

## **ETHNIC DIFFERENCES IN CULTURAL MODELS OF BREAST CANCER SUPPORT GROUPS\***

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### **ABSTRACT**

Given the well-documented underrepresentation of ethnic participants in mainstream support groups and the disparity in breast cancer survivorship among ethnic minorities, the current proliferation of ethnic-specific cancer support groups is not surprising. This study employed qualitative and quantitative methods, including cultural consensus analysis, to examine core elements of breast cancer support group models among African-American, European American, and Latina women and describe the perceived role of support groups in the recovery experience. Results indicate a core cultural model of breast cancer support groups exists and the fundamental elements of peer support and encouragement, helping others, talking about worries/fears, staying active/involved, friendship/bonding, and learning from others are broadly shared across ethnically diverse communities. Elements distinctive to ethnic-specific self-help groups were also identified. Findings provide insight into factors motivating attendance and retention in support groups and may guide recommendations for better meeting the social support needs of culturally diverse patients.

**Key Words:** self-help group, breast cancer, Latina, African American, social support

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## BACKGROUND AND OBJECTIVES

The self-help movement, which grew significantly in the United States since the 1970s, has important roots in the Women's Movement of the 20th century. In particular, consciousness-raising as a self-help process influenced diverse peer support groups such as those related to health and social problems (Borkman, 1999; Levine, 1988; Rapping, 1997). Furthermore, women's participation in most types of support groups is much higher than men (Kessler, Mickelson, & Zhao, 1997; Klemm, Bunnell, Cullen, Soneji, Gibbons, & Holecek, 2003; Owen, Goldstein, Lee, Breen, & Rowland, 2007). However, ethnic and minority women have been consistently underrepresented in such groups, for reasons that are poorly understood (Humphreys & Woods, 1994; Kessler et al., 1997; Nápoles-Springer, Ortiz, O'Brien, Díaz-Méndez, & Pérez-Stable, 2007). Although some evidence suggests there are no differences in the percentage of African-American women who have *ever participated* in a breast cancer support group compared to white women (Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004), the gap in sustained participation (i.e., becoming a regular member) appears to be real.

In recent years, many areas of the United States have witnessed the emergence of ethnic-specific cancer support groups, particularly for breast cancer. Some of these groups are affiliated with a national association, such as the Sisters Network, "a national African American breast cancer survivorship organization" with chapters in 18 states (<http://www.sistersnetworking.org/>). Local affiliates of the Sisters Network function as support groups with action-oriented education and outreach activities to promote the larger mission of understanding and eliminating ethnicity-related disparities in breast cancer (Newman & Jackson, 2003). Other ethnic support groups are locally based or serve a region, such as the Native American Cancer Survivors' Support Network (Burhansstipanov, Gilbert, LaMarca, & Krebs, 2001) and the Life is Precious Project designed for Hmong women in California (Kagawa-Singer, 2008).

Attrition is high within all kinds of support groups and only a minority of attendees become long-term members (Bottomley, 1997; Owen et al., 2007). One line of inquiry for understanding low retention in support groups has focused on individual-group fit, or the compatibility between potential members and group characteristics (Grande, Myers, & Sutton, 2006; Humphreys & Woods, 1994; Kennedys & Humphreys, 1994; Luke, Roberts, & Rappaport, 1993). For example, studies of African-American women's participation in breast cancer support groups suggest cultural dissonance may account for African Americans dropping out of mainstream support groups (Matthews, 2000, 2008).

"Cultural models are cognitive schema that represent the shared understanding of phenomena among members of a social group. A cultural model consists of an interrelated set of elements forming a mental template for understanding and responding to life situations" (Coreil, Wilke, & Pintado, 2004, p. 906). When

applied to self-help groups, the concept is similar to the notions of illness representations (Levanthal, Brissette, & Leventhal, 2003), community narrative (Rappaport, 2000), ethos (Riessman, 1997), and collective experiential knowledge (Borkman, 1999), and can be viewed as cultural concepts of shared ideology and values learned within the group (e.g., the basic principles of 12-Step programs for addictions).

This multiphase study builds upon our previous work with European American breast cancer survivors, which identified a shared cultural model that included the recovery narrative (the ideology espoused by the group regarding a desirable recovery experience), group metaphors (e.g., “sisterhood” and “family”), perceived benefits, group processes, and contested domains. This follow-up study examined core elements of the breast cancer support group model as espoused by ethnically diverse comparison groups, African American, European American and Latina women, in Central Florida. The goal of the study was to describe the perceived role of support groups in achieving a good recovery experience. Specifically, variation in elements recognized as fundamental to the support group process across ethnically diverse populations were examined in an effort to formulate recommendations for meeting the psychosocial support needs of culturally diverse patients.

