

Online Cancer Support Groups: *Experiences with Underserved Immigrant Latinas*

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ABSTRACT

Online support groups (OSGs) may be a particularly promising option for immigrants. They can be a cost-effective method that easily addresses geographic isolation and immigrants' needs for privacy. This article examines the viability of OSGs for Hispanic immigrants with breast cancer and the effectiveness of OSGs for the participants. The authors hypothesized that OSGs are a feasible mechanism for delivering support to Latina women with breast cancer, as immigrant Latinas with breast cancer in OSGs showed significant improvement compared to a control group on depression, in coping with pain, in quality of life, and personal growth. Of 85 potential participants approached, 68 Spanish-dominant speaking immigrant women with breast cancer were recruited into the Virtual Community for Immigrants with Cancer (VCIC). Forty-eight were randomly assigned to OSGs and 20 were assigned to a usual care control group. VCIC participants were grouped into OSGs with eight participants in each. Each group met for 90 minutes once a week for 30 weeks. The groups were facilitated by trained bilingual facilitators and issues of interest to the group were discussed, such as managing symptoms and side effects from medications, family concerns, and alienation. The dropout rate from the groups was 13%. The VCIC experiences suggest that OSGs are acceptable to and feasible for immigrant minorities, including those with limited English proficiency. While none of the outcome measures showed statistically significant change pre-post compared to the control

Needs Assessment: "Online Cancer Support Groups" discusses a compelling issue in cancer support that has heretofore not received enough focus, the needs of patients with limited English proficiency. It also demonstrates how innovative online methodologies can effectively reach this often neglected segment of the cancer patient community.

Learning Objectives:

- Give examples of barriers faced by immigrant women with breast cancer in accessing psychological support.
- List four scales to study the effectiveness of psychosocial interventions targeting cancer patients.
- Describe the potential benefits of online support groups for cancer patients.

Target Audience: Primary care physicians and psychiatrists.

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This activity has been peer-reviewed and approved by Eric Hollander, MD, chair and professor of psychiatry at the Mount Sinai School of Medicine, and Norman Sussman, MD, editor of *Primary Psychiatry* and professor of psychiatry at New York University School of Medicine. Review Date: August 21, 2008.

Drs. Hollander and Sussman report no affiliation with or financial interest in any organization that may pose a conflict of interest.

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Disclosures: The Virtual Community for Immigrants with Cancer, was supported by the Langeloth Foundation during the study period (the research for which this financial support was granted, which was used for this article, officially ended in 2005). Additional support was received from the Lance Armstrong Foundation (the research for which this financial support was granted, which was used for this article, officially ended in 2006).

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group, statistical trends were noted suggesting beneficial impact on outcomes. When compared to the controls, the experimentals had increases in seeing new possibilities ($F=2.81$, $P=.09$) and increased feelings of strength ($F=3.59$, $P=.06$).

INTRODUCTION

In 2000, the United States was home to 31.1 million immigrants.¹ Over 21 million immigrants in the US, including 25% of New York City residents, have limited English proficiency.^{2,3} The diagnosis of cancer in immigrants is often the cause for much fear and can lead to isolation from family and community.^{4,5} Immigrants are frequently marginalized from institutional, social, and psychological support, including cancer care.⁵

The value of cancer support groups is widely accepted. The National Cancer Institute advises that support groups can help people affected by cancer feel less alone and can improve their ability to deal with the uncertainties and challenges that cancer brings.⁶ A meta-analysis by Rehse and Pulkrop⁷ summarized the results of 37 published, controlled studies investigating the effectiveness of non-Internet psychosocial interventions on the quality of life (QOL) of adult cancer patients. They found an overall effect size of 0.31 for psychosocial interventions.⁷ The most important moderating variable identified was the duration of psychosocial intervention, with interventions lasting >12 weeks being significantly more effective than those of shorter duration. Support groups for cancer patients have led to improvement in QOL, reduction of psychological symptoms, improvement in coping responses, and reduction in pain.⁸⁻¹¹

A few studies have examined ethnicity and support groups. Miano and colleagues¹² reported that the traditional support group model has not been effective in reaching the Hispanic population. Instead, they developed a program facilitated by Spanish-speaking social workers using other professionals within the institution to promote a multidisciplinary approach to provide support services. They reported that participants experienced an increased sense of social and emotional well being, expanded their knowledge of health-related information, and became aware of other services and benefits available to them. A second study involving cancer patients in Texas¹³ examined the role of informal and formal social support networks in mitigating barriers to cancer treatment among whites, African Americans, and Hispanics. Minorities were more apt to report that the formal support groups helped patients to continue treatment. In addition, informal social support networks, such as extended families and civic clubs, were seen as more helpful for African-Americans and Hispanics

as compared with whites. Finally, Alferi and colleagues¹⁴ examined predictors of use of complementary therapies by African American, Hispanic, and non-Hispanic white patients with early-stage breast cancer who also received standard medical treatment. Most patients used ≥ 1 complementary therapy, most commonly psychotherapy, support groups, meditation, and spiritual healing.

