



Published in final edited form as:

Cancer Nurs. 2006 ; 29(6): 441–452.

White Cancer Patients' Perception of Gender and Ethnic Differences in Pain Experience

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Abstract

Not considering cancer patients' own views and experience with pain, especially gender and ethnic differences in their cancer pain experience, was reported to be a major contributor to the miscommunication that frequently results in inadequate cancer pain management. The purpose of this study was to explore white cancer patients' perception of gender and ethnic differences in pain experience through an online forum. This was a descriptive qualitative study among 29 white cancer patients based on a feminist approach. Nine topics related to cancer pain experience were used. The data were analyzed using thematic analysis: 5 themes were identified. First, the participants perceived that pain accompanies cancer throughout the diagnosis and treatment process. Second, the specific characteristics of the participants' individual culture and its view of pain and cancer could result in different cancer pain experience even among white cancer patients. Third, the participants complained that women's pain was not taken seriously by health care providers. Fourth, the participants reported highly individualized pain experience with emotional pain. Finally, the participants wanted to have a control of their own pain management process. Based on the findings, implications for nursing research and practice are proposed.

Keywords

Cancer; Pain; White; Culture; Ethnicity; Gender

Since 1990, approximately 18 million new cases of cancer have been diagnosed.¹ This year about 553,768 Americans (22.9% of all deaths) are expected to die of cancer, which is the second leading cause of death in the U.S., exceeded only by heart disease.¹ Numbers such as these clearly demonstrate the enormity of this disease in terms of morbidity and mortality. Furthermore, the physical and psychosocial manifestations of cancer affect virtually all aspects of patients' lives. One such manifestation that has received considerable attention from health care disciplines, professional organizations, and governmental agencies is cancer pain.² Although currently available therapies have the potential to be effective in most cases, undertreatment is common, and about 30 percent of cancer patients never achieve adequate relief.^{3–6}

Among the barriers to adequate cancer pain management, miscommunication between patients and health care providers has been identified as the primary barrier to good pain management even when standardized practice guidelines are in place.^{7–9} Not considering cancer patients' own views of and experience with pain, especially gender and ethnic differences in their cancer

pain experience, was reported to be a major contributor to the miscommunication that frequently results in inadequate cancer pain management.^{10, 11}

Recently, gender and ethnic differences in pain descriptions have begun to be reported.^{12, 14} In studies of experimentally-induced pain, men have been reported to have a higher pain tolerance and higher pain threshold than women.^{14, 15} In such studies, women were able to discriminate among heat intensities better than men, indicating that gender-related variations in pain perception were probably due to physiological differences, rather than only psychological differences in willingness to report pain.^{15, 16} In another study, whose authors describe gender differences in responses toward electrical stimulation, female subjects reported more pain than males, particularly at higher levels of stimulation.¹⁷ In a recent study, gender differences in pain characteristics were also reported¹⁸: when severity and type of cancer pain are controlled, men more often presented somatic pain while visceral pain was more often reported among women. Gender differences in functional status related to cancer pain have also been reported: men tend to have higher physical functions than women.¹⁹ Additionally, gender differences in help seeking behaviors were reported: men were more likely to seek information while women more likely to seek encouragement and support.^{20, 21}

Ethnic differences in pain descriptions have been reported as well: ethnic variability is evident in ideas about cancer, pain expectations, pain tolerance, pain expression, and health care practices.^{22–26} Rabow and Dibble²⁷ reported that ethnic minority cancer patients reported more pain than white cancer patients. Vallerand et al.²⁸ reported that African American cancer patients had significantly higher pain intensity, more pain-related stress, and reported more pain-related interference with function than white cancer patients. Chin²⁹ reported that Chinese patients might not complain of pain and might not want to “bother” the nurse to ask for pain medication. Guarnero³⁰ indicated that Mexicans might want pain relief as quickly as possible and prefer using words to describe pain easier than using numbers.

Despite these findings on gender and ethnic differences, these factors have not been systematically studied as to how they might affect cancer pain assessment and treatment in the practice arena. The purpose of this study was to explore white cancer patients’ perception of gender and ethnic differences in pain experience through an online forum, as part of a larger web-based study of 4 major ethnic groups in the U.S., of which only the findings from an online forum among white cancer patients are presented here.

To guide this online forum, a feminist approach was used. Science carries a variety of assumptions and methods, some of which tend to devalue research participants’ own experiences.³¹ When science is used to support predominant androcentric and ethnocentric views and interests, those who are not part of this dominant group are marginalized, and their issues are either not considered relevant for a study or not reflected accurately in research.³² Therefore, feminist researchers prioritize research participants’ own views, perspectives, opinions, and experiences.³³ In addition, feminists believe that there can be no pure biology, because people do not live in a vacuum.³⁴ Rather, all feminist theory posits gender as a significant characteristic that interacts with other factors, such as ethnicity, race, and class, to structure relationships among individuals.³⁵ In this study, a feminist stance was taken that assumed that inadequate assessment of cancer pain reported by patients did not only come from pure biology, but from their continuous interactions with their environment and from biases reflecting the ways they and their health care providers view the world.³⁴ Using a feminist approach, patients’ own views were prioritized, and gender and ethnicity were viewed as significant characteristics for structuring cancer pain experience.

Adherence to standards of rigor in feminist qualitative research including dependability, reflexivity, credibility, relevance, and adequacy assured scientific adequacy.³³

Dependability was ensured by examining the methodological and analytic decision trails created throughout the online forum. *Reflexivity* was supported by chronological research diary, memos, and field notes. *Credibility* and *relevance* were achieved by asking the participant's responses to the study findings by posting the study findings on the online forum site. *Adequacy* was assured by continuously questioning research methods, goals, research questions, design, scope, analysis, conclusions, and impact of the study within the social and political environment.

Methods

This was a descriptive qualitative study via an online forum in which 29 white cancer patients participated. The study was approved by the Internet Review Board of the institution where the author is affiliated.

