



A Community-Based Exercise and Support Group Program Improves Quality of Life in African-American Breast Cancer Survivors: A Quantitative and Qualitative Analysis

Nora L. Nock^{1,4,*,#}, Cynthia Owusu^{2,4,#}, Susan Flocke^{1,3,4}, Susan A. Krejci⁴, Emily L. Kullman⁵, Kris Austin⁶, Beth Bennett⁶, Stephen Cerne⁶, Carl Harmon⁶, Halle Moore⁷, Mary Vargo⁸, Paul Hergenroeder⁹, Hermione Malone³, Michael Rocco¹⁰, Russell Tracy¹¹, Hillard M. Lazarus^{2,4}, John P. Kirwan⁵, Ellen Heyman⁶ and Nathan A. Berger^{2,4}

¹Department of Epidemiology and Biostatistics, Case Western Reserve University, USA

²Medicine, Case Western Reserve University, USA

³Family Medicine and Community Health, Case Western Reserve University, USA

⁴Case Comprehensive Cancer Center, University Hospitals Case Medical Center, USA

⁵Department of Pathobiology, Cleveland Clinic, USA

⁶The Gathering Place, Beachwood, OH, USA

⁷Solid Tumor Oncology, Cleveland Clinic, USA

⁸Department of Physical Medicine and Rehabilitation, MetroHealth Medical Center, USA

⁹Oncology, MetroHealth Medical Center, USA

¹⁰Cardiovascular Medicine, Cleveland Clinic, USA

¹¹Department of Pathology and Biochemistry, University of Vermont, USA

*Corresponding author: Nora L. Nock, Associate Professor, Department of Epidemiology and Biostatistics, Case Western Reserve University, 2103 Cornell Road, Cleveland OH 44106-7281, USA, Tel: 1-216-368-5653, E-mail: nln@case.edu

#Co-first authors

Abstract

African-American (AA) breast cancer (BCa) survivors have higher mortality rates, more comorbidities and are less likely to meet national physical activity guidelines after diagnosis compared to Caucasian BCa survivors. We previously reported that a 20-week resistance exercise intervention coupled with a support group and home walking program, conducted using facilities and personnel at a community cancer support center, in Stage I-III AA BCa survivors improved strength, fitness and circulating C-peptide levels. Here, we report our findings on changes in quality of life (QoL) and other behavioral measures associated with this 20-week intervention and, discuss findings from a qualitative analysis of semi-structured patient interviews. We found a clinically relevant improvement in QoL using the Functional Assessment of Cancer Therapy for Breast Cancer (FACT-B) (Baseline, B: 101.1 ± 21.5; End-of-Intervention, EOI: 108.5 ± 21.6; p = 0.05) and, a significant decrease in depression using the Beck Depression Inventory-II (B: 11.9 ± 8.1; EOI: 9.0 ± 5.5; p = 0.03). Our analysis of the patient interviews support improvements in these behavioral measures in

that participants stated that they “feel better”, were “more motivated” and “uplifted” after the program. The patient interviews also provided insights to the primary motivators (e.g., social support, improvements in strength and function, weight loss) and barriers (e.g., family and health issues) in adhering to the program and provided suggestions for improving the program (e.g., incorporating nutritional and treatment related side-effect discussions). Our results suggest that community-based lifestyle interventions may improve QoL and depression in AA BCa survivors and lend insights for improving future programs.

Keywords

Breast cancer, African-American, Lifestyle program, Community-based

Introduction

We previously evaluated the feasibility of conducting a group-based, resistance exercise intervention coupled with a support group

and home walking program at a community cancer support center in African-American breast cancer (BCa) survivors [1]. We found that the community-based program was feasible and resulted in statistically significant changes in body composition and circulating biomarkers in women who attended 70 percent or more of the exercise sessions [1].

