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Preliminary Evaluation of Psychoeducational Support Interventions on Quality of Life in Rural Breast Cancer Survivors Post-Primary Treatment

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Abstract

While most cancer survivors are at risk for being lost in the transition from treatment to survivorship, rural breast cancer survivors face special challenges that might place them at particular risk. This small scale preliminary study had two specific aims: (Aim 1) establish the feasibility of rural breast cancer survivors participation in a longitudinal quality of life (QOL) intervention trial; (Aim 2) determine the effects of the BCEI, the Breast Cancer Education Intervention, on overall QOL. Fifty-three rural breast cancer survivors were randomized to either an Experimental (n=27) or a Wait Control arm (n=26). Participants in the Experimental arm received the BCEI consisting of three face-to-face education and support sessions, two face-to-face and three telephone follow-up sessions along with supplemental written and audiotape materials over a six month period. BCEI modules and interventions are organized within a QOL framework. To address the possible effects of attention, Wait Control participants received three face to face sessions and three telephone sessions during the first six months of participation in the study, but not the BCEI intervention. Research questions addressing Aim 1 were: (a) can rural breast cancer survivors be recruited into a longitudinal intervention trial and (b) can their participation be retained. Research questions for Aim 2 were: (a) do participants who received the BCEI show improvement in overall QOL and (b) is the QOL improvement sustained over time. Data were analyzed using repeated measures general linear mixed models. Results demonstrated the ability to recruit and retain 53 rural breast cancer survivors; that the Experimental arm showed improvement in overall QOL ($p=0.013$), and; there were significant differences in overall QOL between the Experimental and Wait Control groups at both month 3 and month 6. Thus, it appears that at least some rural breast cancer survivors can and will participate in a larger trial, will maintain their participation and that those that do participate experience significant QOL benefit.

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Keywords

rural; cancer survivors; breast cancer; quality of life; psychoeducational support interventions

Introduction

Rural breast cancer survivors are an at-risk population of cancer survivors. Unfortunately, they are underrepresented in cancer control research^{1, 2}, have disparities in mammographic screening^{3, 4}, are often diagnosed with late stage disease⁵, receive less than optimal quality treatment^{6–8}, are at risk for poor cancer treatment outcomes^{7, 9–17}, and do not consistently receive survivorship care planning post-treatment¹⁸ -- all of which can lead to poor overall survival^{1, 19}. The Institute of Medicine strongly recommends that all cancer survivors receive a survivorship care plan that provides practical information about post-treatment side effects, cancer surveillance activities, and psychosocial adaptation¹⁸. While breast cancer survivors represent the largest group of cancer survivors² and may have access to post-treatment surveillance and psychoeducational support, few rural breast cancer survivors are able to access these services post-treatment for several reasons. Geographic diversity, transportation challenges, socioeconomic status, and communication difficulties are factors that can greatly limit access to post-treatment survivorship services and increase health disparities among this population^{21–22}. Thus, practical interventions to maintain or improve quality of life (QOL) for rural breast cancer survivors during post-treatment survivorship are urgently needed.

In this paper we report on our attempts to: (Aim 1) establish the feasibility of rural breast cancer survivors participating in a longitudinal intervention trial, and (Aim 2) evaluate the effects of an established and effective psychoeducational support intervention (BCEI) on overall QOL. Research questions addressing Aim 1 were: (a) can rural breast cancer survivors be recruited into a longitudinal intervention trial and (b) can their participation be retained. Research questions addressing Aim 2 were: (a) do participants who received the BCEI show improvement in overall QOL and (b) is the QOL improvement sustained over time. A secondary aim addressed the identification of effect patterns of the BCEI on four QOL domains: psychological, social, physical and spiritual.

Background and Literature Review

This paper is framed within the larger background of *cancer survivor* and *cancer survivorship research*. Briefly, the definition of cancer survivor is based on the National Coalition of Cancer Survivorship (NCCS) definition which states that “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.”²³ Cancer survivorship research is based on the National Cancer Institute (NCI) perspective which “focuses on the health and life of a person with a history of cancer *beyond* the acute diagnosis and treatment phase.” Using the NCI definition, cancer survivorship research studies include the “physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment, and interventions to prevent and control adverse late outcomes such as late effects of treatment, second cancers, and poor quality of life”.²⁰

Using these definitions, the following literature review confines its focus to the needs of rural breast cancer survivors beyond the acute diagnosis and treatment phase, and examines extant literature related to interventions to prevent or control adverse late outcomes and poor QOL. Published reviews that provide the reader with an overarching discussion of breast cancer patients needs during treatment are outside the scope of this paper. The following literature review begins with international and United States-based studies of rural breast cancer survivor

needs and health disparities^{22, 24–30} followed by a discussion of reported interventions specifically directed at addressing rural breast cancer survivors needs.

