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“Shielded from the Real World”: Perspectives on Internet Cancer Support Groups by Asian Americans

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Abstract

Background—Despite positive reports about Internet cancer support groups (ICSGs), ethnic minorities, including Asian Americans, have been reported to be less likely to use ICSGs. Unique cultural values, beliefs, and attitudes have been considered reasons for the low usage rate of ICSGs among Asian Americans. However, studies have rarely looked at this issue.

Objective—The purpose of this study was to explore (a) how Asian Americans living with cancer who participated in ICSGs viewed ICSGs, (b) what facilitated or inhibited their participation in ICSGs, and (c) what cultural values and beliefs influenced their participation in ICSGs.

Methods—The study was a one-month qualitative online forum among 18 Asian American cancer patients recruited through a convenience sampling method. Nine topics on the use of ICSGs organized the forum discussion, and the data were analyzed using thematic analysis.

Results—Four themes emerged from the data analysis process: (a) “more than just my family,” (b) “part of my family,” (c) “anonymous me,” and (d) “shielded from the real world.”

Conclusions—The overarching theme was Asian Americans’ marginalized experience in the use of Internet cancer support groups.

Implications for Practice—Offering the most current information on cancer and cancer treatment is essential for nursing practice in developing a culturally competent ICSG for Asian Americans. Also, emotional familiarity should be incorporated into the design of the ICSG, and the ICSG needs to be based on non-judgmental and non-discriminative interactions.

In the past 20 years, psychosocial group interventions for people living with cancer have been developed.¹ One such intervention is support groups, which employ diverse approaches focusing on behavior, symptoms including pain and fatigue, and the expression of emotions.² Cancer support groups (including Internet Cancer Support Groups [ICSGs]), most of which are structured and short-term, have been an effective and efficient means of providing support.² Although support groups in general provide people living with cancer with health education, emotional support, relaxation practice, guided imagery, neuropsychological training, and stress management,³ ICSGs tend to mainly provide emotional support through the Internet and sometimes information and links to resources.

ICSGs, which provide social support in three broad categories: emotional, information, and companionship, recently became popular among people living with cancer.^{4,5} ICSGs are beneficial because people in pain or discomfort can participate in them without having to travel or physically move beyond what is necessary to use a computer.⁴ Some studies also reported several unique positive characteristics of ICSGs. Coulson⁶ pointed out that ICSG members have access 24 hours a day, seven days a week. Ferguson⁷ reported that a large proportion of online support in ICSGs occurs between 7:00 pm and 1:00 am. Participants can also receive support in their own homes, free from concerns about travel time, work, or family commitments.⁶ Braithwaite et al⁸ reported that ICSGs are safer environments for members to engage in comforting and creative expressions of support. Despite these positive reports about ICSGs, some studies have also reported negative aspects, including hostile encounters, lack of explicit rules of interaction, lack of social cues, and inaccurate information.⁶

These studies, furthermore, rarely included Asian Americans living with cancer as research participants, and very little is subsequently known about cultural perspectives that hinder Asian Americans' participation in support groups in general. For example, when PUBMED, CINAHL, and PsycINFO databases were searched using the key words "Asian American," "Asians," "online support groups," and "Internet cancer support groups," only four articles were retrieved.^{9–13} Among them, only one article was related to Asian Americans' use of ICSGs, but it was not specific to ICSGs or Asian Americans.⁹ In this article, James et al.⁹ reported that (a) relatively few patients (4.8%), but a high proportion of caregivers (48%), accessed the Internet directly for cancer information; (b) about half of the patients used Internet information provided by someone else, generally a family member; (c) the use of Internet information was uniformly low among ethnic minorities; and (d) those who accessed Internet information reported high levels of satisfaction and generally rated it higher than booklets or leaflets. Thus, this study may be the first that explores Asian Americans' cultural perspectives on ICSGs.

The purpose of this pilot study was to explore (a) how Asian Americans living with cancer who participated in ICSGs viewed ICSGs, (b) what facilitated or inhibited their participation in ICSGs, and (c) what cultural values and beliefs influenced their participation in ICSGs. "Asian Americans" refers to those having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent.¹⁴

Theoretical Basis: A Feminist Perspective

The study was theoretically guided by a feminist perspective on the Internet interactions. We used a feminist perspective as a cultural lens that would help explore Asian Americans' unique perspectives on ICSGs. At the beginning of the Internet era, feminists thought that non-face-to-face interactions on the Internet might foster a disruption in the shaping of human identities^{15–17} and that, subsequently, people who represent the body through images and symbols are freer to perform their identities since empirical verification imposes no limits.¹⁸ In other words, they thought that human interactions through the Internet would make the people free from the current oppression in the real physical world (e.g., racism, classism, sexism, etc).¹⁹ However, the Internet turned out to be a replica of conventional power relations in the real physical world.^{19–22} Indeed, recent researchers report that Internet interactions are clearly influenced by the current sociopolitical contexts of the real physical world.^{23–25} From this feminist point of view on Internet interactions, we assumed that the lack of use of ICSGs by Asian Americans living with cancer may reflect current constraints and oppressions in the real physical world, and that their perspectives on ICSGs are based on their continuous interactions with the real physical world and on cultural and social biases which reflect the ways they view and are viewed in the real world.

