Patients' Attitudes Toward Internet Cancer Support Groups

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Purpose/Objectives: To explore patients' attitudes toward Internet cancer support groups (ICSGs) through an online forum.

Research Approach: Qualitative study using a feminist perspective.

Setting: Internet and real settings.

Participants: 16 patients with cancer.

Methodologic Approach: An online forum was held for one month with six discussion topics. The data were analyzed using thematic analysis.

Main Research Variables: Attitudes toward ICSGs.

Findings: Through the data-analysis process, four themes were found related to patients' attitudes toward ICSGs. First, the participants universalized patients' needs for and attitudes toward ICSGs. Second, most of the participants wanted to use ICSGs for emotional support, information, and interactions. Third, many of the participants used ICSGs because they could reach out to other patients with cancer without traveling and without interrupting their busy schedules. Finally, many participants were concerned about the security of interactions on ICSGs, so they wanted ICSGs that could ensure privacy and safeguard the anonymity and confidentiality of what they shared online.

Conclusions: Patients view ICSGs positively. Additional studies should examine gender-specific and multilanguage ICSGs by recruiting more ethnic minority patients.

Interpretation: Despite concerns about the security of Internet interactions, ICSGs would be an excellent source of social support that is acceptable to patients with cancer.

Key Points . . .

➤ Female participants expressed appreciation of gender-specific Internet cancer support groups (ICSGs) because they wanted to share the "women things" that men could not understand.

➤ A common perception among the participants, who were mostly white, was that ethnic minority patients with cancer would not have difficulties using existing ICSGs if the groups supported diverse languages.

➤ The time flexibility in ICSGs helped participants join and participate.

➤ ICSGs were perceived as convenient by most of the participants because they could reach out to other patients with cancer while maintaining anonymity.

L ittle is known about patients' attitudes toward Internet cancer support groups (ICSGs). The few studies that have been conducted indicate that patients view ICSGs positively as a source of support and that patients' use of health information and groups on the Internet increases social support by reducing social isolation and increasing personal empowerment and self-esteem (Fernsler & Manchester, 1997; Fogel, Albert, Schabel, Ditkoff, & Neugut, 2002a, 2002b, 2003; Gustafson, Wise, McTavish, & Taylor, 1993; Gustafson, Hawkins, Pingree, McTavish, & Arora, 2001; Houston, Cooper, & Ford, 2002; Klemm, Reppert, & Visich, 1998; Lieberman, Golant, & Giese-Davis, 2003; McTavish, Gustafson, & Owens, 1995; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1996; Winzelberg, Classen, & Alpers, 2003). Participation in ICSGs also has been reported to reduce depression and cancer-related trauma (Houston et al.; Lieberman et al.; Winzelberg et al.). Campbell, Meier, and Carr (2001) asserted that the anonymity of online chat groups (one interactive format for ICSGs) appeared to provide a more comfortable forum for some people to discuss sensitive personal health issues.

Patients' attitudes toward ICSGs also can be inferred from some of the findings on attitudes toward Internet use in general. Some patients with cancer go online to look for information related to their cancer, are willing to use the Internet for information and emotional support, and generally find the cancer-related information on the Internet to be useful (Pautler et al., 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Satterlund, McCaul, & Sandgren, 2003; Ziebland et al., 2004). Other studies, however, have reported that only 7%–10% of patients with cancer actually were meeting their needs for information or support through the Internet, and the patients were undecided about the trustworthiness of the medical information they could find online (Diefenbach et al., 2002; Mills & Davidson, 2002; Pereira et al.; Raupach & Hiller, 2002).

Studies have indicated gender and ethnic differences in ICSG use (Klemm, Hurst, Dearholt, & Trone, 1999; Pautler

et al., 2001; Sharf, 1997); patients participating in ICSGs tend to be highly educated, high-income whites in early stages of cancer. Also, the studies reported that men were more likely to seek information, whereas women were more likely to seek encouragement and support (Klemm et al., 1999; Sharf). More women (63%) than men (46%) consulted the Internet for health information (Pew Internet and American Life Project, 2000). Ethnic minorities have been underrepresented even in traditional cancer support groups (Classen et al., 2001; Hegelson, Cohen, Schulx, & Yasko, 1999; Magen & Glajchen, 1999; Michalec, Willigen, Wilson, Schreier, & Williams, 2004).