The Internet has enabled non-immigrant patients to help one another through the emotional turmoil of cancer.¹⁵ It is estimated that one out of three cancer patients in the developed world is online.^{16,17} A virtual community is one of the most powerful uses of the Internet, as people can meet, interact, share interests, and exchange social support via online support groups (OSG).

Fifteen million Internet users in the US have visited OSGs.¹⁸ Furthermore, when asked whether they visited an OSG on the previous day, 1.6 million responded in the affirmative. Results from a 2007 Harris poll indicated that 160 million US adults searched for health information online.¹⁹ In an analysis of a recent National Cancer Institute public data set,²⁰ approximately 50% of the cancer sample comprised of both men and women used the Internet to locate information about cancer and approximately 5% of men and 8% of women had participated in an Internet cancer support group. However, there are few outcomes studies on OSGs. Klemm and colleagues²¹ identified 10 non-controlled, descriptive research studies on cancer OSGs. Nine of the 10 studies concluded that OSGs help people to cope more effectively, but none of them used randomization to groups or a control group. Eysenbach²² conducted a comprehensive, systematic review of online, peer-led OSGs that included efficacy data and found few studies ($n=38$). Three studies²³⁻²⁵ focused on the effects of OSGs for breast cancer patients. OSGs for breast cancer patients may reduce depression, cancer-related trauma, and perceived stress.²³⁻²⁵ A study²⁶ of The Wellness Community (TWC)-facilitated chat groups for women with breast cancer found that participation in 16 weekly groups significantly reduced depressive symptoms and negative reactions to pain and showed a trend toward increased post-traumatic growth. Sixty-seven percent of patients found the groups beneficial. Several studies examined the processes associated with benefit. They found that greater expression of anger in OSGs for women with breast cancer was associated with higher QOL and lower depression in previous studies, while the expression of fear and anxiety was associated with lower QOL and higher depression.²⁷ Insightful disclosure played a crucial and significant role.²⁸

OSGs may be a particularly promising option for immigrants. One in three Spanish-dominant Hispanics in the US uses the Internet.²⁹ OSGs can be a cost-effective method of

intervention with minimal, if any, transportation requirements. OSGs also easily address geographic isolation as well as needs for privacy, both of which may be heightened among immigrants. However, OSGs for immigrants with cancer are sorely lacking. In fact, no previous studies of Latina women with breast cancer and OSGs are available.

This study examines the viability of OSGs for Hispanic immigrants with breast cancer and attempts to bridge the digital divide with a culturally relevant online intervention. The authors test the feasibility of providing professionally led Internet groups for Spanish-speaking immigrant women with breast cancer and attempt to determine if Spanish-speaking immigrant women with breast cancer can be recruited and retained for OSGs. In addition, the authors wanted to gather pilot data on effectiveness of OSGs for the participants. The leadership model and measures used in the current study are similar to the model employed in a previous study reporting statistically significant pre-post changes in depression, reactions to pain and a trend towards increased growth.²²

Specifically, the authors tested three central hypotheses. First, OSGs are a feasible mechanism for delivering support to Latina women with breast cancer. Second, immigrant Latina women with a breast cancer diagnosis in online, professionally facilitated support groups will show significant improvement compared to a control group (ie, usual care) on depression, coping with pain, QOL, and personal growth. Last, women with breast cancer who start the group with high levels of distress will show significantly greater improvement than those with lower levels of distress.

Method

In 2001, the Virtual Community for Immigrants with Cancer (VCIC) was launched to bridge the immigrant Internet support group divide. VCIC was developed to advance immigrants' ability to cope with cancer and to increase their confidence in accessing treatment options. VCIC provides informational, emotional, and social network support to Spanish-speaking women with breast cancer through an OSG. The study was a replica of a previous study²³ of non-Hispanic whites with breast cancer. Both the intervention as well as the outcome measures were identical except that in the present study, the language of intervention and measures was Spanish.