Methods

This was a part of a parent study on the use of ICSGs among people living with cancer that included (a) an Internet survey; (b) an expert review; and (c) an online forum.^{26, 27} Each part of the study dealt with different research questions, and only the findings from the online forum are presented in this paper. Other parts of the study did not influence the online forum reported in this study. More information on the Internet survey and the expert review can be found elsewhere.^{26,27} The Institutional Review Board of the institution where the researchers were affiliated approved the study.

Settings and Participants

A total of 117 Asian Americans living with cancer that could read and write English were recruited in the parent study during the four months from September 2008 to January 2009. Of these 117 participants, 18 participants agreed to participate in the online forum, and all those who agreed to be in the study were included. By the end of the one-month online forum, a total of 14 participants remained. The forum participants who dropped from the online forum did so due to changes in daily life schedules (e.g., trip, working schedule) and deterioration in condition (e.g., hospitalization, changes in treatment modalities). Usually, 6–12 participants are thought to be ideal for a focus group discussion, including online forum discussions.²⁸ Thus, 18 participants were considered to be acceptable (and would allow for attrition) for this online forum discussion. All of the participants self-reported to be over 18 years old. Children under 18 years were excluded because their needs and perspectives would be different from those of adults’.

To recruit the participants, two types of recruitment sites were approached: (a) ICSGs and (b) Internet Communities/groups for Asian Americans (ICAAs). ICSGs and ICAAs were searched for on Google.com, and a total of 210 ICSGs and ICAAs were retrieved. All the administrators of the retrieved ICSGs and ICAAs were contacted and asked to post an announcement regarding the study. A total of 15 administrators agreed to post an announcement on their website; the others did not respond to the contact emails. The announcement included general information about the study and contact numbers, e-mail addresses, and the dates that data would be collected. There was no way to trace which participant was recruited through which specific ICSG or ICAA. Eleven of the 18 participants were born outside the U. S. The participants included eight Chinese, one Japanese, two Filipinos, two Indians, and one Persian living with cancer; four participants did not specify their ethnicity. The participants of this study tended to be midlife, female, well educated, and middle class; this agreed with the sociodemographic characteristics of the participants of a previous Internet survey that recruited its participants through ICSGs.²⁹ Table 1 summarizes sociodemographic characteristics of the participants.

Online Forum Topics on the Use of ICSGs

Nine topics on the use of ICSGs were used to administer the online forum (see Table 2). Each topic included introductions and prompts that were posted on the online forum in a serial fashion over one month of data collection (2–3 topics per week). These topics and introductions/prompts were developed by two professionals who had expertise in oncology, Internet cancer support groups, Internet research, and qualitative research. Then, four experts in oncology and two experts in qualitative research who were also experts in cultural competence, information science, Asian American health, or Internet cancer support groups reviewed the topics. Finally, the topics were modified based on their comments.

Data Collection Procedures

For the parent study, a project website was developed conforming to the Health Insurance Portability and Accountability Act (HIPAA) and the SysAdmin, Audit, Network, Security/

Federal Bureau of Investigation (SANS/FBI) recommendations and published on an independent, dedicated website server (the actual web-address of the project website will be added here). The project website included several web-pages consisting of an informed consent sheet, Internet survey questions, and online forum sites. The informed consent sheet was viewed when the participants visited the project website for the first time. Informed consent was obtained through the Internet by asking them to click an “I agree to participate” button. Then they were queried to verify that they met the inclusion criteria (age, literacy, Internet access, and ethnic identity). Only those who met the inclusion criteria were allowed to enter the Internet survey web page and asked to answer the Internet survey portion of the parent study. When individuals did not meet the inclusion criteria, they were automatically connected to a ‘thank you, but you are not eligible’ message. About 93% of the visitors passed the screening process. At the completion of the Internet survey, the participants were asked if they would be interested in participating in an additional online forum.