Samples and Settings

A total of 29 self-identified non-Hispanic white cancer pain patients were recruited from 122 participants of a web survey who were themselves recruited using a convenience sampling method through Internet cancer support groups (ICSGs). When a participant who completed the web survey agreed to participate in an additional online forum, she/he was later contacted and asked to visit the online forum site when the online forum was initiated. All the web survey participants who agreed to participate in the additional online forum were invited, yet only 29 actually participated in the online forum. In general, 6–12 participants are thought to be ideal for a focus group discussion,³⁶ and in qualitative study designs including this online forum method, intensive focus and in-depth data collection are of greater value than a large number of participants. Thus, 29 is an adequate number for the online forum discussion.

The inclusion criteria for research participants were: online cancer patients aged at least 18 years who can read and write English and whose self-reported ethnic identity is non-Hispanic (N-H) white. The reason for excluding children under 18 years is that, developmentally, they can not respond adequately to the questions asked in the study. The study assumed that participants were able to differentiate their cultures from others and describe differences in their cultures. Sociodemographic characteristics of the participants are summarized in Table 1. The mean age of the participants was 44.31 years ($SD=10.35$), and about 86% were women. More than 80% of the participants were college graduates, and about 41% were employed. More than 50% reported that their family income was sufficient or more than sufficient, and about 58% were protestants. About 97% were born in the U.S. About 52% perceived that they were healthy.

The online forum was held for 6 months. A total of 291 messages were posted to the forum site. 22 participants posted messages on all the topics spanning the 6-month period, thus participant retention was high. To minimize attrition during this period, we employed a variety of retention strategies. Examples of the retention strategies are: (a) establishing bonds between the participants and researchers via respectful and trustworthy interactions through online forums; (b) assigning 1 research staff member to follow the online forums consistently for 6 months; (c) providing a modest monetary incentive of \$50 to each participant at the completion of the online forums; and (d) providing web links to resources on various types of cancer and Internet support for cancer patients.

Discussion Topics

Nine topics related to cancer pain experience were used for the online forum. The 9 topics were as follows: (a) terminology to describe cancer pain and their linguistic meanings; (b) verbal and nonverbal communication styles used to relate cancer pain; (c) culturally universal and specific

descriptions of cancer pain; (d) gender differences in pain descriptions; (e) patient's responses to cancer pain; (f) patient's evaluation of cancer pain assessment conducted by health care professionals; (g) patient's evaluation of cancer pain assessment tools; (h) patient's evaluation of cancer pain management provided by health care providers; and (i) patient's preferences for cancer pain management strategies. To help the participants understand and discuss the topics better, several examples of questions related to each topic were provided to the participants so that they could consider the questions before discussing the topics. These topics and the examples of questions were developed by the authors and reviewed by an expert panel of oncology nurses. Based on the feedback by the expert panel, the topics were modified. Then, the topics were pilot-tested among 9 white cancer patients, and the findings from the pilot study can be found elsewhere.³⁷

Data Collection Procedures

As explained above, participants for online forums were recruited from a larger group who had taken a web survey and who agreed to be in the online forum by clicking "I agree to participate" after completing the survey. The participants were asked to visit the online forum site by using the username and passwords that they chose during the registration process of the web survey. Also, the participants were asked to choose pseudonyms for the online forum discussions so that their real names could not be identified by other participants. The IDs and passwords had to be used whenever participants logged in at the online forum site, and they were used to link quantitative and qualitative data at the individual level. Also, their visits at the online forum sites were recorded, monitored, and controlled. Only those who registered were allowed to enter the online forums to ensure confidentiality and protect privacy.

When an adequate number of participants (29 in this online forum) were recruited, the online forum was initiated. One of the researchers sent out e-mails to inform the registered participants of the initiation. The opening page of the online forum sites showed the introductory questions so that participants could introduce themselves when they visited the site for the first time. The introductory questions and 9 discussions topics were posted serially on the forum site and remained there for the whole 6 months, and participants could post messages about the topics at their convenience in any forms they wished (e.g., stories, conversations, responses to others' messages, etc.). A research staff member who was in charge of online forums steered discussions about Topics 1 to 9 throughout the 6-month period, using prompts as needed and always considering the content and flow of discussion. The number and length of messages were not limited. During the fifth month, the participants were asked to add topics that they wanted to discuss with other participants, and the added topics were available on the online forum site for the remainder of the 6 months.

Data Analysis

Thematic analysis guided the analysis of data from the forums, which occurred simultaneously with online forum discussion. After the first week of data collection, the analysis process was started. First, data from the discussions were printed out directly from the online forum site as transcripts, which were thoroughly read and re-read for line-by-line coding. The codes from the line-by-line coding process were summarized as a coding book. Using the coding book, categories that emerged from internal cognitive processing and reflexive thinking were constructed by analyzing content and context. Then, relationships between categories were formulated by mapping associative links among the categories. Based on the relationships between categories, commonalities and differences in cancer pain experiences between men and women were sought. At the same time, ethnicity-specific and/or culture-specific unique cancer pain experience of white women was sought. Also, the effects of variable contextual factors including variable health status, socioeconomic circumstances, families' responses and roles, stability of their daily lives, and social support networks, along with other factors, were

examined. In addition, an interactive process that involved reading and re-reading text to produce successively more abstract and refined ideas about domains of interest was used to identify themes common to research participants. This process served as an ongoing system of checks and balances.

Findings

Five themes were identified through the analysis process. First, the participants perceived that pain accompanies cancer throughout the diagnosis and treatment process. Second, the participants perceived that culture is more than ethnicity, which could result in different cancer pain experiences. Third, the participants complained that women's pain was not taken seriously by health care providers. Fourth, the participants reported highly individualized pain experience with emotional pain: some experienced no pain at all while others were suffering due to serious uncontrolled pain. Finally, the participants wanted to have a control of their own pain management process. Each theme is presented as follows.