At the program's inception, three focus groups were conducted with Spanish-speaking breast cancer survivors, including women who had attended face-to-face support groups. The focus groups provided direction to the content and design structure for VCIC's Web site³⁰ and OSGs in addition to informing topics for chat sessions. A team of web-designers and public health professionals worked

together to design a site with culturally appropriate visuals and content, navigable by those with little or no familiarity with the Internet and computer technology.

The authors of this article did not want to restrict VCIC to Internet-savvy participants or those who had computers or Internet access at home. Several participants had never used a computer prior to joining VCIC. The authors secured refurbished computers and provided them to the participants, along with dial-up Internet connections. Staff provided one-on-one, at-home, half- to full-day training to the participants on using computers, the Internet, and the VCIC OSG, as needed.

VCIC participants were grouped into OSGs with eight participants in each. Each time eight people enrolled, a new group would begin. Each group met for 90 minutes once a week for 30 weeks. The groups were facilitated by trained bilingual facilitators and issues of interest to the group were discussed, such as managing symptoms and side-effects from medications, family concerns, and alienation.

Sample

Within a 2-year period, the authors identified and approached 85 potential participants. Seventeen declined participation, and 68 Spanish-dominant-speaking immigrant women with breast cancer were recruited into VCIC. Forty-eight were randomly assigned to the OSGs and 20 were assigned to a usual care control group. Of those in the intervention, 42 participated fully and 6 dropped out. Key stakeholders in the community, including volunteer survivors, aided with the recruitment. Sample characteristics of the intervention and control groups are shown in Table 1.

Measures

Depression was measured by the Center for Epidemiological Studies Depression Scale Spanish language (CES-D).³¹ The CES-D scale is a 20-item self-report measure designed to assess depressive symptoms in the general population. It has been found to have high internal consistency ($\alpha=.89$) with cancer patients and adequate test-retest reliability. The instrument permits comparison with other cancer studies using this measure, is sensitive to intervention effects, and is easily administered.³²

Personal growth was measured by the authors' translation of the Posttraumatic Growth Inventory (PTGI).^{33,34} The PTGI was developed to assess positive changes experienced by traumatized individuals. The 21-item scale yields a total score and five subscale scores, namely new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. Items are rated on a 6-point Likert scale, ranging from "I did not experience this change as a result of my crisis" (0) to "I experienced this

change to a very great degree as a result of my crisis” (5). While internal consistency of the total score was .95 in a previous sample of cancer survivors, the translated version has never been tested for internal consistency.

QOL was measured by translation of the functional analysis of cancer therapy (FACT-B). The FACT-B measures multidimensional QOL in patients with cancer. The α coefficient total score is $\alpha=.90$, with subscale α coefficients ranging from .63–.86.³⁵

The authors translated three subscales⁸ to assess pain, First, pain intensity-Likert scale ranges from 0 (none) to 10 (excruciating). Second, pain interference during household chores, yard work, or shopping; socialization with friends; recreation and hobbies; sexual relations; and physical exercise. Last, reactions to pain (ie, agonizing, intolerable, unbearable, awful, distressing, unpleasant, distracting, uncomfortable, tolerable, bearable, and none).

To score the transcript interaction the authors used the Linguistic Inquiry and Word Count (LIWC).³⁶ The dictionary provides a method for studying the various emotional, cognitive, structural, and process components present in written speech. The dictionary includes 17 standard linguistic dimensions (eg, word count, percentage of pronouns, articles), 25 categories tapping psychological constructs (eg, affect, cognition), 10 dimensions related to “relativity” (time, space, motion), and 19 personal/content concern categories (eg, work, home, leisure activities). This procedure has been extensively utilized in studies examining the beneficial effects of writing about traumatic life events. Two scales were assessed, namely emotional (anger) and cognitive

(insight) dimensions. The transcripts of the meetings were first translated in English and then scored using the LIWC scales. All scores are corrected for number of words.

Statistical Analysis

To test improvement compared to a control group (usual care) on depression, coping with pain, QOL, and personal growth over time, a repeated measures multivariate analysis of variance (MANOVA) was used. Four outcome measures were used, including CES-D, total pain, sum of the FACT-B, and PTGI scales, were used. Three control variables were used as covariates, namely length in the US (proxy for acculturation), cancer stage, and level of education. A bonferonni correction was used to control for the inter-correlation of the three measures. Because the use of a summed score for both the FACT-B and PTGI may mask some of the possible changes, a separate repeated measures MANOVA with the covariates was used for the subscales of the PTGI and FACT-B.

