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A National Online Forum on Ethnic Differences in Cancer Pain Experience

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- ***Background:*** Cultural values and beliefs related to cancer and pain have been used to explain ethnic differences in cancer pain experience. Yet, very little is known about similarities and differences in cancer pain experience among different ethnic groups.
- ***Objective:*** The objective of this study was to explore similarities and differences in cancer pain experience among four major ethnic groups in the United States.
- ***Methods:*** A feminist approach by Hall and Stevens was used. This was a cross-sectional qualitative study among 22 White, 15 Hispanic, 11 African American, and 27 Asian patients with cancer recruited through both Internet and community settings. Four ethnic-specific online forums were conducted for 6 months. Nine topics related to cancer pain experience were used to guide the online forums. The collected data were analyzed using thematic analysis involving line-by-line coding, categorization, and thematic extraction.
- ***Results:*** All participants across ethnic groups reported "communication breakdowns" with their healthcare providers and experienced "changes in perspectives." All of them reported that their cancer pain experience was "gendered experience." White patients focused on how to control their pain and treatment selection process, whereas ethnic minority patients tried to control pain by minimizing and normalizing it. White patients sought out diverse strategies of pain management; ethnic minority patients tried to maintain normal lives and use natural modalities for pain management. Finally, the cancer pain experience of White patients was highly individualistic and independent, whereas that of ethnic minority patients was family oriented.
- ***Discussion:*** These findings suggest that nurses need to use culturally competent approaches to cancer pain management for different ethnic groups. Also, the findings suggest further in-depth cultural studies on the pain experience of multiethnic groups of patients with cancer.

- ***Key Words:*** cancer · culture · ethnic minority · experience · pain

In 1999, at the request of the U.S. Congress, the Institute of Medicine (IOM) assessed the extent of disparities in the types and quality of health services received by U.S. racial and ethnic minorities and nonminorities (IOM, 2002). The IOM reported that U.S. racial and ethnic minorities were less likely to receive routine medical procedures and that they experienced a lower quality of health services (IOM, 2002). The few studies on ethnic variations in cancer pain experience also supported the finding of ethnic disparities in cancer pain assessment and management that ethnic minorities tend to be undermedicated despite reporting higher pain scores than that of others (Anderson et al., 2000, 2002; Laliberte, 2003). These studies indicated that disparity in cancer pain management results from interactions among patients, providers, and the environment (McNeill, Reynolds, & Ney, 2007). Also, these studies suggested that the ethnic variations in cancer pain management might stem from the status of cancer as a medically defined disease, associated with a complex network of culturally shaped meaning that affects how people cope with the disease (Barkwell, 2005).

Despite an increasing number of studies on the cancer pain experiences of ethnic minority patients, very few of them compared cancer pain experiences across different ethnic groups of patients with cancer, and study findings on ethnic differences were inconsistent. Some reported ethnic differences in perceived severity and frequency of cancer pain (Anderson et al., 2002; Im, Guevara, & Chee, 2007), whereas others reported no significant ethnic differences (Foley et al., 2006; Jayadevappa, Johnson, Chhatre, Wein, & Malkowicz, 2007; Rabow & Dibble, 2005). Also, despite a relatively large number of researchers exploring the cancer pain experience of a specific ethnic group of patients (Anderson et al., 2002; Ashing-Giwa et al., 2006; Edrington et al., 2004; Eversley et al., 2005; Meghani & Keane, 2007), there exist very few qualitative studies comparing the cancer pain experiences of different ethnic groups in the current literature (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007; Foley et al., 2006).

The purpose of this study was to compare the cancer pain experiences of four major ethnic groups in the United States through ethnic-specific national online forums. Online forums were chosen for the study because (a) they are a mechanism commonly used to provide elective emotional and

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informational support, especially among patients with cancer, and (b) they have been reported to provide a more comfortable mode of communication for some people to discuss sensitive personal health issues and have been suggested as a feasible alternative to traditional face-to-face focus groups (Campbell et al., 2001; Hsiung, 2000). Because some cultures are reported to stigmatize cancer (American Cancer Society, 2006), it was believed that online forums would be more effective in helping participants feel comfortable with disclosing their experiences compared with traditional face-to-face focus group discussions. Whereas traditional face-to-face focus groups require their participants to be present physically at the meetings, online forums allow participants to discuss and share their experiences and opinions without physically attending; this also allows participants in geographically dispersed areas to communicate with each other without long-distance travel or time constraints; an aim of this study was to reach out to patients with cancer in geographically dispersed areas to recruit an adequate number of ethnic minorities. Furthermore, online forums usually are administered for a long time period (e.g., 6 months, 1 year, and 3 years), which allows a more flexible time frame and subsequently reduces the burden of participation and time pressure (Saba & McCormick, 2001). More details on advantages and disadvantages of online forums (as a qualitative research method) that were found in this study are reported elsewhere (Im & Chee, 2006).

