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Participant Evaluation of Teleconference Support for African American Women with Breast Cancer

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Abstract

Background—African American women with breast cancer face obstacles such as transportation and family obligations when attending standard support groups. Teleconference Support circumvents barriers such as transportation to participation but few evaluations have been reported about teleconference support.

Objective—The purpose of this paper is to describe the format of a teleconference group and to provide a descriptive account of the participants' feedback about a teleconference group intervention.

Interventions/Methods—A descriptive design was used. Participants completed the Overall Support Group evaluation tool at the end of the tenth group session.

Results—Teleconference group participants' feedback indicated that they perceived they had gained knowledge about breast cancer and coping. The participants expressed that the group helped them to reach out and ask for support and improved family and work relationships. Also, participants rated the group highly for the presence of therapeutic factors. On a scale of 1-4 with 4 being the highest, mean scores ranged from 3.97 to 3.56.

Conclusions—The participants gave high ratings of satisfaction in terms of knowledge gained, leadership style and benefits. The participants perceived that the group increased their knowledge about cancer, improved family connections and increased their ability to deal with their cancer.

Implications for Practice—Utilizing teleconferencing technology to deliver a support group to African American breast cancer patients is a beneficial method to reach a disadvantaged population that may be unable to attend face-to-face groups.

Multiple studies have established the benefits of therapeutic groups (TG) for European American women with breast cancer.¹⁻⁷ However, only one study and anecdotal reports describe the value of TGs for African American women with breast cancer.⁸⁻¹¹ Taylor and colleagues in examining the outcomes of a support group for African American women with cancer reported improved mood and psychological functioning for the women randomized to the intervention arm.¹¹ However, the participants' feedback about the group experience were not evaluated. The telephone has been used extensively to deliver individual support, counseling and education to cancer patients.¹²⁻¹⁶ However, the delivery of group interventions by teleconference for cancer patients is rare.^{17, 18}

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Teleconference groups have similar as well as different benefits from face-to-face groups. Connection and support occur in either format. However, in the teleconference group, the emotional expression and sharing of intimate information is greater due to the facelessness of the group. This advantage outweighs the loss of visual non-verbal cues.¹⁷⁻¹⁹ A teleconference group offers further advantages for rural, isolated or physically impaired individuals. Teleconferences require no travel and less energy expenditure than face-to-face groups. Thus, a patient undergoing treatment and experiencing high fatigue would have less difficulty in attending a teleconference group accessible from home than one at a treatment facility. Surprisingly, despite these advantages, only one report documented participant feedback of a teleconference group.¹⁹ None to date have described a teleconference group for African American women with breast cancer. Given the minimal data on teleconference groups for cancer patients and the absence of data on African American women's feedback of a teleconference group adapted specifically for them, this work is especially warranted.

The purpose of this paper is to describe the format of a teleconference group and to provide a descriptive account of the participants' feedback about the intervention. Obtaining feedback from the participants was the specificity component of the intervention integrity/treatment integrity plan used by the researchers.²⁰ Other strategies used by the researchers but not reported in this paper include a process evaluation.²¹ This group was the intervention arm of a randomized behavioral study conducted exclusively among African American women with breast cancer. This paper discusses the intervention participants' feedback from the first 10 of the 15 waves of the trial. We gathered feedback about therapeutic factors, cancer knowledge, social connection, group structure and group leadership. Therapeutic factors included connection, universality and catharsis. Findings have been reported elsewhere and document that the intervention arm had improved social well-being.²²

Methods

Summary of Teleconference Intervention and Related Procedures

Teleconference Group—Breast Cancer in African Americans also known by the acronym (STORY) was a randomized trial designed to test the effectiveness of a therapeutic group via teleconference for African American women with breast cancer. The study was approved by the Institutional Review Board (IRB). Participant evaluation was part of the original protocol submitted for IRB review. We have previously reported on recruitment procedures and recruitment findings.²³

Patients were excluded if they had been diagnosed with metastatic disease, had a current diagnosis of psychosis, dementia, or major cognitive impairment, had a previous history or current diagnosis of breast or other types of cancer (except basal cell or squamous cell of skin), or were participating in another behavioral clinical trial. Eligibility requirements were as follows; participants were U.S. born, English speaking, African American women older than 21 years who were diagnosed with invasive ductal carcinoma, including medullary, colloid, and tubular subtypes, and whose treatment was, or would be excision biopsy or lumpectomy with adjunctive treatment (radiation and/or chemotherapy).