To test whether women with breast cancer who start the group with high levels of distress will show significantly greater improvement than those with lower levels of distress, the authors used an analysis of variance. Distress was assessed by Time 1 CES-D scores, dividing the sample into those who at Time 1 did not show clinical depression (score of ≤ 17) and those defined by the CES-D as clinically depressed (score of >17). The dependent variable was CES-D at Time 2. The independent variables were experimental/control and high or low depression at Time 1. Covariates were the three cited in the previous paragraph.

Results

The mean participant age for VCIC was 46.8 years, with a range of 22–84 years of age. The participants hailed from 12 Latin American countries. The top two countries of origin were the Dominican Republic (25.5%) and Colombia (18.2%). The mean age in the United States was 16.7 years, with a range of 0.25–43 years. Forty-point-seven percent of the participants had not completed high school, and 32.7% of the participants were employed outside their home. Eleven-point-three percent of participants did not have health insurance.

Eighty percent of potential participants approached enrolled into VCIC. Reasons for declining included not having a stable place to live, not having a telephone at home to dial in for Internet access, becoming nervous around computers, and family issues such as family member death and illness.

The themes of the chat sessions were varied. They included faith; family as well as lack of family in the US; relationships; financial and insurance issues, including what insurance covers and how they could procure free wigs; and breast recon-

TABLE 1
CHARACTERISTICS OF THE SAMPLE

	<i>Experimental</i>	<i>Controls</i>
Age	46.2 (12.1)	50.8 (13.9)
Years in United States	14.0 (9.7)	24.2 (12.0)
Time since diagnosis (years)	1.0 (4.5)	3.2 (4.6)
<i>Stage of treatment</i>		
Awaiting surgery	4	2
Active treatment	27	9
Recovered	8	9
<i>Education</i>		
Less high school	18	10
High school	14	8
College	18	5
Higher degree	2	0

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struction, sharing personal experiences and concerns. The women expressed fears and provided emotional support. Pain was often discussed, with participants seeking and offering suggestions to decrease symptoms.

The dropout rate from the groups was 13%. Reasons for dropout included participants' death, eviction from apartment, disconnection of telephone, feeling too tired after work to participate, changes in work schedule, and returning to home country.

OUTCOMES

Table 2 shows both the repeat measure multivariate analysis of covariance of the summary measures (ie, CES-D, Total Pain, FACT-B, and PTGI) and the repeat measure multivariate analysis of covariance for the subscales of the PTGI and the FACTB. Length of time in the US and previous support group was used as a covariate because of the difference between the experimental and control group. Table 3 shows the adjusted means for all the outcome measures.

Overall, none of the outcome measures showed statistically significant change pre-post compared to the control group. However, some PTGI subscales, when analyzed separately, showed a statistical trend. A multivariate analysis of the five PTGI scales, using the three covariates described in the main analysis and a bonferroni correction, found an overall trend ($F=2.13, P=.07$).⁵ Univariate analysis showed a statistical trend in two of the scales. The experimentals compared to the controls had increases in seeing new possibilities ($F=2.81, P=.09$) and increased feelings of strength ($F=3.59, P=.06$). The means of that analysis are also shown in Table 3 for comparison purposes. The significant items on the PTG included: "I am more likely to try to change things which need changing," "An appreci-

ation for the value of my own life. A feeling of self-reliance," "A willingness to express my emotions. Being able to accept the way things work out," "Appreciating each day. Having compassion for others," "I am able to do better things with my life," "New opportunities are available which would not have been otherwise," "Putting effort into my relationships," "I developed new interests," and "I established a new path for my life."

TABLE 3
ADJUSTMENT MEANS FOR ALL OUTCOME MEASURES

	<i>Experimental</i>	<i>Controls</i>
CESD1	15.8 (9.3)	18.8 (10.4)
CESD2	16.6 (11.2)	18.8 (10.4)
FACT-B1	67.3 (14.7)	64.1 (14.1)
FACT-B2	68.7 (17.1)	62.5 (17.7)
pain 1	13.6 (8.2)	16.5 (8.2)
pain 2	13.1 (8.6)	15.4 (11.0)
PTGI1	23.0 (5.4)	24.2 (4.3)
PTGI2	20.2 (5.0)	19.1 (3.0)
Relate	4.6 (5.0)	4.7 (4.5)
New possibilities	4.6 (5.0)	4.7 (4.3)
Strength	4.6 (4.4)	4.6 (4.6)
Spiritual	4.7(5.4)	5.3 (5.4)
Appreciation of life	5.0 (1.3)	4.3 (1.03)

Means were corrected for the influence of covariates; length time in US, education and cancer stage.

CES-D=Center for Epidemiological Studies Depression scale; FACT-B=functional analysis of cancer therapy; PTGI=Posttraumatic Growth Inventory; US=United States.

