

Oncol Nurs Forum. Author manuscript; available in PMC 2009 July 22.

Published in final edited form as:

Oncol Nurs Forum. 2008 July; 35(4): 653-660. doi:10.1188/08.ONF.653-660.

# An Online Forum on Cancer Patients' Needs for Help: Gender and Ethnic Differences

Alexa K. Stuifbergen and Eun-ok Im

#### **Abstract**

**Purpose**—The purpose of this study was to qualitatively explore gender and ethnic differences in cancer patients' needs for help. A feminist perspective guided the research process theoretically.

Research Approach—This was a qualitative online forum study.

**Setting**—Both Internet and real settings.

**Participants**—Sixteen self-identified online cancer patients aged at least 18 years who could read and write English.

**Methodologic Approach**—Using six discussion topics on cancer patients' needs for help, the online forum was administered for one month. Then, the data were analyzed using thematic analysis.

**Findings**—Four major themes emerged: (a) from side effects to racism; (b) same or double stress; (c) cultural hesitance and God; and (d) a family disease with mistrust. Depending on gender and ethnicity, the participants' concerns were various and ranged from a simple physical need to a social need for elimination of racism in the U.S. society. Women tended to report double burden and stress as cancer patients due to their gender. Ethnic minorities tended to be hesitant to talk about cancer and seek for help due to stigmatized nature of cancer. Ethnic minority cancer patients perceived cancer as a family disease that they needed to go through as a family, and they tended to mistrust health care providers.

**Conclusions**—The overriding theme was ethnic minority cancer patients' marginalized experience.

**Implications**—Researchers need to include cultural needs as a separate category of needs, and consider contextual factors influencing cancer patients' needs in their daily lives.

#### **Keywords**

Cancer; N	Needs; Culture; Ethnicity; Gender	

#### Key Points:

- Cancer patients have various types of needs for help ranged from a simple physical need to a social need for elimination of racism in the U.S. society.
- Because of their Confucian culture prescribing that women should be a wise mother and good wife, Asian women were suffering from double burdens from doing household works while struggling with cancer.
- Because of their cultural attitudes stigmatizing cancer of sexual organs and emphasizing "macho men", Hispanic men might
  not be able to seek for help because of possible embarrassment involved with their attempts to seek for help.
- Stigmatized nature of cancer might make ethnic minority cancer patients not disclose their diseases and openly seek out help for their needs.

Gender differences in cancer patients' needs for help have not been explicitly explored. Rather, most studies have implicitly supported gender differences in diverse aspects of cancer-related needs (Sanson-Fisher et al., 2000; Thome & Hallberg, 2004). In a recent study on lung cancer patients' concerns, women tended to report a significantly larger number of concerns than men (Hill, Amir, Muers, Connolly, & Round, 2003). The instruments measuring cancer patients' needs for help were separately developed for breast cancer and prostate cancer (Dale, Jatsch, Hughes, Pearce, & Meystre, 2004; Templeton & Coates, 2001). Gender differences in helpseeking behaviors also imply gender differences in perceived needs for help: men were more likely to seek information while women were more likely to seek encouragement and support (Dale, Jatsch, Hughes, Pearce, & Meystre, 2004; Klemm, Hurst, Dearholt, & Trone, 1999; Sharf, 1997). Also, studies on pain and symptoms of cancer patients imply gender differences in physical needs. In a systematic review of the literature on gender differences in pain, fatigue, and depression, Miaskowski (2004) reported that research studies yielded inconsistent results. Some recent studies reported none (Edrington et al., 2004; Turk & Okifuji, 1999) while certain differences were reported in others (Feine, Bushnell, Miron, & Duncan, 1991; Vallerand, 1995).

Ethnic differences in cancer patients' needs have been reported as well. Caucasian cancer patients tend to place the highest priority on their own individual experiences and interests and want to have control of their own bodies and lives while cancer patients in some cultures (e.g., Asian or Hispanic cultures) tend to emphasize on the welfare of one's family (familism) (Pinquart & Sorensen, 2005). According to Arraras et al. (2004), in the U.K. or Scandinavian countries, all information is frequently disclosed, while in Japan open disclosure is less frequent. African American women were reported to depend more on God for support rather than either family, friends, or health care professionals, and Internet use was reported less often as a source of support (Henderson & Fogel, 2003). Cleeland et al. (1997) found that patients treated in ethnic minority settings were three times more likely to be undermedicated than patients seen in non-minority settings. Bernabei et al. (1998) reported that ethnic minority cancer patients were more likely to receive no analgesia.

Despite these findings, very little is still known about gender and ethnic differences in cancer patients' needs for help. A MEDLINE search of the past 15 years (1990–2005) using search terms including "ethnicity," "gender," "cancer," and "needs" retrieved only 17 articles; through another search of "ethnic difference," "cancer," and "needs" retrieved only 7 articles; and a search using "gender difference," "cancer," and "needs" retrieved only 11 articles. Even these retrieved articles were not actually about gender and ethnic differences in cancer patients' needs for help. The purpose of this study was to explore gender and ethnic differences in cancer patients' needs for help through a qualitative online forum.