BCa is the most common non-skin cancer among women in the U.S., accounting for 29 percent of all new cancer cases annually and, is the second leading cause of cancer death in women [2]. African-American BCa patients, compared to non-Hispanic Whites, have a poorer prognosis when diagnosed at a similar age and stage [3]. Locally, in Northeast Ohio, the mortality rates of BCa in African-American women are also greater than those observed in Caucasian women and, incidence and mortality rates in both ethnic groups exceed the national averages [4].

The reasons for this racial disparity in BCa mortality rates are not completely known but may include socioeconomic status, differential access to health care and, potentially, disease-related molecular mechanistic differences [5]. In addition, behavioral risk factors such as poor diet and physical inactivity can lead to more weight gain in African-American BCa survivors [6] and, hence, may play a role in the poorer survival observed in African-American women. African-American BCa survivors are also known to have higher rates of obesity, especially in long term survivors [7], and higher rates of related comorbid conditions including cardiovascular disease [8], even in younger women [9], compared to Caucasian women with BCa. The Carolina Breast Cancer study found that African-American, compared to Caucasian women, are significantly less likely to meet national physical activity guidelines after diagnosis [10] and, the Sisters Network Inc. suggests that only 47% of African-American BCa survivors may be meeting these physical activity guidelines. Furthermore, in a recent evaluation of Northeast Ohio BCa survivors, we found steeper declines in physical activity levels after completing high school in African-American compared to Caucasian women and that only 12.3% percent of African-American BCa survivors were meeting exercise guidelines [11].

Overall quality of life in BCa survivors has been shown to be improved with aerobic and/or resistance exercise training programs [12,13]. However, most of the evidence comes from randomized controlled trials (RCTs) that have been conducted in predominantly Caucasian populations and hospital- and clinic-based settings. Overall, there is a paucity of literature on the evaluation of exercise and lifestyle programs targeting African-American BCa survivors on outcomes such as quality of life and on the particular setting and delivery preferences of exercise and nutritional programs in African-American BCa survivors. A few reports suggest that African-American BCa survivors may prefer community-based, culturally-sensitive and socio-ecologically informed programs [6,14,15]. Furthermore, a recent evaluation in the Sisters Network Inc. found that email or web-based delivery of lifestyle programs may be acceptable to African-American BCa survivors [16].

Therefore, as mentioned above, we evaluated the feasibility of a group-based resistance exercise intervention coupled with a support group and home walking program at a community cancer support center (The Gathering Place, Beachwood, Ohio) in a local population of African-American BCa survivors. We have previously reported on the feasibility of the program and on changes in strength, fitness, body composition and cancer-related circulating biomarkers [1]. The goal of this evaluation was to determine if conducting the 20-week exercise and support group program in African-American BCa survivors could improve quality of life and other behavioral measures and, to elucidate the motivations, barriers and potential improvements to the program using semi-structured participant interviews. We hypothesized that the program would lead to improvements in quality of life and anticipated that qualitative analysis of the participant interviews would lend insights to motivations, barriers and potential improvements to the intervention to enhance adherence in future programs.

Materials and Methods

Study population and intervention procedures

We previously reported the study design and intervention procedures of this trial [1]. Briefly, patients were African-American BCa survivors, 18 years of age and older, who were within 12 months of completing treatment (surgery, chemotherapy and/or breast irradiation) for Stage I-III disease at University Hospitals Case Medical Center, Cleveland Clinic, or MetroHealth Medical Center, which are all located in Cleveland, Ohio. All participants included in this study provided informed written consent and all study protocols and procedures were approved by the Institutional Review Board of University Hospitals. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Between August, 2011 and February, 2012, 35 patients who were deemed potentially eligible by collaborating oncologists were approached and informed about the study requirements by the referring oncologist. Nineteen patients were fully eligible and consented to the trial.