A feminist approach by Hall and Stevens (1991) was used in the design and analysis of the online forums to explore the cancer pain experience of patients with cancer and to explore how contextual factors such as gender, ethnicity, and socioeconomic status influence cancer pain experience. This approach provides valuable information on possible reasons for ethnic differences in cancer pain experience by accounting for cultural contexts. By using the feminist approach, throughout the research process, research participants' own views, perspectives, opinions, and experiences were respected and disclosed. Also, as part of this approach, it was assumed that there can be no pure biology and that inadequate cancer pain management among ethnic minority patients could come from patients' interactions with their environments as well as their biology. Furthermore, gender and ethnicity were considered important factors that structure pain experiences of patients with cancer. Finally, various retention strategies were used in the hopes of keeping participants involved by changing the study dynamics such that researchers were more accessible to participants.

Methods

This study was part of a larger study on cancer pain management, which included two phases: data collection and development of a decision support system for healthcare providers. The data collection phase included both a quantitative Internet survey and qualitative online forums. Only the findings from the qualitative online forum data are presented here. More detailed information on the quantitative Internet survey can be found elsewhere (Im, Chee, et al., 2007), as can be ethnic-specific findings of each online forum (Im, 2006; Im, Chee, et al., 2007; Im, Lim, Clark, & Chee, 2008; Im, Liu, Kim, & Chee, 2008). The study was approved by the institutional review board of The University of Texas at Austin.

Settings and Samples

A total of 75 self-identified patients with cancer (22 non-Hispanic [N-H] White, 15 Hispanic, 11 N-H African American, and 27 N-H Asian) were recruited from among 480 patients with cancer of the larger study. The participants of the larger study were recruited using a convenience sampling method, posting study announcements through both Internet and community settings nationwide (e.g., Internet cancer support groups, Internet groups for ethnic minorities, cancer support groups for ethnic minorities, and ethnic minority churches). The online forum participants were recruited from among the larger study participants when they indicated their interest in participating in additional 6-month online forums. Six to 10 participants usually are thought to be adequate for a focus group including this type of online forum (Stevens, 1996). To start with at least 30 participants for each ethnic group and end with at least 6 participants, all 145 patients with cancer who indicated their interest in participating in additional 6-month online forums were invited. A total of 75 remained by the end of the 6-month period. Thus, the overall retention rate was 57% (76% among N-H White, 34% among Hispanic, 50% among N-H African American, and 54% among N-H Asian patients). All participants were online patients with cancer at least 18 years old who could read and write English and whose self-reported ethnic identity was N-H White, Hispanic, N-H African American, or N-H Asian. Except for Texas (n = 21) and New York (n = 16) where community settings were located, the participants were spread evenly throughout the states across the nation. Sociodemographic characteristics of the participants are summarized in Table 1.

Instruments: Online Forum Topics

For the online forums, nine topics on cancer pain experience were used. The topics were posted in each ethnic-specific online forum serially, and 7 to 10 prompts associated with each topic were used to help participants understand the questions before discussing the topics. These topics and the prompts were developed based on an expert review and tested through a pilot study (Im & Chee, 2004). Online forum topics are listed in Table 2.

Data Collection Procedures

When participants agreed to be in the online forums, they were then asked to register. During registration, they were provided with usernames and passwords, and participants were asked to log in to the online forum sites. At the beginning of the online forum, participants were asked to choose pseudonyms for the forums so that real names would not be used. When an adequate number of participants were recruited for each ethnic-specific online forum (around 30 was regarded as an adequate number to initiate a forum), participants were asked to visit the online forum site. At their first visits, they were asked to introduce themselves to other participants and to discuss the nine discussion topics one by one (one to two topics per month). The participants could choose any form of postings (e.g., stories, conversations, and responses to others' messages),

TABLE 1. Sociodemographic Characteristics of the Participants (*N* = 75)