As the theoretical basis of the study, a feminist perspective was used. There is no unitary feminist perspective. Rather, literature shows diverse perspectives within feminism including liberal, essentialist, radical, Marxist, socialist, and postmodern feminism. Yet, distinctions among diverse feminist perspectives become blurred in contemporary feminism, which can be summarized by several principles that all feminist perspectives have in common. The principles are: (a) it is important to center and make problematic women's diverse situations and the institutions and frames that influence those situations; (b) all feminists refer the examination of that problematic theoretical, policy, or action framework in the interest of realizing social justice for women; (c) all feminist theory posits gender as a significant characteristic that interacts with other factors such as race and class to structure relationships between individuals; (d) with the exception of liberal feminism, most feminist theories reject the neutral objective observer for a social construction of scientific research based on the standpoint of the observer, which is influenced by gender, as well as other factors such as race and class; (e) most feminist theories reject dualism; (f) women's experience is important; (g) the distance between observer

and object of study is shortened; and (h) unicausal, hierarchical approaches are rejected (Im, 2007). These principles were used in the study reported in this paper, and the following approach was taken to guide the online forum. First, patients' own views were prioritized during the research process (Hall & Stevens, 1991). As significant factors influencing and structuring cancer patient's experience, gender and ethnicity were considered during the data collection and interpretation process (Rosser, 1994). During the online forum discussion, contact information of the research staff was provided to the participants, so the participants could directly contact the research staff members. Additionally, the criteria by Hall and Stevens (1991) for feminist research was used to ensure rigor of the study. For example, to ensure the *dependability* of the study, the research team regularly met during the data collection and analysis process and created and discussed the methodological and analytic decision trails created throughout the data collection and analysis process. Also, to ensure the *reflexivity* of the study, the research team wrote chronological research memos and notes, and held regular group meetings to discuss any issues related to the study.

#### Methods

This was a qualitative online forum study among 16 cancer patients who were recruited through both Internet and real settings. The approval from the Internet Review Board of the institution where the authors were affiliated was obtained.

# Samples and Settings

A total of 16 self-identified cancer patients were recruited through both Internet and real settings using a convenience sampling method. The Internet settings were Internet cancer support groups that were identified through MSN.com searches; and the real settings included a cancer clinic in a Central Texas region and a cancer support group in New York. Six to 12 participants are regarded as ideal for a focus group discussion including online forum discussion (Hall & Stevens, 1991). Thus, 16 is an adequate number for the online forum discussion.

The inclusion criteria for research participants were: self-identified online cancer patients aged at least 18 years who could read and write English. Sociodemographic characteristics of the participants are summarized in Table 1. The participants included 12 Whites, 1 Hispanic, 1 African American, and 2 Asians. The mean age of the participants was 51.19 years (SD=10.20), and about 81% were women. More than 80% of the participants were college graduates or had graduate degrees, and about 44% were employed. More than 76% reported that their family income was sufficient or more than sufficient, and about 25% were Catholic. About 75% were born in the U.S. Among those who were born outside the U.S., the length of stay in the U.S. varied from 55 to 523 months (Mean=312.67 months, SD=237.56). More than 60% perceived that they were healthy or very healthy.

The online forum discussion was conducted for one month. The reason for using the online forum was to reach out cancer patients in dispersed geographical areas so that diverse experience of cancer patients could be heard. One to two topics per week were posted on the forum site, and the participants were asked to visit the forum site and post their messages when new topics were posted. To retain the participants, multiple strategies were used. First, bonds between the participants and researchers were established via respectful and trustworthy interactions through online forums, and one research staff member was assigned to follow the online forums consistently. Also, a modest monetary incentive of a \$50 gift card was provided to each participant at the completion of the online forum.

## **Discussion Topics**

The online forum discussion topics included: (a) cancer patients' attitudes and responses to cancer; (b) cancer patients' daily life schedules, and hardships and sufferings in daily lives; (c) cancer patients' needs for help (culturally universal and ethnic-specific); (d) gender and ethnic differences in cancer patients' needs for help; (e) things/life events influencing cancer patients' needs for help in their daily lives; and (f) currently available supports and cancer patients' preferences for supports. Several prompts related to each topic were provided to help the participants understand the topics. These topics and the prompts were developed by the authors and reviewed by an expert panel of oncology nurses.

#### **Data Collection Procedures**

When a potential participant agreed to join the online forum by email or in person, the participant was asked to visit the online forum site. The participant was given a username and a password that were randomly assigned by the researchers, and asked to use them when the participant logged into the forum site. The participant could change her/his username and password at any time during the online forum discussion, and the participant was also asked to choose and use a pseudonym for the online forum discussion to ensure anonymity. In addition, her/his visits at the online forum site were recorded and monitored, and only those who registered were allowed to enter the online forums.

When 24 participants were recruited, the online forum was initiated, but only 16 were retained by the end of the online forum. One of the researchers emailed to the registered participants and informed them the initiation of the online forum discussion. On the opening page of the online forum, introductory questions were posted so that the participants could introduce themselves when they visited the site for the first time. Then, the topics were posted serially on the forum site for the one month period. The participants could post their messages at their convenience in any forms (e.g., stories, conversations, responses to others' messages, etc.), and the number and length of messages were not limited.

