were allowed to enter the forum site.

Findings

Four major themes emerged: (a) a lack of communication about undermedication; (b) macho men and *abnegada*; (c) family is more important than cancer pain; and (d) feeling like a prisoner.

A Lack of Communication About Undermedication

Participants had rarely communicated with their health care providers regarding inadequate management of their cancer pain. Some of them could not communicate about undermedication of their pain because of language barriers. Others mentioned financial problems that made them under-use medication to save money, and in addition could not communicate this to their health care providers. One participant also mentioned fear of drug dependency and addiction. The following shows two participants discussing inadequate cancer pain management, for different reasons:

Sometimes we do not have much money and we must save our money that we do have. I have to go with my daughter and she is the one that can help me; she lives in the same city.

It is difficult to not have much money for everything.

When I had the pain, I wanted to wait because I got addicted to the medication called Vicodin and now I am not taking the same medicine. Thank God, I am no longer addicted to the medicine. I would prefer not to take the medication. I don't like the idea of becoming dependent upon the medication.

Stoic attitudes toward pain were also identified among participants as a possible reason for inadequate pain management. Since pain was regarded as a natural outcome of cancer and the participants perceived pain as a punishment from God for transgressions in the past, the participants tried to tolerate pain. Most of the participants were Catholic, and used prayers as a pain management strategy. One of the participants said:

I am a Christian, and I prayed a lot to my God. At times I did feel that I had been abandoned by everyone including my God. But then I came to my senses and realized that I was far better off being alive and in pain than the alternative. So I pray to my heavenly Father and He helps me stay in good spirits because I have had much pain this time with cancer. Also, at other times when I have the pain, I call my daughter and she helps and prays for me.

When pain was not adequately managed with Western medicine, many participants chose to use herbs and plants. Because cancer was equated with death among the participants and because many of the participants believed that cancer could not be cured through modern Western medicine, they did not hesitate to use complementary and alternative medicine if medications did not work for their pain. One participant said:

Some people use their own remedy for the pain. I use some herbs that I got from Mexico. I put herbs in the microwave then put the herb paste on my leg and this helps me. I also sometimes go to the health food store and buy some herbs.

Macho Men and *Abnegada*

Although male participants of the study did not mention noticing any gender differences in the pain experiences of men and women, female participants mentioned that men would rarely express their pain because of the “macho man” stereotype in Hispanic culture. Indeed, in the online forum, male participants were mostly silent about pain even when it was explicitly asked about in discussion topics and prompts. The following is what one man and one woman mentioned about gender differences in cancer pain expression:

Being a female to me means that I am just as strong emotionally as a man just a little weaker physically. I really don't think that there are any differences in pain experiences between men and women. Each person is different and each person deals with their pain differently. My pain cannot be the same as the next person. Being a female or male has nothing to do with how intense or not intense the cancer pain might

be. I think that being a woman is okay to express your pain, but for a man they tend to not let anyone know their pain because they don't want to be weak.

As a man I think there is a stereotype that we are supposed to be tough and not show we are in pain. But because I expressed my pain and did not give in to the macho perspective, it was probably easier to treat my pain and find out what the problem was. I think trying to be tough and pretending like nothing is wrong makes it worse. Also, it shouldn't be that men should tolerate more pain. We're all humans and some can handle the pain. If you can't and you need to let your emotions out then do it. Don't worry what the status quo should be. Just be yourself.

Being a woman in Hispanic culture was not advantageous for pain management either, as being a mother in Hispanic culture required that women sacrifice themselves for their children and place their own needs (including needs for pain management) behind other family members' needs. Those women who sacrifice themselves for their family are called *abnegada*. Female participants needed to shoulder all the burdens from household tasks and child-rearing despite their disease. Also, all decisions on pain management as well as overall cancer diagnosis and treatment process were made by husbands or fathers of the female participants. One female participant mentioned that her husband blamed her for being lazy due to her disease and pain:

My husband does not understand me. He sees me in bed because I am in pain. He wants for me to get up from the bed and fix his meals. When he sees me in the bed, he says that I am like a lazy pill bug.

Family More Important than Cancer Pain

All the participants talked about tremendous support from family members during the cancer diagnosis and treatment process. Family members became a team and made decisions on diagnosis and treatment choices. They provided transportation to treatment centers and accompanied participants to clinical visits. Family was in the center of participants' daily lives dealing with their disease. One participant talked about family support that she received during the treatment process:

The only people that I count on to help me out are my family. I get support from my husband and the children. I call my children when I am in severe pain. Since I have my family, I really don't need a support group, since my family is the support group.