Patients were consented at a location of their choice (usually their home). The consent allowed for the audio-taping of each therapeutic group session. All consents were read to patients regardless of their reading level to assure consistency and to avoid embarrassment for low literacy.

All participants received a gift card and a small gift for each completed assessment. Such gifts were culturally appropriate and acknowledged the contribution the patient was making

to the study. Inexpensive thank you gifts were provided throughout the duration of the wave to both control and intervention participants.

History and Development of the Intervention

Our initial experience with a teleconference group was a community group for women with cancer.²⁴ The participants in this non-research teleconference group expressed high satisfaction with the convenience of attendance, anonymity, lack of travel and possibility of attendance when fatigue or other side effects made regular group attendance problematic. Based on our clinical experiences with this group we implemented a pilot study but limited it to women with breast cancer. We reported on our pilot study and its evaluation.^{19, 25} The results of the pilot study were instrumental in our receiving funding for the STORY project.

Our pilot study sample was 28 % African American women. We were surprised that this number was quite high in comparison to sample descriptions in other studies of support groups. In fact, many studies did not report race and of four which did, African American women with breast cancer participation comprised less than 10%.²⁶⁻²⁹ With small samples, the actual number of African American women with breast cancer was as low as four of 41 participants.²⁶ After further review of the literature on the needs and experiences of African American women with breast cancer and the minimal evidence about support group benefit we wondered if we should focus exclusively on African American women with breast cancer in a larger study.

Subsequently, we held a focus group of African American professionals most of whom were involved in cancer care. We asked them if the purpose of our study should focus on African American women and we explored the advantages and disadvantages of a group specifically for African American women with breast cancer as a research study. We considered recruitment and health disparities in South Carolina and the lack of scientific knowledge about the benefits of support group participation for these women. During these deliberations, the PI co-founded a community support group for African American women with breast cancer. Clinical experience with this group provided data about the needs of African American women with breast cancer and the issues and problems involved in implementing the group. Further literature review indicated that when African American women with breast cancer participated in support groups, they found them lacking in cultural sensitivity.^{8, 9, 30} We concluded that given the limited knowledge about support groups for African American women with breast cancer and the need to address cultural issues within the group, we should proceed with developing a research plan to study the effectiveness of a therapeutic group by teleconference for African American women with breast cancer. Thus, STORY was born.

Modification of the Intervention for Low Literacy and Cultural Sensitivity

The TG by teleconference intervention was based on our experiences reported above and a group intervention developed by Fawzy and Fawzy³¹ and refined in our pilot study.^{19, 25} The pilot study consisted of six sessions by teleconference. Our evaluation of that intervention and outcomes validated that we needed to increase the number of sessions and include booster sessions. Our findings from the pilot demonstrated a significant improvement in our outcome, mood, at the first post intervention assessment but this was not sustained at the second post intervention assessment (4 months from baseline).²⁵ Also, since we were focusing exclusively on African American women with breast cancer, we knew from our literature review and focus group that the intervention would need significant revisions to assure cultural sensitivity.^{32, 33} For example, Fawzy and Fawzy's material was multi-cultural and its illustrations featured various ethnicities. Also, given our two decades of working with African American cancer patients and their families, we knew that we were

primarily working with individuals with low literacy. Prior to submitting our grant application, we convened both Professional and Patient Advisory Committees to critique major aspects of the intervention. The members of the committees were all African Americans. Based on their feedback, the schedule of the sessions and the session content was modified. The handbook used as an adjunct to sessions was accordingly modified. We describe the handbook modifications below. The investigator incorporated recommendations for changes into the scripted group leader manual used for the intervention.

For the handbook, we followed both overall low literacy guidelines and health literacy guidelines. For health literacy and cultural sensitivity, we used work by Davis and colleague³⁴ and guidelines by Guidry.³² We used references from 2002 to 2004 because of the time of our grant application and the start date of its award. We did not perform readability scores for each section of the handbook; Session One tested as having a readability level of 3.7. Instead of relying on readability scores, we had each section of the handbook reviewed by members of the Professional Advisory Committee and the Patient Advisory Committee. We asked members of these groups to use Guidry's guidelines to evaluate each section for cultural sensitivity and for health literacy. We noted each recommended change and made changes before the handbook was distributed to participants. One modification was the illustrations that accompanied each coping scenario which was a part of each session. The coping scenarios (which we called coping stories) were like a parable with an example of less effective coping followed by an example of more effective coping. They were accompanied by illustrations. Lively debate often ensued over the illustrations. For example, in one illustration the woman is sitting at her kitchen table eating breakfast. The original illustration included a box of cereal. Some members of the Advisory Committee recommended that grits, a traditional Southern food be substituted for the cereal. Others indicated that such a change would present a stereotyped illustration. When disagreement occurred, we sought consensus. In this particular instance, the illustration was narrowed to focus more on the woman's expression than the items on the table.