When the participants indicated their interest, they were contacted again at the initiation of the online forum. In the contact email, usernames and passwords that they could use to log in to the online forum sites were provided. For security, the participants’ information was kept on a password-protected computer and in a filing cabinet which remains locked at all times in a research office. Then, the participants were asked to introduce themselves when they logged in to the online forum site for the first time and encouraged to engage in the discussion. Each week, two to three new topics and a summary of the previous discussion were posted on the online forum site. Through eleven periodical encouragement emails, the participants were asked to post responses and provide their feedback at their convenience. Then, at the end of the online forum, participants were asked to add any topics that they wanted to discuss with other participants; no topic was added. All e-mail communication between participants and the research team was kept confidential by saving e-mails on a firewall-protected computer that was accessible only by research team members using passwords that were kept in a locked research lab. In addition, the participants’ email addresses were used to contact the participants in order to mail out \$50 gift cards for reimbursing their participation. After reimbursement, the email addresses were kept separately from the participants’ data in a locked cabinet in a locked research lab.

Data Management and Analysis

The data from the online forum were analyzed using thematic analysis.³⁰ Any identifying information was separated from the data, and only serial ID numbers assigned by the researchers were attached to the data. The data were analyzed as soon as they were collected. First, the data were directly printed out as transcripts, and the printed transcripts were thoroughly read and reread for line-by-line coding. Then, the codes were summarized in a coding book. Categories were made as they emerged from the internal cognitive process and reflexive thinking of the researchers by analyzing content and context, and by using the coding book. Finally, to extract the themes representing Asian Americans’ experience of the use of ICSGs, relationships between categories were formulated by mapping associative links among the categories. During the analysis process, influences of other possible contextual factors such as gender, age, health status, socioeconomic circumstances (income level and education level), family responses and roles, stability of their daily lives, social support networks, immigration status, and length of stay in the U.S. were examined as well.

The standards of rigor in feminist qualitative research by Hall and Stevens³¹ were used to ensure the rigor of the study. The standards are: dependability, reflexivity, credibility, relevance, and adequacy. The methodological and analytic decision trails created by the investigators during the course of the study itself were examined to ensure dependability. A chronological research diary, memos, and field notes were written to ensure reflexivity. The

developing analytic categories were posted on the website, and the participants were asked to provide their feedback on the analysis in order to achieve credibility and relevance for the study. Finally, to ensure the adequacy of the study, research methods, goals, research questions, design, scope, analysis, conclusions, and impact of the study within the social and political environment were continuously questioned. Weekly group meetings with the research team were held to ensure the quality of data collection and analysis.

Findings

Four major themes emerged from the data analysis process: (a) “more than just my family support,” (b) “part of my family,” (c) “anonymous me,” and (d) “shielded from the real world.” Each major theme had several associated sub-themes that were linked to it. The sub-themes are presented with each major theme in the following sections, and the quotes supporting the sub-themes are provided in Tables 3 to 6 according to the four major themes. To convey vivid descriptions and voices of the participants’ experience, the quotes are not edited.

More than Just My Family

The major theme of “more than just my family” involved three sub-themes: strong family support, burden from family responsibility, and less than adequate family support. The supporting quotes are provided by the sub-themes in Table 3. The participants thought that they had very strong family support, but felt a heavy burden from family responsibilities despite their diseases. They also thought that their family support was less than adequate, which made them think they would need more than just family support to manage living with cancer. Each sub-theme is discussed with supporting quotes as follows.

Strong family support—Asian American cancer patients said that family was one of the reasons they had to live and was the only source that provided practical help in their lives with cancer. Family provided physical transportation to clinics for medical treatment, and sat beside them in the hospitals. Family members made a strong network of support for all the participants. For some, this actually made them consider not participating in the ICSGs at all because they thought they had all the support they needed.

Burden from family responsibilities—Family was perceived as a burden to most of them, especially many women who continued to shoulder the heavy burden of household tasks despite their disease. To most of the men, family was the reason for their worries, because they had a strong sense of responsibility to their families and because they could not function normally as the heads of their households (e.g., bread winners). In both cases, family was a burden as well as support, which made them eager for supplementary support in their lives with cancer.

Less than adequate family support—All the participants, except one, wanted to participate in the ICSGs to get the support that their families could not provide (e.g., getting the most updated information on cancer treatments, getting support from those who have the same disease, etc). The participants wanted to communicate with their peers who had the same diseases, because they believed that even their families could not understand the cancer experiences that they were currently having, and also because they had more needs than those that their families could help meet.

Part of My Family

The second major theme of ‘part of my family’ involved two sub-themes: (a) seeking new families, and (b) seeking heart. The supporting quotes by the sub-themes are in Table 4. The participants wanted to have new families to rely on in this new country; even second and third generation immigrants perceived that their families were located in their countries of origin.