Participants themselves also placed the highest priority on their families during the diagnosis and treatment process. Even when they were in pain, they would not complain because they did not want their family members to worry about them. Although they were patients with cancer who experienced serious fatigue and pain, they did what they usually did for their family members. If they could not perform as usual, they blamed themselves for being lazy or not being a good parent. One female participant mentioned:

The other thing that I have to deal with is the usual mother duties of caregiver for my children and spouse. It does at times become very overwhelming because I don't feel well and all I would like to do is just lie down and rest. It has been a little bit hard getting the support I need. My children have school to contend with and my husband works, so it has been hard for them to be able to always support me in my time of need.

Feeling Like a Prisoner

Participants did not feel they had any voice for advocating to get adequate treatment for cancer pain. Although many of them mentioned, in the forum, receiving unfair treatment from their health care providers or staff members at clinics, they said that they could not say anything in the moment about the unfair treatment. Actually, participants were grateful for any treatment

that they received through the U.S. health care system. Like prisoners in a jail, participants did not feel they had any voice to invoke their rights to appropriate, adequate, and fair treatment. Consequently, they had no way to ask for help for their pain. Two participants mentioned:

When I came to the clinic, I noticed that there was a Caucasian lady ahead of me while waiting in line. The clerk treated her very well. She asked her how she was doing. But, when it was my turn, she was very short and cut with me and she treated me very differently.

The clerk did not treat me the same as the other people. This made me feel very uncomfortable but I cannot do anything about this situation.

Many participants also mentioned difficulties in getting proper treatment for their disease and pain because of their immigration status. As mentioned previously, most immigrants had language barriers because they were first-generation immigrants. They had difficulty in getting transportation to clinics in order to receive treatments. Family members needed to cancel all commitments in order to accompany them to clinic appointments. Many participants also had financial issues to deal with. Even parking fees at clinics were burdensome to some participants. Due to their marginalized status as immigrants in the U.S., most of them felt that they were treated like they were invisible and did not have a voice in the U.S. health care system. Two participants said:

I try to communicate with the doctor and nurses about my cancer pain. I think that they can understand me but truthfully, I am not sure if they understand me, for sure. Also, I have difficulty when they (doctors and nurses) don't understand me since I speak Spanish and the nurses and doctors speak English. I don't know if they understand me well. The customs are very different from Mexico and the United States. There is much difference in communication.

I have a co-pay for my medicines. I pay \$7 but, I sometimes do not have the \$7. If I don't have the money, I ask my children to begin looking throughout the house for loose change. I sometimes can find the money in the house but I still have a problem in paying for the medicines.

Discussion

The overriding theme in the online forum reported on in this paper is a marginalized pain experience of Hispanic patients with cancer. Because of having immigrant status in the U.S., financial difficulties, language barriers, and cultural factors placing family as the highest priority, most of the participants in the study could not adequately describe and manage their pain within the confines of the U.S. health care system. This finding is consonant with the current literature on Hispanic patients' cancer pain experiences (Delgado, 1995; Juarez et al., 1999); this literature reports that cancer pain of Hispanic patients in the U.S, especially those of lower socioeconomic status, was undertreated because of various reasons related to their immigration transition.

The first theme of the study findings addressed the lack of communication concerning undermedication, a finding which complements existing literature on the cancer pain experience of Hispanic patients (Ashing-Giwa, et al 2004). Most participants were of low socioeconomic status and spoke Spanish as their primary language. For the participants of this study, Spanish speaking health care providers were frequently available, and interpreters could be called if there was no Spanish speaking provider or family member who could interpret. Despite these efforts to reduce communication problems, most participants reported difficulties in communicating about being undermedicated for pain. A possible reason for this could be Hispanics' attitudes toward health care providers. A feature of Hispanic culture is to not openly

challenge the role of health care providers, especially physicians (Ashing-Giwa, et al., 2004). Participants believed that the physician was ultimately in control and they should not question the medical regimen of providers. Another possible reason for not communicating undertreatment with health care providers could be a lack of finances. Findings reported here indicated that participants did not have money for medications even when the co-pay was the only cost incurred; this finding was also in current literature (Baquet & Commiskey, 2000). In addition, as mentioned above, Hispanic patients' religious and spiritual beliefs might lead them to be silent about and tolerant of pain if the diagnosis is willed by God or is punishment from God (Ashing-Giwa et al., 2004; Guarnero, 2005; Spector, 2000).