The trial was a single-arm, 20-week exercise and support group intervention conducted in collaboration with The Gathering Place (TGP) located at 23300 Commerce Park Drive in Beachwood, Ohio. TGP is a non-profit, community-based cancer support center whose mission is to support, educate and empower individuals and families touched by cancer through a variety of programs and services, offered free of charge, that address their social, emotional, spiritual and physical needs. All exercise sessions were conducted at TGP under the supervision of exercise specialists and American College of Sports Medicine (ACSM) Oncology Certified exercise trainers employed by TGP. The exercise intervention consisted of strength training sessions approximately 1 hour in duration conducted 2 times per week for 20 weeks. The resistance training protocol was developed following the Resistance Training Strategies for Individuals with Cancer (RTSIFIC) protocol [17] and ACSM guidelines for cancer survivors [18]. Patients were also asked to perform moderate intensity walking at home for 30 minutes a day on five days of the week (150 minutes/week) for 20 weeks based upon the current recommended guidelines for cancer patients [18]. The intervention was delivered in two small groups consisting of eight and eleven patients each during the evenings (Tuesday/Thursday and Monday/Wednesday, respectively). Transportation was provided to those in need both to and from the TGP and to and from the hospital for baseline and end of intervention testing.

All support group sessions were held at TGP and led by a licensed, female African-American social worker employed by TGP. These 1 to 1.5 hour meetings were conducted just prior to one of the exercise sessions on a weekly basis (i.e., conducted on a Monday or Tuesday) for 20 weeks. The support group offered an opportunity for the African-American BCa survivors to come together with others of similar background for mutual support and education. Discussion topics included stress management, coping with fear and uncertainty, body image, sexuality and spirituality [19].

Demographic and clinical measures

Baseline demographic and clinical information was abstracted from medical charts (e.g., age, cancer stage, treatment). In addition, a self-administered questionnaire was utilized to obtain general information on other demographic and risk factors (e.g., education, income, smoking, alcohol use). Eighteen patients completed the baseline general information questionnaire.

Behavioral measures

Questionnaires to assess quality of life, fatigue, depression and other health behaviors were administered at baseline and at the end of the intervention/20-week program (EOI). Eighteen participants

completed the behavioral questionnaires at baseline but only twelve of the nineteen patients enrolled in the program completed all of the behavioral questionnaires at the EOI.

We used the Functional Assessment of Cancer Therapy - General (FACT-G), which is a 27-item questionnaire, to evaluate physical, functional, social, and emotional well-being and overall quality of life (QoL) and, the FACT-B, which includes an additional 16-item subscale specific to breast cancer [20]. We assessed fatigue using the FACIT-F Fatigue Scale, a 13-item scale designed to assess fatigue in terms of intensity and interference with performing everyday functions [21]. Depression was measured using the Beck Depression Inventory (BDI)-II, a 21-item instrument of depressive symptoms [22].

Sleep was assessed using the Pittsburgh Sleep Quality Index (PSQI), which provides a global score of sleep quality and disturbance over the past month [23], and has been validated in cancer patient populations including breast cancer survivors [24]. Physical activity habits were assessed with the Godin Leisure-Time Exercise (LSI) questionnaire, which assesses the frequency and duration of leisure-time mild, moderate, and vigorous exercise during a typical week [25]. Dietary intake of fruits and vegetables was assessed using the National Cancer Institute (NCI) Fruit and Vegetable Screener, which is a 19-item instrument querying the frequency of consumption of 10 categories of fruits and vegetables over the past month [26].

Exercise readiness was assessed with a single item scale based on the Stages of Change (Transtheoretical) Model for exercise with the following six stages [27-29]: 1 = I currently do not exercise and I do not intend to start exercising in the next 6 months (pre-contemplation); 2 = I currently do not exercise but I am thinking about starting to exercise in the next 6 months (contemplation); 3 = I currently do some exercise but not regularly (i.e., I exercise less than 5 days per week) (preparation); 4 = I currently exercise regularly (i.e., at least 5 days per week for 30 minutes or more per day) but I have only begun doing so in the last 6 months (action); 5 = I currently exercise regularly (i.e., at least 5 days per week for 30 minutes or more per day) and have done so for longer than 6 months (maintenance); 6 = I exercised regularly (i.e., at least 5 days per week for 30 minutes or more per day) in the past but I am not doing so currently (relapse).