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TABLE 2
MULTIVARIATE TESTS

<i>Effect</i>		<i>F</i>	<i>Hypothesis df</i>	<i>Error df</i>	<i>Sig.</i>	<i>Eta Squared</i>
Between Subjects	When move	1.536	4.000	55.000	.205	.100
	Education	0.39	4.000	55.000	.815	.028
	Stage	0.717	4.000	55.000	.584	.050
	Exp. control	0.141	4.000	55.000	.966	.010
Within Subjects	Time	0.489	4.000	55.000	.744	.034
	Time * when move	3.314	4.000	55.000	.017	.194
	Time * education	1.007	4.000	55.000	.412	.068
	Time * stage	0.252	4.000	55.000	.907	.018
	Time * Exp. control	0.678	4.000	55.000	.610	.047

F=variance; df=degrees of freedom; Sig.=statistical significance; Eta=variance explained; exp=experimental.

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LEVEL OF DISTRESS

For this analysis, the authors of this article used 21 controls; 12 were low distress and 11 were high distress. The experimental sample of 40 women was divided; 22 were in low distress and 18 were in high distress. As expected, there was a difference between all the subjects, the high-low yielded an $F=25.7$, $P=.000$, indicating that people with high distress in both experimental and control groups show lower (better) scores over time regardless of the experimental conditions.

The authors' previous research on OSGs with breast cancer patients found that two mechanisms measured by Pennebaker's LIWC showed significant effects on outcomes. Women who expressed more negative emotions and more insightful behaviors in the groups showed more positive changes. A similar analysis comparing the Latino sample to the non-hispanic whites^{27,28} found that the critical group characteristics identified (ie, group's participant expression of negative emotions and insightful disclosure)²⁷ using the Pennebaker text analysis software were significantly linked to positive change. The Latina support groups were significantly lower in these dimensions, as were the facilitators in encouraging this behavior. Mean scores for the expression of anger were .22 (.16) for non-Latina sample, .17 (.11); insight 1.9 (.77) and 1.4 (.85). T-test anger scores were $t=4.57$, $P=.05$; insight $t=6.95$, $P=.00$.³⁷

DISCUSSION

The VCIC experiences suggest that OSGs are acceptable to and feasible for immigrant minorities, including those with limited English proficiency. The participant feedback has been overwhelmingly encouraging. Participants have commented that VCIC has allowed them "desahogo," or to "undrown" themselves. They have commented often that they had not been able to talk with anyone about their situation prior to VCIC. Participants have consistently expressed their immense gratitude.

Several obstacles were encountered in setting up this study related to the living situations of the population recruited. These need to be taken into account when implementing OSGs in similar immigrant communities. Space at the participants' homes was an issue. Several apartments were cramped, and the refurbished computers occupied a large amount of space. The computers purchased after the first batch were considered for their size. Dial-up Internet access was provided free of cost to the participants. However, the authors of this article did not take into account the participants' limited landline phone access. A few participants had very restricted plans. By dialing up once a week for 90 minutes, they exceeded their monthly telephone minute allowance. This resulted in a higher

bill and, for one participant, a reluctance to dial up. Remedial measures were taken to augment the participants' phone plans, allowing them to continue to participate.

Because of their unfamiliarity with the Internet, participants were provided with the project coordinator's telephone number for assistance. However, this was limiting. Most participants did not have a second phone, to call the coordinator once they were online. They would have to log off the Internet to place a call, compromising their ability to describe the problem, and the potential for the coordinator to assist them. This would result in missed chat sessions.

Since completing this pilot study, the Wellness Community has been experimenting with providing online support groups through the Virtual Wellness Community-Spanish website.³⁸ It has been learned anecdotally that patients prefer to start their online support group experience with cancer-related specific information (ie, managing side effects from treatment, preparing for chemotherapy). In this model, the first half of the online support group is education and the second half is support. It is easier and more comfortable for Spanish-speaking participants to express emotions in the context of the information presented. It is as if the information provides a safe distraction for participants to express emotions that would otherwise be burdensome on the rest of the group members without the initial focus on education. This insight and practical methodology should be explored in future studies. However, it should be noted that no outcome data is available from the Virtual Wellness Community-Spanish Web site. It is not known if this experiment would yield more robust outcomes.