Literally this is correct, as most of their relatives still lived in their countries of origin. The participants also wanted empathy and heartfelt support. Thus, the participants wanted the ICSGs to be part of their family.

Seeking new families—Asian Americans living with cancer perceived the ICSGs as their extended family. Asian Americans living with cancer searched the ICSG for useful information and also sought interpersonal relationships. More importantly, through attending ICSGs, they wanted emotional support from others. This was the major reason for their participation in ICSGs. As immigrants living with cancer in a new country, they were seeking somebody upon and from whom they could rely and get support. In other words, they were searching for new families in this new country to replace those in their countries of origin, especially at this critical point of their lives.

Seeking heart—Because they wanted the ICSGs to be part of their families, they preferred the ICSGs of the same ethnic group, those that use the language of their mother tongue and share the same cultural beliefs, values, attitudes, foods, and even jokes. Through the ICSGs, they could share news and concerns from their countries of origin, which could enhance the participants' sense of the ICSGs as an extension of their family. Also, because participants wanted the ICSGs to be extensions of their families, they valued the emotional familiarity with and the particular feeling of affection for other members of ICSGs.

Anonymous Me

The third major theme of 'anonymous me' evolved from three sub-themes: (a) cancer as a private matter, (b) staying normal, and (c) nobody knows. The supporting quotes are provided according to the sub-themes in Table 5. The participants thought that cancer was a private matter that should not be shared with others, and that they should be able to keep it separate from their normal life. Subsequently, anonymity was an important aspect of the ICSGs for them.

Cancer as a private matter—Most of the participants considered cancer a private matter that should not be disclosed to strangers and that could not be discussed even with family members. Rather, they perceived it as their own problem.

Staying normal—All the participants wanted to be seen as healthy normal people in their daily lives. They did not want others to know about their conditions and did not want attention from others - they thought that the cancer experience could not be shared with those who did not have the disease. Thus, most of them hid their disease from others in their work settings and daily lives and tried to maintain their normal life.

Nobody knows—Asian American participants preferred the ICSGs to traditional face-to-face cancer support groups because they hesitated to give up their privacy and let others know of their condition. The participants did not need to use their real names and identities in the ICSGs, so they could be free from being identified as cancer patients in their real lives. Although face-to-face interactions, which were a part of the ICSGs, were viewed positively and they participated in these interactions regularly, they still enjoyed not disclosing their identities even in the face-to-face interactions. They did not need to use their real names in the face-to-face meetings if they chose not to. Also, even when their identities were disclosed in the face-to-face interactions, they felt more okay with it, because they all shared the experience of being cancer patients.

Shielded from the Real World

The last major theme of ‘shielded from the real world’ evolved from three sub-themes: (a) barriers in life, (b) online versus physical world, and (c) want to be in the mainstream. The quotes supporting the sub-themes are in Table 6. The participants perceived multiple barriers in getting support in their daily lives, and thought that they would not encounter the same barriers on the Internet, as they would not need to disclose their identity. Their main reason to be in the ICSGs was that they could stay in the mainstream and would not be marginalized as they felt they were in their daily lives in the real physical world. Consequently, they felt shielded from the discrimination and marginalization of the real world.

Barriers in life—The participants expressed that they liked getting more support, but that there were always barriers in their life in the real physical world which prevented them from doing so. Different customs, health beliefs, and languages were the main barriers in their real lives to getting support from others. Also, they expressed difficulties in finding people in the same stage and with the same type of cancer in the real physical world. They thought that, compared with traditional face-to-face cancer support groups, ICSGs had a number of advantages - accessibility, readiness, rapidity, unlimited time, unlimited places, etc.

Online versus physical life—The participants perceived the ICSGs as shields against negativity from the real physical world. Because the ICSGs are online and they could stop participating at any time, the ICSGs were more convenient and comfortable places for the participants to share their experiences and opinions. They felt safer in the ICSGs compared with face-to-face cancer support groups, because they could easily withdraw themselves if there was any negativity directed towards them.

Wanting to be in the mainstream—While participants listed the advantages of ICSGs, they also indicated that ICSGs might be more valuable to Whites than to Asian Americans. This is because most of the currently available ICSGs are geared more towards mainstream groups of people living with cancer; the forum participants felt they could not join them. They were also afraid to be identified as Asian Americans in the general cancer support groups when they participated; they did not want to be discriminated against because of their ethnic identity. Some participants expressed their concerns on being in ethnic-specific ICSGs because they believed that the general ICSGs would provide better information and opportunities (state-of-science information and funding) for their members compared with ethnic-specific ICSGs. Even the less acculturated participants who had stayed in the U.S. for less than 5 years preferred the general ICSGs. The ICSGs with only Asian Americans members were viewed as marginalized, and the participants did not want to be marginalized on the Internet as an ethnic minority group. Rather, they wanted to remain unidentified in the general ICSGs, not disclosing their ethnic identities, so that they could get closer to the mainstream.