The second theme, macho men and *abnegada*, could be a root of stoicism toward pain among Hispanic patients. Machismo, a Hispanic cultural feature, is well known in the current literature on gender roles for men and women of Hispanic descent in the U.S. (Marin & Marin, 1991, p. 16). Hispanic culture instructs that men should be strong and in control and help meet the needs of the family, and women should be submissive, not having power or influence (de Pheils, 2005). Subsequently, men are willing to endure a great deal of pain in order to show that they are macho males that do not outwardly show weakness by stating that they are in need of more pain medication (de Pheils, 2005). This was noted in the study reported here: most of the male participants did not report their pain and tended to be silent about gender differences in pain experience.

This finding does not mean that Hispanic women are in a better position to manage cancer pain, as Hispanic culture often emphasizes women's sacrifice for their families and the importance of motherhood. In Hispanic culture, motherhood implies that a woman has completed the transition to adulthood (Guarnero, 2005; Langa & Gonzales-Ramirez, 2003), and can carry multiple roles and responsibilities for their family (de Pheils, & Jaramillo, 2003; Messias, 2003).

The third theme reported in this paper also reaffirms the existing literature on familism among Hispanics in the U.S. As described above, familism is an (often Hispanic) cultural feature of responsibility to family even at the expense of one's own needs (Lagana & Gonzales-Ramirez, 2003; Marshall et al., 1998; Salazar, 1996). Familism has been emphasized as one of the most important aspects of Hispanic culture, and this crucial value denotes strong identification with and attachment to nuclear and extended families, as well as loyalty and reciprocity in helping family members (Marin & Marin, 1991). Consequently, Hispanics tend to emphasize the welfare of one's family (familism) (Pinquart & Sörensen, 2005); Hispanic patients are more likely to seek support from family members in the diagnosis and treatment process including cancer pain management (Gonzales, Gallardo, & Bastani, 2005); and family plays a powerful role in their treatment decision making (Maly, Umezawa, Ratliff, & Leake, 2006).

The final theme, feeling like a prisoner, has many qualities related to the concept of "undocumentedness" posited by Messias (1996). "Undocumentedness" encompasses feelings of being exploited, marginalized, uninsured, discriminated against, illegal, blamed, vulnerable, and out of control (Messias, 1996); this concept was also noted in the findings of the study reported here. Because of their marginalized status as immigrants in the U.S., participants were enduring pain while trying not to bother health care providers or complain about any inconvenience and unfair treatment dealt them in the U.S. health care system. Furthermore, cultural attitudes toward health care providers might lead them to rarely challenge health care providers (Lagana & Gonzalez-Ramirez, 2003). Mexican Americans are reported to consider health care providers as being as close to God as they can get (Lagana & Gonzalez-Ramirez, 2003).

Limitations of the Study

The study has several limitations, some of which are due to the inherent nature of Internet research methodology. First, online forums are not yet a well-established data collection method although recent studies indicate that they generate findings similar to those of traditional data collection methods such as mail survey or telephone survey (McCabe, Boyd, Couper, Crawford, & D'Arcy, 2002; Truell, Bartlett, & Alexander, 2002). One of the main limitations of Internet-based collection methods, including the online forum, is selection bias and thus limited generalizability, as Internet users tend to be educated, middle class, healthy, married, white, and computer literate (ComputersScope Ltd. and others, 2002; Georgia Tech Graphics Visualisation and Usability Centre, 1999). Indeed, recruits for this study were limited to only those who were computer literate.

Another limitation of this study is: it did not represent all the diverse ethnic subgroups of Hispanics in the U.S. Rather, in this study, Hispanics were treated as one distinct ethnic group. The U.S. Census 2000 data indicated that about 59 % of Hispanics in the U.S. were Mexicans; about 10% were Puerto Ricans; Cubans were about 4 %; and the remaining were of other Hispanic origins (US Census Bureau, 2001). In this study, about 60 percent were Mexican, which is very close to the national percentage. However, the rest of the participants did not represent diverse ethnic groups within Hispanics.

A third limitation is: data collection in the online forum might not reach saturation because of the inherent nature of the forum itself (e.g., non face-to-face interactions, monthly responses to the topics). If saturation simply means the repetition of discovered information and confirmation of previously collected data (Morse, 1994), the data collected through the online forum achieved the saturation because a level of repetition of the information could be found in the data. However, if saturation means theoretical saturation as defined by Strauss and Corbin (1990), saturation was not fully achieved in this study. According to Strauss and Corbin (1990), theoretical saturation can be achieved when no new or relevant data seem to emerge regarding a category; the category development is dense; and the relationships between categories are well established and validated.