Relatively recently, some ethnic differences in attitudes toward ICSGs and in patterns of ICSG use have been reported. Cline and Haynes (2001) reported that African American patients with cancer tended to rely more on the Internet than white patients did, even though whites tended to have more Internet access than African Americans. Mead, Varnam, Rogers, and Roland (2003) reported that disadvantaged people (including ethnic minority patients with cancer) expressed greater interest in e-health than their more affluent counterparts. Both studies suggested that Internet resources may be valued by people who suspect that they are unlikely to establish equal and honest relationships with doctors in real settings because of ethnicity.

Despite the findings, very little is known about patients' attitudes toward ICSGs. The purpose of this study was to explore the topic through a qualitative online forum that would examine attitudes and the contextual factors (variable health status, socioeconomic circumstances, families' responses and roles, stability of daily lives, and social support networks) that might influence attitudes. The study was conducted as part of a larger one that explored psychometric properties of the instruments measuring need for help in patients with cancer and feasibility and usability of online forum topics related to attitudes toward ICSGs. Detailed information on the larger study can be found elsewhere (Im et al., in press).

Theoretical Basis

A feminist perspective was used as the theoretical basis of the study. When the World Wide Web was invented, in the mid-1990s, feminists welcomed the Internet because they believed it would bring the disembodiedness of interaction that subsequently fosters disruption in the shaping of human identities (Featherstone, 2000; Leary, 2000; Plant, 2000; Turkle, 1995). Feminists believed that individuals would be freer on the Internet to choose their identities as a result of non–face-to-face interactions (Waskul, Douglass, & Edgley, 2000). However, the utopian idea of cyberliberation was more problematic than people had hoped because cyberspace was not free from normative gender constraints or from oppression related to embodied identity (Bassett, 1997; Kendall, 1998; Pitts, 2004). Rather, cyberspace became "monocultured" by corporate and media interests and came to reflect the constraints and oppressions of the "real" world (Bell & Kennedy, 2000; Cartwright, 2000; Sardar, 2000). The current study takes a parallel view, assuming that patient attitudes toward ICSGs reflect aspects of their continuous interactions with the real world, as well as biases from the ways that they and their healthcare providers view the real world.

In addition, as feminist researchers have suggested (Andrist & MacPherson, 2001; Ford-Gilbe & Campbell, 1996; Hall &

Stevens, 1991), the researchers respected patients' own views, beliefs, and attitudes in the study; tried to reduce the distance between the researchers and the participants by providing prompt responses to questions and concerns expressed by the participants; and considered gender and ethnicity to be significant factors that influence and circumscribe patients' attitudes toward ICSGs.

Methods

This was a qualitative online forum study among 16 patients with cancer who were recruited through the Internet and real settings. Approval was obtained from the institutional review board at the university with which the authors are affiliated.

Sample and Setting

A total of 16 self-identified patients with cancer were recruited through the Internet and real settings using a convenience sampling method. In addition, 199 ICSGs (identified through searches on MSN.com) were visited, and their eligibility (e.g., being in the public sphere, actually serving patients with cancer, providing support or information related to cancer) was checked. Study announcements were made through the first 20 eligible ICSGs on the list with each webmaster's agreement. The real settings were a cancer clinic in central Texas and a cancer support group in New York. Because 6–12 participants usually are regarded as ideal for a focus group discussion, including online forum discussion (Stevens, 1996), 16 was assumed to be an adequate number for the online forum discussion presented here. The inclusion criteria for research participants were self-identified patients aged at least 18 years who could read and write English.

The online forum was held for only one month. Every Monday during the online forum discussion, one or two topics were posted on the forum site, and the participants were informed by e-mail when topics were posted. During administration of the online forum, several strategies were used to retain the participants: establishing bonds between the participants and researchers via respectful and trustworthy interactions through the online forum, assigning one research staff member to follow the online forum consistently for one month, and providing a modest monetary incentive of $50 to each participant at the completion of the online forum.