Characteristics	White[a] (*n* = 22)	African American[b] (*n* = 11)	Hispanic[c] (*n* = 15)	Asian[d] (*n* = 27)	Total (*N* = 75)
Age (years)					
M (*SD*)	45.09 (10.43)	46.45 (6.91)	49.40 (13.07)	51.63 (9.74)	48.51 (10.30)
Range	28–63	30–81	24–72	30–81	24–81
Education					
Elementary	0 (0.0)	0 (0.0)	3 (20.0)	1 (3.7)	4 (5.3)
Middle school	0 (0.0)	0 (0.0)	7 (46.7)	2 (7.4)	9 (12.0)
High school	2 (9.0)	2 (18.2)	3 (20.0)	3 (11.1)	10 (13.3)
College	20 (91.0)	7 (63.7)	2 (13.3)	10 (37.0)	39 (52.0)
Graduate school	0 (0.0)	2 (18.2)	0 (0.0)	11 (40.7)	13 (17.3)
Employment					
Employed	10 (45.0)	7 (63.6)	1 (6.7)	7 (25.9)	25 (33.0)
Unemployed	12 (55.0)	4 (36.4)	14 (93.3)	20 (74.1)	50 (67.0)
Income satisfaction					
Totally insufficient	0 (0.0)	1 (9.1)	12 (80.0)	7 (25.9)	20 (26.7)
Somewhat insufficient	8 (36.4)	6 (54.5)	0 (0%)	7 (25.9)	21 (28.0)
Sufficient	11 (50.0)	3 (27.3)	3 (20.0)	10 (37.0)	27 (36.0)
More than sufficient	3 (13.6)	1 (9.1)	0 (0.0)	2 (7.4)	6 (8.0)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.7)	1 (1.3)
Gender					
Female	20 (91.0)	11 (100)	12 (80.0)	21 (77.8)	64 (85.0)
Male	2 (9.0)	0 (0.0)	3 (20.0)	5 (18.5)	10 (13.0)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.7)	1 (1.0)
Religion					
Protestantism	13 (59.1)	2 (18.2)	1 (6.7)	5 (18.5)	21 (28.0)
Catholicism	5 (22.7)	0 (0.0)	12 (80.0)	0 (0)	17 (22.7)
Buddhism	1 (4.6)	0 (0.0)	0 (0.0)	6 (22.2)	7 (9.3)
Islam	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.7)	1 (1.3)
Others	1 (4.6)	9 (81.8)	2 (13.3)	4 (14.8)	16 (21.3)
No religion	2 (9.1)	0 (0.0)	0 (0.0)	11 (40.7)	13 (17.3)
Born in the United States					
Yes	21 (95.5)	11 (100)	7 (46.7)	1 (3.7)	40 (53.3)
No	1 (4.5)	0 (0.0)	8 (53.3)	26 (96.3)	35 (46.7)
General health					
Very unhealthy	0 (0.0)	0 (0.0)	1 (6.7)	5 (18.5)	6 (8.0)
Unhealthy	8 (36.4)	2 (18.2)	5 (33.3)	8 (29.6)	23 (30.7)
Don't know	0 (0.0)	0 (0.0)	2 (13.3)	7 (25.9)	9 (12.0)
Healthy	14 (63.6)	9 (81.8)	6 (40.0)	6 (22.2)	35 (46.7)
Very healthy	0 (0.0)	0 (0.0)	1 (6.7)	1 (3.7)	2 (2.7)
Primary cancer site					
Colorectal	1 (4.6)	0 (0.0)	0 (0.0)	2 (7.4)	3 (4.0)
Breast	8 (36.4)	9 (81.8)	3 (20.0)	12 (44.4)	32 (42.7)
Leukemia	0 (0.0)	0 (0.0)	3 (20.0)	1 (3.7)	4 (5.3)
Lymphoma	2 (9.1)	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.7)
Gynecological	2 (9.1)	0 (0.0)	1 (6.7)	5 (18.5)	8 (10.7)
Endocrine	2 (8.1)	1 (9.1)	1 (6.7)	0 (0.0)	4 (5.3)
Lung	1 (4.6)	1 (9.1)	1 (6.7)	3 (11.0)	6 (8.0)

(*continues*)

TABLE 1. (continued)

Characteristics	White[a] (*n* = 22)	African American[b] (*n* = 11)	Hispanic[c] (*n* = 15)	Asian[d] (*n* = 27)	Total (*N* = 75)
Gastrointestinal	1 (4.6)	0 (0.0)	0 (0.0)	1 (3.7)	2 (2.7)
Combined	0 (0.0)	0 (0.0)	4 (26.6)	0 (0.0)	4 (5.3)
Others	5 (22.7)	0 (0.0)	2 (13.3)	3 (11.1)	10 (13.3)
Stage of cancer					
0	1 (4.6)	1 (9.1)	0 (0.0)	2 (7.4)	4 (5.3)
I	3 (13.6)	0 (0)	1 (6.7)	7 (25.9)	11 (14.7)
II	6 (27.3)	6 (54.6)	0 (0.0)	7 (25.9)	19 (25.3)
III	3 (13.6)	2 (18.2)	0 (0.0)	4 (14.8)	9 (12.0)
IV	7 (31.8)	0 (0.0)	3 (20.0)	3 (11.1)	13 (17.3)
Unknown	1 (4.6)	1 (9.1)	10 (66.7)	1 (3.7)	13 (17.3)
Missing	0 (0.0)	1 (9.1)	1 (6.7)	3 (11.1)	5 (6.7)
Recurrent	1 (4.6)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.3)
Previous treatments					
Chemotherapy only	4 (18.2)	3 (27.3)	3 (20.0)	3 (11.1)	13 (17.3)
Surgery	3 (13.6)	0 (0.0)	1 (6.7)	0 (0.0)	4 (5.3)
Radiation only	2 (9.1)	1 (9.1)	0 (0.0)	1 (3.7)	4 (5.3)
Hormone	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Combined	13 (59.1)	6 (54.5)	11 (73.3)	23 (85.2)	53 (70.7)
Others	0 (0.0)	1 (9.1)	0 (0.0)	0 (0.0)	1 (1.3)
Usage of pain medication					
Yes	12 (55.0)	2 (18.2)	9 (60.0)	11 (40.7)	34 (45.3)
No	10 (45.0)	9 (81.8)	6 (40.0)	16 (59.3)	41 (54.7)

[a]Source: Im (2006).
[b]Source: Im, Lim, et al. (2008).
[c]Source: Im et al. (2007).
[d]Source: Im, Liu et al. (2008).

and they could post at their convenience. Only those who registered were allowed to access the online forum site to ensure confidentiality and protect privacy. In the forum administration, researchers monitored and considered the participants' visits and the content and flow of discussion.