Pain Accompanies Cancer

The participants related their pain experience to cancer and its diagnosis and treatment process. The participants remembered the start point of pain vividly, even recalling the exact moment with its emotional details. One of the participants mentioned that:

It is a quite a long story, but I will summarize: I never had any medical problems until 2000...In June of 2000 I was having the most excruciating pain in my abdomen and chest. All the good, doctors I spoke to kept telling me I had gas pains. I was almost blacking out, the pain could come on so strong. So, needless to say, I knew they were wrong... I ended up having emergency gallbladder surgery and have over 1,000 stones upon removal. To top all that off, they found a massive tumor on my liver while performing the surgery."

The participants remembered their pain experience with the details on the treatment that they have received although most of them reported their easy forgetfulness due to chemotherapy (they called it "chemobrain"). One of the participants described the treatment process that they have received as follows:

Between Thanksgiving and Christmas in 2002, I knew I had to go for my yearly check-up early because of abdominal pain... On Jan. 7th, I spent 4 hours at the clinic with more appointments following 2 days. I had 2 liters of fluid removed from my lungs on 1 of them. I had complete hysterectomy and ovary removal on the 17th. I was diagnosed with Stage 4 ovarian cancer. They gave me 3 months without chemo and a 5% chance to make it for a year following the last treatment, which is my grandson's birthday, May 22. Needless to say, I just started chemo again last Thursday. These treatments always accompanied pain.

In most cases, the participants described that they thought that cancer meant death and demise at the time of diagnosis. However, they later found that they needed to fight the cancer, and they recognized that cancer was the thing that they needed to live with and that pain accompanies cancer throughout the diagnosis and treatment process. Most of them said that pain was the natural and normal process of cancer and that they needed to "suck it up."

Culture Is More Than Ethnicity

When the participants were asked about their perceived ethnic differences in cancer pain experience, most of them raised the question of what culture is. Although all of them were white, they identified themselves as a mixture of specific ethnic backgrounds such as English,

French, Italian, Irish, Scottish, Russian, Dutch, French, Finnish, etc. Two of the participants identified themselves as follows.

I am White mutt that is predominantly Russian, Scottish, Dutch, French, and Finnish with a little English and Irish throw into a third generation American.

White Caucasian: French-Canadian (my father was born in Canada), English, Irish/Scottish, German, Hungarian (grandparents born in Budapest), Polish: these are my 4 grandparents.

The participants viewed their culture regionally, such as non-traditional Southerners, Appalachians, proper Northerners. They also defined themselves according to forms of social organization, particularly economic (work-related), such as a blue-collar, steel mill community culture, and rural farm community culture. One of the participants said:

I live in a rural community. It is mainly a farming community with a lot of lakes also. We have a lot of summer people that come from the bigger cities that visit their cabins. In my younger days, I grew up in a home on the lake and in my married life, we bought land that belonged to my father's side of the family, then went to my mother's and back to my father's.

Most of the participants identified specific characteristics of their individual culture and its view of pain and cancer. These identified characteristics and views certainly support that culture among white cancer patients is more than solely ethnicity and can be differentiated by geographical areas, family traditions, and/or work environments. Also, these findings indicate that these specific characteristics could result in different cancer pain experience even among white cancer patients. One of the participants mentioned:

I realize the difference from then to now (the difference between Hungarian culture of father and German culture of mother). My father's sister got Cancer first and everything was done to accommodate her and then the whole family had an opinion on what she should do and would try and take over her decision making. The German side (of my parents). My mother's sister has Cancer of the Colon, and was getting treatments the same time I was. I only knew this when I told that family, then it was permissible to talk about it. Lots of "God" will help you, put your hands in your faith" was permeated through the Lutheran religion... The Germans do acknowledge pain, verbally, and by going to the doctor. The Hungarians never see a doctor or a dentist, as if it was below them, later I found out it was because they did not trust them. The sides of the family that actually were hospitalized, are all dead from that event.

Women's Pain Not Seriously Taken

Most of the participants mentioned that there were certain gender differences in their perceived cancer pain experience. One of the participants reported their perceived gender differences in cancer pain experience as follows:

I can only compare myself with my husband. I have had lymphoma and have received numerous treatments of chemo, radiation, and surgery. He had a bout with early-stage prostate cancer, got the seed implants, and so far has a very low PSA and is doing fine. I think he thinks more about cancer than I do, but he has always been a worrier and doom and gloom Irish Catholic (life is hard, a testing ground, then we die and go to heaven).

Most of the female participants reported that they were treated differently by their family, friends, and physicians because of their gender, although the male participants did not make any comments on this. One of the female participants made this mention of gender differences:

I think because men tend to be the stereotypical bread-winner, their cancers are taken more seriously by family, friends, and doctors. I think that doctors tend to actually listen to the answers male patients give regarding their health, pain, etc. For some reason, men are given more credence when they say, it hurts. Women, I believe have higher pain tolerances, maybe it's that childbirth thing. I know I don't always speak up right away when I'm in pain. I feel like I'm going to be burden on someone. Whereas men are used to having someone take care of everything, they bring home the bacon, we fry it up, stereotypically speaking... 'Mom' always takes care of everyone, but who take care of 'mom'?

Highly Individualized Pain Experience With Emotional Pain

The participants' pain experience was highly individualized. Some had serious pain from the treatment preparation process, the side effects of treatment, surgery, or cancer itself. One of the participants mentioned their experience of pain, due to preparing for cancer treatment and treatment itself, as follows:

Tram flap has left me in continuing abdominal pain, unable to sit up, lift or push, with a big hernia, requiring a third repair surgery, and my orgasms hurt now because of tram flap reconstruction, so I have no sex life. The pain that cancer surgery caused me continues to this day, even though I supposedly have no cancer.

On the contrary, others reported that they experienced just a little discomfort rather than pain although they went through the treatment process as others who had suffered pain. One of the participants said:

As to pain from my cancer, I really have not had any severe pain, mostly discomfort. For me, Lymphoma, as it affects the lymph system tends to be not painful... I have several nodes in my groin, that at this time are significantly bigger than normal, that cause discomfort, but not pain.