The majority of studies conducted with rural breast cancer survivors post-treatment are understandably descriptive in nature. These investigations used focus groups, qualitative grounded theory techniques, and telephone surveys to determine post-treatment survivorship concerns. The Canadian Breast Cancer Network conducted focus groups with rural breast cancer survivors to examine their specific post-treatment concerns³⁰. A total of 276 rural breast cancer survivor participants were divided into 17 focus groups. The investigators used a standardized discussion protocol across all focus groups. Results showed the following major themes that were vital to include in post-treatment survivorship planning: information access issues, need for appropriate survivor post-treatment support and services. The findings also reflected rural survivors' numerous unmet needs and barriers in accessing survivorship services. These barriers include: transportation problems, lack of access to health information, lack of support services to deal with isolation, employability concerns, and insurance burden.

In Washington State, Wilson and colleagues also conducted 23 focus groups with 128 rural breast cancer survivors to examine their post-treatment survivorship concerns, and to explore ways to improve survivors' knowledge of breast cancer survivorship²⁹. Rural breast cancer survivors with advanced disease specifically reported feeling poorly treated by the health care system. Regardless of disease stage, rural breast cancer survivors reported the need for more education about survivorship and emotional support after treatment.

In rural North Carolina, Lopez and colleagues²⁸ used qualitative grounded theory technique to explore QOL among a small sample of 13 African American breast cancer survivors post-treatment. Findings indicate several QOL concerns that included: seeking safe sources of support, learning to adjust to the role of cancer survivor, getting comfortable about the future, and becoming a role model for other rural breast cancer survivors. This study is one of the first to report concerns specific to African American breast cancer survivors post-treatment.

Two studies used surveys and telephone methods to further explore post-treatment survivorship needs of women living in rural areas^{31, 32}. In California, Collie and colleagues³¹ recruited 100 breast cancer survivors post-treatment to better understand their personal difficulties in interacting with their health care professionals. The participants completed several scales examining self-efficacy, coping, and difficulties interacting with health care professionals. Using multiple regression analysis, their results showed that survivors having difficulty interacting with medical professionals had the following characteristics: not married, used more behavioral disengagement, had less self distraction, and less self efficacy.

In rural Australian states and territories, Davis and colleagues recruited a random sample of 204 rural breast cancer survivors from cancer registries³². Using a telephone survey, they sought to assess rural women's psychosocial and practical needs after treatment. The investigators found that the majority of survivors indicated satisfaction with the information they received. However, less than half (47%) reported receiving financial assistance to travel for treatment. Less than 30% were provided with specific assistance addressing their rural care needs.

Two intervention studies with rural breast cancer survivors were reported in the literature^{24, 25}. Angell and colleagues reported the development and evaluation of a community-initiated Workbook-Journal called the WBJ that was designed to improve psychosocial functioning. The researchers used a small randomized trial to compare the WBJ intervention plus educational materials to educational materials alone (usual care). One hundred women with primary breast cancer living in seven rural California communities participated in the study. Results showed non-significant results between the two groups. However, trends showed that

74% of rural breast cancer survivors benefited emotionally from receiving the WBJ. The distinguishing feature of this study is that the survivors were a mix between those within 3 months of diagnosis and within three months of completing treatment. Thus, this group of survivors was not technically in post-treatment survivorship. Nevertheless, the focus on rural breast cancer survivors is a distinguishing hallmark, and one of its findings showed high retention of 98% at 3 months follow up.

Belkora et al., evaluated 67 survivors and their satisfaction with a “visit preparation” intervention in two rural counties in California²⁵. The visit preparation intervention consisted of training clinical personnel to help patients make a list of questions to ask their doctors during follow up. Researchers used multivariate ordered logistic regression analysis to examine variations in patient satisfaction. Results showed that participants were highly satisfied with the visit preparation intervention. Variation in satisfaction was associated with breast cancer survivors helping breast cancer patients prepare for the visit with their doctor. Similar to the Angell study, the visit preparation intervention was important because it focused on education and support needs of rural cancer survivors during treatment.

In summary, the literature review included international and United States-based studies of disparities experienced by rural breast cancer survivors. While largely descriptive in nature using focus group, grounded theory techniques, questionnaires, and telephone surveys, these studies demonstrate the lack of access to routine post-treatment survivorship services and support that are aggravated by distance to and from an urban cancer treatment center. Further, international colleagues from Australia and Canada have grappled with providing cancer survivorship services to remote and rural sections of their countries. Only two intervention studies of rural breast cancer survivors were located in the literature. Both studies focused on rural cancer survivors, but neither study had a specific focus on post-treatment survivorship. Finally, extant literature shows that rural breast cancer survivors are an at risk population of survivors for whom routine follow-up information, self care management, and cancer survivorship care planning is sorely lacking.

Conceptual Framework

The conceptual framework that undergirded the study was the Quality of Life Model for Breast Cancer Survivors. The QOL model is grounded in two key assumptions: QOL is a multidimensional construct composed of four domains of well being: Physical, Psychological, Social, and Spiritual; and (2) QOL is defined by the individual³³. The QOL Model for Breast Cancer Survivors has been used in prior studies of breast cancer survivors^{34, 35}. The QOL model serves as the basis for organizing the four major components of the BCEI intervention. In addition, the theoretically-based QOL instrument, directly related to the conceptual framework, was used to measure QOL over time.