Discussion Topics

Six online forum topics were used for discussions about patients' attitudes toward ICSGs: (a) attitudes toward computer and Internet technologies, (b) attitudes toward resources and information available on the Internet, (c) attitudes toward (culturally universal and ethnic-specific) and actual use of cancer support groups (CSGs) and ICSGs, (d) gender and ethnic differences in patients' attitudes toward and actual use of CSGs and ICSGs, (e) things and life events and other gender- and ethnic-specific contextual factors influencing participation in CSGs and ICSGs in their daily lives, and (f) preference for ethnic-specific CSGs and ICSGs (e.g., language, content, types of information, moderator, structure, format). Each topic included several prompts to elicit participants' responses and facilitate discussion. The topics and the prompts were developed for this study and reviewed by an panel of five oncology experts.

Data Collection Procedures

For the larger study (Im et al., in press), the participants were asked to take an Internet survey first. When they completed the survey, they were asked about their interest in an online forum. When participants agreed to join the online forum by clicking the button "I agree to participate in an additional online forum," they were asked to visit the online forum site by using the usernames and passwords that were randomly assigned and given to them by the researchers. After they logged into the online forum site, they could change their usernames and passwords at any time. The participants also were asked to choose pseudonyms for the online forum discussion so that their real names could not be identified by other participants. In addition, their visits on the online forum site were recorded, monitored, and controlled. To ensure confidentiality and protect privacy, only those who registered were allowed to enter the online forum.

When an adequate number of participants (24) were recruited, the online forum was initiated. One of the researchers sent e-mails to inform the registered participants of initiation. The opening page of the online forum site showed the introductory questions so that participants could introduce themselves when they visited the site for the first time. The introductory questions and six discussion topics were posted serially on the forum site for the one-month period, and participants could post messages about the topics at their convenience in any form they wished (e.g., stories, conversations, responses to others' messages). The number and length of the messages were not limited, but most participants left only the two messages per topic required for reimbursement of their participation.

Rigor

The researchers used the standards of rigor for feminist research suggested by Hall and Stevens (1991): dependability, reflexivity, credibility, relevance, and adequacy. Dependability of the study was ensured by examining the methodologic and analytic decision trails created throughout the data collection and analysis process; reflexivity was considered through writing chronologic research memos and notes and holding regular group meetings to discuss any issues related to the study; credibility and relevance of the study were obtained through posting and sharing the study findings through the online forum site; and adequacy was considered carefully by discussion of issues related to research methods, goals, research questions, design, scope, analysis, conclusions, and impact of the study in the social and political environment through biweekly research meetings.

Data Analysis

The online forum data were printed as transcripts and analyzed through thematic analysis (Boyatzis, 1998; Luborsky, 1993). From the first week of data collection, the analysis process was initiated. First, the transcripts that were printed from the online forum site were read thoroughly and reread for line-by-line coding. The codes from the line-by-line process were summarized as a coding book, and categorization was accomplished through internal cognitive processing and reflexive thinking while the researchers analyzed content and context. The relationships among the categories that emerged from the process were postulated from links among the categories. Then, themes related to patients' attitudes toward ICSGs were sought through reviewing and reformulating the relationships. At the same time, how variable contextual factors (including variable health status, socioeconomic circumstances, families' responses and roles, stability of their daily lives, and social support networks) influenced the participants' attitudes toward ICSGs was examined. In addition, the texts were read and reread to provide more abstract and refined ideas about domains of interest, and themes common to research participants were identified.

Findings

Sample

Sociodemographic characteristics of the participants are summarized in Table 1. The participants consisted of 12 whites, 1 Hispanic, 1 African American, and 2 Asians; their mean age was 51.19 years (SD = 10.20); 81% were women. More than 80% had college diplomas or graduate degrees, and about 56% were employed despite their disease.

Five themes related to the attitudes of patients with cancer toward ICSGs emerged: universalizing, seeking, reaching out, belonging, and safeguarding.