The participants tended to divide pain experience into physical pain and emotional pain. Many of the participants mentioned that emotional pain had been much crueler than physical pain. One of the participants said:

As far as pain.. I have 2 types... physical and emotional. The physical is much as Jane explained... As for the emotional pain that comes from having a form of cancer no one seems to think of as "real" cancer. We typically don't do chemo or traditional radiation. And every doctor you meet and every website refers to it as the "good" cancer, so of course none of my in-laws take it seriously... However, 3 days in isolation after injecting a chemical they brought to my room in a 20 lb lead container on a 4 foot dolly while wearing hazmat clothing, and having tape and plastic covering because they don't want you to contaminate it, having to catch my urine and pour it into a lead container...feeling like the proverbial leper...it's painful.

Controlled or Controlling

The participants were struggling with the issues related to their control of their own bodies and lives in cancer pain assessment and management process. Many of the participants felt that they did not have any choice, that their lives were not in their own control, and that they just needed to bear the experience. One of the participants mentioned:

I have to say, I had no choice in the matter, and just had to go through it. I did whatever I had to do, to try to be better as quickly as possible... I can do nothing about how I feel or the pain I can sometimes find myself in due to muscle spasm etc. I simply have to live with them, and I have to say, I am glad to be living!

Except for 2 cases, all the participants were upset about ignorance of their pain by health care providers. One of the upset participants mentioned that:

I hate to talk about my pain to someone in oncology, as they don't seem to understand pain. Radiation folks didn't want to hear about it, and kept telling me radiation doesn't hurt. Well, let me tell you the pain is there and watching the skin peel off my genitals was most disturbing. Their attitude seemed as if 'I'm getting rid of your cancer, what else can you want?' I felt few nurses, doctors, or clinic techs wanted to know about how I felt. I often laid there and cried, and all I got was a Kleenex!

Some participants were talking about firing their health care providers because they wanted to control their bodies and lives in the cancer pain management process, and because they wanted a caring health care provider. One of the participants said:

I've had to find my own doctors who listen to me and I've fired more doctors and nurses in the last 2 years than I've know in my entire life. I pay them to take care of me and helping me as a complete human being is part of their job.

Another finding related to "controlled" in the process of cancer pain management was related to cancer pain assessment tools. Most of the participants regarded pain assessment tools as useless for their pain management. Rather, they thought that pain assessment tools are designed solely for health care providers and would not work for actual assessment and management of their pain. One participant said:

Only a home health care nurse...questioned my reply of "4" because she could see I was writhing in pain and not speaking easily. I changed the rating to "6"...Nobody ever insulted me with smiley and frowny faces asking about pain. I think I would have thrown up on them if I could have. This should be used for children and non-native speakers of the language in the country where the person is hospitalized. It is insulting to English-speaking, educated patients. Pain management or lack thereof is the single biggest shame in the medical profession, and that is quite a statement.

Most of the participants were trying to do their best to live with cancer and pain while controlling their bodies and lives. Many of them were talking about "living life to the fullest" and "not sweating the small things." The participants reported that they finally felt okay when their treatment and pain management were in their own control and when they kept up with a positive view on everything. One of the participants said:

Cancer and death make any decision you make different from an ordinary disease because the question is you control the treatment including pain management. Once you give yourself to your Cancer Doctor you give up that control... I am in control of what my body can do or not do now. I can heal myself. So, come on Cancer, rear your ugly head again! I will defeat you myself, again! You can see the change in attitude, huh? ... I try and fix myself before I go to a Western doctor. So I have changed. I am in control of me, at least I think so.

Discussion

Some themes found in the study are consistent with those from previous studies among cancer patients, while others add new information about cancer and cancer pain experience of white cancer patients. The first theme of the study, "pain accompanies cancer," agrees with findings from previous studies that have indicated patients' tumultuous experience of balancing the elation of surviving life-threatening illness with the demands of chronic health concerns, information needs, family supports, and altered life meaning.³⁸⁻⁴⁰ Indeed, studies have indicated the psychological processes that occur over time as the individual and those in their social world, manage, learn from, and adapt to the multitude of changes which have been precipitated by cancer and its treatment.⁴¹ The findings reported in this paper also support the

view of cancer as a chronic rather than a terminal disease. As the findings show, the participants first thought that cancer meant death. Then, while they went through the disease process, they found that they needed to live with cancer as a chronic disease while “sucking it up,” and that pain was a natural part of the disease process. This finding agrees with those among some other ethnic groups including African Americans,⁴² Ethiopians,⁴³ and Central Americans.⁴⁴

The second theme, “culture more than ethnicity,” also agrees with the existing literature on ethnic differences in cancer pain experience. As mentioned above, ethnic differences in pain descriptions have been reported in the literature: some are stoic and rarely report pain while others express pain freely^{45–48} Although the study findings reported in this paper did not directly report ethnic differences in their pain descriptions, they certainly agree with findings from previous studies. The other finding related to this theme was that many participants perceived their geographical, work, and generational culture as important as their ethnic culture. Actually, some of them perceived these sub-cultures as more important than their ethnic culture. Because race is a more salient distinction in the U.S. than ethnicity, nearly all of the European ethnic groups tend to get blurred together because they are so similar. Although there is no standard definition of culture, culture is usually defined as the sum of beliefs, practices, habits, likes, dislikes, norms, customs, rituals, and so forth that we learned from our families during the years of socialization.⁴⁹ From this definition of culture, the geographical, work, and generational culture can be considered as a type of culture. As the findings of the study presented in this paper indicated, thus, culture can be more than ethnicity. Practitioners who wish to account for the mediating effects of culture on cancer pain experiences need to be aware that different groups identify with different components of an overarching concept called “culture,” whether class, religion, or ethnicity.

The third theme, “women’s pain not seriously taken,” supports gender differences in cancer pain experience. In a systematic review of the literature on gender differences in pain, fatigue, and depression in patients with cancer, Miaskowski⁵⁰ reported that research studies on gender differences in cancer-related pain, fatigue, and depression were minimal in number, were restricted to studies of the differences in prevalence rates and severity scores, and for the most part had yielded inconsistent results. Indeed, some recent studies reported that there were no gender differences in the pain intensity measures and the pain severity measures.^{51, 52} However, in most studies, certain gender differences have been reported,^{53–55} and the findings of the study presented in this paper agrees with this side. The participants of the study presented in this paper were deeply concerned about gender inequity in pain management process, especially health care providers’ unfair treatment for women’s pain reports.