#### **Data Analysis**

The transcripts were directly printed out from the online forum site. Then, they were analyzed using thematic analysis (Boyatzis, 1998; Luborsky, 1994). First, the printed transcripts were thoroughly read and re-read for line-by-line coding, and the codes from the line-by-line coding process were summarized as a coding book. Based on the coding book, categorization was done through internal cognitive processing and reflexive thinking by analyzing content and context. Then, while formulating the associations between the categories, gender and ethnic differences in cancer patients' needs for help were sought through reviewing and reformulating the relationships. Also, the influences of variable contextual factors (e.g., health status, socioeconomic circumstances, families' responses and roles, stability of their daily lives, and social support networks) on the participants' needs for help were examined. Additionally, to get more abstract and refined ideas about gender and ethnic differences in cancer patients' needs for help, the texts were read and re-read, and themes representing gender and ethnic differences in cancer patients' needs for help were identified. During this analysis process, weekly group meetings were held.

# **Findings**

Four themes related to gender and ethnic differences in cancer patients' needs for help emerged through the analysis process: (a) from side effects to racism: (b) same or double stress: (c) cultural hesitance and God; and (d) a family disease with mistrust. Each theme is described as follows.

#### From Side Effects to Racism

Depending on gender and ethnicity, the participants' concerns were various and ranged from a simple physical need to a social need for elimination of racism in the U.S. society. Most of the White cancer patients were concerned about side effects from cancer, medication, and chemotherapy, subsequent physical limitations, lack of socialization, and low energy. Among ethnic minority groups, financial issues and medical insurance concerns were the biggest concern that was frequently reported. Other than these, Asian women were concerned about bone density, insomnia, work performance, help for cooking, and having difficulties in finding a support group. A Hispanic woman was concerned about emotional issues (e.g., how to deal with crying, and how to talk about emotional issues). An African American woman was concerned about low energy, loss of friendship, personality change, and changes in the meanings of life. One of the Asian women was talking about her concerns as follows.

Since I decided not to have chemo therapy and radiation, so I didn't have as many side effects as others. However, I still have to deal with the sudden menopause after my hysterectomy. The worst part is insomnia. I have had constant fatigue due to the lack of sleep. Sometimes, my job can be demanding too. I am very lucky to have some of the best coworkers you can imagine, not my boss though. With osteoporosis runs in the family, I feel it's not my advantage to have to take Aramosin which will increase the body density loss. I have tried hard to make sure I do exercise, take calcium and check may bone density to ensure it doesn't lose more than the average.

An African American woman also mentioned about her concerns as follows:

I am a black female...I think that my race has experienced many challenges over the years. Racial, political, cultural, etc. In regard to cancer, I feel that a number of blacks have been unable to receive the proper treatment that they need because of economic hardship. Then, again there is miseducation about the illness, myths, and lack of proper resources. I think in our culture a lot of the older people ignore going for proper check ups. So do the younger ones.

#### Same or Double Stress

Men tended to perceive that there were no gender differences in needs for help. On the contrary, women reported certain gender differences in cancer experience in general and in subsequent needs for help. One man briefly described his opinion on gender differences as follows:

I don't think that there are any differences or similarities between men or women because it affects us all the same way.

A woman described her experience as follows:

When I was confirmed with breast cancer, a general surgeon wanted me to go into the operating room and he would "open me up and then decide what he was going to do." I asked for and got a second opinion from strictly a breast surgeon and feel that was the best thing I ever did. The first surgeon was upset that I wanted a second opinion and just left the room. I doubt this was due to my gender, more to his godlike attitude... When I was having chemo it was in a large room with up to 10 others. There were men and women there with all types of cancer, many much worse than breast cancer. I found that men seemed to like to chat or watch TV, while the women tended to sleep or read. I did notice that there were far fewer men than women who attended our local cancer services educational support group.

White women posited that women tended to have more difficulties in getting adequate health care than men although women were more likely to seek out for help than men. Some White women even mentioned that men were not serious about cancer as much as women were. Asian

women reported that women usually had a tougher life than men because men had some privileges in their particular culture. One Asian woman wrote that women in her culture were suffering from "double stress," and getting cancer would usually add another dimension of stress. A Hispanic woman mentioned that Hispanic men would have more difficulties in their lives (related to cancer) compared with Hispanic women because Hispanic culture emphasizes "macho men." One of Asian women said:

As a woman, I think that we have a tougher life than man. In today's world, women have to work just as hard, if not harder than man on the job. However, you have more responsibilities at home as a mom and/or as a wife. My husband will help, as he always reminds me, but I still feel tired because I am the one makes sure laundry is done, coffee is on the post, dinner is ready and the house is presentable. He will help as long as you tell him what to do. Same comes to parenting, I was the one to make sure teacher conference days on the calendar, doctors appointments were set and the list goes on. Now both my kids are grown up, well, I am again the one to make sure we arrange the family gatherings and keep good contacts with them.