Themes

Universalizing: Most of the participants believed that ICSGs should be provided according to type of cancer rather than ethnicity or gender. Many of the white participants saw no gender and ethnic differences in patients' needs for ICSGs and believed that ICSGs do not need to target specific ethnic groups. One white man said, "Cancer sucks no matter what you are; it supersedes culture, it supersedes gender. If you think you need or want support, then you get it regardless of culture." A white woman echoed,

> I felt that the primary factor was having cancer, and my being a woman or being white didn't really have anything to do with how my cancer got treated or my participation in a support group or use of any other resource to help myself get through the cancer.

Another participant said,

> I am comfortable using the Internet because I speak and think in English. I can only imagine it hard for someone who speaks a different language to find an Internet support group that deals solely in their language (other than English). Apart from obvious language barriers, I see no reason why race is a consideration when using the Internet.

Although most of the participants saw no gender and ethnic differences in their needs for ICSGs, they talked about gender differences in patterns of patients' participation in ICSGs. A white woman said,

> I think women also feel more comfortable discussing their health, feelings, and problems with a support group than men. Men still seem reluctant to open up and participate in a support group. . . . There is very little attendance and almost no participation from the men in the groups. Online, it might be easier for men to participate and they might do it more often, but . . . I can't really tell.

Table 1. Sociodemographic Characteristics

Characteristic	n	%
Age (years)		
X̄ (SD) = 51.19 (10.20)	–	–
Range = 21–64	–	–
Annual family income		
X̄ (SD) = $48,603.33 ($35,300)	–	–
Ethnicity		
White	12	75
Hispanic	1	6
African American	1	6
Asian	2	13
Religion		
Protestant	3	19
Catholic	4	25
Others	6	38
No religion	3	19
Gender		
Female	13	81
Male	3	19
Marital status		
Married	11	69
Divorced	3	19
Single, never partnered	2	13
Income satisfaction		
Totally insufficient	3	19
Somewhat insufficient	1	6
Sufficient	9	56
More than sufficient	3	20
Employed		
No	7	44
Yes	9	56
Education		
High school	1	6
Partial college	2	13
College degree	9	56
Graduate degree	4	25
Born in the United States		
Yes	12	75
No	4	25
Support from family members, relatives, or friends		
None of the time	1	6
A little of the time	3	19
Some of the time	4	25
Most of the time	8	50
Primary cancer site		
Female reproductive organs	8	50
Head and neck	2	13
Other (i.e., lung, colon, brain, or skin)	4	25
Combined	2	13
Health status		
Unhealthy	3	19
I do not know.	3	19
Healthy	9	56
Very healthy	1	6
Cancer stage		
I	3	19
II	8	50
III	2	13
IV	3	19
Pain medication		
Yes	7	44
No	9	56
Treatments received		
Only radiation therapy	1	6
Only chemotherapy	5	31
Only surgery	2	13
Combined	8	50

N = 16

Note. Because of rounding, percentages may not total 100.

The African American participant said,

I think that women are more likely to participate in Internet support groups. I think that we are more expressive in dealing with issues that we have than men. Men seem to keep things bottled up more. In regard to things that they are feeling, like pain . . . they don't want people to think that they are weak. It's that whole macho thing.

Some of the participants, especially women, spoke about the necessity of gender-specific ICSGs. They reasoned that only through gender-specific ICSGs could women share the "women things" that men could not understand or topics, such as women's sexual organs, that would be embarrassing to discuss with men present. The African American woman said,

I am a black woman. To me, it does not matter the color of the women in a support group unless it was one just about women. I think that women experience a lot of experiences that are the same. However, I would prefer to be in a support group with women as opposed to men. I just think that as women we can relate a bit more to different issues than men. I feel more comfortable opening up with women on some of the things that I am going through.

Others preferred gender-mixed groups because they could share some universal experiences related to cancer and they could learn and discuss the issues related to their cancer more comprehensively. Two of the female participants said, respectively

I would like to see men watching a women's support group and women watching a men's group. In that way, they would try and understand it from each others' viewpoints. But I wouldn't let the other know about this. This way everyone would be honest and not afraid to be open (the spouses need this the most).