Since the study presented in this paper is a qualitative research study, the findings can not provide generalizable findings on gender differences or provide a direction of the gender differences, but the findings certainly support that the female participants’ cancer pain experience and management experience were different from the male participants’. In addition, this theme, “women’s pain not seriously taken,” conforms to the general patriarchal attitudes toward women’s health/illness in the US health care system, such that women’s bodily experiences tend to be easily ignored, and their voices usually inaudible.³⁵

The fourth theme of “highly individualized pain experience with emotional pain” also agrees with the findings of the existing literature. Pain is a subjective, highly individual experience that does not lend itself to direct quantification by physiological or behavioral parameters.^{56, 57} Therefore, a patient’s self-report of pain is regarded as the single most reliable indicator of pain.^{58, 59} Related to this, all the participants of the study presented in this paper except 2 indicated their concerns related to the cancer pain assessment tools. Their position was that the pain assessment tools such as the Visual Analogue Scale, the Verbal Descriptor Scale, and the Face Scale were just for health care providers, not useful for patients themselves at all. They

raised a question about how the highly subjective pain experience could be objectified and measured. Some of the participants pointed out that they felt humiliated when their pain was assessed by using the face scale in health care settings, and that their pain report was corrected by health care providers during the pain management process, which raised questions about the objectivity of the pain assessment tools.

The fifth theme of “controlled or controlling” indicates how important the controllability of their own bodies and lives was to the participants in their pain experience. This theme somewhat conforms to the findings of the existing studies on cancer pain experience among white cancer patients. Many studies have indicated the adjustment process of cancer patients, and many of these studies have indicated the transcendent experiences of cancer patients through the adjustment process, which can be viewed as an effort to control their own bodies and lives.^{60, 61}

The theme of “controlled and controlling,” however, is different from some findings among African American and Asian cancer patients. Some studies of African American cancer patients indicated that the patients wanted to cede medical decisions to the health care providers, who had medical training and experience.^{62, 63} Im and her colleagues⁶⁴ reported that Korean breast cancer patients tended to blame themselves and focus on their own problems, such as not being happy or not enjoying their current status of life, rather than giving attention to those who would control and who would be in control.

Finally, the fourth theme of “highly individualized pain experience with emotional pain” and the fifth theme of “controlled or controlling” also indicate the strong individualism embedded in the participants’ lives. Typical attributes associated with individualism are independence, autonomy, self-reliance, uniqueness, achievement orientation, and competition.⁶⁵ Individualists are portrayed as having control over and taking responsibility for their actions.⁶⁵ While not denying that societies exist or that people benefit from living in them, individualism holds that the individual is the primary unit of reality and the ultimate standard of value. Usually, Western culture is viewed as emphasizing individualism, while non-Western cultures of ethnic minorities are viewed as emphasizing collectivism.⁶⁶ The individualism-collectivism dimensions has been widely used to describe, explain, and predict cross-cultural differences in attitudes, values, behaviors, cognition, communication, attribution, socialization, and self-concepts.⁴⁷

The theme of “highly individualized pain experience with emotional pain” can be viewed with this individualistic basis of white culture.⁶⁷ White cancer patients placed the highest priority on their own individual experiences and their own interests, and their cancer pain experience ranged from no pain to extreme pain depending on their individual contexts. Also, the theme of “controlled or controlling” reflects their individualism; white cancer patients wanted to have control of their own bodies and lives. This finding contrasts with the findings among cancer patients in some other cultures (e.g., Asian culture, Hispanic culture) who would expect their family members to take care of them because their cultural background emphasizes collectivism, such as the welfare of one’s family (familism).⁶⁶

Finally, the study presented in this paper had some limitations because the participants tended to be young, high-income, highly educated women cancer patients. As frequently reported in Internet research studies, the online population tends to be a selected group of people.^{68, 69} That would be the reason that the participants of the online forum looked like a select group of cancer patients: all of them were recruited through the Internet. Furthermore, male participants tended to be silent compared with female participants, so male participants’ voices were rarely heard throughout the online forum. Indeed, although an equal number of potential

participants from each gender were invited to participate in the study, more women agreed to be in the group.

Conclusions and Implications

In this paper, the findings from an online forum among white cancer patients were presented. These findings suggest some directions for future research and practice related to cancer pain management among white cancer patients.

First, researchers and health care providers need to respect cancer patients' own experience, attitudes, and meanings related to cancer pain during pain assessment and management process. In the current literature, cancer patients' own voices are hardly heard and their own experience, attitudes, and meanings are usually ignored.^{11, 70, 71} Yet, as the findings of the study presented in this paper showed, the cancer patients' own experience, attitudes, and meanings related to cancer pain experience may be different from those that researchers or health care providers can usually expect. For example, researchers or health care providers have tried to make standardized pain assessment and management tools while assuming that the assessment tools are the essentials for adequate cancer pain management. However, the findings indicated that cancer patients perceived the pain assessment tools were just for health care providers, not useful for patients themselves at all. Furthermore, the findings reported that some patients even felt humiliated when their pain was assessed by the face scale.

Second, when white cancer patients' pain is assessed and/or explored, geographical, work, and generational cultures need to be considered as important factors that could influence cancer patients' attitudes toward pain and its assessment and management process. Researchers and health care providers tend to erase the differences between white Americans in the interest of constructing a "white ethnicity," despite the fact that white Americans have heterogeneous forms of values, traditions, and social organization. However, as the findings indicate, there are diversities within the culture, and the definition of culture is broader than ethnicity. Without considering the diversities within the culture itself, cancer pain management cannot be adequate for some white cancer patients.

