

The Pain Experience of Hispanic Patients With Cancer in the United States

Eun-Ok Im, PhD, MPH, RN, CNS, FAAN,
Enrique Guevara, MSN, and Wonshik Chee, PhD

Purpose/Objectives: To explore Hispanic patients' cancer pain experience from a feminist perspective to find explanations for inadequate pain management.

Design: A qualitative online forum study.

Setting: Internet and community settings.

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

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

Main Research Variables: Cancer pain experience.

Findings: Four major themes emerged related to the following findings. The first was a lack of communication with healthcare providers regarding undermedication. The second was that women and men were enduring pain because of traditional gender roles guiding their behaviors. Third, participants placed the highest priority on family during the diagnosis and treatment process, thus setting aside their needs for pain management. The fourth theme was that participants were enduring inconvenience and unfair treatment in the U.S. healthcare system while simultaneously appreciating the treatment they had received.

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

Implications for Nursing: 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 . . .

- Hispanic identity or immigrant status in the United States, financial difficulties, language barriers, and cultural values placing family as the highest priority interfere with descriptions and management of pain.
- Because of traditional gender roles emphasizing machismo, Hispanic men rarely complain about pain.
- Cultural traditions among Hispanic women emphasizing an obedience and obligation to sacrifice for their families resulted in women enduring pain while fulfilling their multiple roles and responsibilities.
- Hispanic patients with cancer place their highest priority on family while managing cancer pain.

cluded that approximately 28% of Hispanic patients received analgesics that were insufficient in strength to manage their pain and that physicians underestimated pain severity in 64% of Hispanic patients.

Several possible factors could explain why 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, Gonin, Baez, Loehrer, & Pandya, 1997). Another factor could be fewer resources and greater difficulty in accessing care and filling analgesic prescriptions, especially among patients of lower socioeconomic status (Cleeland; Cleeland et al.). A third factor could be difficulty on the part of healthcare providers in assessing pain because of differences in language proficiencies and cultural backgrounds (Cleeland; Cleeland et al.). The most common factor cited for noncompliance with pharmacologic treatment by Hispanic patients with cancer was inability to understand instructions (Juarez et al., 1999).

Eun-Ok Im, PhD, MPH, RN, CNS, FAAN, is a professor in the School of Nursing, Enrique Guevara, MSN, is a doctoral candidate in the School of Nursing, and Wonshik Chee, PhD, is an assistant research professor in the College of Engineering, all at the University of Texas at Austin. (Submitted October 2006. Accepted for publication March 4, 2007.)

Digital Object Identifier: 10.1188/07.ONF.861-868

Juarez, Ferrell, and Borneman (1999) reported that Hispanic patients 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 among Hispanic patients with cancer in the United States, particularly Hispanic patients of lower socioeconomic status, seems to be undertreated (Delgado, Lin, & Coffey, 1995; Eley et al., 1994). Cleeland, Gonin, Baez, Loehrer, and Pandya (1997) found that Hispanic patients treated in ethnic minority settings were more likely to be undermedicated than patients treated in nonminority settings. Hispanic patients also reported experiencing less pain relief and receiving inadequate analgesia dosages compared to patients from other ethnic groups. Anderson et al. (2004) noted that physicians underestimated baseline pain intensity and provided inadequate analgesics for greater than 50% of the Hispanic and African American patients with cancer in their study. In a separate study, Anderson et al. (2002) con-

Finally, stoicism, largely based in religious beliefs and fatalism among Hispanic patients with cancer, has been considered another factor (Juarez et al.; Luquis & Cruz, 2006; Rifkin, Dodd, Karagji, & 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, the lack of verbal and behavioral expression of pain does not indicate a lack of pain itself (Juarez et al.).