Data Analysis

The online forum data were processed using thematic analysis (Braun & Clarke, 2006). For each ethnic-specific online forum, the data of the online discussion were printed out directly from the forum site as transcripts. Then, three research team members read and reread the transcripts thoroughly, and each team member did a line-by-line coding according to the ethnic group. Upon unanimous agreement among the research team members, the codes were finalized. Then, the codes were categorized and summarized in a coding book for each ethnic group. In each ethnic group, the relationships among the categories were examined and linked to each other, and the links were analyzed to extract themes representing the cancer pain experience of each ethnic group.

Researchers discussed the commonalities and differences in the themes of cancer pain experience among the four different ethnic groups through a comparative analysis within each online topic. During the process, the possible effects of contextual factors such as health status, financial status, families' responses and roles, stability of their daily lives, and social support networks were also considered. Throughout the data collection and analysis process, reading and rereading text were done continuously to refine ideas about commonalities and differences in the cancer pain experience of the four ethnic groups. This process used an ongoing system of checks and balances through providing opportunities to reconsider continuously the themes representing the commonalities and differences.

Rigor of the Study

To ensure the rigor of this study, the criteria of rigor in feminist research suggested by Hall and Stevens (1991) were used. In this study, reflexivity was ensured by maintaining a chronological research diary, memos, and field notes. Then, dependability was established by examining the research diary, memos, and field notes for the methodological and analytic decision trails created throughout the four ethnic-specific online forums. To ensure two other criteria (credibility and relevance), the researchers sought participants' feedback through a message board that was available on the project Web site to make researchers available for participants'

TABLE 2. The Online Forum Topics[a]

Topic no.	Contents of topics
Topic 1	Terminology used to describe cancer pain and their linguistic meanings
Topic 2	Verbal and nonverbal communication styles used to convey cancer pain
Topic 3	Culturally universal and specific descriptions of cancer pain
Topic 4	Gender differences in pain descriptions
Topic 5	Patients' responses to cancer pain
Topic 6	Patients' evaluations of cancer pain assessment conducted by healthcare professionals
Topic 7	Patients' evaluations of cancer pain assessment tools
Topic 8	Patients' evaluations of cancer pain management provided by healthcare providers
Topic 9	Patients' preferences for cancer pain management strategies

[a]Sources: Im (2006); Im, Lim, et al. (2008); Im et al. (2007); and Im, Liu, et al. (2008).

questions and verification of intent and to receive feedback about how the study would matter for participants. Finally, in this study, adequacy was ensured through continuously reexamining research questions and methods, goals, design, scope, analysis, conclusions, and impact of the study within the social and political environment.

Results

Three themes reflecting similarities among the four ethnic groups and three themes reflecting differences among the four ethnic groups were identified through the data analysis process. Each theme is described in detail in the following sections. The quotes supporting the themes came directly from the transcripts, and they were not edited purposely, to reflect the participants' own voices.

Commonalities Across the Ethnic Groups

Communication Breakdown Across ethnic groups, participants expressed having difficulties communicating with healthcare providers regarding their pain, although the specific reasons for those difficulties differed by ethnic group. One White participant mentioned,

> When I was suffering horribly after tram flap breast reconstruction and simultaneous mastectomy, I could barely speak English. I expressed pain with grimaces, twisting in pain and rolling in bed. Not one hospital worker acknowledged the terrible pain I was in, and one actually refused to call my very-young plastic surgeon, who had ordered inadequate pain medications for me.

One African American participant mentioned,

> I have a problem with Neuropathy. It is really hard to get someone to understand the severity of your pain. I've been given a paper with the numbers usually. It gives the doctors only an idea of how you feel at that moment. I feel that actually describing the pain is a more effective way. However, I do get the impression with some of my doctors that they think that I'm just complaining. It's so hard to get someone to understand what you are feeling.

Most Hispanic and Asian participants also mentioned difficulties in communicating with their healthcare providers about their cancer pain, but their reason was language barriers. One of the Hispanic participants said,

> I am a woman from Mexico. The differences: here they speak English and in Mexico they speak Spanish. I have problems when they do not understand me, because I speak Spanish and the nurses and the doctors speak English. I do not know if I have a right communication with them.

One of the Asian participants stated,

> My education background is: MBA graduate education. However, the communication in American medical institutions is still a big difficulty.

Changes in Perspectives Across ethnic groups, participants reported changes in their perspectives and attitudes toward their lives after the diagnosis of cancer. They realized how precious life is; they were thankful to be alive; and they found new meaning in their lives. Many of them talked of "living life to its fullest" and of having a "positive attitude." These changes in their perspectives made their cancer pain experience more tolerable. One of the White participants mentioned,

> I have accepted the new Me, I am much happier rather now that I'm no longer sitting in the dark afraid to do anything and I'm more apt to try new things as I let go of the old ways!…I had to find new meaning to the life and different body that I've been given…which made my pain more tolerable.