## METHODS

Both qualitative and quantitative methods were used to understand elements fundamental to the support group process and test the hypothesis that the three comparison groups possess distinct cultural models of the support group experience. Women were recruited from six breast cancer support groups, which served primarily women of African American ( $n = 2$ ), European American ( $n = 2$ ) and Hispanic/Latina ( $n = 2$ ) descent. Each group was recognized as a “breast cancer support group” by the American Cancer Society, the Sisters Network, or by recognized Cancer Centers in either Tampa or Orlando, Florida. While each group was advertized and meetings announced through these institutions, there were no active referral processes, no direct links with the individual’s medical provider and, anecdotally, most women find the group on their own. Two of the groups (one African American and one Latina) held meetings at a Cancer Center. However, all support groups were independent of the health care system. Groups were free of charge and participation was open. With the exception of one professionally-led European American group, which was organized at the local cancer center, all groups were true “self-help” support groups (i.e., member-led support groups). The one professionally-led group was co-led by a member who was a breast cancer survivor.

This study took place in Central Florida between April 2007 and December 2009. The study was conducted in two phases; 1) Phase I: Ethnographic Semi-structured Interviews and 2) Phase II: Cultural Consensus Analysis using the

Group Culture Questionnaire. The study was approved by the Institutional Review Board of the University of South Florida and written, informed consent was obtained from all participants.

During Phase 1, ethnographic data were collected through semi-structured interviews with 36 African American and Latina cancer survivors and support group leaders from six local support groups using an open-ended interview guide.

The guide, designed to replicate our 2001 pilot study with European American women, sought to elicit perspectives on the role of support groups within the recovery narrative of the group and the breast cancer experience generally. The interview guide was translated into Spanish for use with Spanish-speaking participants by a professional translation service using a forward/backward translation procedure.

All interviews were digitally recorded and transcribed verbatim in the language of interview. Data were then entered into MAXQDA<sup>®</sup> (VERBI Software, Berlin-Marburg-Amöneburg, Germany 2007), a computer-assisted analysis program. A coding scheme was developed based on themes which emerged through participants' shared stories and experiences and content analysis of transcripts. Emergent themes were analyzed by extracting coded interview segments and analyzing relationships across codes. Analysis of Spanish language interviews were conducted by bilingual coders. Transcripts were independently coded by trained primary and secondary coders who compared coding, discussed discrepancies and reached agreement on assigned codes. Patterns of similarity and difference across ethnic groups were recorded. Members of the research team also attended 16 support group meetings (2-3 observations per group), where they observed activities, interactions, and commentary. Detailed field notes were recorded and helped to inform the interpretation of findings.

Direct quotes related to each theme identified in the in-depth interviews were extracted from the transcripts for use in developing the Group Culture Questionnaire which was administered in Phase II. Results from our 2001 study were used to inform the development of additional questions to ensure relevance for European American women and enhance comparisons across groups. Items were constructed using phrasing close to the original statements made by respondents in both studies (cf. Kempton, Boster, & Hartley, 1995). Each question presented a 4-point Likert-scale response (strongly agree, agree, disagree, strongly disagree; or very important, important, not very important, not important) or utilized sets of paired comparisons. Paired comparisons, a strategy employed when individuals are being asked to choose between a number of options, were used to evaluate important elements of a support group (i.e., helping others, staying active and involved, learning things from others, friendship and bonding, receiving encouragement, talking about worries and fears). The final Questionnaire included 65 questions designed to assess cultural knowledge and values across groups. This Group Culture Questionnaire was translated into Spanish by a

professional translation service using a forward/backward translation procedure and pilot tested with 2-3 individuals from each group.

Phase II involved the application of cultural consensus analysis (CCA), a systematic statistical technique for measuring degree of agreement among a set of informants regarding a defined cultural domain (Dressler, 2005; Romney, Weller, & Batchelder, 1986; Weller & Romney, 1988) through the administration of the Group Culture Questionnaire. CCA is built upon the premise that cultural knowledge is shared across groups (Romney et al., 1986; Scott Smith, Morris, Hill, Francovich, McMillin, Chavez, et al., 2004). Thus, it can be expected that group participants will respond in a similar pattern and responses to a series of questions will provide insight into the core culture and values of the group. Additionally, differences in cultural knowledge and values across groups can be determined. The statistical procedures used are similar to factor analysis, but unlike factor analysis which groups sets of related scale items, consensus analysis groups informants by similarity of response patterns across a set of items (Romney, 1999).

CCA was performed on data collected through the Group Culture Questionnaire with demographic questions used to control for group differences. Quantitative data collected through the Group Culture Questionnaire were analyzed using UCINET<sup>®</sup> (Analytic Technologies, 2002) and PASW<sup>®</sup> Statistics 18.0 (SPSS, Inc., 2009) to identify rankings for core elements of the model and perform bivariate analysis of Likert-type items.

The first step in CCA involves examining common factors in the matrix, treating informants as variables. If a single first factor accounts for most of the variation relative to the other factors (i.e., all informants cluster on a single factor), the assumption is that all the informants are drawing on a single, underlying, shared cultural model. The standard criterion, a ratio of 3.0 or higher between the first and second factor eigenvalues (Romney, Moore, Batchelder, & Hsia, 2000) was used to assess consensus. Cultural competence coefficients (cultural knowledge scores) were generated to indicate the degree to which responses of each informant matched the shared consensus model. Presence of a consensus model is noted by a large and positive competence coefficient. An average competence score  $> .50$  was used to interpret consensus as present.