In addition to these possible explanations, studies have supported the idea that inadequate cancer pain management among Hispanic patients could be linked to the cultural attitude of familism (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Marshall, Koenig, Barnes, & Davis, 1998; Orona, Koenig, & Davis, 1994; Salazar, 1996). Familism, the cultural tradition of responsibility toward family at the expense of one's own needs, has been discussed frequently (Marshall et al.; Salazar). Blackhall et al. 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 (Orona et al.). Marshall et al. reported similar findings among Latinos: families protected patients with cancer from knowing about a terminal diagnosis because the families did not want to "harm" the patients with the knowledge of their short life expectancy, believing that withholding painful information was more merciful than telling them the truth. Although Caucasian patients with cancer tended to place their 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 family over individual welfare (Pinquart & Sorensen, 2005). Consequently, Hispanic patients with cancer were more likely to seek support from family members and friends during the diagnosis and treatment process, including the management of cancer pain (Gonzalez, Gallardo, & Bastani, 2005). Thus, family plays a powerful role in treatment decision making in this population (Maly, Umezawa, Ratliff, & Leake, 2006). Within the context of physicians' inattention to cultural and ethnic identity, coupled with a familism-style approach to managing cancer diagnoses, Hispanic patients' pain was not adequately assessed and managed.

Purpose

The current study explored Hispanic patients' cancer pain experience using an online forum. The online format was chosen because it reportedly provides a more comfortable arena in which to discuss sensitive personal health issues (Campbell et al., 2001). In addition, an online forum allows patients with cancer in different geographic areas to communicate and exchange experiences and opinions (Fawcett & Buhle, 1995).

Theoretical Basis

Using a feminist perspective, the authors 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 (Hall & Stevens, 1991). Feminists view gender as a significant characteristic that interacts with ethnicity, subsequently influencing culture (Campbell & Wasco,

2000). The authors assumed that Hispanic patients' inadequate cancer pain management would result from interactions with their environments rather than from any biologic 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 interest of not wanting her family members to worry about her and not wanting to disturb their already busy lives. Her healthcare 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 consideration of cultural factors such as familism. Therefore, undermedication of Hispanic patients' cancer pain might be a result of cultural differences between Hispanic patients with cancer and healthcare providers who have been trained in modern medicine based on Western culture. Undermedication also might result from not considering patients' views and attitudes toward cancer pain. In the current study, patients' views and attitudes toward cancer pain were highlighted and gender and ethnicity were considered significant factors that might influence patients' cancer pain experience.

Methods

The current study used an online forum involving 15 Hispanic patients with cancer and was conducted as part of a larger study on the cancer pain experiences of four different ethnic groups. The findings regarding the cancer pain experiences of other ethnic groups (i.e., Caucasians, Asians, and African Americans) are available elsewhere (Im, 2006; Im, Lim, Clark, & Chee, 2007; Im, Liu, Kim, & Chee, 2007). Quantitative findings comparing the cancer pain experiences of the four major ethnic groups studied can be found elsewhere as well (Im et al., in press).

Settings and Samples

Fifteen self-identified Hispanic patients with cancer were recruited from a sample of 105 Hispanic participants in an Internet survey in the larger study. The participants were recruited through the Internet and in community settings using a convenience sampling method. Data collection was done only through the Internet. Forty-four Hispanic participants in an Internet survey were invited to participate in the additional online forum; 15 remained in the online forum at the end of the six-month period. Stevens (1996) suggested that 6–10 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 (see Table 1). 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. The mean age of participants was 49.4 years ($SD = 13.07$). Eighty percent of participants were women, and 80% were Catholic. About 47% of the participants were middle-school graduates. Ninety-three percent were employed, and the median annual family income was \$1,200 (range = \$0–\$33,600). The majority (80%) reported that their family

Table 1. Sociodemographic Characteristics

Characteristic	n	%
Age (years)		
X = 49.40	—	—
SD = 13	—	—
Education		
Elementary school	3	20
Middle school	7	47
High school	3	20
Partial college	2	13
Employment		
Employed	1	7
Unemployed	14	93
Income satisfaction		
Totally insufficient	12	80
Sufficient for essentials	3	20
Annual family income (\$)		
\bar{X} = 5,501	—	—
SD = 9,077	—	—
Gender		
Female	12	80
Male	3	20
Religion		
Catholic	12	80
Protestant	1	7
Other	2	13
Born in the United States		
Yes	7	47
No	8	53
Self-identified ethnicity		
Mexican	9	60
Chicano	1	7
Cuban	1	7
Guatemala	1	7
Hispanic American	2	13
Not specified	1	7

N = 15

income was totally insufficient for their basic needs. About 47% of the participants were born in the United States. Sixty percent reported their ethnic identity as Mexican, and 13% reported their ethnic identity as Hispanic American. The mean number of months participants had resided in the United States was 112.56 (SD = 109.47).