I think everyone joining a support group is doing it either to find out more information about their type of cancer (if it is a group on a particular type of cancer), to have the access to talk to others going through the same ordeal, or to help others that are not coping well with the diagnosis or treatment. I don't think one gender has a set reason of why they join though.

When the participants were asked about the need for ethnic-specific ICSGs, most mentioned language-specific needs. Many believed that ethnic minority patients would not have difficulties using ICSGs that currently exist if the groups operate in languages including Spanish or Portuguese. They did not believe that any ethnic-specific or culture-specific needs could be taken care of through ethnic-specific ICSGs. Two white women echoed this sentiment. "I think it will help to many minorities if there are many different language support groups," "The new immigrants are having least support than the people who speak perfect English," and

The only difficulty coming from different ethnic backgrounds when participating in an Internet cancer support group is language, making sure we are all understood and provide easily understood and clear responses.

The Hispanic woman raised an interesting issue related to ethnic-specific ICSGs. According to her, participants in

English-language ICSGs are more open to discussion than those in Spanish-language ICSGs. She had been participating in Spanish-language ICSGs specifically for Hispanic patients in the United States, and her experience in the ethnic-specific group made her move to the English-language group. She said participants in the Hispanic group did not respond and were indifferent to other participants.

> I think that some cultures might think support groups are not good, as they think that personal problems should be handled internal to the person or family, not discussed in public. My ethnic group/culture doesn't have any such misgivings and actually encourages participation. . . . I use both languages, but if I had to choose one I would choose English. We can give each other more resource of info than the Spanish-speaking patients would be able to do. They are not as open into searching as the English-speaking people are.

Seeking: Most of the participants wanted to use ICSGs that would provide emotional support, interactions, and information. Female participants mentioned their needs to get emotional support through ICSGs. One white woman said the following about her needs for emotional support.

> Professional services for emotional support should be provided immediately upon diagnosis, whether the patient has requested it or not. My medical condition put me in an emotional state that I would not wish on my worst enemy, and not once was I offered any emotional support. Not because I was emotionally unstable, but because my emotional condition was a result of my treatment and would pass.

No gender or ethnic differences were identified in participants' needs to get information related to their disease. Rather, all of the participants were eager to get more information on their disease. Two of the female participants related the following.

> What I would expect from any support group . . . is good, solid information that is easy to understand. I would want general experience from my peers, not some horror story. . . . I know that each person reacts differently to treatments, so I would always be looking for good, general type of information.

> I have found the answers to my questions via the Internet cancer support groups, so I guess their content is acceptable as is. . . . My first question was what my likely life expectancy could be, then after that I wanted to know everything! I found clear explanations for my treatments, time scales for what I was going through, and support for my dwindling brain cells.

Some participants expected ICSGs to provide a variety of resources, including financial and transportation resources. One of the women said,

> I would expect to get offered the following resources: medical information regarding cancer in general, cancer in particular, treatment, side effects, options; Web sites with more information or new information; places where a person could apply for financial, medical supply, or transportation assistance; holistic information regarding health, diet, exercise, etc.; and the reassurance that if I

needed something else I could ask and they would find out if there was a resource for that.

Many of the participants were much more satisfied with ICSGs compared with traditional face-to-face support groups because they could avoid uncomfortable personal face-to-face interactions with strangers, they did not need transportation for ICSGs, and they could get more up-to-date information through ICSGs. One of the white women mentioned,

> I have attended both "live" educational support groups and those online and find that I actually get more comprehensive, up-to-date, and better information online. The live sessions seem to be too general to get much benefit from them, while the online sessions seem to have more people who have a wider range of information.