To determine the sample size for ordinal data, two considerations were taken into account: the degree of agreement among respondents (average Pearson correlation coefficient) and the desired level of validity (degree of correlation between the response choices of the study participants and the culturally correct answers to questions). In cases with a high level of agreement about a cultural domain, the sample size needed to reach a high level of validity is small. Conversely, if low agreement characterizes the domain, a larger number of informants is needed to achieve validity. With no prior knowledge about the degree of agreement among support group participants regarding recovery from breast cancer or the core elements of a support group, we estimated average cultural competence to

be moderately low (0.36) and set a validity criterion of 0.95 for correct selection of response choices. Based on these criteria, a minimum of 17 respondents were needed to perform CCA (Weller & Romney, 1988).

Based on the criteria for CCA, 64 respondents (African American,  $n = 19$ ; European American,  $n = 23$ ; and Latina,  $n = 22$ ) were recruited from the six participating breast cancer support groups. As Phase I and Phase II were independent, participation was not limited to those involved in Phase I. Participants completed the Group Culture Questionnaire, which also included a brief illness history and demographic information. Consensus analysis was performed on the data.

Presentations of study findings were also made at five of the six participating support groups (two African American, two European American, and one Latina) in an effort to validate study findings. Following presentations, the research team discussed the findings in detail with participants and elicited feedback. This process further informed interpretation of findings.

## RESULTS

Demographic characteristics for Phase I and Phase II participants are presented in Table 1. Participants ranged in age from 32 to 81 years of age, with an overall mean age of 53.7 years and 57.0 years for Phase I and II respectively. Approximately half of participants in both Phases I and II reported being currently married. Participants reported an average of 2.1 children in Phase I and 1.8 children in Phase II. While levels of educational attainment were collected differently between the two phases, education was shown to vary across the sample. Phase I participants reported degrees ranging from high school/GED to doctoral degrees. Similarly, Phase II participants reported between 13 and 15 years of education, with a mean of 14 years. With the exception of one participant in the Phase II sample, all Latinas were born outside the United States. The majority of African Americans reported being Protestant, while Latinas and European Americans were more evenly divided between Protestant and Catholic affiliation. Aside from religion, comparison groups did not differ significantly on demographic variables.

### Phase I: Ethnographic Findings

During the in-depth interviews, women were asked several questions related to their perceptions of and experience with support groups and the perceived role of support groups in their recovery from breast cancer. In addition, women were asked to talk about what motivated them to first attend a group, how their expectations changed after attending, perceived benefits of participation, what they appreciated the most about the group, and what they would change about the group. Narrative responses to these questions were analyzed to identify important elements of what we call the support group model.

Table 1. Demographic Characteristics

	Phase I			Phase II		
	African American	Latina	N = 17	African American	European American	Latina
Sample size	N = 19	N = 17	N = 22	N = 19	N = 23	N = 22
Mean age (years)	59.5	51.9	51.6	59.5	59.9	51.6
Education (years)	—	—	13.4	14.2	14.3	13.4
High school/GED (%)	21.1	46.7	—	—	—	—
Some college or technical school (%)	42.1	13.3	—	—	—	—
College degree	26.3	26.7	—	—	—	—
Advanced degree	10.5	13.3	—	—	—	—
Marital status (%)						
Single	5.3	6.7	27.3	27.3	17.4	27.3
Married	42.1	6.0	42.1	42.1	56.5	59.1
Divorced	42.1	33.3	18.2	18.2	21.7	13.6
Widowed	10.5	0	9.1	9.1	4.4	0
No. of children	2.1	2.1	1.7	1.7	1.9	1.9
Religious affiliation (%)						
Catholic	0.0	50.0	0.0	0.0	43.5	50.0
Protestant	78.9	50.0	100.0	100.0	26.1	45.5
Other/None	21.1	0	0.0	0.0	30.4	4.5

## Peer Support and Encouragement

The importance of having a trusted source of psychosocial support emerged as the most important element of the support group, as well as being perceived as central to a woman's recovery. While most women identified family and friends as important sources of support, some worried about the effect of their health on their family. For these women, the support and encouragement provided by the group was essential and most, even those with strong support networks, emphasized the importance of receiving support during their journey from a group of women who had walked a similar path.

They may have their mother, father, sisters or brothers to talk to, but when you are talking with a group of women who have gone through what you've gone through it's a totally different feeling. Because we not only sympathize but we empathize. (African American)

The benefits [of support groups] are good. Above all, having the support of all the others is a good idea because if a person is depressed, there they have the support. And many are very quiet and [being in the group] then motivates you to express things and to speak about how you feel. That is important. (Latina)

Inherent to peer support was the importance of shared experiences and the encouragement that women received from one another. As one African-American woman stated, "*she's walked a mile in my shoes.*" Many respondents mirrored this sentiment with the common phrase, "*only another survivor can understand.*" For many, this was a key issue, having someone who understood and shared similar experiences to lean on during recovery. Findings illustrated two basic aspects of this theme: listening to others' stories, which was noted as a source of comfort and reassurance, and sharing one's own experience, which allowed women to give back.