During the six-month period while the online forum was being administered, a total of 227 messages were posted. Each participant posted an average of 2.5 messages per month, which was a higher number of messages than requested by the researchers (one message per topic was mandatory for reimbursement). To motivate participants to contribute for the entire six-month period, the research staff aimed to ensure 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 to participants at the completion of the online forum and bimonthly newsletters describing the study in 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

10 topics, 9 were the original topics that researchers posted and 1 topic was added at the end of the fifth month based on participants' feedback. Each topic included several related prompts. For example, the first topic, which was about 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) "What do you call pain?" (d) "Are there 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 with nine patients with cancer (Im & Chee, 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 they responded.

Procedures

Although 44 participants originally agreed to take part in the forum, only 15 were retained. When the forum was initiated, e-mail messages were sent to inform invited participants that the forum was starting. When participants logged onto the forum site for the first time, they were asked to introduce themselves to other participants. Then, participants were asked to read and discuss the discussion topics one by one. Each person was required to visit the online forum site at least twice per month. Participants could post messages at their convenience, and the messages could be stories, conversations, or responses to others' messages. Prompts related to the topics were used as needed. The researchers monitored the content and flow of discussion and tried not to interrupt the interactions among participants. Researchers became involved in the interactions only when an intervention was needed (e.g., when participants posed a question to the researchers).

Data Analysis

First, the data were saved in ASCII format in the database. Then, data were printed out directly from the online forum

Table 2. Topics for the Online Forum by Month

Month	Topic
1	Terms to describe cancer pain and their linguistic meanings
2	Verbal and nonverbal communication styles used to relate cancer pain
3	Culturally universal and specific descriptions of cancer pain Gender differences in pain descriptions
4	Patients' response to cancer pain Patients' evaluation of cancer pain assessment conducted by healthcare professionals
5	Patients' evaluation of cancer pain assessment tools Patients' evaluation of cancer pain management provided by healthcare providers
6	Patients' preferences for cancer pain management strategies Other topics added based on the participants' feedback

site for close reading. Because these were non-face-to-face discussions, the researchers 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. 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 read and reread thoroughly and coded line by line. The codes were recorded in a coding book and categorized using internal cognitive processing and by 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, the researchers examined data to determine the culturally unique cancer pain experience of Hispanic patients. Potential effects of contextual factors (e.g., patients' health status, financial status, families' responses and roles, stability of daily lives, social support networks) on the participants' pain experiences also were explored during analysis. The transcripts were continuously read and reread to extract more ideas and more refined ideas about the cancer pain experience of the patients in the study. Researchers regularly checked their interpretations against the original transcripts.

Study Rigor

As mentioned previously, a feminist perspective was used for the current study, and the standards of rigor in feminist research by Hall and Stevens (1991) were used to guide the study. Dependability was ensured by examining the methodologic and analytical decision trails that were created throughout the online forum process. For reflexivity, a chronologic 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 Web site or in person, if needed. Finally, adequacy of the study was sought through continuously reexamining 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 at the authors' institution approved the study. Recruits were asked to consent to participate by clicking on a hyperlink button at the Web site saying, "I agree to participate." Then, they were asked to register for the online forum and were given initial usernames and passwords during the registration process that they could later change at their convenience. The participants were asked to choose and use pseudonyms in the forum. 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) lack of communication about undermedication, (b) macho men and *abnegada*, (c) family is more important than cancer pain, and (d) feeling like a prisoner.