Design and Methods

A longitudinal, repeated measures research design was used to answer the specific aims and related research questions. A convenience sample of 53 participants was recruited from either a regional cancer center or private oncology offices in the Southeast region of the United States. Two criteria were used to establish rural residence: (a) US Census Bureau definition of rural residence as living in a census tract with a population density of less than 1000 persons per square mile or (b) a FITA (Florida Index of Treatment Accessibility) score greater than 4.0^{36, 37}. The FITA was developed by the investigators to determine the probable ease or difficulty in accessing treatment or post-treatment support services. The greater the difficulty in accessing cancer treatment and follow up surveillance services, the higher the FITA score. The FITA is based on two sets of factors, (1) population density of the census tract in which a person lives and (2) a travel factor that takes into account the distance and estimated travel

time from a person's home to a specific treatment or support facility that is appropriate to meet their treatment or post treatment support needs. Population density was calculated from United States Census data.

To determine estimated travel time, we used Mapquest. Mapquest's route identification, distance calculation and time estimation technology is widely used by the commercial trucking industry and numerous organizations including the American Automobile Association. The general calculation methodology for the FITA is described more fully in the *Study Measures* section of this paper.

In addition to the rural-residence criterion, cancer survivorship inclusion criteria were: women at least 21 years of age with histologically confirmed Stage 0-II breast cancer; within one year of cancer diagnosis; at least one month post treatment in which to recover from acute side effects of surgery, radiation therapy, or chemotherapy; able to communicate in English. Participants may have been on hormonal therapy (i.e., aromatase inhibitor or tamoxifen) at study entry. The exclusion criterion included presence of advanced, metastatic or recurrent disease at diagnosis or treatment.

Study Protocol and Procedures

The investigators received approval by the respective Institutional Review Boards (IRBs) of the university and participating cancer centers. Cancer center research staff identified potential subjects using a Study Eligibility Checklist. The research staff briefly explained the study and elicited eligible subjects' interest in participation. Breast cancer survivors expressing interest signed the preliminary consent form giving permission to have their names, telephone numbers, and addresses released to the BCEI research study office. Upon receipt of the consent, the Project Director called potential subjects and explained the study objectives, time commitment, and addressed concerns and questions. Subjects who agreed to participate gave in-person written informed consent that was consistent with university, cancer center, and federal policies prior to study entry. After subjects completed baseline measures, they were randomly assigned to either the Experimental or Wait Control arm. Randomization was accomplished by selecting pairs of participants in the chronological order that they completed baseline. Using a random number table, each member of the pair was assigned a random number. This number was used to determine the member of each pair that was assigned to the Experimental arm and the member that was assigned to the Wait Control arm.

Components of the BCEI Psychoeducational Support Intervention

The BCEI is an established and effective psychoeducational support intervention designed specifically for breast cancer survivors during post-treatment survivorship³⁴. The monthly sequence of the BCEI intervention components is depicted in Figure 2. The BCEI consists of three Education and Support (Ed-S) sessions delivered face-to-face by an Intervention Nurse, five follow-up education and support sessions (FU Ed-S) [i.e., 3 telephone and 2 face to face] and reinforced with written and audiotape materials. The three face to face Ed-S sessions spanned 60–90 minutes. Participants assigned to the Experimental arm received the BCEI intervention within the first month of study enrollment. Participants assigned to the Wait Control arm received an initial face to face attention control session, three telephone calls and two face to face attention checks. The attention control consisted of contacting the participants, checking in with them about how they were doing, and engaging their continued interest to participate. Wait Control participants differed from usual care in that they received monthly check in telephone calls or visits from the research team. Standard usual care consists of a three to six month follow up visit with the oncology team.

The three face to face Education and Support sessions focused on common issues facing breast cancer survivors. The sessions were organized around a QOL framework and the specific content of each session was derived from the BCEI ³⁴. The BCEI intervention is not directed toward specific symptom reduction and management. Rather, the BCEI intervention is directed toward educating and supporting breast cancer survivors to better understand common symptoms as they influence QOL. Thus, the outcome measures were largely QOL rather than specific to lymphedema, pain, fatigue, or menopausal symptoms.

The specific components and details of the BCEI intervention components are listed on Table 1. For example, *Session #1* focused on physical well being education related to pain, lymphedema and cancer-related fatigue. The Intervention Nurse explained ways to prevent or manage these common treatment-related side effects. *Session #2* focused on psychological and social well-being education about common menopausal symptoms experienced after breast cancer and ways to maintain health. The Emotions component highlighted the most frequent psychological late effects during breast cancer survivorship including mood swings, cognitive changes, psychosocial distress and problematic areas such as anxiety and depression, and fear of recurrence. A discussion about family and social relationships; work, financial, and insurance concerns were covered in this session. The Intervention Nurse explained ways to promote healthy lifestyle behaviors such as increased physical activity, improving nutrition and diet, and managing cancer surveillance activities (e.g, mammograms, osteoporosis screening and treatment). *Session #3* focused on spiritual well-being education. This session covered spiritual changes in survivorship such as hope, uncertainty and meaning in illness. Follow up Education and Support sessions lasted about 30 minutes each and were designed to evaluate the participants' learning and provide reinforcement for education and support.