Discussion

The general theme that overarches the four major themes identified in this study is Asian Americans’ marginalized experience in the use of ICSGs. Because most of them were immigrants from other countries, they were isolated from mainstream American culture and relied only on their family members for support. Their immigration transition caused them to be far from their families in their countries of origin, making them depend more on ICSGs for support, and as extensions of their families. Even though some of them were second or third generation Asian immigrants, they still felt marginalized. Although participants were more comfortable with the ICSGs of their same ethnic group, they believed general ICSGs would be more valuable to them. This is compared to ethnic specific ICSGs, which participants felt could come with possible marginalization as a group for ethnic minorities. Because of their

marginalized status in the real physical world, they wanted to use the ICSGs as a shield from the real physical world. They enjoyed anonymity in the ICSGs that allowed them to share their experiences and opinions without disclosing their real identities.

The first theme of “more than just my family” adds new information to the current literature on the use of ICSGs by Asian Americans living with cancer. It is well known that Asian Americans place their families as a central priority. Thus, their family members are usually the main source of support, and individuals tend not to share their opinions and experiences with others outside their family members.³² Sometimes patients themselves are not well-informed about their cancer, and the head of household frequently is the one who makes decisions on treatment.³³ However, the first theme of “more than just my family” certainly indicated that Asian Americans living with cancer wanted more support than what came from their family members.

The second theme of “part of my family” also adds new information to the current literature on the use of ICSGs by Asian Americans, but also agrees with some findings from previous studies on immigration transitions. Because of the immigration transition that most of the participants were going through, they sought somebody to rely on in this new country, especially at such a critical moment in their lives. Also, because of their status as ethnic minorities, even the second and third generation Asian immigrants felt lonely and marginalized in the U.S. This tendency has been reported in the literature.^{34–37} Ethnic minorities, especially immigrants from other countries, tend to rely on friends and family for support. Thus, the theme of “part of my family” can be understood within the context of their immigration transition and their marginalized status as ethnic minorities. Yet again, this finding has rarely been reported in the literature on ICSGs among Asian Americans.

The third theme of “anonymous me” supports Asian Americans’ hesitance to disclose their private matters with others, a custom which has been frequently reported in the literature. This theme can be easily linked to their marginalized experiences as ethnic minorities living with cancer. The literature is solid in representing that ethnic minorities are reluctant to share personal and family issues with non-family members, including health care providers.³⁸ From a feminist perspective, this attitude of being silent could be interpreted as a reflection of Asian Americans’ experience with oppression in U.S. society; living marginalized daily lives, they might rely on only their networks of families and friends while not sharing their experiences with strangers, including health care providers. This may have made them perceive “being anonymous” as the best aspect of the ICSGs. Indeed, feminist literature has suggested that people of color tend to rely more on their networks of friends than do Whites.^{39–43} In the case of the participants of this study, the Asian cultural heritage of hesitance to disclose private matters with others made the situation worse. They really valued anonymous interactions on the Internet.

The third theme, “anonymous me,” also indicates the importance of seeming normal for Asian American cancer patients because of the stigmatized nature of cancer within this specific ethnic group. Indeed, Asian Americans have been reported to stigmatize cancer itself because of their belief that cancer is a genetic or transmittable disease.^{44, 45} Also, being normal is a strategy of face-saving because, among Chinese people for example, cancer is often connected with bad luck or fate.⁴⁴ It was also reported that the cause of cancer was related to personal, moral or character weakness in most Asian cultures,⁴⁵ and the cause of cancer could further intertwine with other contextual information to form a pattern of disharmony.⁴⁴ Thus, Asian cancer patients may try to normalize their disease so that they can be free from the stigma of cancer and retain their integrity in social relations,^{44,45} and not worry or burden their families.⁴⁶

The final theme of “shielded from the real world” is loud and clear in this study and can be obviously linked to the overall theme of the study—Asian Americans’ marginalized experience in the use of ICSGs. This theme can also be easily linked to the third theme of “anonymous me.” Because of their marginalized experience in the real physical world, the participants wanted to remain unidentified and anonymous in ICSGs, which they believed provided a shield against negativity from the real physical world. This may also reflect their marginalized experience in the current health care system and their experience with racial/ethnic discrimination in U.S. society. Indeed, previous studies have indicated that ethnic minorities tend to view health care systems suspiciously and untrustingly because of the history of medical and research atrocities committed against ethnic minorities.⁴⁷