Lack of Communication About Undermedication

Participants had rarely communicated with their healthcare 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 caused them to underuse medication to save money, in addition to being unable to communicate this to their healthcare providers. One participant also mentioned fear of drug dependency and addiction. The following quotes are from two participants concerning 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 also were identified among participants as a possible reason for inadequate pain management. Because pain was regarded as a natural outcome of cancer and the participants perceived pain as a punishment from God for transgressions in the past, they tried to tolerate pain. Most of the participants were Catholic and used prayer 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 them believed that cancer could not be cured through modern Western medicine, they did not hesitate to use complementary and alternative medicine if traditional 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 rarely would express their pain because of the machismo or "macho man" stereotype in Hispanic culture. Indeed, in the online forum, male participants mostly were 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 men, 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, because being a mother in Hispanic culture requires that women sacrifice for their children and place their own needs (including needs for pain management) behind other family members' needs. Women who sacrifice themselves for their family are called *abnegada*. Female participants believed that they needed to shoulder all the burdens of household tasks and child rearing despite their disease. Also, all decisions made during the cancer diagnosis and treatment process, including decisions about pain management, were made by husbands or fathers of the female participants. One female participant mentioned that her husband accused her of being lazy because of her disease and pain.

My husband does not understand me. He sees me in bed because I am in pain. He wants 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 Is More Important Than Cancer Pain

All of the participants talked about receiving tremendous support from family members during the cancer diagnosis and treatment process. Family members became a team and made decisions regarding treatment choices. They provided transportation to treatment centers and accompanied participants to clinical visits. Family was in the center of participants' daily lives as they dealt with their disease. One participant talked about the 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 also placed their highest priority on their families during the diagnosis and treatment process. They said that

they would not complain, even when they were in pain, because they did not want their family members to worry about them. Although the participants were patients with cancer who experienced serious fatigue and pain, they continued to perform the same tasks 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 wrote,

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 receive adequate treatment for cancer pain. Although many of them mentioned receiving unfair treatment from their healthcare 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. healthcare system. Participants did not feel they could invoke their rights to appropriate, adequate, and fair treatment. Consequently, they had no way to ask for help for their pain. Two participants mentioned the following.

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 curt 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 experienced language barriers because they were first-generation immigrants. They had difficulty getting transportation to clinics to receive treatments. Family members needed to cancel commitments to accompany patients to clinic appointments. Many participants also had financial issues to deal with. Even parking fees at clinics were burdensome to some participants. As a result of their marginalized status as immigrants in the United States, most felt that they were treated like they were invisible and did not have a voice in the U.S. healthcare system. The following are comments from two participants.

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 copay for my medicines. I pay seven dollars, but I sometimes do not have the seven dollars. 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 was one of a marginalized pain experience among Hispanic patients with cancer. Because of their immigrant status in the United States, financial difficulties, language barriers, and cultural factors placing family as their highest priority, most of the participants could not adequately describe and manage their pain within the confines of the U.S. healthcare system. This finding is consistent with the other literature on Hispanic patients' cancer pain experiences (Delgado et al., 1995; Juarez et al., 1999), which reports that cancer pain among Hispanic patients in the United States, especially those of lower socioeconomic status, was undertreated because of various reasons related to their cultural traditions and marginalized status as immigrants.

The first theme of the study findings related to a lack of communication concerning undermedication, a finding that 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 in the current study, Spanish-speaking healthcare providers were frequently available and interpreters could be called if no Spanish-speaking provider or family member was available to interpret. Despite the efforts to reduce communication problems, most participants reported difficulties in communicating undermedication for pain. A possible reason for this could be Hispanics' attitudes toward healthcare providers. A feature of Hispanic culture is to not openly challenge the role of healthcare providers, especially physicians (Ashing-Giwa et al.). Participants believed that the physician was ultimately in control and that they should not question the medical regimen of providers. Another possible reason for not communicating undertreatment with healthcare providers could be a lack of finances. Findings of the current study indicated that participants did not have money for medications even when the copay amount was the only cost incurred; this finding also is reflected in current literature (Baquet & Commiskey, 2000). Hispanic patients' religious and spiritual beliefs also might have led them to be silent about and tolerant of pain if they believed the diagnosis was willed by or a punishment from God (Ashing-Giwa et al.; 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 United States (Marin & Marin, 1991). Hispanic culture instructs that men should be strong and in control and help meet the needs of the family and that women should be submissive and not have power or influence (de Pheils, 2005). Subsequently, men are willing to endure a great deal of pain to show their machismo and that they are unwilling to show weakness by stating that they need more pain medication (de Pheils). This phenomenon was noted in the current study—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, because 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; Lagana & Gonzales-Ramirez, 2003) and that they can carry multiple roles and responsibilities for their family (de Pheils & Jaramillo, 2003; Messias, 2003).