Supplemental material included the BCEI Education Binder which consisted of written material to reinforce the Education and Support sessions. Thirty-eight Tip Sheets were included and were short 1–3 page tips on ways to manage the concern or problem. Audiotapes supplemented the Education and Support sessions to help reinforce learning.

Intervention Fidelity

Several strategies were used to train the research staff and to maintain intervention fidelity. First, the entire research team received didactic training in rural care, rural cancer survivor needs, and cultural sensitivity to rural issues. Second, the Intervention Nurses participated in mock intervention and follow up sessions to better understand and increase skills in consistent delivery of the intervention. Third, the Intervention Nurses tape-recorded all Education-Running Support sessions. The Principal Investigator reviewed a random sample of 20 percent of these sessions using a quality assurance monitoring checklist. This checklist was used to monitor the quality and ensure consistency of the intervention, provided a summed intervention fidelity score, and was used as the basis for inter-rater reliability checks. Intervention fidelity scores below expectation were reviewed with the Intervention Nurse and modifications were made as needed. Finally, the research team discussed formative process evaluation to examine intervention delivery and fidelity issues and challenges on a monthly basis during team meetings.

Study Measures

One study measure, the FITA, was used as a screening tool to determine rural residence. Two study measures were used to gather the data: (1) the Breast Cancer Treatment and Sociodemographic Data Tool (BCTSDT); and (2) the Quality of Life-Breast Cancer Tool (QOL-BC). The BCTSDT and QOL-BC data were collected at Time-1 (Baseline), Time-2 (three months after study entry), and Time-3 (six months after study entry).

FITA Scale—FITA (Florida Index for Treatment Accessibility) is a scale that determines the probable ease or difficulty in accessing treatment³⁷. The greater the difficulty in accessing cancer treatment and follow up surveillance services, the higher the FITA score. FITA is based on two factors: travel time and population density. FITA score was calculated by dividing (distance × adjusted travel factor) by an adjusted population density factor. FITA scores greater than 4 were used as criteria to determine rural inclusion. As previously suggested, the FITA is based on United States Census data and utilization of Mapquest technology; a technology relied on by a wide range of users from the commercial trucking industry to the Automobile Association of America.

Breast Cancer Treatment and Sociodemographic Data Tool—This descriptive tool consists of 32 items that captures breast cancer treatment variables (i.e., surgery, radiation therapy, chemotherapy, hormonal, and anti-HER2 therapy) and sociodemographic characteristics (e.g., age, race, ethnicity, education, marital status, employment status, telephone and communication patterns, family income, etc). Where significant differences in treatment and/or sociodemographic data were identified, the variables were treated as covariates in the analysis. These variables are identified in the Results section.

Quality of Life –Breast Cancer Survivors (QOL-BC)—The QOL-BC is a 50 item, 10 point ordinal scale that measures overall QOL and four individual QOL domains of physical, psychological, social, and spiritual well being. This tool was adapted from the QOL-Cancer Survivors Scale^{35, 38}. Test-retest reliability was 0.89 and Cronbach's alpha was 0.93; both scores were established using the original QOL-CS. In the present study, alpha coefficients for overall QOL and domain scores were as follows: Overall QOL = 0.91; Physical well-being = 0.99; Psychological well-being = 0.96; Social well-being = 0.84; and Spiritual well-being = 0.85.

Each QOL item is rated on a 10 point scale asking participants to rate their QOL from 0 (= no problem) to 10 (= worst problem). Thus, a lower score closer to 0 reflected fewer problems and higher QOL; while a higher score reflected more problems and lower QOL.

Data Analysis

The endpoint variable of primary interest was the overall QOL score. Secondary outcomes of interest were the four QOL domain scores - Physical, Psychological, Social, and Spiritual well-being. The analysis was based on data collected at three time points – Time-1 (Baseline), Time-2 (three months after study entry) and Time-3 (six months after study entry). Data were entered using SPSS-version-12³⁹. Statistical analysis was conducted using SAS v. 9.2⁴⁰. The longitudinal analysis was conducted using repeated measures general linear mixed models⁴¹. Linear mixed methods allow for modeling the correlation of the repeated observations on the same subjects.

Results

The results are presented in the following order: demographic results followed by the results of the specific aims and the related research questions. Demographic results showed the following: Fifty-three breast cancer survivors whose rural status was determined by the census criteria and FITA scores participated in the research study. Twenty-seven participants were randomly assigned to the Experimental arm, and 26 were assigned to the Wait Control arm. Figure 1 illustrates the CONSORT diagram of participation over time.