#### **Cultural Hesitance and God**

Another prominent ethnic difference was: whites tended to be more open to talk about cancer and seek for help while ethnic minorities tended to be hesitant to talk about cancer and seek for help. One of the reasons would be the stigmatized nature of cancer in some cultures. The Hispanic participant viewed cancer in sexual organs as a loss of sexuality and a cause for public embarrassment. Consequently, the participant was hesitant to ask for help for her needs related to cancer. The African American participant was specifically talking about racism, lack of insurance, and financial issues that prevented her from having adequate support for her needs and from having appropriate and adequate health care service in the U.S. health care system. The following is what the African American woman talked about her experience with cancer in general and about having their needs for help met by current resources and support systems.

I was very fortunate that my medical team was very quick and responsive in dealing with my diagnosis and treatment. I'm 43 and they were quite surprised to find someone at my age with lung cancer. My treatment was aggressive. However, I think that blacks do not also receive the best treatment, due to lack of insurance, economics, racism, etc.

Religious beliefs embedded in some cultures were also influencing the participants' experience and their needs for help. An African American woman stated that Christianity was a major factor influencing her needs for help. She was also talking about "keeping in the fate" and her belief that God would be with her throughout the course of their disease. Among Asian women, Confucian cultural beliefs were influencing their needs for help. For example, one of the Asian women believed that: (a) women should be wise mothers and good wives; (b) women should place their own needs behind the needs of their family members; and (c) women should shoulder the burdens of household tasks and child rearing responsibilities even when they are sick. A Hispanic woman was talking about their cultural taboo inhibiting them from openly talking about cancer and their concerns and their cultural tradition not letting cancer patients know about their own disease. Therefore, she chose to talk with God. The Hispanic woman said:

...so there you can see that in the Cuban and Hispanic background they are not used to letting the patients directly of their illness, and since we live in Miami which is multiethnic and most of it is Hispanic they still follow it up to a point. I have made sure that all my doctors talk to me and not my family members...my Cuban oncologist...doesn't want to talk much about it...I said damm why did I have to

ask...then I searched the Internet and had a little talk with God and I realized that God sent it that way to get me to have more faith in him...

#### A Family Disease with Mistrust

Cancer was perceived as a family disease in Hispanic, African American, and Asian cultures. All the participants in these ethnic groups mentioned about the importance of family support in their lives. However, at the same time, many of them were talking about concerns on marital relationships. A Hispanic woman was concerned about her husband's alcohol problem that occurred after the diagnosis of her cancer. An Asian woman was concerned about her marital problem due to her disease. The following is what the Hispanic woman was talking about her family.

The girl [her daughter] hasn't spoken to me in two years and now I will not try for her to talk to me just out of pity, but the boys are wonderful to me and offer their help in whatever, my husband I guess he is having one hell of a time dealing with my illness since he went back to drinking, and he confided one day that he was afraid of losing me, but I right away reassured him that I was not planning on going anywhere for quite a while...but he still drinks. I guess I just ignore whenever he says words not nice and there I pray a lot for him and for God to grant me peace and serenity through all of this ordeal...

Some of the participants were satisfied with the current support from their family members, local resources, and health care services. Others reported that the current resources were not helpful for them to meet their needs. Some were using the Internet for the information related to their disease, and others were using message boards and chat-groups to get emotional support. One African American woman said:

My family was very supportive during this whole ordeal. The chemotherapy left me with neuropathy, which I am still dealing with. My younger nieces and nephews massage the feet to help with the pain. My cancer has affected my whole family. It really is a family disease. The younger ones in my family did not take my diagnosis well. I just constantly remind them that I am doing well and that everything is okay. They have questions about cancer, and I answer those questions for them.

## An Asian woman mentioned:

There were a few negatives of family response to my diagnosis within the extended family. Take for example my dad's sister, who I do not care for anyways, but she is what you could describe as a "hypochondriac" in which she feels she has anything someone else has...she's been this way for all my life as far as I can remember. So she was always into eating only certain foods...well not even a week after my diagnosis she was at our house and she told me and my parents that the reason I had cancer was due to my diet. She insisted I ate the wrong foods my entire life and then said about doing herbal/alternative methods of treatment. Needless to say my partners nor I were happy with that conversation, and have never forgotten it.

Many of the participants mentioned about their hesitance to interact with their family members, relatives, and friends and about their self-isolation from others. One of the participants mentioned:

One of my major concerns during this whole thing is the loss of friendships. I am not able to spend time with my friends like I used to. And there is a major change in my personality. I am more selfish with my time, I refuse to spend time on nonsense. I don't want any of my time wasted because I feel that I need ever moment. I do a lot more things for me. I take the time to relax and do things that I enjoy. I've started taking Yoga and I try to surround myself with beautiful things.

Some of ethnic minority participants mentioned about their mistrust on health care providers. An African American woman was talking about her difficulties with her health care providers while mentioning about racism and financial issues embedded in the U.S. health care system. An Asian woman was talking about her mistrust on the medical equipments that were used in the diagnosis process of her disease. The following is what the Asian woman was talking about her mistrust on her health care providers and medical diagnosis process.

I felt the lump myself and went to see my doctor. The doctor could feel it, but thought it's not alarming at all. I did mammogram, but it didn't show up the lump. Again, I was sent to the surgeon. This time the surgeon could not even feel the lump. The surgeon agreed to do one more thing, the ultrasound, and this time it came back suspicious. The biopsy of course confirmed it's a tumor...I was lucky that the cancer was caught early. However, it also points out a big problem...why the mammogram could not detect it? If I didn't insist to get all available tools what the consequences may be? My case will be delayed for at least another year and again, the mammogram may still come back negative, right? How many women be underserved because we believe the doctors or the medical equipment know everything?