The third theme of the study also reaffirms the existing literature on familism among Hispanics in the United States. As described previously, familism is a 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 (Pinquart & Sorensen, 2005). Hispanic patients are more likely to seek support from family members in the diagnosis and treatment process, including cancer pain management (Gonzalez et al., 2005), and family plays a powerful role in their treatment decision making (Maly et al., 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). The concept also was noted in the findings of the current study. Because of their marginalized status as immigrants in the United States, participants were enduring pain while trying not to bother healthcare providers or complain about any inconvenience or unfair treatment they received in the healthcare system. Furthermore, cultural attitudes toward healthcare providers might lead participants to rarely challenge them (Lagana & Gonzalez-Ramirez, 2003). Mexican Americans are reported to consider healthcare providers as being godlike (Lagana & Gonzalez-Ramirez).

Study Limitations

Some of the study limitations are the result of 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; therefore, the study has limited generalizability because Internet users tend to be educated, middle class, healthy, married, white, and computer literate (Georgia Tech Graphics Visualization and Usability Centre, 1999). Indeed, recruits for the current study were limited to only those who were computer literate.

In addition, the study did not represent all the diverse ethnic subgroups of Hispanics in the United States. Rather, in the current study, Hispanics were treated as one distinct ethnic group. The U.S. Census data indicated that nearly 66% of Hispanics in the United States were Mexicans, about 10%

were Puerto Ricans, 4% were Cubans, and the remaining were of other Hispanic origins (U.S. Census Bureau, 2004). In the current study, about 60% were Mexican, which is very close to the national percentage. However, the rest of the participants did not represent diverse ethnic groups within the Hispanic population in the United States.

A third limitation was that 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 is defined simply as the repetition of discovered information and confirmation of previously collected data (Morse, 1994), the data collected through the online forum achieved saturation because a level of repetition of the information could be found in the data. However, the data did not achieve theoretical saturation, which is defined as 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 (Strauss & Corbin, 1990).

Conclusions and Implications

In the current study, Hispanic patients' cancer pain experience was explored through an online forum. The findings indicated that their experiences were heavily influenced by their cultural traditions and marginalized status as immigrants in the United States. Because of these factors, they rarely communicated with their healthcare providers regarding undermedication of their pain. Because of traditional gender roles emphasizing machismo, Hispanic men rarely complained about their pain. As a result of 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 their highest priority on family during the diagnosis and treatment process, including cancer pain

management. Finally, because of their marginalized status in the United States, Hispanic patients were enduring inconvenience and unfair treatment in the U.S. healthcare 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. 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 the cancer pain experience of diverse Hispanic groups is essential for continued 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 healthcare providers are needed for better understanding of their cancer pain experience and management of cancer pain. The lack of communication about undermedication of cancer pain did not arise only from language barriers. Rather, it was a result of 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. Finally, family members should be included in the cancer pain assessment and management processes for Hispanic patients. Families were at the center of daily lives of Hispanic men and women with cancer, and families were the only resources and support systems for the patients in most cases.

Author Contact: Eun-Ok Im, PhD, MPH, RN, CNS, FAAN, can be reached at eim@mail.utexas.edu, with copy to editor at ONFEditor@ons.org.