The participants' mean age was 53.58 years (SD: 11.55); 94.3% were Caucasian, 3.8% were African-American, and 1.9% were Hispanic or Latina. English was the primary language for

98.1% of the subjects while Spanish was the primary language for 1.9%. Nearly 25% had some high school education and 51% had some college education. Seventy-eight percent were married or living with a partner; the remaining 21.8% were single, divorced or widowed. Sixty-two percent of subjects were employed full or part time with 40% of subjects having annual family incomes of less than \$50,000. Over 90% did not receive counseling or participate in cancer support groups. There were no significant differences in demographic characteristics between the Experimental and Wait Control arms.

All rural participants resided within a four-county region of the Southeastern United States in Central Florida. Each participant resided in a Florida-designated urban county that contained rural pockets of sparsely populated areas of less than 1000 persons per square mile. It was in these rural pockets within a designated urban county where the rural participants resided. Participants had early stage I or II disease. All rural participants completed primary breast cancer treatment and were within 8 months of their initial breast cancer diagnosis. Participants eagerly agreed to participate in the research study. None developed recurrence during study participation.

Treatment-related variables indicated 50.9% of subjects had Stage I and 49.1% had Stage II disease. The average time since diagnosis was 8.6 months (std. dev. = 2.7). Over 51% had breast conserving surgery; 34% and 15% had single and bilateral mastectomy, respectively. Over 60% received primary or post-operative radiation therapy. Sixty-two percent received adjuvant chemotherapy. Over 64.2% received hormonal therapy with either tamoxifen or an aromatase inhibitor. Table 2 compares the demographic and treatment variables between EX and WC arms. Cancer treatment variables of stage of disease ($p=.02$) and radiation therapy ($p=.01$) showed significant difference between the groups, and were included as covariates in the longitudinal models.

Feasibility of the BCEI Intervention with Rural Breast Cancer Survivors Post Treatment

Aim #1 was to establish the feasibility of participation of rural breast cancer survivors in the BCEI, a longitudinal quality of life (QOL) intervention trial. Research questions addressing Aim 1 were a descriptive evaluation to answer the following: (a) can rural breast cancer survivors be recruited into the BCEI and, (b) can their participation be retained in the study over time.

First, 53 of the estimated 69 rural participants who were approached with details about the study eventually enrolled as research participants. They were informed that the BCEI study focused on interventions designed to decrease common post-treatment problems and maintain or improve QOL after treatment ended. They were also informed that the BCEI Intervention was not specifically designed for rural breast cancer survivors, per se, but that the information could benefit them regardless of their rural residence. Thus, the BCEI was of interest to the majority of rural breast cancer survivors and they were able to participate. Second, none of the 53 rural participants dropped out of the study. There was a remarkable 100% retention. We were able to obtain complete data at each of the three data collection time points.

Effect of the BCEI Intervention on Overall QOL

Aim #2 was to determine the effects of the BCEI on overall QOL. The first research question for Aim #2 was: (a) do participants who received the BCEI show improvement in overall QOL. Longitudinal analyses were conducted to test whether the BCEI intervention resulted in a significant improvement in QOL. Table 3 displays the summary statistics for the QOL scores by time and treatment arm. Figure 3 illustrates the plot of the average overall QOL scores over time from baseline to month 3 and month 6. The reader will note that *the lower the QOL score, the fewer the problems and thus, the higher the reported QOL*. It is also important to note

that changes from Baseline to Time-2 and Baseline to Time-3 are modeled. Thus, in this particular case the intervention effect estimates are the mean group differences in change at Time-2 and at Time-3. Even though an analysis for an interaction between Time-2 and Time-3 was included, no time-effects between Time-2 and Time-3 were identified.

First we examined whether there were any baseline QOL differences between participants in the two treatment arms. Results showed that, at baseline, the Experimental arm reported better overall mean QOL and better QOL domain scores across physical, psychological, social and spiritual well being compared with the Wait Control arm. Hence, the longitudinal models used for the analysis controlled for baseline scores and other covariates (i.e., stage of disease and radiation therapy) that differed significantly between the groups at baseline.

Despite the small sample size, we were able to establish a significant effect of the BCEI intervention on overall QOL which was the main outcome of interest. The longitudinal models showed a significant improvement in mean overall QOL score in the Experimental arm compared to the Wait Control arm over time, adjusting for baseline. The adjusted difference in mean overall QOL scores between Experimental and Control arms at follow-up (from month 3 to month 6) was estimated at -0.429 (S.E.=0.18, $p=0.013$).