## **Discussion**

In the literature, cancer patients' needs are roughly categorized into physical, psychological, information, support, and communication needs (Foot, 1996; Foot & Sanson-Fisher, 1995). Concisely speaking, physical needs are those related to coping with physical symptoms and side effects of treatment, performing usual physical tasks and activities of daily living, and self-management of medical treatment routines and health care at home. Psychological needs are those related to psychological and emotional issues. Information needs relate to diagnosis, investigative tests, family issues, and financial issues; support needs are in relation to family, friends, and health care professionals. Communication needs are those related to interpersonal relationships and the interactional skills and communication styles of health care providers. The first theme of "from side effects to racism" reflects these various types of needs.

Studies have also indicated that socioeconomic status and available social support are associated with cancer patients' needs (Clarke, Booth, Velikova, & Hewison, 2006; McIllmurray et al., 2001; Sanson-Fisher et al., 2000). Low socioeconomic status (SES) has been reported to influence cancer screening behaviors (Cui et al., 2002; Jacobellis & Cutter, 2002; Lannin et al., 1998; Li, Malone, & Daling, 2003), which has a direct effect on the stage of tumor at diagnosis and, therefore, cancer patients' needs. Low SES cancer patients tend to delay in presentation, referral from primary care and diagnosis, which results in a later stage of disease at presentation and differences in treatment of cancer (Pollock & Vickers, 1998; Wrigley et al., 2003). The study reported in this paper echoed certain influences of socioeconomic status, employment, and health insurance on cancer patients' needs for help, and cancer patients' continuous efforts to deal with financial issues with few resources.

Studies have reported certain gender differences in cancer patients' needs. As mentioned above, women are more likely to report significantly larger number of concerns than men (Hill, Amir, Muers, Connolly, & Round, 2003). Men are more likely to seek information while women are more likely to seek encouragement and support (Dale, Jatsch, Hughes, Pearce, & Meystre, 2004; Klemm, Hurst, Dearholt, & Trone, 1999; Sharf, 1997). There is a gender difference in help seeking behaviors (Smith, Pope, & Botha, 2005). Some recent studies reported certain gender differences in physical needs (Feine, Bushnell, Miron, & Duncan, 1991; Vallerand, 1995). The second theme of "same or double stress" reflects how the participants perceived gender differences in their cancer experience and subsequent needs for help in the contexts of their culture. Because of their Confucian culture prescribing that women should be a wise mother and good wife, Asian women were suffering from double burdens from doing

household works while struggling with cancer. Because of their cultural attitudes stigmatizing cancer of sexual organs and emphasizing "macho men", Hispanic men might not be able to seek for help because of possible embarrassment involved with their attempts to seek for help.

The third theme of "cultural hesitance and God" agrees with the findings from existing studies among Hispanic, African American, and Asian cancer patients. The existing studies have reported that these ethnic minority groups tended to stigmatize cancer itself because they believed that cancer is a genetic disease or cancer is a transmittable disease (Bailey, Erwin, & Berlin, 2000; Lipson & Dibble, 2005; Phillips, Cohen, & Moses, 1999). This stigmatized nature of cancer might make cancer patients from these ethnic groups not disclose their diseases and openly seek out help for their needs. Also, the findings reported in this paper also agree with this previous finding on heavy reliance on God among African American and Hispanic cancer patients. Studies have reported that a reliance on God to cure cancer without medical intervention was prevalent among African Americans (Lannin, Mathews, Mitchell, & Swanson, 2002; Mitchell, Lannin, Mathews, & Swanson, 2002; Wilson-Ford, 1992).

The fourth theme of "a family disease with mistrust" agrees with these findings on the importance of family in Hispanic and Asian culture and their cultural attitudes toward cancer and needs for help. Existing studies have reported that Caucasian cancer patients place the highest priority on their own individual experience and interests and want to have their own control of bodies and lives while cancer patients in Asian and Hispanic cultures respect the welfare of one's family (familism) (Pinquart & Sorensen, 2005). Also, family-centered models of decision making among Chinese American and Mexican American families coping with cancer have been frequently reported (Nakamura, 1999; Orono, Koenig, & Davis, 1994). The fourth theme also agrees with the findings of existing studies on Asians' cultural attitudes toward cancer. The studies among Asian cancer patients have reported Asians' belief that even thinking about cancer may cause the disease (Bottorff et al., 1998; Owens & Randhawa, 2004; Sadler, Nguyer, Doan, Au, & Thomas, 1998). Also, these studies have indicated that Asians did not discuss cancer outside their families because future marriage chances of children could be affected. Asians were also reported to place their families' needs precedence over their own and to be reluctant to seek help from health care providers especially for their intimate parts of the body because of their cultural values on personal modesty (Bottorff et al., 1998; Im, Lee, & Park, 2002; Im, Park, Lee, & Yun, 2004; Owens & Randhawa, 2004; Sadler, Nguyer, Doan, Au, & Thomas, 1998).