Self-efficacy for eating behaviors was assessed using the Weight Efficacy Lifestyle (WEL), which evaluates eating behavior self-efficacy under negative emotions, food availability, social pressure, physical discomfort and positive activities [30,31]. Self-efficacy for exercise behaviors was assessed using the SEQ/PASES 8-item questionnaire [32].

Quantitative Statistical Analyses

Changes in outcome variables in individuals from baseline to the end of the intervention (EOI) were analyzed using paired sample t-tests (two-sided; significance: $\alpha \leq 0.05$). We also explored differences in baseline characteristics relative to adherence (i.e., those who attended at least 70% (the mean attendance) of the exercise sessions ('More Adherent' group); those who attended < 70% of the exercise sessions ('Less Adherent' group)). Due to the exploratory nature of this feasibility study, we did not correct for multiple testing. All analyses were conducted using SAS v9.2 (SAS Institute Inc., Cary, NC).

Participant Interviews and Qualitative Data Analyses

Semi-structured, telephone interviews with the participants were conducted within one month of completion of the 20-week program by a female, African-American community relations expert employed by the Case Comprehensive Cancer Center. This individual was not involved with conducting the support group sessions or delivering any other aspects of the intervention program. The interview guide included open-ended questions about the participant's experience including questions on the following topics: 1) overall program satisfaction; 2) satisfaction with the facility and personnel; 3) motivators and barriers to participating in the support group; 4)

motivators and barriers to participating in the exercise program; and, 5) suggestions to improve the program. Fifteen of the nineteen participants who enrolled in the program and that could be reached by telephone agreed to and completed the participant interviews. Participant responses were transcribed (typed) as verbatim responses. Two qualitative analysts independently reviewed the data and, then, shared preliminary findings with study team members for context and further interpretation. A written synthesis of the findings, supported by specific examples of participant responses, is provided in the Results section.

Results

On average, the patients were 56.5 ± 11.0 years old, the majority were employed (65.9%) and had received some college education (76.5%) (Table 1). The average travel time to the intervention facility was 16.9 ± 6.0 minutes. In terms of exercise readiness at baseline, 52.9% of patients were in the 'contemplation' phase (currently do not exercise but thinking about starting to exercise in the next 6 months), 41.2% were in the 'preparation' phase (do some exercise but not regularly) and 5.9% were in the 'relapse' phase (exercised regularly in the past but not doing so currently). Attendance rates were, on average, $70.0 \pm 19.1\%$ for the exercise sessions and $63.1 \pm 13.8\%$ for the support group sessions. Five (23%) of the patients utilized the transportation services to attend sessions at TGP (99 total roundtrips) and to attend baseline or EOI testing at the hospital (11 total roundtrips).

Behavioral Questionnaire Measures Results

At baseline, depression scores using the BDI-II were, on average, less than 13 (Table 2) and, therefore, in the 'normal' range (i.e., scores between 1 and 13). Overall sleep quality scores, as assessed by the PSQI, were greater than 5, suggesting these patients had 'poor' sleep quality at baseline. In terms of physical activity, no patients reported engaging in strenuous activity at baseline.

Table 1: Characteristics of the 'Exercising Our ABCs' Study Population at Baseline