One of the Hispanic participants mentioned,

> After that year I was on a pursuit to become a better person and to change the world for the better. The changes were very positive for me and since then I have constantly surprised myself on how far I have gone and how fortunate I am for the people around me…These changes made me to be patient about pain as well…

One of the Asian American participants mentioned,

> At that time, I thought there was no meaning in life for me. I tried to commit suicide. But now, I have learned a lot about life from my friends, books, and cancer patients around me. So I am not afraid of death now and I can stand the pain. Whenever there is pain in my life, I compare it to the pain in my chemo and I can stand it.

Gendered Experience Another common theme of cancer pain experience across ethnic groups was as follows: Their cancer pain experience was a gendered experience. Many participants mentioned that women were disadvantaged in

cancer pain management. They thought that men's cancer pain was taken more seriously and that people tended to acknowledge men's pain more easily than women's pain. One of the female White participants mentioned,

> I have noticed that if my husband so much as mentions that he has any pain what so ever he is taken care of right off with pain medications, therapy and so forth, but when I express any pain I'm treated like I'm just trying to get my hands on drugs and told to basically take two aspirin and a hot bath or as my oncology doctor tells me…

Most of the female participants believed that being a woman, especially being a mother, required them to have a higher tolerance for pain than that of men. They had to shoulder all the burdens of household tasks and child rearing despite their disease status. One of the female Hispanic participants mentioned,

> Having 3 children and a husband doesn't really give me the luxury to do that but I have been able to balance it all so far. I believe that women are used to handling higher degrees of pain for longer periods of time. Women are stronger in dealing with pain. With the cancer pain, I have to depend on others, when other people normally depend on me; this is very different for me…

One of the Asian woman participants mentioned,

> When a woman got cancer, she will become stronger and braver, especially being a mother. She will become brave to face the treatment and to survive for her children. When a man got cancer, I saw some trying to avoid, blame God and people and could not face it.

Most of the female participants across ethnic groups thought that women tolerated pain more readily than did men because women are the gender who lives with pain through childbirth and menstruation. One of the female Asian participants mentioned,

> I am more tolerant for pain. I used to be patient to wait until it is over. I try to do things to avoid thinking about the pain. Until it really gets serious, then I take pills. Women know pain all our lives, so it is not that horrible to deal with. I see some man can be really off when he has a little pain, like my husband.

One of the White women wrote,

> Regarding pain, I think that I tolerate more than my husband, and it probably has something to do with having given birth three times and having less of an "I'm vulnerable" outlook on life…I think women may be used to chronic type pain, ie our monthly menses, we become used to the cramping etc.

Differences Among the Ethnic Groups

Controlling Versus Minimizing Whereas Whites tried to control their pain and treatment selection process, ethnic minorities tended to minimize and normalize their pain. Many of the White participants were agitated about healthcare providers who neglected their pain. They left healthcare providers who did not listen to them and found others because they wanted a caring provider who would treat them respectfully. One of the White participants mentioned,

> I still don't hesitate to fire a doctor if they don't listen to me. I try very hard to be quick and thorough and I expect to pay them for the same or I find someone who will. I have left some doctors because their staff is continually deaf, and I tell the doctor at least twice—the third time…

Ethnic minorities thought differently about cancer pain: Cancer was related to death and was still a dirty word to use, and increasing pain meant that cancer was getting worse. Subsequently, many of them did not want to talk about pain but minimized it. Especially Asian participants tried to hide pain because pain from cancer was seen as a result of "bad karma" or punishment of a sin in the past. Most ethnic minorities were also minimizing their pain through depending on religious faith, which played a very important role in helping the participants face cancer and pain; faith, and taking comfort in faith, made the pain tolerable. They thought there was a divine will that they got cancer. One of the Hispanic participants said,

> I focus more on the spiritual/faithful side. I asked God to help me and I give Him thanks. I start to pray and sing to God. Many people come and pray for me. Only God is the one that can help me and we pray and I go to prayer meetings. I have faith in God and if He wants, he can take this cancer and pain away from me. I try to keep a positive outlook…

One of the Asian participants wrote,

> I am a person who believes there is a God. I was once afraid of death and had difficulty to tolerate pain. Later, contributing to the contact of the thinking of Buddhism, Christian, and Confucianism and the related articles, I have a totally new understanding toward life and death. When pain comes, I try to use deep breath and meditate and murmur "Amitofo" to distract attention and to decrease pain or fear.

Searching for Versus Naturalizing Most of the White participants wanted to treat their cancer using Western medicine. They searched for diverse strategies of pain management through the Internet, support groups, pain clinics, and other sources. They searched for the best doctors who were most qualified to treat their cancer and provide adequate cancer pain management. They wanted a healthcare provider who was sensitive to their needs. They constantly researched, asked questions, and networked with their fellow survivors. One White participant said,

> I have tried a lot of different things and even seen the holistic practitioner for a length of time. I like doctors who use the holistic approach to medicine. They are trained to treat the patient like a human being and not just "the patient." The human factor goes along way in the healing and pain process. When I feel I have a doctor or nurse who is sensitive to my needs, it seems to make recovery a lot easier.