For the secondary outcomes of interest, the longitudinal models showed a significant improvement in mean Psychological QOL score for the Experimental arm compared to the Wait Control arm over time, adjusting for baseline. The adjusted difference in mean Psychological QOL scores between Experimental and Wait Control arms at follow-up was estimated at -0.545 (S.E.=0.26, $p=0.048$). Table 4 summarizes the estimated effects of the BCEI intervention on changes from baseline to month 6 in overall QOL score and for each of the four well-being domain scores. Figure 4 illustrates the plots of average QOL scores for each of the four domains of well-being: Physical, Psychological, Social and Spiritual. Although the intervention effect estimates for the other three Physical, Social and Spiritual QOL scores showed benefit, the small sample size might not have had enough statistical power to detect significance in these three particular well-being domains.

Sustainability of the QOL Intervention Effect over Time

The second research question for Aim #2 examined whether the overall QOL improvement was sustained over time. In the longitudinal models used for analyzing the main and secondary outcomes, we tested the overall effect of time on QOL scores, in order to assess whether QOL scores changed from month 3 to month 6 and thus determine whether the beneficial effects of the BCEI intervention were maintained over time. We also tested a time by treatment interaction in order to assess whether changes in QOL scores from month 3 to month 6 were different across treatment arms. The initial models were adjusted for baseline scores, time, time*intervention and two covariates that showed significant difference between the treatment arms at baseline (i.e., stage of cancer and radiation therapy). Time, time* intervention were not significant in any of the models, indicating that there was no significant change in overall QOL and Psychological QOL scores from month-3 to month 6. Hence, the models showed that the beneficial effect of the BCEI intervention on overall QOL and Psychological QOL score was maintained over time.

Discussion

The feasibility of rural breast cancer survivors participating in intervention trials such as the one described herein was established by the reality that we were able to recruit 53 rural participants who were able to drive as much as 50 miles to participate. Perhaps an even more impressive indication of these women's desires and probable needs lies in the fact that there were no dropouts in either the Experimental or Wait Control arms. One might question why

there were no dropouts; particularly in the Wait Control group. While the data do not allow confirmation of our speculation regarding complete participant retention, our thinking has drawn us to two major assumptions regarding retention.

First, it is possible that women who live in rural areas and participated in the study perceived substantial benefit for being able to actually access post-treatment support. The second speculation builds on our first assumption and is specific to the Wait Control group. If rural participants perceived substantial benefit, the fact that the Wait Control participants were being contacted throughout the first six months of their participation and knew that they would be receiving the BCEI Intervention at month 6 might have increased their continued participation for the duration of the study.

In spite of the small sample of this rural sample, the effectiveness of the BCEI in improving overall QOL was established. It is particularly interesting that the small sample did not prevent establishing a statistically significant effect for Psychological well-being, one of the four QOL domains and secondary measures ($p=0.048$).

While not statistically significant at the 0.05 level, the BCEI intervention effects on the other three QOL domains also showed a trend toward benefit. Thus, it is likely that the significant favorable effect of the BCEI intervention on overall QOL scores ($p=0.013$) resulted from aggregating the favorable effects on each of the four domains. Obviously, a significant effect in one or more of these domains might be observed in a larger sample.

The BCEI Intervention effect on overall QOL was maintained over time in the Experimental arm. Likely, the 100% study participation with complete data across the 3 time points and no participant attrition helped to determine the sustainability of the intervention effect. Since our rural breast cancer survivors were able to maintain participation over time, they received the specified intervention dose of 60 minutes per Ed-S session, and 30 minutes for each follow up session. With the close monitoring of intervention fidelity and discussion at research team meetings, the intervention was consistently delivered.

As with most preliminary studies, several **limitations** should be noted. As might be expected, some results that are suggestive but inconclusive exist. While participants in the Wait Control were contacted for data collection and in an attempt to partially control for attention, it is not possible to determine whether these participant sought information elsewhere. A richer understanding of the activities of Wait Control participants prior to receiving the intervention would address this potential limitation. Even though the participants lived in rural areas and experienced additional travel challenges, they agreed to participate in this study which required face-to-face contact. However, other women reported that they would not participate because of travel and time commitment considerations. Thus, the face-to-face intervention may be an impractical and cost-prohibitive intervention for some rural dwelling women. Other alternatives for reaching these women should be explored. Finally, participants were largely Caucasian survivors. Future research should address issues of racial and ethnic diversity. Thus, while limitations exist, they do not detract from the fundamental finding: regardless of where they live, if breast cancer survivors receive the BCEI post-treatment service, it has a beneficial effect on their quality of life.

Ideally, interventions are best when specifically tailored to differential groups (i.e., rural versus urban). Yet, our findings demonstrated that rural breast cancer survivors, regardless of residence, can and do participate in a longitudinal intervention study aimed at breast cancer survivors, in general. Our research observations showed that rural breast cancer survivors consistently engaged in the study and expressed desire to participate in research that may benefit future rural breast cancer survivor. With so few studies of rural breast cancer survivor

interventions reported in the literature, these findings have practical application for future research.

Implications for Cancer Nursing Research and Practice

Several implications for cancer nursing research and practice become evident. First, rural breast cancer survivors can derive benefit from psychoeducational support interventions during post-treatment survivorship. Given our experience with 100% participation and complete data at all measurement time points, our data suggest that rural breast cancer survivors are able to receive information to help them maintain or improve QOL during post treatment survivorship.