The Latina women's change in attitudes towards the future and their feelings of empowerment suggest potential impact of the groups. However, the scales used to measure difference were not transcated but merely translated, potentially limiting their utility severely. Future studies should consider the use of specifically created and/or validated scales for this population. Additionally, reflections of effectiveness (eg, empowerment in decision making, completion of treatment) were potentially not measured. Unfortunately, there is little guidance from previous studies of both face-to-face and OSGs to provide a context for these findings. There are no studies comparing Latina and non-Latina women in support groups. Alternatively, it may be that women of color have sufficient interpersonal support in their own communities and do not need the extra support offered by these computer-mediated groups, while the Caucasian women are using the group so much for everyday life exchanges because they do not have similarly rich and effective support from their friends or families. Moreover, what they did while they used discussion group was different. Their comments were much less likely to be about day-to-day events than were those of Caucasian women, suggesting that women of

color used the discussion group to focus very tightly on breast cancer. Another possible clue to the differences in the Wellness Community studies of breast cancer support groups,^{31,32} and this study with Latina immigrant women may be found in the quality of the groups themselves. In previous studies on online breast cancer support groups, three critical group and leader characteristics were isolated using the Pennebaker text analysis software that were significantly linked to positive change of the participants: the group's cohesiveness, participant expression of negative emotions, and insightful disclosure.²⁷ The Latina support groups were significantly lower in these dimensions, as were the facilitators in encouraging this behavior. Thus, the absence of significant change in depression, QOL and addressing physical pain may in part have been contributed to by more inexperienced leadership and the low experienced cohesiveness, expression of negative emotions, and insightful disclosure.

Another possible explanation lies in the cultural characteristics of the Latina women. Here the possibilities are broad and varied and obviously do not rise above the level of speculation. That the women in the study emigrated from 12 countries, each with its own special culture, makes an explanation based on culture even more suspect. These individuals represent diverse nationalities, sociopolitical histories, races, ethnicities, and cultures.

Many researchers of Latino culture have attempted to describe some general characteristics of their culture despite the above cited differences.^{37,39-42} For example, traditional Western values stress the desirability of individualism, autonomy, and competition, whereas Hispanic cultural traditions emphasize the importance of collectivism, interdependence, and cooperation. The data available to the investigators in this study does not provide a source of empirical information on the effects of culture on their attitudes and behavior for OSGs. The following is offered as a speculation on why the effectiveness of OSGs for Latina breast cancer patients was limited.

"Familismo" (ie, family values and the value of family) has been described an allocentric cultural value that stresses attachments, reciprocity, and loyalty to family members beyond the boundaries of the nuclear family.^{41,42} Allocentrism is a cultural value by which people understand themselves through others, emphasizing social relationships and highlighting group goals rather than individual ones. "Personalismo" refers to a preference for relating on a personal, rather than formal or institutional, level.⁴³ Irrespective of gender, physical touch is used more liberally by Hispanics than Euro-Americans, and the appropriate conversational distance for Hispanics is much closer.⁴⁴ "Marianismo," which is rooted in the Roman Catholic reverence for the Mother Mary, refers to some traditional cultural prescriptives assigned to women. With motherhood, women achieve an elevated status of spiritual superiority to men and

consequently enjoy a certain amount of power.³⁷ However, in keeping with reverence for the Madonna, mothers are expected to embody the virtues of selflessness and to endure suffering with dignity.³⁹ Though collectivist ideals are consistent with the self-sacrifice of all individuals, because women are considered to be more virtuous than men, they are deemed capable of greater sacrifice. Religion and Spirituality. Faith, rooted in Roman Catholicism, is generally the cornerstone of Hispanic life in many communities.⁴⁵ The belief that God is the author of one's destiny is prevalent across the Spanish-speaking world and is evident in widespread references to God's will.⁴⁶

How could these common cultural touchstones impact on the study's intervention? There are no definitive answers. Perhaps the emphasis on closeness and touching influenced their experience of the relative "coolness" of Internet communication. Perhaps the propensity to endure suffering may have limited the women's willingness to speak of the burdens associated with their breast cancer diagnosis. Perhaps even more important was the use of tools that were not validated in these communities and may not have accurately measured the intervention's impact.

THREATS TO THE STUDY'S VALIDITY

Numerous problems mitigate the authors' conclusions. The randomization protocol was compromised by selecting patients serially as they registered, signed the human subjects forms, and completed the measures. The first eight people were placed in a group, then the next eight people formed the next group, and so on until 48 people were enrolled into 6 groups. Finally, the control group was formed from the last 20 who registered. Reliance on merely translated Spanish versions of the measures raises the question of differences in language usage and cultural norms. The computer analysis of the interaction may be problematic because the translations of the transcripts and the language usage and cultural norms may have a major effect on the authors' conclusions. Words describing abstract concepts (eg, emotions) are not as readily interpreted.⁴⁷ The findings from previous studies on the effect of emotional expression and cognitive processes are based on non-Hispanic Caucasians. The authors provide no evidence suggesting that these are critical for the immigrant Latina sample studied.