Ethnic minorities, however, tended to try to maintain normal lives and use natural modalities for pain management. Ethnic minorities, especially Asian participants, thought that cancer pain was a universal human experience that should not be emphasized at all. They wanted to reduce pain in natural ways instead of treating it aggressively through Western medicine. One of the Asian participants mentioned,

> I prefer the non-conventional treatment since it's less invasive and it's also quite relaxing. I feel great with my choices. I also practice GuoLing Qigong, to reduce pain and help recovery.

Individualized Versus Family Oriented Cancer pain was an individualized experience for most of the White participants, whereas it was a family experience for most ethnic minorities. The White participants' cancer pain experience tended to be very individualistic and independent. One of the White participants wrote,

> First making the decision to have radiation was hard enough, and once made I was loath to stop it. Now I had to make the decision again! I was outraged and confused. My husband kept quiet and I made this important choice by myself…I think I pissed off the radiation clinic, or perhaps the doctor. Either way no communication existed after that.

Ethnic minorities differed. They received a lot of support from their families during the cancer treatment process, and they fought cancer for their families. The families were involved deeply in the decision-making process related to cancer treatment and pain management. One of the Hispanic participants wrote,

> I have family and I can't and will not let cancer beat me. I want to grow old and I want to see my children have children. It might be years away but I will be here for my grandchildren. I just will make the effort to be strong through all of this and treat my body well.

One of the Asian participants mentioned,

> There is worry, heart pain in families, especially my mom. She helped me go through a very difficult period. She taught me everything would pass over and I would get well. Then she taught me how to read Buddhism. She read Buddhism everyday in front of the statue of Buddha and begged Buddha to bless me.

Discussion

When considering the lack of comparative studies on cancer pain experience among the four major ethnic groups of patients with cancer in the United States, the study presented in this article certainly adds new information to the current literature. Yet, despite the paucity of the literature on this topic, some of the findings reported in this article agree with previous findings of the few studies that have taken place. First, the themes representing the commonalities in cancer pain experience across ethnic groups that are reported in this article agree with previous findings in the literature. The themes of communication breakdown and gendered experience affirm the findings of previous studies (Chan & Woodruff, 1997; Laliberte, 2003). Indeed, the previous studies have reported that miscommunication was a major reason for inadequate cancer pain management, especially for ethnic minority patients with cancer, and that, across the ethnic groups, women were the ones who should shoulder the burdens of household tasks despite their diseases. The second theme representing the commonalities in cancer pain experience across ethnic groups, changes in perspectives, also agrees with findings of the few previous studies. The studies have reported the adjustment process and transcendent experiences of patients with cancer throughout the adjustment process, which frequently results in changes in perspectives (Fatone et al., 2007; Foley et al., 2006). The specific changes in perspectives according to ethnicity (that are reported in this study) also agree with the findings of previous studies (Green et al., 2003; Pinquart & Sorensen, 2005). Among White participants, the changes in their perspectives were for control of their own bodies, diseases, and lives; among ethnic minority participants, the changes in perspectives focused on the welfare of their families.

The findings reported in this article add new information to the current literature as well. The first theme of the differences in cancer pain experience among the four ethnic groups, controlling versus minimizing, reflects how differently cultures view cancer and cancer pain, which has been rarely reported in the literature. Most White participants viewed cancer as a chronic condition that they could overcome by controlling their own bodies and disease processes, whereas ethnic minority participants tried to minimize their pain because of the stigmatized nature of cancer in their culture, their cultural stoic attitudes toward pain, or both. These ethnic differences may come from cultural differences among the four ethnic groups. First of all, individualism embedded in White culture views individualists as having control over and taking responsibility for their actions (Green et al., 2003), which might make White participants focus on how to control their pain and bodies. African American culture that stigmatizes cancer as a contagious disease, God's punishment for improper behavior or not living according to His will, or the work of the devil (Bailey, Erwin, & Belin, 2000) might make African American people hide their disease and minimize their pain. *Machismo*, a Hispanic cultural feature (which instructs that men should be strong and in control and help meet the needs of the family), and Hispanic cultural values that emphasize women's sacrifice for their families and the importance of motherhood (De Pheils & Jaramillo, 2003) might make Hispanics behave stoically toward pain. Finally, Asian culture based on Confucianism and Taoism in which stoicism is valued highly (Chung, Wong, & Yang, 2000) might inhibit them from expressing pain and other potentially disruptive and distressing emotions including fear, anxiety, sadness, or anger.