Intervention Details

The TG by teleconference consisted of 8 weekly sessions and two boosters (at two and four weeks after Session Eight) that were 1½ hours long. The sessions were structured so that didactic content decreased over the eight sessions and emotional support time increased. Each session included story sharing (a prime cultural coping strategy).³⁵ The last two sessions contained no new content and were devoted to story sharing and termination; they were intended to assist in weaning participants away from group support and connecting to family and community.

Sessions—Session One focused on introductions, sharing of personal cancer stories, and instructions about the teleconference. The only content presented was a brief description of three methods of coping (active-behavioral, active-cognitive, and avoidance). Sessions Two through Eight included 15 minutes of introductory story sharing, 15 minutes of information by the group leader, 50 minutes of patient story sharing and discussion of the coping story, and 10 minutes for closure. The information in each session, the coping story discussed, and the emphasis are shown in the Figure, Schedule for Sessions

The sessions were not rigid and static. The three conceptualized active ingredients (information, story, therapeutic factors) were integrated into each session. Information was given on breast cancer, its treatment, side effects, symptom management, and active coping strategies. The coping story was presented like a parable with an example of less effective coping followed by an example of more effective coping. Then participants discussed the

type of coping described in each story and evaluated its effectiveness. They were encouraged to tell how their personal story was the same or different from the coping story.

Group Leadership—The group was led by two experienced African American group therapists/social workers with extensive experience in working with African American cancer patients. In total, five group leaders rotated leadership responsibilities for the ten waves reported in this paper. Group leaders used a scripted manual and process focused group leadership techniques described by Yalom.³⁶ These approaches include reflecting on commonalities, encouraging exploration of concerns, and moderating anxiety.³⁷ To enhance connection, commonality, and catharsis, leaders paid close attention to non-verbal cues such as tone of voice and inflection.²⁴ Leaders especially monitored participants who seemed to drop out of the discussion. To decrease this problem, the leaders used name repetition and checked in with silent members.³⁸ Other than attention to non-verbal cues and monitoring for long silences in members, group leadership techniques were no different than those used in a face-to-face group.

Methods

The Overall Support Group Evaluation Instrument was included in the handbook at the end of session ten. Group leaders read the instructions and the items at the end of the session. Participants were instructed to mail the completed form to the STORY office in self-addressed stamped envelopes included with the notebook.

Measurement

The Overall Support Group Evaluation was to obtain feedback about various aspects of the group experience including therapeutic factors, cancer knowledge, social connection, group structure and group leadership. The form was modified from our pilot study and previous work which established face validity and reliability.^{19, 39} The current form contained 19 items ten of which were Likert-type items that obtained feedback on therapeutic factors within the group. The Cronbach's alpha for the original scale was 0.70. Cronbach's alpha for the current ten Likert items on the scale is 0.83. This level of internal consistency probably reflects the uni-dimensional nature of the therapeutic factors. No psychometric data, other than face validity, are available on the forced choice, multiple choice, and open-ended items. Open-ended items were placed throughout to encourage completion of all pages and avoid response bias on the Likert items.

In developing the evaluation instrument, we primarily followed overall low literacy guidelines since the evaluation instrument did not contain health information but instead evaluated the participants' perceptions of their experiences. We used strategies for developing low literacy materials based on *Guidelines: Writing for adults with limited reading skills*.⁴⁰ These include guidelines in layout, font style and size and use of white space. We also utilized some excellent early work on health literacy, especially in cancer.⁴¹ We previously used these resources for developing a patient handbook for pediatric oncology.⁴²

Using the readability function in Microsoft Word 2007⁴³, the evaluation form is rated as having a Flesch Reading Ease of 77.4 and a Flesch-Kincaid Grade Level of 4.0. According to the Help function in Microsoft Word, the ratings are based on number of syllables in a word and number of words in a sentence. As to reading ease, the higher the score, the more readable the document with desired scores being between 60 or 70. Most readability formulas including those used by Microsoft have limitations which include: they were originally developed to assess children's literature; they do not take into account design and

layout that may enhance or hinder readability and they emphasize quantitative assessment.⁴⁴ For these reasons, we combined the readability assessment in Microsoft Word 2007 with other recommended strategies to increase readability. In addition to assessing readability, we also examined usability by having it evaluated by representative patients and using our clinical and research experiences in program evaluation.⁴⁵⁻⁵¹ Our intent with our evaluation was to make it as readable as possible even though the form was read to participants at the end of the teleconference session. Also, we hoped that this format would encourage return of the surveys. The overall therapeutic group evaluation was obtained at the end of the tenth session.