Basically they have blazed the trail for you, you don't have to go and make your own, you can just follow through their path and ask them "Hey, my hair fell out" and they can say "it's okay, it'll grow back." (Latina)

They helped me too to have a positive attitude about things . . . although the doctors had told me but it was like, the doctors had no had breast cancer so they are telling you what they thought was probably read in the book or taught in school. But I was dealing with people who are like me, have cancer." (African American)

Because there are others that have gone through what they did, well I think that listening—listening to what happened to them, what happens to the other person, . . . one feels calmer. [It's like] "She made it so many years and look how good she looks; well I can do it, too." (Latina)



*Friendship and Bonding*

For many, friendship, bonding and a feeling of solidarity grew out of support group participation.

When I see a person in the street or something and they have a pink ribbon, I get the urge to say, 'Are you a survivor, or do you know someone?' It's like . . . a bond, like something special that says "I know what you went through. . . ." (Latina)

Participants discussed the camaraderie and support they encountered in the group as well as a sense of belonging or being part of something bigger than themselves. Survivors discussed the strength they garnered from the bonds formed and the affection that grew from this experience. For many, these relationships became the primary reason for their regular attendance in the support group.

*Learning from Others*

For the survivors in this study, support groups served as valued sources of information and trusted places for advice. Many participants, particularly those in treatment, reported seeking information and guidance, often citing this as a primary reason for first joining the group. Participants believed groups presented a combination of scientific knowledge, personal experiences and advice, providing the opportunity to learn from other survivors and health care professionals. Women were quick to point out that the group "*wasn't talking about a sickness, it was talking about educational things you should know going through the process.*" Informational presentations, touching on everything from the latest treatments to diet, exercise, health and wellness, accessing services, or cosmetics, were often given at group meetings by doctors, nurses, social workers, American Cancer Society representatives or researchers.

The information gleaned at meetings was credited with reducing worry, fear, and anxiety about cancer. Learning from others about treatment options, hearing different experiences with medications, and discussing the countless health and personal issues faced by fellow survivors gave many of the participants a sense of "*power.*" The support group was the mechanism through which they learned where to access resources and navigate services.

*Helping Others*

While many participants reported initially attending groups to fulfill their own needs, helping others emerged as one of the most important elements of the experience. Participants discussed "*not dwelling*" on themselves but rather being "*thankful for the opportunity to help others*" and a vast majority of participants expressed helping others as their motivation for continued attendance. In particular, long-term survivors reported it gave them a chance to "*help other*

women get through it [cancer]” and they would continue to attend because others needed them. The focus on helping others was so strong that one Latina stated, “I thank God for the experience [cancer] because I have now been able to help other women.”

Helping others was often described in terms of giving one’s personal testimony of survival. Sharing one’s story as someone who had “made it” allowed women to serve as a living example of survivorship. Their stories provided hope and offered valuable guideposts for coping.

#### *Talking about Worries and Fears*

The support group provided a safe outlet for women to talk about their worries and fears, helping to reduce uncertainty about the cancer experience.

... being in the group has taken away some of the fear and some of the anxiety about cancer.” (African American)

... from what I heard from the others and from the speakers, I learned a lot. I learned that all [the other survivors] have more or less the same fears, of dying. . . .” (Latina)

Women attested that involvement in a support group helped them form realistic expectations about the future. Through the group, they could interact with women at different phases in their recovery process. Those newly diagnosed felt better prepared for treatment and felt empowered, armed with firsthand information which enabled them to better communicate with their physicians. Knowing what to expect enhanced a woman’s sense of control over what was perceived as an otherwise unpredictable situation.

#### *Group Leader*

Another prominent theme expressed in interviews was the importance of the group leader. Participants reported a strong leader was vital to the success of the group, identifying important characteristics as being knowledgeable, connected to resources, outgoing, creative, energetic, upbeat, and empathetic. Participants often gave examples of their own group leaders to exemplify these characteristics.

Over the course of our studies, the crucial role that leaders play in sustaining the dynamism, morale, and functioning of the group was apparent. Members often referred to the groups by the leader’s name, as in “I go to Mary’s group,” and leaders were influential in molding the ethos of the group. Not surprisingly, groups experienced setbacks when leaders had personal problems, became ill, or passed away. Several instances were observed where groups stopped meeting, fell into disarray, or encountered problems attributed to leadership transitions. As an example, data collection was delayed several months due to the death of one of the leaders in the study. Another group stopped meeting after the leader moved away.

*Distinctive Elements to Ethnic Support Groups*

While the main themes discussed above were central to all groups, African American and Latina women perceived differences between their group when compared to groups serving those of other ethnicities. Participants discussed subtle nuances such as styles of interaction, touching, or sharing emotions which were perceived as specific to their group. Women identified these nuances as elements that helped them feel comfortable in the group and both African-American and Latina women emphasized the value in being with women who shared a similar background.