Reaching out: Although traditional face-to-face CSGs could provide more real-time activities (e.g., meetings with guest speakers, hiking trips, races), some participants preferred the ICSGs because they needed more flexible time commitments. Because of their busy schedules and their disease status, attending regularly scheduled face-to-face groups would have been difficult. Most participants reported feeling isolated by their busy schedules or by their specific geographic areas, but the ICSGs provided them with a channel to reach out to other patients with cancer in similar circumstances. Two white women said, "It is nice when you can't sleep at 2 am and you can get on and talk to others that are in the same boat" and "When I was working it took all of my energy, and now that I'm on my fifth line of chemo it has taken all of my energy. But the online support groups are there all the time, so that was helpful."

Also, ICSGs were perceived as convenient by most of the participants because they could reach out to other patients who were total strangers without even giving their real names. Although the importance of anonymity decreased over time, the participants perceived it as one of the strengths of ICSGs. One white woman said,

> I think Internet cancer support groups fill an important need. First of all, they do not require that you drive to a meeting, and they allow a certain amount of anonymity, although I have found the anonymity to be less important as time goes on in the group. They are often available any time of the day or night, so you can get help and support when you really need it or when it's convenient for you.

Belonging: The participants valued being members of a group. Most of them wanted meaningful interactions with others because they tended to have difficulties interacting with their family members and friends because of their disease. One of the white women mentioned,

> Often, I found others who were in my exact situation online. . . . There was no surgeon in my health plan in my city. . . . There was really no one locally that I could discuss this with. However, in the online support forums, I found people all over the U.S. who had even gone to my same reconstructive surgeon and had the same surgery. I felt I had much more support online than in person.

Many of the participants also wanted ICSGs that they could claim as their own communities or groups. One of the participants articulated her desire to be a member of a group.

> The difference in situations caused a lot of frustration for me, because since the day I was diagnosed it felt like I was alone on a ["back road"] parallel to the "main highway"—where all my friends were. They worried about being overweight, I worried about keeping weight on my body due to not feeling well, etc. I no longer was taking life for granted like most of my friends. . . . So the different lifestyle that I was now experiencing lacked others who had similar worries and feelings, and that is one thing I found within the group. I also found a type of support from people I didn't even personally know, but that was so helpful (in a different way from the support I received from family and friends).

Most of the participants did not like groups in which other participants were not responsive to others' messages and postings. Some complained about their bad experiences with ICSGs in which some members were rejected because the moderators did not like the specific members and nobody was giving them attention. Other participants praised groups they felt to be helpful and lively as communities. A white woman mentioned her excellent moderator and her positive experience with her group.

> The first . . . support group I joined has an oncology nurse from the cancer center as the moderator. She is excellent. . . . She does not give advice, but she is a great source of information and she can also help members navigate the local healthcare system. She arranges guest speakers based on our input, shares information about conferences, . . . and other resources. This group feels like it is our group.

Safeguarding: Most of the participants, especially the white participants, were concerned about the security of the ICSGs. Although they wanted to get support online, they always had some anxiety related to privacy, anonymity, and confidentiality of the discussions to which they were contributing. One white woman talked about her concern.

> Some groups call themselves moderated groups with membership being approved or denied. You need to be careful of their conditions—some require that personal information and e-mails be provided for membership. . . . I wouldn't even consider joining a group on [a large national Internet service provider] with those requirements because you can't always trust the moderators or their motives. That type of information has no bearing on your needs and wants from an Internet support group.

Consequently, most of the participants wanted ICSGs that could protect them from possible harms from outside, secure the privacy of their discussions, and ensure their anonymity or the confidentiality of their identities. One white woman said,

> I would expect [support] groups to respect and protect my privacy, that any information I choose to share is my choice and is not shared by others without my knowledge. My real name, address, phone number, e-mail address, etc., should all be protected.

Discussion

Despite the lack of knowledge about attitudes of patients with cancer toward ICSGs, a few studies have reported that patients positively viewed ICSGs as a support source for them and that patients' use of health information and groups on the Internet increases social support by reducing social isolation and increasing personal empowerment and self-esteem (Fernsler & Manchester, 1997; Fogel et al., 2002a, 2002b, 2003; Gustafson et al., 1993, 2001; Houston et al., 2002; Klemm et al., 1998; Lieberman et al., 2003; McTavish et al., 1995; Sharf, 1997; Weinberg et al., 1996; Winzelberg et al., 2003). The findings of the current study support patients' positive attitudes toward ICSGs. The theme of seeking supports especially well the benefits that have been reported in the literature. The participants were seeking emotional support, information, and interactions and viewed ICSGs as an excellent source.