Finally, researchers and health care providers need to view pain as a chronic condition that cancer patients live through until they die; in some cases, they live with cancer for several decades. To the degree that cancer has been considered an incurable disease by practitioners in the current Western medical paradigm, it has been regarded as a terminal disease rather than as a chronic condition.^{72, 73} However, with advances in medical knowledge and technologies, cancer is increasingly a chronic condition accompanied by pain.^{40, 72} Some types of cancer including ovarian cancer are now regarded as a chronic disease rather than a terminal disease.^{72, 73} The findings of the study presented in this paper support this notion of cancer as a chronic condition rather than a terminal condition.

Acknowledgements

This analysis was conducted as part of a larger study funded by the National Institute of Health (1 R01 NR007900-01A1). Special thanks to Dr. Michael Erard who thoroughly edited the paper and to my research staff members who worked for this online forum including Dr. Wonshik Chee, Ms. Melinda Bender, Ms. Robin Page, Ms. Hsiu-Min Tsai, Ms. Chia-Ju Lin, Mr. Enrique Guevara, and Ms. Joyce Neuman.

References

1. American Cancer Society (ACS). Cancer facts and figures-1993. Atlanta, GA: The American Cancer Society; 2004.
2. Morgan AE, Lindley CM, Berry JI. Assessment of pain and patterns of analgesic use in hospice patients. *Am J Hosp Palliat Care* 1994 Jan/Feb;13-24. [PubMed: 8117486]

3. Cleeland CS, Janjan NA, Scott CB, Seiferheld WF, Curan WJ. Cancer pain management by radiotherapists: A survey of radiation therapy oncology group physicians. *Int J Radiat Oncol Biol Phys* 2000;47(1):203–208. [PubMed: 10758325]
4. Delgado DJ, Lin WY, Coffey M. The role of Hispanic race/ethnicity and poverty in breast cancer survival. *PRHSJ* 1990;14(2):103–116.
5. Eley JW, Hill HA, Chen VW, Austin DF, Wesley MN, Muss HB, Greenberg RS, Coates RJ, Correa P, Redmond CK. Racial differences in survival from breast cancer. Results of the National Cancer Institute Black/White Cancer Survival Study. *JAMA* 1994;272(12):947–54. [PubMed: 8084062]
6. Kalua PM. Cancer pain guidelines: Are they being used? Results of a multi-site study conducted by the Hawaii Cancer Pain Initiative. *Hawaii Med J* 1998;57(10):655–660. [PubMed: 9844301]
7. Chan A, Woodruff RK. Communicating with patients with advanced cancer. *J Palliat Care* 1997;13(3):29–33. [PubMed: 9354038]
8. Thompson TE, McCune JS, Bernard SA, Winer EP, Tremont S, Lindley CM. Cancer pain survey: Patient-centered issues in control. *J Pain Symptom Manage* 1998;15(5):275–284. [PubMed: 9654832]
9. Von Roenn JH, Cleeland CS, Gonin R, Hatfield AK, Pandya K. Physician attitudes and practice in cancer pain management. *Ann Intern Med* 1993;119:121–126. [PubMed: 8099769]
10. Dodd M, Janson S, Facione N, Faucett J, Froelicher ES, Humphreys J, Lee K, Miaskowski C, Puntillo K, Rankin S, Taylor D. Advancing the science of symptom management. *J Adv Nurs* 2001;33(5):668–676. [PubMed: 11298204]
11. Im EO, Chee W. A feminist critique of research on cancer pain. *West J Nurs Res* 2001;23(7):726–752. [PubMed: 11675798]
12. Payne R. Practice guidelines for cancer pain therapy. Issues pertinent to the revision of national guidelines. *Oncology* 1998;12(11A):169–175. [PubMed: 10028511]
13. Ramer L, Richardson JL, Cohen MZ, Bedney C, Danley KL, Judge EA. Multimeasure pain assessment in an ethnically diverse group of patients with cancer. *J Transcult Nurs* 1999;10(2):94–101. [PubMed: 10476160]
14. Vallerand AH. Gender differences in pain. *Image J Nurs Sch* 1995;27(3):235–237. [PubMed: 7590808]
15. Feine JS, Bushnell MC, Miron D, Duncan GH. Sex differences in the perception of noxious heat stimuli. *Pain* 1991;44:255–262. [PubMed: 2052394]
16. Feine JS, Miron D, Bushnell Duncan GH. Sex differences in facial pain perception. *J Dent Res* 1989;68:329.
17. Lautenbacher S, Rollman GB. Sex differences in responsiveness to painful and non-painful stimuli are dependent upon method of stimulation. *Pain* 1993;53:255–264. [PubMed: 8351155]
18. Mercadante S, Casuccio A, Pumo S, Fulfaro F. Factors influencing the opioid response in advanced cancer patients with pain followed at home: The effects of age and gender. *Support Care Cancer* 2000;8(2):123–130. [PubMed: 10739359]
19. Given CW, Given B, Azzouz F, Stommel M, Kozachik S. Comparison of changes in physical functioning of elderly patients with new diagnoses of cancer. *Med Care* 2000;38(5):482–493. [PubMed: 10800975]
20. Klemm P, Hurst M, Dearholt SL, Trone SR. Gender differences on Internet cancer support groups. *Comput Nurs* 1999;17(2):65–72. [PubMed: 10194883]
21. Sharf BF. Communicating breast cancer on-line: Support and empowerment on the Internet. *Women Health* 1997;26(1):65–84. [PubMed: 9311100]
22. Beck SL. An ethnographic study of factors influencing cancer pain management in South Africa. *Cancer Nurs* 2000;23(2):99–100.
23. Chung JWY, Yang JCS, Wang TKS. The significance of pain among Chinese patients with cancer in Hong Kong. *Acta Anaesthesiol Sin* 1999;37:9–14. [PubMed: 10407521]
24. Thompson TE, McCune JS, Bernard SA, Winer EP, Tremont S, Lindley CM. Cancer pain survey: Patient-centered issues in control. *J Pain Symptom Manage* 1998;15(5):275–284. [PubMed: 9654832]