African-American women stressed the importance of having role models from the African-American community. One woman stated, "*Especially in the African-American culture, we never had a lot of role models to relate to as survivors.*" Most women stressed it was easier to talk about difficult issues with women from the same cultural background, and this allowed them to identify more with the group. One woman expressed, "*I feel real warm to African-American ladies because they are of my color, they seem to sympathize more with you, and I feel more of a family around them.*"

Participants from predominantly African-American groups also discussed differences in styles of interaction among their groups when compared to others, describing their groups as less rigid, more relaxed, spontaneous and lively, with lots of touching, showing of emotions and caring. Ultimately, participants felt a greater sense of trust among African-American members and discussed feeling free to openly express themselves within a group of similar women.

This group is unique to me in contrast to the one where I was because I'm an African American. So to be with other African Americans made it even more comfortable than it ever could be in another group because I know they have the same background that I have. We have the same beliefs, the same values. (African American)

... if it had been another group [not African American] and that was the only group that I had to attend, I would attend it but I wouldn't feel so free to express myself like I do with [this] group. (African American)

Similarly, Latinas talked about being more comfortable and able to express themselves openly in a support group with women from the same ethnic background. An important aspect of this was the language of communication. For most participants, Spanish was the first language; many spoke only Spanish. It was vital that these participants belong to a group where everyone spoke the same language and they could receive materials and information in their native tongue.

My husband doesn't like to see me cry, but sometimes I tended to cry. [In the group, it was ok] all the time. That was important because you can cry and get it out. (Latina)

The importance of emotional expression was salient across interviews with Latinas. Women discussed this as an element perceived to be unique to their group. To corroborate, participants contrasted their experience expressing emotion in the Latina group with other European American groups they had visited and perceived to be less emotional.

There might have been one or two that cried. . . . In the Latino groups, everybody cried. . . . In the American group, if one cried, it was, as the tears fell, they would hide it so no one would see. (Latina)

Latina respondents shared stories of members crying at meetings, in some cases for the first time after diagnosis. Overall, there was agreement among respondents that sometimes survivors just needed to “*get it out*” and in some cases this was imperative for them to accept their diagnosis and move on.

[The group] helped me a lot because I began to see that one is worth more than a pair of breasts and one’s hair. But it was a process, where I cried, I think I cried a lot, a lot, a lot. (Latina)

While emotional expression was important, a need for balance was also cited as excessive crying or “*carrying on*” was seen as detrimental to both the individual and the group.

This concept was shared in African-American groups where women frequently cited the need for open expression of emotion but affirmed the group was “*no pity party*.” Women believed strongly one should not dwell on negativity and it was unhealthy to feel sorry for oneself. There was a strong desire for the group to maintain a positive outlook.

. . . your meeting needs to be an upbeat meeting. Not one where we are just there to talk about our cancer. It’s not a crying group. (African American)

Some participants were even critical of members who cried frequently or had excessive emotional outbursts:

She doesn’t want anything to help her because she just wants to sit and dwell on this issue. (African American)

Results indicate the need for a delicate balance between expressing emotion and the upbeat nature deemed important for the effectiveness of the group.

I have this thing I always say, you are allowed to have your pity party, but you have to flush every now and then. You do. I think because we are so positive and upbeat and there are times when we, we have our meetings where it’s just let it all out. If you want to cry, talk about something, this is the day. We have those times. (African American)

Observations at meetings further revealed the awkwardness that can occur when someone expresses too much emotion. In one of the African-American groups, a member was chided for her excessive negativity. During another observation at

a European American group, a new member broke down while discussing her diagnosis and the turmoil it caused. An uncomfortable silence fell over the room as the leader patted her on back. In our notes we recorded:

One attendee was there for the first time and had been diagnosed a few months before. When the members went around introducing themselves, this woman broke down in tears. The response of the leader was to rush over and immediately comfort the woman and tell her she did not need to continue speaking, they could move on, presumably giving the woman a chance to compose herself. But the woman continued to speak and express her sad feelings. [Comment: the leader appeared to assume the woman would not feel comfortable continuing to speak after she had lost emotional control in front of others. This may be an example of how the group conveys the message to members that emotional expression in meetings is a sensitive issue.]

Such observations underscore the delicate balance between meeting the emotional needs of a survivor and the desire for a positive support group environment.

Among Latinas, special activities and the role of the support group in the community also emerged as core elements of the group. Latina groups were perceived by participants as being “*not exclusively focused on illness.*” Through interviews with survivors and observations, it became clear that the social aspect, including sharing food and music, was important to participants. While the meetings were social in nature and less like a “regular meeting,” Latina groups also discussed conferences, workshops and other special activities that helped to define the group’s identity. While sociality was important to the other groups, this was much more prominent a factor among the Latina groups, who regularly hosted outings, sightseeing trips, parties and came together for special occasions. This social aspect was noted by group leaders and survivors as being highly desirable and a useful recruitment tool. Women even mentioned “members” who no longer participate in the support group but still attend special activities.