Results

Participants Attendance and Survey Return

Sixty one patients were randomized to the therapeutic arm of the study in ten replicate sets, Waves 1 through 10. Participants' attendance at the 10 sessions of the ten waves ranged from 20 to 100 percent. The average attendance of all patients was 72.79 percent. Attendance at Session 10 was 72 percent. This attendance was better than our pilot.¹⁹ Of the 46 patients who attended Session 10, 39 returned the survey resulting in a return rate of 84.78 percent. Although acceptable return rates for survey research instruments vary from 50 to 75 %, our rate of almost 85 percent is commendable given the low literacy of our sample. Literacy was not formally assessed but estimated based on 2 decades of clinical work and the known low literacy of South Carolina's population.⁵²

Descriptive statistics are given in Table 1. The mean age of those attending session 10 and returning a survey was 56 (8.68) with a range of 29 to 73 years.

Therapeutic Factors

We wanted to know if the participants perceived that the group process contained the following therapeutic factors as described by Yalom:³⁶ universality, catharsis, imparting information, interpersonal learning, cohesiveness, and instillation of hope. Table 2 details the therapeutic factor being measured, the ten items, and the means of the participants' responses. Overall the participants indicated a high level of agreement that therapeutic factors were present in group sessions (mean ranged from 3.56 to 3.97 with higher score signifying greater agreement. The item least acknowledged to occur in the group was "learning other ways to deal with problems" (mean 3.56). The highest level of agreement about the value of the group was that participants liked "learning from other patients about their feelings" (3.97). Three other items received high ratings: support of group members, sharing with each other, and feeling hopeful about the future when hearing from other people in the group.

Knowledge

Three items ascertained participants perceptions about knowledge gained from participating in group sessions. The mean score of the item, "How much did you learn in the group sessions" was 3.97 with "a lot" being scored as a 4. When asked about the helpfulness of the information presented, the participants' mean score was 3.79 with 4 being the highest possible score. When asked if the participant had noticed if she experienced a change in her level of understanding about breast cancer, 85 % replied positively (33/39).

Changes in Social Connection

Five items measured perceived changes in relationships and coping and if these changes could be attributed to group participation. Sixty-seven percent of the respondents (26/39) noticed that they were better able to reach out to others for help and support. Forty-six

percent (18/39) reported improved family relationships and 44 % (17/39) noted better work relationships. Thirty-three percent (13/39) reported better communication with a spouse/partner.

Open-Ended Questions of Group Value

We were interested in the patient's perceptions about what the best part of the group was and what could be improved. Overwhelmingly, the most favorable aspect of the group was the sharing and the stories as noted by over half the participants (25 of 39). A sample quote was "Each group member listen (ed) to me and the one thing I truly needed was to be able to talk & know some one cared." No common theme emerged from the question, "What could be done to make the group better?" Most people answered with either a "no" or "nothing." Similarly, to the question, "What other needs or concerns do you have that were not discussed?" the majority of the respondents answered none or wrote another comment about the value of the group. Examples of quotes are "I think everything discussed in the group was good and that made me feel good. By listening to the group it helped me learn a lot" and "This handbook, the facilitators and the breast cancer survivors sharing their knowledge and experience have covered all my concerns."

Group Leadership

We evaluated two aspects of group leadership: participant satisfaction and leadership methods used. For the satisfaction item, "How would you rate the group leaders?", the mean score was 3.97 with 4 being "very good." A second item rated perceived helpfulness of group leadership methods. The highest rated strategy was that the group leaders encouraged members to verbalize unexpressed thoughts and feelings (27/39 = 69 %). The second rated strategy was the group leader provided information (24/39 = 62 %). The strategies of offering suggestions and giving examples were less helpful (41% and 26 % respectively). Since the leaders were charged with providing information, we wanted to know if participants felt that they had enough time to discuss their concerns. Thus, we evaluated the balance between group leader and group member discussion. Thirty seven of the 39 participants (95 %) reported that the time spent by members versus leaders was "just right."