Characteristic	Mean (s.d.) or Number (%)
Age at Diagnosis (years)	56.5 (11.0)
Stage I	5 (27.8%)
Stage II	11 (61.1%)
Stage III	2 (11.1%)
Post-Menopausal	13 (76.5%)
Married or Living With Partner	8 (47.1%)
Education	
High School or GED	4 (23.5%)
Some college but No Degree	7 (41.2%)
Bachelor's Degree	2 (11.8%)
Some Graduate School	4 (23.5%)
Income	
Less than \$20,000	4 (25.0%)
\$20,000-\$39,999	4 (25.0%)
\$40,000-\$59,999	4 (25.0%)
\$60,000-\$99,999	1 (6.2%)
Over \$100,000	3 (18.75%)
Employed: Full or Part Time	9 (58.9%)
Ever Smoker	11 (64.7%)
Alcohol	
Never	4 (23.5%)
<1 drink/week	5 (29.4%)
1-2 drinks/week	6 (35.3%)
3-5 drinks/week	2 (11.8%)
Hypertension	3 (17.6%)
Arthritis	9 (52.9%)
Body Mass Index (BMI: kg/m ²)	32.5 (6.3)
Time to Intervention Facility (minutes)	16.9 (6.0)
Readiness to Exercise ¹	
Contemplation Phase	9 (52.9%)
Preparation Phase	7 (41.2%)
Relapse Phase	1 (5.9%)

¹ See the Methods section for a description of the various stages of change

We found a clinically relevant improvement [33] in overall quality of life (QoL) with the FACT-B score [23,24] (B: 101.1 ± 21.5; EOI: 108.5 ± 21.6; p = 0.05) and a non-statistically significant (p < 0.10)

Table 2: Behavioral Measures at Baseline and After the 20-Week Intervention (EOI)

Measure	Baseline Mean (s.d.)	EOI Mean (s.d.)	p-value
Quality of Life			
FACT-G Score (Total: 0-108)	78.0 (17.2)	83.8 (15.7)	0.10
Physical (0-28)	20.6 (5.3)	22.4 (4.8)	0.06
Social (0-24)	19.3 (6.5)	21.1 (6.5)	0.26
Emotional (0-24)	19.1 (3.2)	19.4 (3.4)	0.74
Functional (0-28)	19.0 (5.3)	20.8 (4.6)	0.16
FACT-B Score (Total: 0-144)	101.1 (21.5)	108.5 (21.6)	0.05
Breast (0-36)	24.0 (6.9)	24.8 (8.2)	0.71
Fatigue Score (0-52)	37.2 (9.3)	39.2 (11.7)	0.38
Depression			
BDI-II Score (Total: 0-63)	11.92 (8.07)	9.00 (5.48) ¹	0.03
Sleep			
PSQI Score (Total: 0-21)	11.42 (4.27)	10.58 (2.43) ²	0.44
Hours of Sleep	5.46 (1.25)	5.58 (1.10)	0.78
Physical Activity			
LSI: Mild (mins/wk)	20.42 (58.01)	32.50 (51.90)	0.37
Moderate (mins/wk)	26.25 (62.05)	100.42 (104.11)	0.04
Strenuous (mins/wk)	0 (0)	39.58 (45.35)	0.01
Diet: Fruit & Vegetable Intake			
NCI F&V Screener (servings/day)	5.10 (4.29)	7.34 (7.03)	0.07
Self Efficacy: Exercise			
SEQ/PASES Score (0-4)	2.08 (0.45)	2.23 (0.46)	0.30
Self Efficacy: Diet			
WEL Score (Total: 0-180)	132.08 (22.77)	143.08 (22.30)	0.07
Negative Emotions (0-36)	26.67 (8.39)	28.50 (4.40)	0.46
Food Availability (0-36)	22.92 (6.63)	25.17 (7.93)	0.20
Social Pressure (0-36)	26.75 (5.26)	29.50 (4.96)	0.01
Physical Discomfort (0-36)	29.17 (6.59)	32.42 (3.42)	0.17
Positive Activity (0-36)	26.58 (5.20)	27.50 (6.49)	0.60

¹ A decrease in score represents improvement; BDI-II ≤13 is 'Normal'