Conclusions and Implications

In this study, Hispanic patients' cancer pain experience was explored through an online forum. The findings indicated that Hispanic patients' cancer pain experiences were heavily influenced by their cultural traditions and marginalized status as immigrants in the U.S. Because of these factors, they rarely communicated with their health care providers regarding undermedication of their pain. Because of traditional gender roles emphasizing macho men, Hispanic men rarely complained about their pain. Due to cultural traditions emphasizing women's obedience and obligation to sacrifice for their families, Hispanic women endured pain while fulfilling their multiple roles and responsibilities. Because of familism, Hispanic patients placed the highest priority on family during the diagnosis and treatment process, including cancer pain management. Finally, because of their marginalized status in the U.S., Hispanic patients were enduring inconvenience and unfair treatment in the U.S. health care system while simultaneously appreciating what had been given to them.

These findings suggest several directions for future research and practice related to cancer pain management in Hispanic patients with cancer. First, cultural values, beliefs, and attitudes related to cancer and pain need to be further explored among diverse ethnic subgroups of Hispanic patients with cancer and need to be incorporated into cancer pain management for Hispanic patients. As mentioned above, because of the inherent characteristics of the research method, participants of the study tended to be a select group of Hispanic patients. Thus, further

investigation of cancer pain experience of diverse Hispanic groups is essential for further development of knowledge of cancer pain that will provide directions for culturally competent cancer pain management for Hispanics. Second, more in-depth studies on communication issues between Hispanic patients and health care providers are needed for better understanding of their cancer pain experience and management of cancer pain. As discussed above, the lack of communication on undermedication of cancer pain did not come from only language barriers. Rather, it came from multiple factors including financial issues, cultural norms and stereotypes. Further studies on these factors are essential to prevent inadequate cancer pain management among Hispanic patients, and these factors need to be considered in cancer pain management among Hispanics. Finally, family should be considered and included in cancer pain assessment and management processes for Hispanic patients. As the findings indicated, families were in the center of daily lives of Hispanic patients with cancer who were men or women, and families were the only resources and support systems for the patients in most cases.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Sociodemographic characteristics of the participants (N=15)

Characteristics	N (%)	Characteristics	N (%)
<i>Age</i>		<i>Gender</i>	
Mean (SD)	49.40 (13.07)	Women	12 (80.0)
<i>Education</i>		Men	3 (20.0)
Elementary	3 (20.0)	<i>Religion</i>	
Middle-school	7 (46.7)	Catholic	12 (80.0)
High-school	3 (20.0)	Protestant	1 (6.7)
Partial college	2 (13.3)	Others	2 (13.3)
<i>Employment</i>		<i>US Born</i>	
Employed	1 (6.7)	Yes	7 (46.7)
Unemployed	14 (93.3)	No	8 (53.3)
<i>Income Satisfaction</i>		<i>Self-identified Ethnicity</i>	
Totally insufficient	12 (80.0)	Mexican	9 (60.0)
Sufficient for essentials	3 (20.0)	Chicano	1 (6.7)
<i>Annual Family Income:</i>		Cuban	1 (6.7)
Median (range)	\$1,200.00 (\$0-\$33,600)	Guatemalan	1 (6.7)
<i>Length of Stay in the US</i>		Hispanic American	2 (12.6)
(month): Mean (SD)	112.56 (109.47)	<i>Previous Medical Treatments</i>	
<i>General Health</i>		Chemo-therapy only	3 (20.0)
Very unhealthy	1 (6.7)	Surgery only	1 (6.7)
Unhealthy	5 (33.3)	Combined	11 (73.3)
Don't know	2 (13.3)	<i>Usage of Pain Medication</i>	
Healthy	6 (40.0)	Yes	9 (60.0)
Very healthy	1 (6.7)	No	6 (40.0)
<i>Primary cancer Site</i>		<i>Stage of Cancer</i>	
Breast	3 (20.0)	I	1 (6.7)
Lung	1 (6.7)	IV	3 (20.0)
Ovarian	1 (6.7)	Unknown	10 (66.7)
Leukemia	3 (20.0)	Missing	1 (6.7)
Bone	2 (13.3)		
Pancreas	1 (6.7)		
Multiple	4 (26.6)		

Table 2

Topics for the Online forum

Month	Topics with Sample Prompts
1	Topic 1: Terminology to describe cancer pain and their linguistic meanings
2	Topic 2: Verbal and nonverbal communication styles used to relate cancer pain
3	Topic 3: Culturally universal and specific descriptions of cancer pain
4	Topic 4: Gender differences in pain descriptions Topic 5: Patient's responses to cancer pain Topic 6: Patient's evaluation of cancer pain assessment conducted by health care professionals
5	Topic 7: Patient's evaluation of cancer pain assessment tools Topic 8: Patient's evaluation of cancer pain management provided by health care providers
6	Topic 9: Patient's preferences for cancer pain management strategies Topic 10: Other topics added based on the participants' feedback