# **Conclusions and Implications**

In this study, gender and ethnic differences in cancer patients' needs for help were explored using a qualitative online forum discussion. Four themes reflecting the gender and ethnic differences emerged through the data analysis process. The themes are: (a) from side effects to racism: (b) same or double stress: (c) cultural hesitance and God; and (d) a family disease with mistrust. The overriding theme of these four themes was ethnic minority cancer patients' marginalized experience as cancer patients: they were marginalized because of their cultural background stigmatizing cancer and inhibiting them to seek for help to meet their own needs. Yet, these findings need to be carefully interpreted because this study included only 4 ethnic minority persons and 3 men. Based on the findings, we want to conclude this paper with the following suggestions for future research on gender and ethnic differences in cancer patients' needs for help.

First of all, further in-depth studies with a larger number of ethnic minority cancer patients are needed to develop a knowledge base on similarities and differences in cancer patients' needs for help according to gender and ethnicity. The study findings reported in this paper certainly indicate similarities and differences in the needs for help of diverse gender and ethnic groups

of cancer patients. However, because of the small number of ethnic minority cancer patients, ethnic-specific cancer patients' needs for help could not be explored in depth.

Second, researchers need to include cultural needs as a separate category of the cancer patients' needs for help. As mentioned above, the overriding theme of the findings of the study reported in this paper was ethnic minority cancer patients' marginalized experience as cancer patients because of their cultural background. When their cultural needs are not met, their other needs including physical, psychological, information, support, and communication needs could not be fully met.

Finally, researchers also need to consider that cancer patients' needs for help are not only influenced by gender and ethnicity, but also by other contextual factors influencing their daily lives. As the findings indicated, the participants of this study reported several contextual factors that had influenced their needs for help, which included financial issues, family relationships, marital relationships, work environment, social environment, etc. Thus, when exploring cancer patients' needs for help, these contextual factors need to be considered from the study planning process. Finally, the participants of the study reported in this paper tended to be limited to online cancer patients, who are a selected group of cancer patients. Online cancer patients tend to be highly educated, high income, White cancer patients (Fawcett & Buhle, 1995; Im, Chee, Tsai, Lin, & Cheng, 2005). Thus, the generalization of the study findings needs to be carefully done, and further studies with a more systematically sampled group of cancer patients are needed for more generalizable findings on gender and ethnic variations in cancer patients' needs for help.

# **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

## Reference

- Ankem K. Factors influencing information needs among cancer patients: A meta-analysis. Library & Information Science Research 2006;28:7–23.
- Arraras JI, Wright S, Greimel E, Holzner B, Kuljanic-Vlasic K, Velikova G, et al. Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. Patient Education and Counseling 2004;54:235–241. [PubMed: 15288920]
- Bailey EJ, Erwin DO, Berlin P. Using cultural beliefs and patterns to improve mammography utilization among African American women: The Witness project. Journal of the National Medical Association 2000;92:136–142. [PubMed: 10745644]
- Bernabei R, Gambassi G, Lapane K, Landi F, Gatsonis C, Dunlop R, et al. Management of pain in elderly patients with cancer. Journal of American Medical Association 1998;279(23):1877–1882.
- Boonmongkon P, Nichter M, Pylypa J, Sanhajariya N, Saitong S. Women's health in northeast Thailand: Working at the interface between the local and the global. Women Health 2002;35(4):59–80. [PubMed: 12216992]
- Bottorff JL, Johnson JL, Bhagat R, Grewal S, Balneaves LG, Clarke H, et al. Beliefs related to breast health practices: The perceptions of South Asian women living in Canada. Social Science and Medicine 1998;47(12):2075–2085. [PubMed: 10075248]
- Clarke S, Booth L, Velikova G, Hewison J. Social support. Gender differences in cancer patients in the United Kingdom. Cancer Nursing 2006;29(1):66–72. [PubMed: 16557124]
- Cleeland CS, Baez L, Pandya KJ. Pain and treatment of pain in minority patients with cancer. Annals of Internal Medicine 1997;127(9):813–816. [PubMed: 9382402]
- Cui YD, Whiteman MK, Langenberg P, Sexton M, Tkaczuk KH, Flaws JA, et al. Can obesity explain the racial differences in stage of breast cancer at diagnosis between white and black women? Journal of Women's Health and Gender-Based Medicine 2002;11(6):527–536.

Dale J, Jatsch W, Hughes N, Pearce A, Meystre C. Information needs and prostate cancer: The development of a systematic means of identification. BJU International 2004;94:63–69. [PubMed: 15217433]