Second, research with rural cancer survivors is somewhat limited, and fewer studies specifically focus on QOL issues in this population. While the BCEI interventions were not specifically tailored to rural needs, future researchers may target communication and support disparities and other specific needs of this population so tailored interventions can address currently unknown concerns in post-treatment survivorship.

Third, the fact that there was no attrition in either group may be an important finding. A possible implication is that rural survivors perceive substantial need for post-treatment support services. Thus, future studies addressing the possibility of differentials between rural and urban survivors are warranted.

And finally, while the results of this study are promising, they are also limiting. The practicalities of using the face-to-face components of the six-month intervention package may limit the broader application to larger numbers of rural breast cancer survivors. Both cost considerations of face-to-face support and management complexity of maintaining such a system has prompted us to consider the use of delivery systems that might not require extensive travel and face-to-face support. Thus, the use of alternative modes to deliver interventions such as telephone⁴², computer⁴³ and audio conferencing⁴⁴, and internet^{45–46} must be considered.

There is preliminary evidence that such approaches might show promise. Most recently, Jefford and colleagues in Australia developed their evidence-based DVD containing information about experiences of cancer survivors⁴⁷. They used focus groups with cancer survivors and health professionals to establish the DVD content. The product was a 52-min DVD with nine chapters featuring cancer survivors and health professionals. The DVD can serve as a useful resource for other cancer survivors in rural parts of Australia.

Future research may also include proximal measures of the intervention since the current measures did not allow for evaluation of the specific mechanisms of action (e.g., pain, anxiety, etc.)

Clinical Implications

Findings suggest the greater opportunity to develop, implement and examine the effectiveness of survivorship care planning for rural cancer survivors in the future. A formal survivorship care plan based on IOM recommendations that details information about late side effects, health maintenance and cancer surveillance is essential for rural survivors who may not be able to readily access their primary oncologist and healthcare team.

The many limitations and barriers that rural cancer survivors encounter once they leave urban-based cancer treatment centers is largely under recognized. Nurses can help ensure that their rural patients have the resources and education to manage potential symptoms at home where oncology-specific care may be lacking. Nurses who practice in rural settings who see breast

cancer survivors post-treatment can become more knowledgeable about survivorship care plans and cancer surveillance procedures. Innovative collaboration among oncology providers is crucial to meeting needs, managing side effects and maximizing quality of life in cancer survivorship.

Summary

In summary, we reported preliminary evidence of a longitudinal psychoeducational support intervention on overall QOL outcome in a small sample of rural breast cancer survivors during post-treatment survivorship. Rural breast cancer survivors may be at particular risk of not receiving beneficial post-treatment support services. The present study not only demonstrated the feasibility of participating in longitudinal post-treatment intervention trials, but also documented beneficial effects of the BCEI in improving QOL. Developing and validating more cost-effective delivery systems will ideally result in the provision of a conduit through the barriers that rural survivors face to access services. The validation of delivery systems remains an important focus for future research.

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Figure 1.
Intervention schema. Copyright: Meneses K, 2009.

BCEI Intervention Schema

Figure 2.
CONSORT diagram of the preliminary trial.

Figure 3.

Average overall QOL scores over time for experimental and wait-control groups. Lower scores indicate fewer problems and higher QOL; higher scores indicate more problems and poorer QOL.

Figure 4.

Average QOL scores over time for QOL domains. Lower scores indicate fewer problems and higher QOL; higher scores indicate more problems and poorer QOL.

Table 1

Components of the Rural BCEI Psychoeducational Support Intervention

Psychoeducational Support Session	Content	Range of Time
Session #1 Physical Well being Pain Lymphedema Cancer-Related Fatigue	<ul style="list-style-type: none"> General introduction about the purpose of the intervention Elicit participant's willingness to participate & answer questions Teach about common physical side effects (i.e., pain, lymphedema, and cancer-related fatigue) Help participant to develop skills to self-assess and communicate QOL problems Discuss range of interventions to manage these problems Select appropriate interventions and TIPS Review skill building management techniques Reinforce Teaching Material and intervention audiotapes Schedule Session #2 	<ul style="list-style-type: none"> 30 min 05 min 05 min 05 min 05min 05 min 05 min
		Total: 60 min
Session #2 Psychological and Social Well being Menopausal Symptoms Emotions Family, financial and social relationships Health Maintenance	<ul style="list-style-type: none"> Review Session #1 and questions about pain and fatigue & elicit participant's willingness to continue in the research study Teach about common menopausal symptoms (e.g., hot flashes, sleep problems, sexual function, fertility) Teach about common emotional changes post-treatment (e.g., mood swings, cognitive changes, anxiety, depression, fear of recurrence) Discuss social, family and work relationship changes Discuss range of interventions to manage these problems Select appropriate interventions and TIPS Reinforce Teaching Material and intervention audiotapes Schedule Session #3 	<ul style="list-style-type: none"> 05 min 15 min 15 min 10 min 05 min 05 min 05 min
		Total: 60 min.
Session #3 Spiritual Well being Hope Meaning in illness Uncertainty over the future Spirituality	<ul style="list-style-type: none"> Review Session #2 and questions about pain and fatigue & elicit participant's willingness to continue in the research study Teach about common holistic changes in soul and body (e.g., hope, meaning in illness, uncertainty over the future, spirituality) Discuss range of interventions to manage these concerns Select appropriate interventions and TIPS Reinforce Teaching Material and intervention audiotapes Thank participant for time over past 3 sessions and describe follow up intervention and support sessions 	<ul style="list-style-type: none"> 05 min 30 min 10 min 05 min 05 min 05 min
		Total: 60 min.