These findings need to be carefully interpreted though, because this study has several limitations inherent in the nature of a pilot Internet study. First of all, the sample size of 18 could be a limitation. Yet in qualitative study designs, intensive focus and in-depth data collection are of greater value than having a large number of participants.⁴⁸ Second, this study was an online forum amongst Asian Americans living with cancer that were recruited only through Internet settings using a convenience sampling method. Thus, the participants might not fully represent diverse sub-ethnic or socioeconomic groups of Asian Americans living with cancer. In fact, the participants of this study tended to be a select group of Asian Americans who were highly educated, foreign-born, and Chinese. Despite multiple motivational strategies to retain participants, the retention rate was moderate (78%). This retention rate was due to changing health/illness situations of the participants such as hospitalization, changes in treatment modalities, and changes in overall health status. Finally, although the participants provided their feedback on the online forum in general, none of them provided their feedback on the findings, which may limit the credibility of the study findings reported in this paper.

Conclusion and Implications

The findings of this study provide implications for nursing practice in developing and providing a culturally competent ICSG for Asian Americans. First of all, Asian Americans living with cancer were seeking help through ICSGs to supplement what their family members could provide. They mainly sought the most up-to-date information on cancer and cancer treatment. Thus, offering the most current information on cancer and cancer treatment is essential in future development of a culturally competent ICSG for Asian Americans. Second, emotional familiarity should be incorporated into the design of the ICSG while still providing informational support. The coordinator of the ICSG should take into account strategies to encourage trusting, reliable, and consistent relationships among the users of the ICSG while making their website more attractive to Asian Americans (e.g., preferable color, design, etc). Third, the ICSG needs to be based on secure and safe Internet interactions by adopting the most up to date computer technologies. Preventing any possible hacking or threats from outsiders would make participants feel more secure and safe and retain their anonymity. Finally, the ICSG needs to be based on non-judgmental and non-discriminative interactions so that the participants would feel comfortable sharing their experience and opinions.

The findings also suggest some implications for future research. First, more in-depth studies of cultural influences on the use of ICSGs among Asian Americans are needed. Although the findings of this study certainly indicate some cultural influences on Asian Americans’ use of ICSGs, the cultural influences could not be fully elicited because of the inherent nature of a pilot study with a small number of participants. Further studies with larger numbers of participants in a longer period of data collection are needed to confirm the findings reported in this paper. Second, more studies with diverse groups of Asian Americans are needed. Again, because of the inherent nature of a pilot study, participants tended to be a select group of Asian Americans living with cancer. Thus, the study participants did not represent diverse

experiences of Asian Americans in terms of sub-ethnicity, socioeconomic class, etc. With diverse groups of Asian Americans living with cancer, their experience with the use of ICSGs could be further disclosed and explored so that a culturally competent ICSG could be designed and developed according to their actual needs.

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Table 1

Sociodemographic characteristics of the participants (N=18)

	N (%)	Total = 18	Mean±SD	Range
<u>Age (yrs)</u>			39.89±13.06	22~62
<u>Gender</u>				
Female	15	(83.3)		
Male	3	(16.7)		
<u>Education</u>				
Less than high school	0	(0.0)		
High school graduate	0	(0.0)		
Some college	2	(11.1)		
College graduate or more	16	(88.9)		
<u>Religion</u>				
Protestant	3	(16.7)		
Catholic	4	(22.2)		
Buddhism	4	(22.2)		
Islam	2	(11.1)		
No religion	4	(22.2)		
Other	1	(5.6)		
<u>Marital status</u>				
Married	12	(66.7)		
Partnered	1	(5.6)		
Divorced	0	(0.0)		
Widowed	0	(0.0)		
Single	5	(27.8)		
<u>Employment</u>				
Yes	12	(66.7)		
No	6	(33.3)		
<u>Family income (K\$/yrs)</u>			69.35±55.76	0~250
<u>Family income</u>				
Totally insufficient	0	(0.0)		
Somewhat insufficient	5	(27.8)		
Sufficient	11	(61.1)		
More than sufficient	2	(11.1)		
<u>Sub-ethnicity</u>				
Chinese	8	(44.4)		
Japanese	1	(5.6)		
Filipino	2	(11.1)		
Indian	2	(11.1)		
Persian	1	(5.6)		
Not-specified	4	(22.2)		
<u>Born in U.S</u>				
Yes	7	(38.9)		