25. Uki J, Mendoza T, Cleeland CS, Nakamura Y, Takeda F. A brief cancer pain assessment tool in Japanese: The utility of the Japanese Brief Pain Inventory--BPI-J. *J Pain Symptom Manage* 1998;16(6):364–373. [PubMed: 9879161]
26. Lubeck DP, Kim H, Grossfeld G, Ray P, Penson DF, Flanders SC, Carroll PR. Health related quality of life differences between black and white men with prostate cancer: Data from the cancer of the prostate strategic urologic research endeavor. *J Urol* 2001;166(6):2291–2292. [PubMed: 11696754]
27. Rabow MW, Dibble SL. Ethnic differences in pain among outpatients with terminal and end-stage chronic illness. *Pain Med* 2005;6(3):235–241. [PubMed: 15972087]
28. Vallerand AH, Hasenau S, Templin T, Collins-Bohler D. Disparities between black and white patients with cancer pain: The effect of perception of control over pain. *Pain Med* 2005;6(3):245–250.
29. Chin, P. Chinese. In: Lipson, JG.; Dibble, SL., editors. *Culture & Clinical Care*. San Francisco: UCSF Nursing Press; 2005. p. 98-108.
30. Guarnero, PA. Mexicans. In: Lipson, JG.; Dibble, SL., editors. *Culture & Clinical Care*. San Francisco: UCSF Nursing Press; 2005. p. 330-342.
31. Harding, S. Introduction: Is there a feminist method?. In: Harding, S., editor. *Feminism and Methodology*. Bloomington, Ind: Indiana University Press; 1987.
32. Ford-Gilboe M, Campbell J. The mother-headed single-parent family: A feminist critique of the nursing literature. *Nurs Outlook* 1996;44:173–183. [PubMed: 8871999]
33. Hall JM, Stevens PE. Rigor in feminist research. *ANS Adv Nurs Sci* 1991;13:16–29. [PubMed: 1901470]
34. Young, IM. *Throwing like a girl and other essays in feminist philosophy and social theory*. Bloomington, IN: Indiana University Press; 1990.
35. Rosser, SV. *Women's health-missing from U.S. medicine*. Bloomington, Ind: Indiana University Press; 1994.
36. Stevens PE. Focus groups: Collecting aggregate-level data to understand community health phenomena. *Public Health Nurs* 1996;13(3):170–176. [PubMed: 8677232]
37. Im EO, Chee W. Issues in Internet survey among cancer patients. *Cancer Nurs* 2004;27(1):34–42. [PubMed: 15108950]
38. Ferrell BR, Dow KH. Portrait of cancer survivorship: A glimpse through the lens of survivors' eyes. *Cancer Pract* 1996;4(2):76–80. [PubMed: 8715444]
39. Hughes LC, Hodgson NA, Muller P, Robinson LA, McCorkle R. Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *J Nurs Scholarsh* 2000;32(1):25–30. [PubMed: 10819735]
40. Markman M. Viewing ovarian cancer as a “chronic disease”: What exactly does this mean? *Gynecol Oncol*. In press
41. Brennan J. Adjustment to cancer-coping or personal transition? *Psychooncology* 2001;10:1–18. [PubMed: 11180573]
42. Waters, CM.; Locks, S. African-Americans. In: Lipson, JG.; Dibble, SL., editors. *Culture & Clinical Care*. San Francisco: UCSF Nursing Press; 2005. p. 14-26.
43. Beyene, Y. Ethiopians and Eritreans. In: Lipson, JG.; Dibble, SL., editors. *Culture & Clinical Care*. San Francisco: UCSF Nursing Press; 2005. p. 161-176.
44. Kunkel, PJ.; Aragon, DR.; de Kunkel, MMM. Central Americans. In: Lipson, JG.; Dibble, SL., editors. *Culture & Clinical Care*. San Francisco: UCSF Nursing Press; 2005. p. 85-97.
45. Chung JWY, Yang JCS, Wang TKS. The significance of pain among Chinese patients with cancer in Hong Kong. *Acta Anaesthesiol SIN* 1999;37:9–14. [PubMed: 10407521]
46. Ramer L, Richardson JL, Cohen MZ, Bedney C, Danley KL, Judge EA. Multimeasure pain assessment in an ethnically diverse group of patients with cancer. *J Transcult Nurs* 1999;10(2):94–101. [PubMed: 10476160]
47. Uki J, Mendoza T, Cleeland CS, Nakamura Y, Takeda F. A brief cancer pain assessment tool in Japanese: The utility of the Japanese Brief Pain Inventory--BPI-J. *J Pain Symptom Manage* 1998;16(6):364–373. [PubMed: 9879161]