Discussion

The majority of the participants attended 7 out of 10 sessions. When considering that these women were still undergoing treatment, that most were still working and caring for families, their ability to attend 7 sessions is remarkable. Further that 75 percent (46 of 61 participants) attended Session 10, supports the feasibility of the intervention. Also, since 39 of those 46 women returned a three-page survey is a testament to their willingness to provide feedback to the researchers.

Since information was one of the three hypothesized active ingredients in the intervention, our evaluation strongly confirmed that the participants perceived that they increased their knowledge about breast cancer and coping. The active ingredients of therapeutic factors and story were theorized to promote better relationships with partner, family and non-kin. The overall evaluation also supported that the patients felt the group helped them to reach out and ask for support and improved relationships. The open-ended questions provided a more personal view into the value of the group for the participants as their own words expressed poignantly the bonding and knowledge they had found. Further research is needed to refine the feedback measurement tool and add additional items to examine therapeutic factors and story. Also, future research should attempt to link outcomes from the teleconference group to participant feedback about the intervention.

Several nursing practice implications emerged from the participants' feedback. Novice teleconference group leaders may be hesitant to stimulate catharsis during the group due to the absence of visual cues to monitor distress. However, emotional expression was clearly valued by participants. Also, nurse group leaders should maintain a balance between leader and member verbalization. Our leaders kept a process log which helped them to “see” group interactions and monitor the discussion. Nurses have long recognized the value of story sharing;⁵³ its value to African American women with breast cancer is re-affirmed by feedback from participants.

Several limitations were present in this type of descriptive account of participants' feedback. The variance in the responses was narrow (3.97 to 3.56). While the return rate was adequate, the responses that were returned may have been from highly satisfied participants. Also, the participants may have rated the group positively due to feelings about other group members and/or the group leader. They may have been reluctant to report negative reactions even though the evaluation form was not given to the group leaders.

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Information and Session	Coping Story	Emphasis
1. Methods of coping	Diagnosis	Sharing personal stories
2. Feelings, Fears, Myths	Feeling Blue	Normalizing reactive depression Positive ways to manage feelings
3. Stress Management Communication	Doctor-Patient Relationships	Overview of stress management Talking with the health care team
4. Family Relationships	Family	Broad perspective on family Family reactions and cancer stigma
5. Treatment	Treatment	Treatment modalities, managing side effects
6. Intimacy & Self Image	Sexuality	Fears about partner abandonment, future relationships
7. Recurrence	Future Planning	Fears about the future
8. Social Network	Returning to Normal	Reactions from co-workers, friends and church members
9. Booster 1	Personal Stories	Building on therapeutic factors - connection, universality, catharsis
10. Booster 2	Personal Stories	Building on therapeutic factors - connection, universality, catharsis

Figure.

Table 1
Demographic Characteristics of the Participants (n=39)

Variable	N (%)
	All intervention participants who attended session 10 and returned survey
Highest Education	
≤ High School	18 (46)
Associate/Bachelors degree	19 (49)
Master's degree	2 (5)
Income	
<\$19,999	10 (27)
\$20,000 - \$49,999	23 (62)
≥ \$50,000	4 (11)
Missing	2
Head of Household	
Yes	24 (62)
No	15 (38)
Currently Employed	
Yes	20 (51)
No	19 (49)
Marital Status	
Married	14 (37)
Not married	24 (63)
Missing	1
Treatment	
Chemotherapy	10 (26)
Radiation	13 (33)
Both	16 (41)

Descriptive Statistics for Questions Evaluating Therapeutic Value of Intervention, STORY from 2004 to 2009.

Table 2

Therapeutic Factor	Item	N	Mean	SD	Range
Interpersonal learning	It was good to learn from other patients about their feelings.	39	3.97	0.16	3-4
Cohesiveness	I felt supported by the group members.	39	3.87	0.34	3-4
Universality	I liked the sharing with other women with breast cancer.	38	3.84	0.37	3-4
Instillation of hope	I felt hopeful about the future when hearing from other people in the group.	39	3.82	0.39	3-4
Interpersonal learning	The group helped me feel better about myself.	39	3.79	0.41	3-4
Interpersonal learning	The group helped me cope with having cancer.	39	3.74	0.44	3-4
Catharsis	I was able to express my feelings	39	3.72	0.45	3-4
Catharsis	I was able to express my concerns in the group.	39	3.72	0.45	3-4
Catharsis	I could share thoughts in the group that I could not share with most people.	38	3.63	0.49	3-4
Interpersonal learning	I learned other ways to deal with problems.	39	3.56	0.55	2-4

Scores range from strong agree (4) to Strong Disagree (1).