	N (%)Total = 18	Mean±SD	Range
No	11 (61.1)		
<u>Length of stay in U.S (yrs)</u>		23.82±9.06	5~39
<u>Level of acculturation</u>		16.82±3.31	12~22
<u>General health</u> *		3.50±1.04	2~5
<u>A period of diagnosed cancer(yrs)</u>		2.25±2.28	0.06~8.00
<u>Treatment</u> **			
Radiation therapy	11 (61.1)		
Chemotherapy	13 (72.2)		
Surgery	7 (38.9)		
Hormone therapy	4 (22.2)		
Others	3 (16.7)		
<u>Pain Medication</u>			
Yes	5 (27.8)		
No	13 (72.2)		
<u>Regular Access to Health Care</u>			
Yes	18 (100.0)		
No	0 (0.0)		
<u>Social support</u> ***		3.50±0.62	2~4
<u>No. of friends</u>			
0	0 (0.0)		
1-2	1 (5.6)		
3-5	4 (22.2)		
More than 5	13 (72.2)		
<u>No. of children</u>			
0	7 (38.9)		
1-2	8 (44.4)		
3-5	3 (16.7)		
More than 5	0 (0.0)		

* 1(very unhealthy) ~ 5(very healthy)

** Multiple selections allowed.

*** 1(None of the time) ~ 4(Most of the time)

Table 2

The online forum topics

Topic #	Contents of Topics
1	Cultural attitudes and responses to cancer
2	Daily schedules and hardships
3	Currently available support and preferences for support
4	Attitudes toward and general use of computers and Internet technologies [culturally universal and culture-specific]
5	Attitudes toward resources currently available on the Internet [type, availability, and quality of resources, culturally universal and culture-specific]
6	Attitudes toward and use of currently available cancer support groups (CSGs) and ICSGs [culturally universal and culture-specific]
7	Perceived ethnic differences in attitudes toward and use of CSGs and ICSGs
8	Life events and other contextual factors influencing the use of CSGs and ICSGs in daily life [culturally universal and culture-specific]
9	Preferences for Asian American specific CSGs and ICSGs [e.g., language, content, types of information, moderator, structure, format]

Table 3

Sub-themes and quotes related to the major theme of "More than Just My Family"

Sub-theme	Citations
Strong family support	<p>"Well when I told my mom, she was so sad. She decided to start making a lifestyle change herself. Instead of going out to gamble so much, she would start staying home with me more. Then she started turning to God and praying more. My dad really worried. My aunt really worried. My husband flew back him on emergency leave from deployment to be with me for treatment. I have a really good support system. My family doesn't like me going to my treatments by myself. Not even the radiation therapy that doesn't even hurt, or leave me drowsy. My family has been very good at taking me to my appointments and preparing me healthy foods."</p> <p>"They were all very upset but told me that they supported me and loved me and would do everything in their power to help me. They told me that they would do everything they could make my life to comfort. They have supported me with my cancer treatments but helping me feel more comfortable and doing a lot of household chores that I completed in the past."</p>
Burden from family responsibilities	<p>"My support groups consist of mostly nurses who work nights and have kids. Most of us were diagnosed under the age of 50 so we're will [sic] in the prime of our life like work and social activities especially taking care of small children. By the time we get home from work, we're so tired that we can't even cook or watch TV. Our job is so stressful that all we want to do when we get home is sleep."</p> <p>"Living with this cancer has been difficult and stressful for my family, both financially and emotionally. ... What bothers me most right now (the Holidays) is that I can't buy a lot of presents that I would have liked to buy for the people in my life who have been so good to me. You know what cancer does to yourself but it also does a lot to your family."</p>
Less than adequate family support	<p>"For emotional support, first line of support is my family. However, they sometimes cannot provide all the answers, where peer support helps. Going to support group, and meeting with people who are going through the same/similar treatments helps a lot."</p> <p>"I was so down and my peers/family couldn't handle it and I needed someone who could tell me that it would be OK and that it was normal but also that I needed to stop feeling sorry for myself in a nice way.... I just went online and look for my support group [sic]."</p>

Table 4

Sub-themes and quotes related to the major theme of "Part of My Family"