## **Phase II Quantitative Analyses**

Statistical analyses were conducted on survey items from the Group Culture Questionnaire which were related to the support group model. Analysis on additional items related to ethnic identity and recovery narratives are presented elsewhere (Coreil, Corvin, Nupp, Dyer, & Noble, 2012). The first set consisted of a series of paired comparisons of factors identified through in-depth, ethnographic interviews as important for a breast cancer support group: talking about worries and fears; helping other survivors; learning things from others; finding friendship and bonding; and receiving peer support and encouragement. Additionally, staying active and involved, a factor identified through our 2001 study with European American women, was also included for comparison purposes. Participants were asked to indicate which element of each pair of items was more important for their support group. Calculation of the total number of times an

item was chosen among the pairs determined its final ranking. The second set of items consisted of 27 statements describing aspects of a good support group which emerged through analysis of qualitative results. Cultural consensus analysis was conducted on this set of items to:

1. determine whether there existed a shared cultural model of breast cancer support groups within each ethnic group;
2. determine the average “competence” score for each group (how similar individual responses were to the “correct” or shared response for their group); and
3. rank order the items in terms of their importance by group.

Finally, participants’ identification of the best metaphor for the support group was analyzed across groups.

Results of the rankings for the six elements of a good support group showed a high degree of agreement across ethnic groups (see Table 2). All groups ranked first “helping other survivors,” followed by “staying active and involved,” “learning things from others,” and “finding friendship and bonding.” Variation in rankings was found for only two elements; Latinas ranked “talking about worries and fears” (5th) over “receiving encouragement” (6th), while African Americans and European Americans ranked the latter two items in reverse order.

Results of CCA for the 27 statements about breast cancer support groups indicated that a shared model of support groups exists both for the total sample and for each of the three ethnic groups analyzed separately. The ratio between first and second eigenvalue for the total sample was 4.2, above the 3.0 threshold generally considered the criterion to determine the existence of culturally shared models. The average competence for the total sample was .60, again showing strong agreement (above .50 is considered the cutoff). For the three ethnic groups, eigenvalue ratios were 7.1 for African Americans, 6.4 for Latinas and 13.4 for

Table 2. Ranking of Elements Important for Support Groups from Paired Comparisons by Ethnic Group

	Total sample	African American	European American	Latina
Helping others	1	1	1	1
Staying active and involved	2	2	2	2
Learning things from others	3	3	3	3
Friendship and bonding	4	4	4	4
Receiving encouragement	5	5	5	6
Talking about worries and fears	6	6	6	5

European Americans, indicating that level of cultural sharing reached the threshold for cultural consensus in all groups, and was notably higher for the latter group. Average competences were .60 for African Americans, .57 for Latinas and .67 for European Americans, indicating high levels of shared knowledge among group members for all three groups.

Interesting differences were observed in comparing ethnic group rankings of the 27 statements about support groups (see Table 3). For African Americans, the most important aspect of their support group was its "involvement in the community." However, being involved in the community was not ranked in the top 10 factors for Latinas (13.5) or European Americans (14). For Latinas, the highest ranked statement was "being a member of my support group helps me feel proud to be a breast cancer survivor." Among European Americans, the most important aspect was "it is comforting to be in the company of others who have been through the same experience as you."

Similar rankings were found for the item "A support group is a place where you are free to express what you really think and feel without being judged," which ranked second among both Latinas and European Americans and third by African Americans. Likewise, being with other survivors also ranked high for all groups. However, being able to express one's emotions at meetings had divergent rankings across groups; it ranked third for European Americans, seventh for Latinas, and eleventh for African Americans. A related statement, "One of the most important functions of a support group is to show members that other survivors have similar fears and worries," also ranked higher among European Americans (4) compared to African Americans (10) and Latinas (15). Learning what to expect about the cancer experience (uncertainty reduction) ranked higher among Latinas (8) compared to African Americans (16) and European Americans (16). Latinas also ranked higher the importance of receiving other kinds of assistance at meetings and perceiving the group as "helping me to make my own decisions," and lower than the other groups in agreement with the statement "sisterhood means that friendship between group members goes beyond the cancer experience." Response patterns were also analyzed for mean differences across groups and the top 12 statements are presented (see Table 3).

While not one of the top ranked statements, "I am more comfortable in a group of women who have a similar ethnic background as me" was ranked higher among African-American (18) and Latinas (18.5) than European American women (21). Similarly, being with women who think and look like you culturally was more important for African American (22) and Latina (17) women compared to European American women (27).

Receiving special items like bras, wigs, and prostheses was also more important for African-American (12.5) and Latina (16) women than for European Americans (23). Latina women placed greater importance on learning what to expect from the cancer experience as a benefit of support group participation, ranking it 7.5 compared to African-American and European American women

Table 3. Ranking and Means for Support Group Model Characteristics by Group<sup>a</sup>