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Table 2
Demographic and Cancer Treatment Characteristics of Rural Study Participants (N=53)

Characteristic	Control (n=26)		Intervention (n=27)		p-value*
	n	%	n	%	
Demographic					
Age, years					
28–35	2	7.7	1	3.7	0.15 ^a
36–45	7	26.9	4	14.8	
45–55	10	38.5	9	33.3	
55–65	3	11.5	8	29.7	
65–80	4	15.4	5	18.5	
Race					
African American	1	3.8	1	3.7	0.99
Caucasian	25	96.2	25	92.6	
Hispanic/Latina	0	0.0	1	3.7	
Primary language at home					
English	26	100.0	26	96.3	0.99
Spanish	0	0.0	1	3.7	
Education					
High School or less	7	26.9	12	44.4	0.18 ^b
At least some college	19	73.1	15	55.6	
Marital status					
Never married	2	7.7	1	3.7	0.36
Married	17	65.4	23	85.2	
Living with partner	1	3.8	0	0.0	
Divorced, widowed	6	23.1	3	11.1	
Employment status					
Full-time	13	50.0	12	44.5	0.65
Part-time	4	15.4	4	14.8	
Retired	8	30.8	7	25.9	
Homemaker	1	3.8	4	14.8	
Family income					
					0.64 ^b

Characteristic	Control (n=26)		Intervention (n=27)		p-value [*]
	n	%	n	%	
≤50,000	9	36.0	11	42.3	
>50,000	16	64.0	15	57.7	
Support services					
Groups or counseling	2	7.7	3	11.1	0.99
None	24	92.3	24	88.9	
Treatment					
Cancer stage					
I	9	34.6	18	66.7	0.02 ^b
II	17	65.4	9	33.3	
Surgery					
Lumpectomy	9	34.6	18	66.7	
Mastectomy	11	42.3	7	25.9	0.06
Bilateral mastectomy	6	23.1	2	7.4	
Radiation therapy					
Received	11	42.3	21	77.8	0.01 ^b
None	15	57.7	6	22.2	
Chemotherapy					
Received	19	73.1	14	51.2	0.11 ^b
None	7	26.9	13	48.2	
Hormonal therapy					
Received	18	62.9	16	59.3	0.44 ^b
None	8	30.1	11	40.7	

^{*} Fisher's exact test unless otherwise noted.

^a Cochran Mantel Haenszel Row Mean Scores test.

^b Chi-Square test.

Table 3
Summary Statistics for QOL Scores* Between Experimental and Wait Control Arms

QOL Domain	Baseline				Month 3				Month 6			
	Control	Mean	Std. dev.	Intervention	Control	Mean	Std. dev.	Intervention	Control	Mean	Std. dev.	Intervention
Overall QOL	3.35	1.63	1.14	3.10	3.36	1.72	1.03	2.74	3.17	1.44	1.01	2.77
Physical	1.89	1.64	1.77	1.03	1.99	1.59	0.97	1.81	1.96	1.29	0.80	1.52
Psychological	3.91	2.02	3.73	1.64	4.01	2.21	1.48	3.28	3.67	1.81	1.49	3.39
Social	3.46	2.05	3.27	1.27	2.85	1.93	1.44	2.40	2.88	1.80	1.22	2.49
Spiritual	4.03	2.12	3.24	1.93	4.33	2.06	2.01	3.11	4.13	1.84	2.04	3.37

* PLEASE NOTE:

Lower scores reflect higher QOL; higher scores reflect lower QOL.

Table 4Intervention Effect Estimates ^a on QOL Scores

QOL Domain	Intervention effect	
	Estimate ^b	p-value
Overall QOL	-0.429	0.013
Physical	-0.315	0.088
Psychological	-0.545	0.048
Social	-0.359	0.223
Spiritual	-0.432	0.139

^a Estimates from repeated measures general linear mixed models. Initial models were adjusted for baseline score, time, time*intervention and covariates: cancer stage, and radiation therapy. Time and time*intervention were not significant in any of the models. Final models included baseline score, intervention, and significant covariates.

^b Estimates <0 indicate an improvement in QOL scores

PLEASE NOTE: Lower scores reflect higher QOL. Higher scores reflect lower QOL.