The theme of reaching out also is consistent with findings from previous studies on the advantages of ICSGs over traditional face-to-face CSGs. Participants in the current study echoed the advantages of ICSGs articulated by Winzelberg et al. (2003), who pointed out that one of the advantages of ICSGs over face-to-face CSGs is the relatively flexible modality through which information can be delivered asynchronously. They asserted that another advantage of ICSGs is the variety of facilitation options, such as scheduling flexibility, and increased accessibility to individuals who otherwise could not participate in such groups because of health status, residence in remote areas, or social anxiety. Another advantage is that fewer resources are required to administer ICSGs, which can tremendously reduce the administrative costs for participants, moderators, and administrators. In the current study, the three advantages were identified through the theme of reaching out that emerged through the data analysis process: Patients positively viewed the flexibility and accessibility of the ICSGs through which they could reach out to other patients with cancer in geographically dispersed areas.

Some studies have reported that patients with cancer were willing to use the Internet for information searches and emotional support and that they found the cancer-related information retrieved on the Internet to be useful (Pautler et al., 2001; Pereira et al., 2000; Satterlund et al., 2003; Ziebland et al., 2004). Other studies have reported that very few patients with cancer were actually using the Internet to get information and support and that patients were not sure about the trustworthiness of the information they got on the Internet (Diefenbach et al., 2002; Mills & Davidson, 2002; Pereira et al.; Raupach & Hiller, 2002). The safeguarding theme agrees with the latter findings: Most of the participants were concerned about trustworthiness of the information provided by ICSGs, and the main reason they hesitated to join an ICSG was that they could not trust the security.

Other recent studies have reported that ICSG members might become over-reliant on their Internet-based relationships, resulting in increased social isolation (Winzelberg et al., 2003). Although the findings of the study reported in this article did not support that possibility, the researchers did find that some patients had negative experiences with ICSGs. Also, the findings of the study strongly support that patients wanted to participate in ICSGs because of their social need to belong to a group.

Some gender and ethnic differences in attitudes toward ICSGs have emerged (Cline & Haynes, 2001; Klemm & Hardie, 2002; Mead et al., 2003; Sharf, 1997). However, the theme of universalizing found in the current study was somewhat different than findings from previous studies. Most participants (especially white men) seemed to contradict possible gender and ethnic differences in patients' attitudes toward ICSGs, asserting instead that cancer affects everybody in the same way. Some of the participants mentioned that they would prefer women-only ICSGs rather than gender-mixed ICSGs. Also, some others emphasized the importance of supporting diverse languages in existing ICSGs. The findings need to be interpreted carefully because the study included only four people who were ethnic minorities and only three men.

Conclusions and Implications

Further studies of patients' attitudes toward ICSGs should be conducted with larger numbers of ethnic minority patients with cancer. Although the findings of the study indicate that most of the patients did not see gender and ethnic differences in patients' needs for and attitudes toward ICSGs, other existing studies have reported certain gender and ethnic differences. Considering the small number of ethnic minority patients included in the current study, further studies with larger numbers of ethnic minority patients with cancer are essential.

Also, ICSGs should strive to meet patients' needs for emotional support, interaction, and validated and credible information; for reaching out to other patients through a flexible and accessible method of delivery; and for belonging to a group that they can perceive and claim as their own community or group. ICSGs should be based on secure Internet interactions.

Finally, although some of the participants believed that gender- and ethnic-specific ICSGs are not necessary, other participants mentioned that they would prefer women-only ICSGs and ICSGs supporting diverse languages. As indicated earlier, this online forum had small numbers of ethnic minorities and men. Thus, further studies with larger numbers of ethnic minorities and men could explore the necessity for gender-specific ICSGs and ICSGs supporting diverse languages.

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