- Edrington JM, Paul S, Dodd M, West C, Facione N, Tripathy D, et al. No evidence for sex differences in the severity and treatment of cancer pain. Journal of Pain and Symptom Management 2004;28(3): 225–232. [PubMed: 15336334]
- Fawcett J, Buhle ELJ. Using the Internet for data collection. An innovative electronic strategy. Computers in Nursing 1995;13(6):273–279. [PubMed: 8529140]
- Feine JS, Bushnell MC, Miron D, Duncan GH. Sex differences in the perception of noxiuous heat stimuli. Pain 1991;44:255–262. [PubMed: 2052394]
- Foley KL, Farmer D, Petronis VM, Smith RG, McGraw S, Smith K, et al. A qualitative exploration of the cancer experience among long-term survivors: Comparisons by cancer type, ethnicity, gender, and age. Psycho-Oncology 2006;15:248–258. [PubMed: 15940742]
- Foot, G. Needs assessment in tertiary and secondary oncology practice: A conceptual and methodological exposition. Doctoral dissertation. University of Newcastle; Newcastle: 1996.
- Foot G, Sanson-Fisher R. Measuring the unmet needs of people living with cancer. Cancer Forum 1995;19:131–135.
- Hall JM, Stevens PE. Rigor in feminist research. Advances in Nursing Science 1991;13:16–29. [PubMed: 1901470]
- Henderson PD, Fogel J. Support networks used by African American breast cancer support group participants. ABNF Journal 2003;14(5):95–98. [PubMed: 14664192]
- Hill KM, Amir Z, Muers MF, Connolly CK, Round CE. Do newly diagnosed lung cancer patients feel their concerns are being met? . European Journal of Cancer Care 2003;12:35–45. [PubMed: 12641555]
- Im E, Lee E, Park Y. Korean women's breast cancer experience. Western Journal of Nursing Research Nov;2002 24(7):751–765. [PubMed: 12428893]discussion 766–771
- Im E, Park Y, Lee E, Yun S. Korean women's attitudes toward breast cancer screening tests. International Journal of Nursing Studies Aug;2004 41(6):583–589. [PubMed: 15240081]
- Im EO, Chee W, Tsai H, Lin L, Cheng C. Internet Cancer Support Groups: A Feminist Analysis. Cancer Nursing 2005;28(1):1–7. [PubMed: 15681976]
- Jacobellis J, Cutter G. Mammography screening and differences in stage of disease by race/ethnicity. American Journal of Public Health 2002;92(7):1144–1150. [PubMed: 12084699]
- Kim H, Lee KJ, Lee SO, Kim S. Cervical cancer screening in Korean American women: Findings from focus group interviews. Taehan Kanho Hakhoe Chi 2004;34(4):617–624. [PubMed: 15502427]
- Klemm P, Hurst M, Dearholt SL, Trone SR. Gender differences on Internet cancer support groups. Computers in Nursing 1999;17(2):65–72. [PubMed: 10194883]
- Lannin DR, Mathews HF, Mitchell J, Swanson MS. Impacting cultural attitudes in African-American women to decrease breast cancer mortality. American Journal of Surgery 2002;184:418–423. [PubMed: 12433605]
- Lannin DR, Mathews HF, Mitchell J, Swanson MS, Swanson FH, Edwards MS. Influences of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. Journal of the American Medical Association 1998;22:1801–1807. [PubMed: 9628711]
- Li CI, Malone KE, Daling JR. Differences in breast cancer stage, treatment, and survival by race and ethnicity. Archives of Internal Medicine 2003;163(1):49–56. [PubMed: 12523916]
- Lipson, JG.; Dibble, SL. Culture and critical care. UCSF Nursing Press; San Francisco: 2005.
- McIllmurray MB, Thomas C, Francis B, Morris S, Soothill K, Al-Hamad A. The psychosocial needs of cancer patients: findings from an observational study. European Journal of Cancer Care (English Language Edition) 2001;10(4):261–269.
- Miaskowski C. Gender differences in pain, fatigue, and depression in patients with cancer. Journal of the National Cancer Institute Monographs 2004;(32):139–143. [PubMed: 15263057]
- Mitchell J, Lannin DR, Mathews HF, Swanson MS. Religious beliefs and breast cancer screening. Journal of Women's Health and Gender-Based Medicine 2002;11(1):907–915.

Molassiotis A, Chan CW, Yam BM, Chan ES, Lam CS. Life after cancer: Adaptation issues faced by Chinese gynaecological cancer survivors in Hong Kong. Psychooncology 2002;11(2):114–123. [PubMed: 11921327]