CONCLUSION

Virtual communities hold tremendous promise for cancer support. Despite the issues noted, underserved communities, including immigrants, can and must be included. Participants eagerly joined and remained in the groups, expressing much

gratitude for their existence. Upon deployment and demonstration of the effectiveness of “e-health” interventions such as VCIC, these interventions will likely present cost-effective alternatives to traditional health interventions for underserved populations. However, sufficient resources need to be devoted to ensure their smooth functioning for communities without prior computer and/or Internet experience. A replication of “e-health” interventions that have been effective in mainstream communities must be carefully tailored to the cultural context of immigrant communities. Further research is important into the content and the processes of online support interventions for immigrants with cancer. **PP**

REFERENCES

- Larsen LJ. US Bureau of the Census. The foreign-born population in the United States: 2003. Current Population Reports [serial online]. 2004;P20-551.1-9. U.S. Bureau of the Census. Washington, DC. Available at: www.census.gov/prod/2. Accessed September 3, 2008.
- United States Census 200. Summary tables on language use and english ability. 2000 (PHC-T-20). Available at: www.census.gov/population/www/cen2000/briefs/phc-t20/index.html. Accessed September 11, 2008.
- Newest New Yorkers 2000: Immigrant New York in the new millennium. New York City Department of City Planning. January 2005. Available at: www.nyc.gov/html/dcp/html/census/nny.shtml. Accessed September 3, 2008.
- Perez TE. Health and civil rights. *Cancer*. 2001;91(1 suppl):217-220.
- Women's Information Network Against Breast Cancer. Breast Buddy Program for Indigent and Underserved. Available at: www.winabc.org/programs/breast-buddy-underserved.htm. Accessed August 25, 2008.
- Facing forward: life after cancer treatment. National Cancer Institute. U.S. National Institute of Health. Available at www.cancer.gov/cancertopics/life-after-treatment/allpages#6. Accessed August 25, 2008.
- Rehse B, Pukrop R. Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Educ Couns*. 2003;50(2):179-186.
- Spiegel D, Bloom JR. Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosom Med*. 1983;45(4):333-339.
- Cain EN, Kohorn EI, Quinlan DM, Latimer K, Schwartz PE. Psychosocial benefits of a cancer support group. *Cancer*. 1986;57(1):183-189.
- Taylor SE, Falke RL, Shoptaw SJ, Lichtman RR. Social support, support groups, and the cancer patient. *J Consult Clin Psychol*. 1986;54(5):608-615.
- Fawzy FI. Malignant melanoma: effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Arch Gen Psychiatry*. 1993;50(9):681-689.
- Miano LY, Rojas MS, Trujillo M. “Platicas y merienda”: reaching Spanish-speaking patients in an oncology setting. *Cancer Pract*. 1996;4(4):199-203.
- Guidry JJ, Aday LA, Zhang D, Winn RJ. The role of informal and formal social support networks for patients with cancer. *Cancer Pract*. 1997;5(4):241-246.
- Alferi SM, Antoni MH, Ironson G, Kilbourn KM, Carver CS. Factors predicting the use of complementary therapies in a multi-ethnic sample of early-stage breast cancer patients. *J Am Med Womens Assoc*. 2001;56(3):120-123,126.
- National Cancer Institute. CIS research agenda: overview of relevant research U.S. Department of Health and Human Services, National Institutes of Health 2005. Available at: http://cis.nci.nih.gov/research/agenda_overview.pdf. Accessed August 25, 2008.
- Fukui S, Kugaya A, Okamura H, et al. A psychosocial group intervention for Japanese women with primary breast carcinoma. *Cancer*. 2000;89(5):1026-1036.
- van Wegberg B, Lienhard A, Andrey. Does a psychosocial group intervention program alter the quality of life of cancer patients? *Schweiz Med Wochenschr*. 2000;130(6):177-185.
- Spooner T, Rainie L. Hispanics and the Internet. Pew/Internet: Pew Internet & American Project for Life. Available at: www.pewinternet.org/reports/toc.asp?report=38. Accessed August 25, 2008.