48. Lubeck DP, Kim H, Grossfeld G, Ray P, Penson DF, Flanders SC, Carroll PR. Health related quality of life differences between black and white men with prostate cancer: Data from the cancer of the prostate strategic urologic research endeavor. *J Urol* 2001;166(6):2291–2292. [PubMed: 11696754]
49. Spector, RE. Cultural diversity in health and illness. 5. Upper Saddle River, NJ: Prentice Hall; 2000.
50. Miaskowski C. Gender differences in pain, fatigue, and depression in patients with cancer. *J Natl Cancer Inst Monogr* 2004;32:139–232. [PubMed: 15263057]
51. Edrington JM, Paul S, Dodd M, West C, Facione N, Tripathy D, Schumacher K, Miaskowski M. No evidence for sex difference in the severity and treatment of cancer pain. *J Pain Symptom Manage* 2004;28(3):225–232. [PubMed: 15336334]
52. Turk DC, Okifuki A. Does sex make a difference in the prescription of treatments and the adaptation to chronic pain by cancer and non-cancer patients? *Pain* 1999;82:139–148. [PubMed: 10467919]
53. Feine JS, Bushnell MC, Miron D, Duncan GH. Sex differences in the perception of noxious heat stimuli. *Pain* 1991;44:255–262. [PubMed: 2052394]
54. Feine JS, Miron D, Bushnell MC, Duncan GH. Sex differences in facial pain perception. *J Dent Res* 1989;68:329.
55. Lautenbacher S, Rollman GB. Sex differences in responsiveness to painful and non-painful stimuli are dependent upon method of stimulation. *Pain* 1993;53:255–264. [PubMed: 8351155]
56. Vallerand AH. Gender differences in pain. *Image J Nurs Sch* 1995;27(3):235–237. [PubMed: 7590808]
57. Cleeland CS, Baez L, Pandya KJ. Pain and treatment of pain in minority patients with cancer. *Ann Intern Med* 1997;127(9):813–816. [PubMed: 9382402]
58. Portenoy RK, Lesage P. Management of cancer pain. *Lancet* 1999;353(9165):1695–1700. [PubMed: 10335806]
59. Portenoy RK, Payne D, Jacobsen P. Breakthrough pain: characteristics and impact in patients with cancer pain. *Pain* 1999;81(1–2):129–134. [PubMed: 10353500]
60. Kinney CK. Transcending breast cancer: reconstructing one's self. *Issues Ment Health Nurs* 1996;17(3):201–206. [PubMed: 8707541]
61. Newshan G. Transcending the physical: spiritual aspects of pain in patients with HIV and/or cancer. *J Adv Nurs* 1998;28(6):1236–1241. [PubMed: 9888368]
62. Torke AM, Corbie-Smith GM, Branch WT. African American patients' perspectives on medical decision making. *Arch Intern Med* 2004;164:525–530. [PubMed: 15006829]
63. Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR, Nelson C, Ford DE. Race, gender, and partnership in the patient-physician relationship. *JAMA* 1999;282(6):583–589. [PubMed: 10450723]
64. Im EO, Lee EO, Park YS. Korean women's breast cancer experience. *West J Nurs Res* 2002;24(5):751–771. [PubMed: 12428893]
65. Green EGT, Deschamps JC, Páez D. Variation of individualism and collectivism within and between 20 countries. *J Cross Cult Psychol* 2005;36(3):321–339.
66. Pinquart M, Sörensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist* 2005;45(1):90–106. [PubMed: 15695420]
67. Oyserman D, Coon HM, Kimmelmeier M. Rethinking individualism and collectivism: Evaluation of theoretical assumptions and meta-analyses. *Psychol Bull* 2002;128:3–72. [PubMed: 11843547]
68. ComputersScope Ltd. NUA Internet surveys. Retrieved on April 29, 2004 from: URL: <http://www.nua.ie/surveys/>
69. Im EO, Chee W. Issues in Internet survey among cancer patients. *Cancer Nurs* 2004;27(1):34–42. [PubMed: 15108950]
70. Thomas-MacLean R. Memories of treatment: the immediacy of breast cancer. *Qual Health Res* 2004;14(5):628–643. [PubMed: 15107167]
71. Kitzinger C, Willmott J. 'The thief of womanhood': women's experience of polycystic ovarian syndrome. *Soc Sci Med* 2002;54(3):349–361. [PubMed: 11824912]
72. Spriggs DR. Ovarian cancer as a chronic disease: A new treatment paradigm. Highlights of a roundtable discussion. *Cancer Control* 2001;8(6 Suppl 1):5–7. [PubMed: 11910332]
73. Michener CM, Belinson JL. Modern management of recurrent ovarian carcinoma. A systematic approach to a chronic disease. *Oncology* 2006;19(10):1277–1285. [PubMed: 16285224]

Table 1
Sociodemographic characteristics of the participants (N=29)

Characteristics	n (%)	Characteristics	n (%)
<i>Age (years)</i>		<i>Gender</i>	
Mean (SD)	44.31 (10.35)	Female	25 (86.2)
Range	25–63	Male	4 (13.8)
<i>Education</i>		<i>Religion</i>	
High School Graduates	5 (17.2)	Protestant	17 (58.6)
College (partial & graduated)	24 (82.8)	Catholicism	7 (24.1)
		Buddhism	1 (3.4)
		Others	1 (3.4)
		No religion	3 (10.3)
<i>Employment</i>		<i>Born in the U.S.</i>	
Not employed	17 (58.6)	Yes	28 (96.6)
Employed	12 (41.4)	No	1 (3.4)
<i>Income Satisfaction</i>		<i>Annual Family Income</i>	
Totally insufficient	4 (13.8)	(mean/SD)	\$56,344
Somewhat insufficient	9 (31.0)		(34193.02)
Sufficient	12 (41.4)		
More than sufficient	4 (13.8)		
<i>Health Status</i>		<i>Cancer Stage</i>	
Very unhealthy	2 (6.9)	Stage I	4 (13.6)
Unhealthy	10 (34.5)	Stage II	6 (20.4)
I don't know	2 (6.9)	Stage III	4 (13.6)
Healthy	15 (51.7)	Stage IV	7 (23.8)
		Non-staged	3 (10.2)
		Recurrent	2 (6.8)
		I don't know	1 (3.4)
<i>Cancer Type</i>		<i>Treatments (have received)</i>	
Colon cancer	1 (3.4)	Chemotherapy (Chemo)	5 (17.2)
Breast cancer	8 (27.2%)	Surgery	4 (13.8)
Leukemia	1 (3.4)	Radiation (Rad)	4 (13.8)
Non-Hodgkin's Lymphoma	3 (10.2)	Hormone therapy (Horm)	1 (3.4)
Ovarian cancer	2 (6.8)	Surgery+Chemo	3 (10.3)
Thyroid cancer	4 (13.6)	Surgery+Chemo+Rad	3 (10.3)
Lung Cancer	2 (6.8)	Surgery+Chemo+Rad+Horm	2 (6.9)
Esophageal cancer	1 (3.4)	Surgery+Chemo+Horm	1 (3.4)
Epithelial cancer	1 (3.4)	Surgery+Rad	2 (6.9)
Carcinoid/Carcinoma	2 (6.8)	Surgery+Rad+Horm	2 (6.8)
Squamous cell carcinoma	3 (10.2)	Surgery+Chemo+Rad+Horm	1 (3.4)
		+Biotherapy	
Retroperitoneal Mucinous Cystadenoma	1 (3.4)	Rad+Chemo	1 (3.4)