	Total sample	African American	European American	Latina
	Rank	Rank	Rank	Rank
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Freedom to express what you think and feel without being judged	1.5 1.20 (.44)	3 1.21 (.42)	2.5 1.22 (.52)	2 1.18 (.40)
Comfort from being with others who have the same experiences as you	1.5 1.20 (.44)	2 1.16 (.38)	1 1.22 (.42)	5 1.23 (.53)
Able to express one's emotions	3 1.33 (.64)	11 1.53 (.84)	2.5 1.26 (.54)	7.5 1.23 (.53)
Helps to stay active and keep outlook upbeat	4 1.36 (.65)	9 1.47 (.77)	5 1.35 (.49)	6 1.27 (.70)
Allows one to help others get through their cancer	5 1.38 (.60)	4 1.37 (.60)	7 1.57 (.62)	3 1.18 (.40)
Helps one feel proud to be a breast cancer survivor	6 1.39 (.75)	7 1.37 (.68)	8 1.57 (.84)	1 1.23 (.69)
Sisterhood; friendship between members goes beyond the cancer experience	7 1.45 (.64)	5 1.32 (.58)	6 1.52 (.73)	13.5 1.50 (.60)
Shows members that other survivors have similar fears and worries	8 1.38 (.52)	10 1.37 (.60)	4 1.26 (.45)	15 1.50 (.51)
Helps in finding other kinds of assistance	9 1.42 (.68)	8 1.26 (.56)	10 1.70 (.82)	4 1.27 (.55)
Common language or way of communicating	10 1.50 (.80)	6 1.37 (.83)	11 1.70 (.80)	9.5 1.41 (.67)
Supportive family is the most important factor for a good recovery	11 1.48 (.64)	12.5 1.42 (.61)	9 1.61 (.66)	9.5 1.41 (.67)
Community involvement	12 1.56 (.83)	1 1.16 (.50)	14 1.91 (.90)	13.5 1.55 (.86)

<sup>a</sup>Ranking derived from cultural consensus analysis procedures; abbreviated statements presented for the top 12 of 27 factors.



who both ranked it 16. Latinas also ranked planning special activities as 12, placing more importance than African-American (15) and European American (17) women.

Women were also asked to choose whether “family,” “sisterhood,” or “club” represented the best metaphor to describe their group. Significant ethnic differences were found. Most African-American (78.9%) and European American (91.3%) respondents likened their group to a sisterhood. However, Latina women were equally divided between calling the group a sisterhood (50%) and a family (50%). Very few African-American (5.3%), Latina (0%), or European American women (4.3%) likened their group to a club.

## DISCUSSION

Findings suggest there exists a core cultural model of breast cancer support groups that is broadly shared across ethnically diverse communities. Key components of the model include the importance of peer support and encouragement (only another survivor fully understands), the helper principle (helping others helps oneself), talking about worries and fears (uncertainty reduction; learning what to expect), staying active and involved, friendship and bonding, and learning from others (access to information). Findings also emphasized the importance of good leadership and emotional balance (allowing open emotional expression at meetings without disruption of a positive atmosphere) for successful group functioning. Through such group processes, women were able to attain a strong feeling of solidarity and the bonds and friendships that formed transcended the regular meetings. Women found comfort in their shared experience, emphasizing how only another survivor could fully understand their worries and fears and provide trustworthy insight into the cancer experience. Mutual sharing of personal stories was considered fundamental to helping women maintain a positive attitude and, through shared experience, women could focus on the good, reduce uncertainty, and help others. Ultimately, there was a shared identity attached to being a breast cancer survivor. Being a support group member also allowed survivors to turn their battle with the disease into something purposeful and useful.

Central to the core elements of a support group was the need to express emotion, which ranked extremely high in the model and emerged through both qualitative and observational data. Importantly, however, both African-American and Latina groups disparaged excessive crying and carrying on, and African-American women affirmed the group was not a “*pity party*.” These findings are indicative of the delicate balance between emotional expression and the upbeat nature deemed important to groups and expressed in our a previous study with European American women (Coreil et al., 2004). Moreover, awkward and uncomfortable moments were observed in some groups when unexpected emotions surfaced, underscoring the difficulties faced by groups in finding balance.

This potential inconsistency in expressed emotion was presented to the groups for interpretation. Members affirmed that groups were a place to openly express oneself and provide whatever type of support a woman needed. However, they qualified this position by noting the need to move on and not bring others down. These findings corroborate existing research on emotional expression among breast cancer survivors that report the importance of expressing negative emotions for psychosocial well-being (Lieberman & Goldstein, 2006). These studies allude to the delicate balance, warning that too much or too little emotion can have negative effects on the support group experience.

In addition to these shared features, distinctive elements of ethnic specific group culture, including the importance of community involvement, special activities, identification with a “sisterhood,” language of communication, and access to assistance and gifts, were identified. The differences between groups that were found represent variation in the *relative importance* of a set of components that are present in all three groups’ cultural models. This was demonstrated by the fact that cultural consensus was present in each of the ethnic groups’ models for a common set of 27 support group characteristics. However noteworthy differences in rank orderings of items were found across groups. As African-American and Latina women assigned significantly more importance than European American women to belonging to a support group composed of women with similar ethnic backgrounds and this appears to be a key factor in the former’s participation in breast cancer support groups, understanding the distinctive elements of these groups is imperative to the effort of better meeting the support needs of ethnic women.