References

- Anderson, K.O., Mendoza, T.R., Payne, R., Valero, V., Palos, G.R., Nazario, A., et al. (2004). Pain education for underserved minority cancer patients: A randomized controlled trial. *Journal of Clinical Oncology*, 22, 4918-4925.
- Anderson, K.O., Richman, S.P., Hurley, J., Palos, G., Valero, V., Mendoza, T.R., et al. (2002). Cancer pain management among underserved minority outpatients: Perceived needs and barriers to optimal control. *Cancer*, 94, 2295-2304.
- Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., et al. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina, and Caucasian cancer survivors. *Psycho-Oncology*, 13, 408-428.
- Baquet, C.R., & Commiskey, P. (2000). Socioeconomic factors and breast carcinoma in multicultural women. *Cancer*, 88(Suppl. 5), 1256-1264.
- Blackhall, L.J., Murphy, S.T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *JAMA*, 274, 820-825.
- Campbell, M.K., Meier, A., Carr, C., Enga, Z., James, A.S., Reedy, J., et al. (2001). Health behavior changes after colon cancer: A comparison of findings from face-to-face and on-line focus groups. *Family and Community Health*, 24, 88-103.
- Campbell, R., & Wasco, S.M. (2000). Feminist approaches to social science: Epistemological and methodological tenets. *American Journal of Community Psychology*, 28, 773-791.
- Cleeland, C.S. (1991). Pain assessment in cancer. In D. Osoba (Ed.), *Effect of cancer on quality of life* (pp. 293-305). Boca Raton, FL: CRC Press.
- Cleeland, C.S., Gonin, R., Baez, L., Loehrer, P., & Pandya, K.J. (1997). Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Annals of Internal Medicine*, 127, 813-816.
- Delgado, D.J., Lin, W.Y., & Coffey, M. (1995). The role of Hispanic race/ethnicity and poverty in breast cancer survival. *Puerto Rico Health Sciences Journal*, 14, 103-116.
- de Pheils, P.B. (2005). Colombians. In J.G. Lipson & S.L. Dibble (Eds.), *Culture and clinical care* (pp. 109-120). San Francisco: UCSF Nursing Press.
- de Pheils, P.B., & Jaramillo, D. (2003). Colombians. In P.F. St. Hill, J.G. Lipson, & A.I. Meleis (Eds.), *Caring for women cross-culturally* (pp. 108-122). Philadelphia: F.A. Davis.
- Eley, J.W., Hill, H.A., Chen, V.W., Austin, D.F., Wesley, M.N., Muss, H.B., et al. (1994). Racial differences in survival from breast cancer. Results of the National Cancer Institute Black/White Cancer Survival Study. *JAMA*, 272, 947-954.
- Fawcett, J., & Buhle, E.L., Jr. (1995). Using the Internet for data collection. An innovative electronic strategy. *Computers in Nursing*, 13, 273-279.
- Georgia Tech Graphics Visualization and Usability Centre. (1999). GVU's 10th WWW user survey [Online]. Retrieved June 18, 2007, from http://www.gvu.gatech.edu/user_surveys/survey-1998-10
- Gonzalez, G., Gallardo, N.V., & Bastani, R. (2005). A pilot study to define social support among Spanish-speaking women diagnosed with a breast abnormality suspicious for cancer: A brief research report. *Journal of Psychosocial Oncology*, 23, 109-120.