- Harris Poll shows number of “cyberchondriacs” – adults who have ever gone online for health information– increases to an estimated 160 million nationwide. Harris Interactive. Available at: www.harrisinteractive.com/harris_poll/index.asp?PID=792. Accessed August 25, 2008.
- Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (NCI). SEER Data, 1973-2005. Available at: <http://seer.cancer.gov/data/>. Accessed September 3, 2008.
- Klemm P, Bunnell D, Cullen M, Soneji R, Gibbons P, Holeczek A. Online cancer support groups: a review of the research literature. *Comput Inform Nurs*. 2003;21(3):136-142.
- Eysenbach G. The impact of the Internet on cancer outcomes. *CA Cancer J Clin*. 2003;53(6):356-371.
- Wellman B. An electronic group is virtually a social network. In: Kiesler S, ed. *Culture of the Internet*. 1st ed. Mahwah, NJ: Lawrence Erlbaum; 1997:170-205.
- Lieberman M, Golant M, Giese-Davis J, et al. Electronic support groups for breast carcinoma: a clinical trial of effectiveness. *Cancer*. 2003;97(4):920-925.
- Winzelberg AJ, Classen C, Alpers GW, et al. Evaluation of an internet support group for women with primary breast cancer. *Cancer*. 2003;97:1164-1173.
- Lieberman MA, Golant M, Giese-Davis J, et al. Electronic support groups for breast cancer: a pilot study of effectiveness. *Cancer*. 2003;97(4):920-925.
- Lieberman MA, Goldstein BA. Not all negative emotions are equal: the role of emotional expression in online support groups for women with breast cancer. *Psychooncology*. 2006;15(2):160-168.
- Lieberman M. The role of insightful disclosure in outcomes for women in peer-directed breast cancer groups: a replication study. *Psychooncology*. 2007;16(10):961-964.
- Pew Hispanic Center and Pew Internet Project. Latinos Online. March 14, 2007. Washington, DC. Available at: www.pewinternet.org/pdfs/Latinos_Online_March_14_2007.pdf. Accessed September 3, 2008.
- CAVIC. Available at: www.cavic.org. Accessed September 3, 2008.
- Cho MJ, Moscicki EK, Narrow WE, Rae DS, Locke BZ, Regier DA. Concordance between two measures of depression in the Hispanic Health and Nutrition Examination Survey. *Soc Psychiatry Psychiatr Epidemiol*. 1993;28(4):156-163.
- Hann D, Winter K, Jacobsen P. Measurement of depressive symptoms in cancer patients: evaluation of the Center for Epidemiological Studies Depression Scale (CES-D). *J Psychosom Res*. 1999;46(5):437-443.
- Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress*. 1996;9(3):455-471.
- Tedeschi RG, Calhoun LG. *Trauma and Transformation: Growing in the Aftermath of Suffering*. 1995. Thousand Oaks: Sage; 1995.
- Cella DF, Tulsky DS, Gray G. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol*. 1993;11(3):570-579.
- Lawrence Erlbaum Associates, Linguistic Inquiry and Word Count. Revised. Mahwah, NJ; 2000.
- Comas-Diaz L. Culturally relevant issues and treatment implications for Latinos. In: DR Koslow, Pathy E, eds. *Crossing Cultures in Mental Health*. Washington, DC: SIETAR International; 1989:31-48.
- The Wellness Community. Available at: <http://espanol.thewellnesscommunity.org>. Accessed September 3, 2008.
- Stevens EP. Machismo and marianismo. *Society*. 1973;10(4):57-63.
- Sue DW. Multidimensional facets of cultural competence. *Couns Psychol*. 2001;29(6):790-821.
- La Roche MJ. Psychotherapeutic considerations in treating Latinos. *Harv Rev Psychiatry*. 2002;10(2):115-122.
- La Roche MJ, Turner C. Self-orientation and depression level among Dominicans in the United States. *Hisp J Behav Sci*. 1997;19:479-488.
- Delgado M, Humm-Delgado D. Natural support systems: a source of strength in Hispanic communities. *Social Work*. 1982;27:83-89.
- Hall ET. The silent language. In: O'Brien RW, ed. *Readings in General Sociology*. 4th ed. Boston, MA: Houghton Mifflin; 1969.
- Nava Y. *It's All in the Frijoles: 100 Famous Latinos Share Real-life Stories, Time-tested Dichos, Favorite Folktales, and Inspiring Words of Wisdom*. New York, NY: Diane Publishing Company; 2000.
- Falicov CJ. The cultural meanings of money: the case of Latinos and Anglo-Americans. *Am Behav Sci*. 2001;45(2):313-328.
- Bond MH, Lai TM. Embarrassment and code-switching into a second language. *J Soc Psychol*. 1986;126(1):179-186.