African-American participants clearly expressed their need for African-American centered groups, citing differences in styles of social interaction. Women reported feeling more comfortable being around others that were like them. African-American women also expressed the need to be in a place where they could share what they were thinking and feeling without being judged. To African-American women, the group was a “sisterhood” and their closeness and ability to express themselves freely became apparent in the perceived social characteristics of the group (touching, showing emotion, and caring). Additionally, the group was a place where they could help others while being helped themselves. The idea of helping others through this experience was so strong that the importance of the group’s involvement in the community was the single most important element of the support group model for African-American women.

Latinas also reported the importance of being with women who were culturally similar and looked and thought like them. This need for Latinas may be related in part to language and communication, which was also an important element of the Latina model. Previous studies indicate Spanish-speaking Latina breast cancer survivors have more difficulty communicating with their doctors than English speaking women and suggest that, even with adequate

information, processing and comprehension remain problematic (Janz, Mujahid, Hawley, Griggs, Hamilton, & Katz, 2008). Others have reported an expressed need by ethnic minorities to receive medical information through interpersonal contact (Janz et al., 2008). Communication is essential to psychosocial support and the nature of support groups, thus being with women who speak the same language is fundamental.

Latina women also conveyed a need for emotional expression, in particular the need to cry and release feelings, during group meetings. Quantitative findings corroborate these results, as Latina women highly ranked “being able to express what you really think and feel without being judged” and “the importance of being able to express one’s emotions” in the support group model. For Latinas, groups were also centered around special activities, which involved family-oriented excursions and activities organized by the group and much emphasis was placed on the family.

### **Recommendations for Social Inclusion and Culturally Diverse Populations**

Findings suggest ethnic focused breast cancer support groups appeal to women of different cultural backgrounds because they provide a place where women can find the ultimate “peer” support. Not only do women find others who have experienced the same illness, but those around them look and think like them, share the same language and priorities, and relate to them like sisters or family. The enhanced sense of shared identity fosters trust and bonding and strengthens the positive impact of group support. Conversely, “mainstream” breast cancer support groups attended by mostly European American women, despite their espousal of similar cultural models of illness, hold limited appeal for ethnic cancer survivors because the membership is perceived as “different” from them. This interpretation is consistent with other studies of collective identity and its significance in support group dynamics (Cunningham, 2005; Humphreys & Woods, 1994; Marmarosh & Corazzini, 1997).

Thus, to reach ethnically diverse survivors, it is important that support groups provide a setting where members feel culturally “at home” (cf. Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993). For women who see themselves as culturally different from the dominant society, cultural compatibility of the group represents an important aspect of the more general process of identifying with a kindred community of survivors found in all support groups (Levine, 1988; Luke et al., 1993; Stevens & Duttlinger, 1998; Ussher, Kirsten, Butow, & Sandoval, 2006; Ussher, Kirsten, Sandoval, & Butow, 2008). Findings also support other studies which highlight the importance of faith and spirituality for African-American and Latina support groups (Erwin, 2008; Gibson & Hendricks, 2006; Levine, Yoo, Aviv, Ewing, & Au, 2007; Mathews, 2000). These factors are important to consider when forming ethnic specific support groups.

Results indicate that for Latina survivors, the participation of family members is a crucial element of support group success. This finding is consistent with research which points to reliance on family support as the reason for low participation of Latina women in breast cancer support groups (Nápoles-Springer et al., 2007). By incorporating family members, Latina support groups are more likely to attract and retain members. Further, holding meetings in Spanish is essential. However, if the only Spanish-language support group available is for breast cancer, the group may find it necessary to open up to men and other forms of cancer. Although none of the Latina women we interviewed expressed negative opinions about the heterogeneity of their membership, opening the group could diminish the sense of “peer” support and reduce the level of intimacy in personal sharing.

Additionally, while accessing information was discussed as a vital part of group attendance and the majority of respondents implied this was the primary reason behind first joining the group, to be successful, support groups must effectively balance the needs of both newly diagnosed and long-term survivors. Further, as learning was such an essential element of the experience, providing additional education and information through support groups may enhance support for treatment and healthcare, allowing support groups to act as valuable extensions of clinical care. Additional research should be conducted to look at the learning processes in support groups to determine the role of the group in continuity of care and enhanced survivorship, particularly among ethnic specific support groups. It is also important to look at the influence of modeling that occurs between participants. Through shared testimonies, individuals learn about everything from treatment options to how to express their emotions appropriately. Studying these processes and outcomes can help to further understand the recovery process.

Further research should also focus on the dynamics of emotional expression within support groups. Through the course of this research, difficulty in expressing painful emotions and the challenges of finding a balance between optimism and negativity were referenced repeatedly. Additional research on the expression of painful emotions may provide insight into this juxtaposition, particularly as we seek to understand both the support for the cathartic release and the likelihood that some members suppress feelings for fear of burdening or disrupting the group’s positive ethos.

In conclusion, our study supports the position that ethnically identified support groups are successful in attracting and retaining culturally distinct populations because members perceive the group as providing holistic peer support, that is, knowledge, experience, and encouragement from others who share not only the problem condition but also a socio-cultural background and life experiences that enable a special bonding. In particular, our findings suggest that ethnic support groups offer a distinctive cultural model of support that is consonant with individual member expectations.

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