The second theme representing the differences in cancer pain experience among the four major ethnic groups, searching for versus naturalizing, highlights cultural differences in cancer pain experience, which adds new information to the current literature. This study indicated that White participants were searching for better treatment of cancer

and management of pain, whereas ethnic minority patients with cancer tried to naturalize their pain and tolerate as much pain as they could. These findings have been reported episodically in the literature, but they tend to be limited to a specific ethnic group in each individual study (Ashing-Giwa et al., 2006). An interesting finding was that naturalizing cancer and pain was much more prominent among the Asian participants compared with that among other ethnic groups. Through acting normally, Asian participants tried not to give cause to worry or to be burdens to their families. This might also result in the prevalent use of complimentary and alternative medicine among Asian participants because complimentary and alternative medicine emphasizes that negative attitudes lead to negative behavior patterns that result in cancer (Im, 2000).

The third theme representing differences in cancer pain experience among the ethnic groups, individualized versus family oriented, also adds new distinction to ethnic differences in cancer pain experience. These findings can also be linked to individualism in White culture and to collectivism in African American, Hispanic, and Asian culture (Gonzalez, Gallardo, & Bastani, 2005; Pinquart & Sorensen, 2005). Because of their individualistic cultural background, White participants experienced and managed their pain independently of family members. Also, because of their collectivistic cultural background, ethnic minorities tended to depend on their families in their cancer pain management process.

The findings of the study reported in this article have several limitations. First of all, the study is limited in its generalizability because the participants were recruited using a convenience sampling method and the data collection was done through the Internet. Subsequently, participants might not fully represent diverse groups of patients with cancer within each ethnic group because of inherent characteristics of a convenience sampling method. Indeed, the participants tended to be highly educated patients with cancer who were willing to use a computer and the Internet and who were able to type. In addition, the participants in each ethnic group did not represent all subethnic groups within each ethnic group. For example, a majority of the Asian participants were foreign-born Chinese patients with cancer and did not represent subethnic groups of Asians in the United States adequately.

Conclusions and Implications

On the basis of the findings, the following recommendations for future research and healthcare practice with patients with cancer from multiethnic groups in the United States are offered. First of all, nurses should be aware of cultural differences in cancer pain experience and use culturally competent approaches to cancer pain management for different ethnic groups of patients with cancer. Cultural competence refers to the acknowledgment and affirmation of cultural sensitivity embedded in cultural knowledge (Spector, 2000). As the findings of the study reported in this article indicated, the cancer pain experience of each ethnic group was unique and culturally embedded. As the IOM (2002) recommended, increasing awareness of disparities in cancer pain management due to cultural differences in cancer pain experience should come first among nurses.

Second, more in-depth studies on subethnic variations in each major ethnic group are needed. As mentioned earlier, the participants of the study reported in this article might not represent diverse ethnic groups of patients with cancer in the United States. When considering various subethnic groups within each major ethnic group and the unique cultural background of each subethnic group, more in-depth studies on subethnic variations are essential for a comprehensive understanding of cancer pain experience in the United States and for culturally competent cancer pain management. As Ho (2000) asserted based on the work of the Asian American Network for Cancer Awareness, Research, and Training, further exploration especially on the pain experience of Asian patients with cancer is needed because very little is still known about their cancer pain experience and because subethnic variations among this population are much more prominent than those among other major ethnic groups (more than 30 subethnic groups among Asians in the United States).

Finally, more in-depth cultural studies on cancer pain experience among diverse gender, ethnic, and socioeconomic groups are needed to develop a cultural knowledge base of cancer pain experience. As discussed earlier, the participants of the study reported in this article tended to be a select group of patients with cancer. Thus, the recommendations by the Agency for Healthcare Research and Quality (2008) are echoed here: Further studies on the cancer pain experiences of diverse gender, ethnic, and socioeconomic groups of patients with cancer are essential for continuous development of cultural knowledge that will provide directions for culturally competent care for ethnic minority patients with cancer in the United States. ▼

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References

Agency for Healthcare Research and Quality. (2008). *Management of cancer pain. Evidence report/technology assessment: Number 35*. Retrieved May 24, 2008, from http://www.ahrq.gov/clinic/epcsums/canpainsum.htm

American Cancer Society. (2006). *Estimated new cancer cases and deaths by sex for all sites, US, 2006*. Retrieved July 21, 2006, from http://www.cancer.org/docroot/MED/content/downloads/MED_1_1x_CFF2006_Estimated_New-Cases_Deaths_by_Sex_US.asp

Anderson, K. O., Mendoza, T. R., Valero, V., Richman, S. P., Russell, C., Hurley, J., et al. (2000). Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer, 88*(8), 1929–1938.

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*(8), 2295–2304.

Ashing-Giwa, K. T., Padilla, G. V., Bohorquez, D. E., Tejero, J. S., Garcia, M., & Meyers, E. A. (2006). Survivorship: A qualitative investigation of Latinas diagnosed with cervical cancer. *Journal of Psychosocial Oncology, 24*(4), 53–88.

Bailey, E. J., Erwin, D. O., & Belin, P. (2000). Using cultural beliefs and patterns to improve mammography utilization among African-American women: The Witness Project. *Journal of the National Medical Association, 92*(3), 136–142.

Barkwell, D. (2005). Cancer pain: Voices of the Ojibway people. *Journal of Pain and Symptom Management, 30*(5), 454–464.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101.

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 & Community Health, 24*(3), 88–103.