- Guarnero, P.A. (2005). Mexicans. In J.G. Lipson & S.L. Dibble (eds.), *Culture and clinical care* (pp. 330–342). San Francisco, CA: UCSF Nursing Press.
- Hall, J.M., & Stevens, P.E. (1991). Rigor in feminist research. *Advances in Nursing Science*, 13, 16–29.
- Im, E.O. (2006). White cancer patients' perception of gender and ethnic differences in pain experience. *Cancer Nursing*, 29, 441–450.
- Im, E.O., & Chee, W. (2004). Issues in Internet survey among cancer patients. *Cancer Nursing*, 27, 34–42.
- Im, E.O., Chee, W., Guevara, E., Liu, Y., Lim, H.J., Tsai, H., et al. (in press). Gender and ethnic differences in cancer pain experience: A multiethnic survey in the U.S. *Nursing Research*.
- Im, E.O., Lim, H.J., Clark, M., & Chee, W. (2007). *African American cancer patients' pain experience*. Manuscript submitted for publication.
- Im, E.O., Liu, Y., Kim, Y., & Chee, W. (2007). *Asian American cancer patients' pain experience*. Manuscript submitted for publication.
- Juarez, G., Ferrell, B., & Borneman, T. (1999). Cultural considerations in education for cancer pain management. *Journal of Cancer Education*, 14, 168–173.
- Lagana, K., & Gonzalez-Ramirez, L. (2003). Mexican Americans. In P.F. St. Hill, J.G. Lipson, & A.I. Meleis (Eds.), *Caring for women cross-culturally* (pp. 218–235). Philadelphia: F.A. Davis.
- Luquis, R.R., & Cruz, I.J.V. (2006). Knowledge, attitudes, and perceptions about breast cancer and breast cancer screening among Hispanic women residing in south central Pennsylvania. *Journal of Community Health*, 31, 25–42.
- Maly, R.C., Umezawa, Y., Ratliff, C.T., & Leake, B. (2006). Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. *Cancer*, 106, 957–965.
- Marin, G., & Marin, B.V. (1991). *Research with Hispanic populations*. Newbury Park, CA: Sage.
- Marshall, P.A., Koenig, B.A., Barnes, D.M., & Davis, A.J. (1998). Multiculturalism, bioethics, and end-of-life care: Case narratives of Latino cancer patients. In J.F. Monagle & D.C. Thomasma (Eds.), *Health care ethics: Critical issues for the 21st century* (pp. 421–431). Gaithersburg, MD: Aspen.
- McCabe, S.E., Boyd, C.J., Couper, M.P., Crawford, S., & D'Arcy, H. (2002). Mode effects for collecting alcohol and other drug use data: Web and U.S. mail. *Journal of Studies on Alcohol*, 63, 755–761.
- Messias, D.K. (1996). Concept development: Exploring undocumentedness. *Scholarly Inquiry of Nursing Practice*, 10, 235–252.
- Messias, D.K.H. (2003). Brazilians. In P.F. St. Hill, J.G. Lipson, & A.I. Meleis (Eds.), *Caring for women cross-culturally* (pp. 63–77). Philadelphia: F.A. Davis.
- Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220–235). Thousand Oaks, CA: Sage.
- Orona, C.J., Koenig, B.A., & Davis, A.J. (1994). Cultural aspects of nondisclosure. *Cambridge Quarterly of Healthcare Ethics*, 3, 338–346.
- Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist*, 45, 90–106.
- Rifkin, A., Dodd, S., Karagji, B., & Pollack, S. (1999). Religious and other predictors of psychosocial adjustment in cancer patients. *Psychosomatics*, 40, 251–256.
- Salazar, M.K. (1996). Hispanic women's beliefs about breast cancer and mammography. *Cancer Nursing*, 19, 437–446.
- Spector, R.E. (2000). *Cultural diversity in health and illness* (5th ed.). Upper Saddle River, NJ: Prentice Hall Health.
- Stevens, P.E. (1996). Focus groups: Collecting aggregate-level data to understand community health phenomena. *Public Health Nursing*, 13, 170–176.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Truell, A.D., Bartlett, J.E., II, & Alexander, M.W. (2002). Response rate, speed, and completeness: A comparison of Internet-based and mail surveys. *Behavior Research Methods, Instruments, and Computers*, 34, 46–49.
- U.S. Census Bureau. (2004). *The Hispanic population in the United States: 2004 detailed tables*. Washington, DC: Author.



Connect to...
Member Benefits.
 Information • Community • Knowledge

Get a Free ONS Membership

Recruit new members into ONS to start earning valuable rewards, including free ONS memberships, conference registrations, and more. Learn more about the Member-Bring-a-Member campaign today in the Membership area of www.ons.org.