- Nakamura, RM. Health in America: A multicultural perspective. Allyn & Bacon; Needham Heights: MA: 1999.
- Orono CJ, Koenig BA, Davis AJ. Cultural aspects of nondisclosure. Cambridge Quarterly of Healthcare Ethics 1994;3:338–346. [PubMed: 7994457]
- Owens A, Randhawa G. 'It's different from my culture; they're very different': providing community-based, 'culturally competent' palliative care for South Asian people in the U.K. Health and Social Care in the Community 2004;12(5):414–421. [PubMed: 15373820]
- Phillips JM, Cohen MZ, Moses G. Breast cancer screening and African American women; fear fatalism, and silence. Oncology Nursing Forum 1999;26(3):561–571. [PubMed: 10214597]
- Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. Gerontologist 2005;45(1):90–106. [PubMed: 15695420]
- Pollock AM, Vickers N. Deprivation and emergency admissions for cancers of colorectum, lung, and breast in south east England: Ecological study. BMJ 1998;317:245–252. [PubMed: 9677214]
- Remennick L. "I have no time for potential troubles": Russian immigrant women and breast cancer screening in Israel. Journal of Immigrant Health 2003;5(4):153–163. [PubMed: 14574066]
- Rosser, SV. Women's health-missing from U.S. medicine. Ind: Indiana University Press; Bloomington: 1994.
- Sadler GR, Nguyer F, Doan Q, Au H, Thomas AG. Strategies for reaching Asian Americans with health information. American Journal of Preventive Medicine 1998;14(3):224–228. [PubMed: 9569224]
- Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, et al. The unmet supportive care needs of patients with cancer. Cancer 2000;88(1):226–237. [PubMed: 10618627]
- Sharf BF. Communicating breast cancer on-line: support and empowerment on the Internet. Women and Health 1997;26(1):65–84.
- Smith L, K. Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: A qualitative synthesis. Lancet 2005;366:825–831. [PubMed: 16139657]
- Tammermagi CM, Neslund-Dudas C, Simoff M, Kvale P. Lung carcinoma symptoms-an independent predictor of survival and an important mediator of African-American disparity in survival. Cancer 2004;101(7):1655–1663. [PubMed: 15378496]
- Templeton HRM, Coates VE. Adaptation of an instrument to measure the informational need of men with prostate cancer. Journal of Advanced Nursing 2001;35(3):357–364. [PubMed: 11489016]
- Thome B, Hallberg IR. Quality of life in older people with cancer -- a gender perspective. European Journal of Cancer Care (English Language Edition) 2004;13(5):454–463.
- Turk DC, Okifuji 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(2):139–148. [PubMed: 10467919]
- Vallerand AH. Gender differences in pain. Image: Journal of Nursing Scholarship 1995;27(3):235–237.
- Wilson-Ford V. Health protective behaviors of rural black elderly women. Health and Social Work 1992;17:28–36.
- Wrigley H, Roderick P, George S, Smith J, Mullee M, Goddard J. Inequalities in survival from colorectal cancer: A comparison of the impact of deprivation, treatment, and host factors on observed and cause specific survival. Journal of Epidemiology and Community Health 2003;57:301–309. [PubMed: 12646548]

Stuifbergen and Im Page 13

 $\begin{tabular}{ll} \textbf{Table 1}\\ Sociodemographic characteristics of the participants (N=16)\\ \end{tabular}$ 

Characteristics	n (%)	Characteristics	n (%)
Age (years)		Gender	
Mean (SD)	51.19 (10.20)	Female	13 (81.3)
Range	21-64	Male	3 (18.8)
Ethnicity		Marital Status	
White	12 (75.0)	Married	11 (68.8)
Hispanic	1 (6.3)	Divorced	3 (18.8)
African American	1 (6.3)	Single, never partnered	2 (12.5)
Asian	2 (12.5)		
Education		Religion	
High-school	1 (6.3)	Protestant	3 (18.8)
Partial college	2 (12.5)	Catholicism	4 (25.0)
College graduates	9 (56.3)	Others	6 (37.5)
Graduate degree	4 (25.0)	No religion	3 (18.8)
Employment		Born in the U.S.	
Not employed	7 (43.8)	Yes	12 (75.0)
Employed	9 (56.3)	No	4 (25.0)
Income Satisfaction		Annual Family Income	
Totally insufficient	3 (18.8)	(mean/SD)	\$48,603.33
Somewhat insufficient	1 (6.3)		(35,300.08)
Sufficient	9 (56.3)		
More than sufficient	3 (19.8)		
Health Status		Cancer Stage	
Unhealthy	3 (18.8)	Stage I	3 (18.8)
I don't know	3 (18.8)	Stage II	8 (50.0)
Healthy	9 (56.3)	Stage III	2 (12.5)
Very healthy	1 (6.3)	Stage IV	3 (18.8)
Cancer Type		Treatments (have received)	
Breast cancer	5 (31.3)	Only radiation therapy	1 (6.3)
Thyroid cancer	1 (6.3)	Only chemotherapy	5 (31.3)
Lung cancer	1 (6.3)	Only surgery	2 (12.5)
Colon cancer	1 (6.3)	Combined	8 (50.0)
Brain cancer	1 (6.3)		
Skin cancer	1 (6.3)		
Ovarian cancer	3 (18.8)		
Nasopharyngeal	1 (6.3)		
Combined	2 (12.5)		
Pain Medication		Regular Access to Health Care	
Yes	7 (43.8)	Yes	15 (93.8)
No	9 (56.3)	No	1 (6.3)
Regular Place for Health Care		Having Difficulties in Getting Health Care	

Stuifbergen and Im

Characteristics n (%) Characteristics n (%)

Page 14

Characteristics	n (%)	Characteristics	n (%)
Clinic or Health Center	14 (87.5)	Yes	4 (25.0)
Others	1 (6.3)	No	11 (68.8)
Missing	1 (6.3)		
Support from family members, relatives, or friends		Number of Children: Mean (SD)	2.13 (0.96)
None of the time	1 (6.3)	Number of Friends: Mean (SD)	3.06 (0.68)
A little of the time	3 (18.8)		
Some of the time	4 (25.0)		
Most of the time	8 (50.0)		
Born in the U.S.		Length of Stay in the U.S.: Mean (SD)	312.67 (237.56)
Yes	12 (75.0)		
No	4 (25.0)		