Chan, A., & Woodruff, R. K. (1997). Communicating with patients with advanced cancer. *Journal of Palliative Care, 13*(3), 29–33.

Chung, J. W. Y., Wong, T. K. S., & Yang, J. C. S. (2000). The lens model: Assessment of cancer pain in a Chinese context. *Cancer Nursing, 23*(6), 454–461.

De Pheils, P. B., & Jaramillo, D. (2003). Colombians. In P. S. Hill, J. G. Lipson, & A. I. Meleis (Eds.), *Caring for women cross-culturally*. Philadelphia: F. A. Davis.

Edrington, J. M., Paul, S., Dodd, M., West, C., Facione, N., Tripathy, D., et al. (2004). No evidence for sex differences in the severity and treatment of cancer pain. *Journal of Pain and Symptom Management, 28*(3), 225–232.

Eversley, R., Estrin, D., Dibble, S., Wardlaw, L., Pedrosa, M., & Favila-Penney, W. (2005). Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncology Nursing Forum, 32*(2), 250–256.

Fatone, A. M., Moadel, A. B., Foley, F. W., Fleming, M., & Jandorf, L. (2007). Urban voices: The quality-of-life experience among women of color with breast cancer. *Palliative & Supportive Care, 5*(2), 115–125.

Foley, K. L., Farmer, D. F., Petronis, V. M., Smith, R. G., McGraw, S., Smith, K., et al. (2006). A qualitative exploration of the cancer experience among long-term survivors: Comparisons by cancer type, ethnicity, gender, and age. *Psycho-Oncology, 15*(3), 248–258.

Gonzalez, G., Gallardo, N., & 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*(1), 109–120.

Green, C. R., Anderson, K. O., Baker, T. A., Campbell, L. C., Decker, S., Fillingim, R. B., et al. (2003). The unequal burden of pain: Confronting racial and ethnic disparities in pain. *Pain Medicine, 4*(3), 277–294.

Hall, J. M., & Stevens, P. E. (1991). Rigor in feminist research. *Advances in Nursing Science, 13*(3), 16–29.

Ho, R. (2000). Disparities in cancer treatment outcomes among Asian Americans: Implications for the Asian American Network for Cancer Awareness, Research, and Training. *Asian American and Pacific Islander Journal of Health, 8*(1), 39–42.

Hsiung, R. C. (2000). The best of both worlds: An online self-help group hosted by a mental health professional. *Cyberpsychology & Behavior, 3*(6), 935–950.

Im, E. O. (2000). A feminist critique of breast cancer research among Korean women. *Western Journal of Nursing Research, 22*(5), 551–565.

Im, E. O. (2006). White cancer patients' perception of gender and ethnic differences in pain experience. *Cancer Nursing, 29*(6), 441–450.

Im, E. O., & Chee, W. (2004). Issues in Internet survey research among cancer patients. *Cancer Nursing, 27*(1), 34–42.

Im, E. O., & Chee, W. (2006). An online forum as a qualitative research method: Practical issues. *Nursing Research, 55*(4), 267–273.

Im, E. O., Chee, W., Guevara, E., Liu, Y., Lim, H.-J., Tsai, H.-M., et al. (2007). Gender and ethnic differences in cancer pain experience: A multiethnic survey in the United States. *Nursing Research, 56*(5), 296–306.

Im, E. O., Guevara, E., & Chee, W. (2007). The pain experience of Hispanic patients with cancer in the United States. *Oncology Nursing Forum, 34*(4), 861–868.

Im, E. O., Lim, H. J., Clark, M., & Chee, W. (2008). African American cancer patients' pain experience. *Cancer Nursing, 31*(1), 38–46.

Im, E. O., Liu, Y., Kim, Y. H., & Chee, W. (2008). Asian-American cancer patients' pain experience. *Cancer Nursing, 31*(3), E17–E23.

Institute of Medicine. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: The National Academies Press.

Jayadevappa, R., Johnson, J. C., Chhatre, S., Wein, A. J., & Malkowicz, S. B. (2007). Ethnic variation in return to baseline values of patient-reported outcomes in older prostate cancer patients. *Cancer, 109*(11), 2229–2238.

Laliberte, R. (2003). *Doctors' guide to chronic pain: The newest, quickest, and most effective ways to find relief*. New York: The Reader's Digest Association.

McNeill, J. A., Reynolds, J., & Ney, M. L. (2007). Unequal quality of cancer pain management: Disparity in perceived control and proposed solutions. *Oncology Nursing Forum, 34*(6), 1121–1128.

Meghani, S. H., & Keane, A. (2007). Preference for analgesic treatment for cancer pain among African Americans. *Journal of Pain and Symptom Management, 34*(2), 136–147.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist, 45*(1), 90–106.

Rabow, M. W., & Dibble, S. L. (2005). Ethnic differences in pain among outpatients with terminal and end-stage chronic illness. *Pain Medicine, 6*(3), 235–241.

Saba, V. K., & McCormick, K. A. (2001). *Essentials of computers for nurses: Informatics for the new millennium* (3rd ed.). New York: McGraw-Hill.

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*(3), 170–176.