Sub-theme	Citations
Seeking new families	<p>"I currently join the cancer support groups called 'job club' which is a branch of American Asian Cancer Organization in Northern California... Every quarter we have a luncheon together, basically is social gathering and information feeding. I always anticipate this day coming. ... And on holiday we have prices[sic] drawing to celebrate the holiday. It feels warm like being be in a family...[sic]"</p> <p>"My family does not live in TX so they do not know what I've been through. I usually need to "check in" when I hear of people that have passed away from cancer or if I get a recurrence scare. It would be nice to be buddy up with another Asian peer to share my thoughts. I have met a number of cancer patients with my specific diagnosis. We correspond daily and they have become part of my extend family."</p>
Seeking heart	<p>"I will feel more comfortable to join the Chinese cancer support group, due to the language the same, and especially the culture the same. The jokes we make will be understandable, a lot of time we care about what is happening back to our origin country. We follow up the news back home closely."</p>
Seeking heart	<p>"I feel more comfortable to mingle with people who have the same color of skin, talk the same language, jokes the same we can understand, interested in the same political issues. With general support group, we will become minority. Our need and concern, may not mean too much to a group as a whole due to the democratic votes we will lost due to the less number of votes. And culture aspect is also important; it is deeply in our root. [It] cannot change, just like we can eat American food once in a while not every day. Caucasian can eat Chinese food once in a while not every day."</p> <p>"It's really nice to have someone who understands what you're going through who may have the same issues with their families that you are having. I've made some great emotional friends in my women's support group on the internet. The idea that someone passes away does really bring me down to earth and then I also look to my internet support group."</p> <p>"I don't believe that an internet support group will always be cold and even if one is, you can always go find another to your liking. That's the great thing about the internet, the diversity and the bountiful groups out there. People that go to online support groups are there for help/support not to gain a competitive edge on others there for support. To me, the online support group means somewhat of a connection to my friends and family."</p>

Table 5

Sub-themes and quotes related to the major theme of “Anonymous Me”

Sub-theme	Citations
Cancer as a private matter	<p>“It is taboo to discuss private matters with non-family members, so sharing personal issues/feelings with a bunch of strangers in a cancer support group probably would not be acceptable.”</p> <p>“I tend to be shy and hesitant to share in face-to-face situations, so online support groups like this one work better.”</p>
Staying normal	<p>“In order not to be detected by the co-worker I had to wear the wig. When they detect I have wig, I ... (said) it’s a middle age crisis. I have never disclosed to my co-worker that I have cancer, because I feel it is very personal.”</p> <p>“Since my last time got diagnosed it has been almost 9 years ago. ... I work in Silicon Valley, the computer center in U.S. Computer industry is very competitive. If this disease does not affect my day to day life, why should I bother to mention to my coworker.”</p>
Nobody knows	<p>“The feel is more freeing (in ICSG) because you can say whatever and not be afraid of someone thinking that you’re out of line or something like that ... I would expect to be able to express my thoughts and feelings anonymously and maybe connect on issues/experiences with others who are going through similar experiences.”</p> <p>“You can gain insight into the cancer and share with others. I think that the only disadvantage is having to put your story ‘out there’ for everyone to know, whereas ONLINE, you can make up a name for yourself, and type in your story and cancer and no one will really know who you are, so you are more likely to say more about yourself.”</p>

Table 6
Sub-themes and quotes related to the major theme of “Shielded from the Real World”

Sub-theme	Citations
Barriers in life	<p>“English is not our mother tongue [sic]. [when we] mingle with Caucasian, it produces some kinds of resistance for us when we want to join their group. Due to language barrier, it is not easy for us to talk like Native, even though I am here almost 30 years. It still has different.”</p> <p>“Different ethnic groups have different traditions, customs, religious etc and I think that those are all important because some religious groups do not believe in certain treatments etc and so that can be conflicting so to know that maybe someone else is going through what you are is helpful.”</p>
Online versus physical life	<p>“Living with cancer can be depressing and can bring out the worst in people too. Participating in an online support group shields you from some of that negativity. You can choose to read what you want, and if you’re not ready to face certain things or don’t like what is being written, you don’t have to read further.”</p> <p>“Cancer means pain and suffering. I feel that cancer is a terrible thing and it’s a shame that we still don’t have a cure for it. ... I never used one (cancer support group) because I don’t think I’m very honest when it’s a group setting. ... I feel it’s easier to let out some feeling online. It’s a fantasy world, real life is too tough sometimes.”</p>
Wanting to be in the mainstream	<p>“Ethnic groups that are more educated and have better socioeconomic status are more willing to participate in the cancer support group and get help. Under-privileged ethnic groups do not have the help provided by cancer support groups in general.”</p> <p>“I don’t have any problems with the internet cancer support group that I belong to. I don’t have any problems because I could speak and read the English language. I don’t have a problem with the internet cancer support group because they don’t even know that I am Asian.”</p> <p>“I will join the Caucasian cancer support group. Due to they represent majority in this country. They get more charity funding, and provide more service to the needed. And participation there, you will feel more involved if we donate our time as volunteer worker here. In order for Asian American cancer support group, we need to have more seats in congress or senate house [sic]. Then they will represent us to voice for us. In the long run we may also get the same attention like the white people receives.” (A 32 year old Indian woman who had been in the US for 5 years)</p> <p>“I would choose a general support group because I think I would get a wider variety of information and different opinions.” (Woman who was born in the U.S.)</p>