² A decrease in score represents improvement; PSQI >5 is 'Poor Sleep Quality'

increase in the physical domain of FACT-G (Table 2). We found a statistically significant decrease in depression scores after compared to before the intervention using the BDI-II [22] (B: 11.9 ± 8.1; EOI: 9.0 ± 5.5; p = 0.03). Although we did not find a statistically significant change in any of the sleep measures using the PSQI, post-intervention scores were greater than 5 (Table 2), suggesting overall sleep quality was still 'poor' [23] at end of the intervention. Self-reported 'moderate' (B: 26.2 ± 62.0 mins/week; EOI: 100.4 ± 104.1 mins/week; p = 0.01) and 'strenuous' (B: 0.0 ± 0.0 mins/week; EOI: 39.6 ± 45.4 mins/week; p = 0.01) physical activity increased significantly after the intervention but 'mild' activity did not change significantly (Table 2). In terms of dietary behavior, we found a non-statistically significant increase in fruit and vegetable intake (B: 5.1 ± 4.3 servings/day; EOI: 7.3 ± 7.0 servings/day; p = 0.07) and a non-statistically significant increase in diet related self-efficacy (B: 132.1 ± 22.8; EOI: 143.1 ± 22.3; p = 0.07), which may be driven, in part, by an improvement in the social pressure sub-domain (B: 26.7 ± 5.3; EOI: 29.5 ± 5.0; p = 0.01).

Exploratory Analyses: Baseline Characteristics by Adherence

To provide insight on what baseline characteristics may have affected adherence to the exercise sessions for the purposes of planning a larger, sustainable community intervention, we explored how certain baseline attributes may have differed in those who attended at least 70% (the mean attendance) of the exercise sessions ('More Adherent' group) compared to those who attended < 70% of the exercise sessions ('Less Adherent' group). We found that distance from the facility was significantly different between the adherence groups with 'Less Adherent' patients tending to be located further from the facility (data not shown; Less-Adherent (0): 10.8 ± 5.5 miles; More Adherent (1): 6.6 ± 2.3; p = 0.04). In addition, baseline BMI and baseline depression scores were significantly different between adherence groups with 'Less Adherent' patients having higher baseline BMI (Less Adherent (0): 37.2 ± 4.2 kg/m²; More Adherent (1): 30.1 ± 5.9 kg/m²; p = 0.02) and higher baseline depression scores (Less Adherent (0): 18.8 ± 9.7; More Adherent (1): 9.3 ± 5.2; p = 0.02). We note that the average depression score at baseline in the 'Less Adherent' group was between 14 to 19, which suggests that this group had a 'mild' level of depression at baseline. Baseline age and quality of life (FACT-B) scores were not statistically significantly different between adherence groups.

Participant Interviews

The primary interview questions and example responses from participants are provided in Table 3. We provide our synthesis of the findings by each major theme below:

Table 3: Sample of Responses to Exit Interview Questions

Question	Response Example 1	Response Example 2	Response Example 3
Would you recommend this program to other Breast Cancer Survivors? If so, why? If not, why not?	"Oh yes. I'm more motivated, uplifted. I feel better about myself."	"Absolutely. The camaraderie that was developed between the survivors was awesome. The exercise was great for us and we can move forward in our lives."	"Most definitely because you have people who have gone through what you've gone through or are going through it. You have your family and friends, but if they haven't gone through it, they don't really know."
Did you have any specific concerns about participating in the support group portion of the program? If so, what were they?	"I guess more apprehensive. I didn't know if I was willing to share, but after I got there, (our facilitator) made it easy and really enjoyable to share."	"Yes, I did. I was concerned that it was going to be very depressing, sad, a lot of crying. And I was pleasantly surprised that that was not the case. Our facilitator was able to help us work through those moments."	"I had at first and then I got in there, it was just great." "Just thinking about being in a group of people and discussing your personal business. Once I got started and got to know people, it was easy."
Did you feel more comfortable about joining the program because the facility and personnel had experience with cancer patients?	"Yes, that was one of the points that won me over. I'm not sure if I would have enjoyed going to a hospital or some place like that."	"Yes, that was a big help. Being around people who knew what you were going through and were able to assist you in any way that they could."	"That influenced me a lot because I liked the fact that there were people there understanding of my situation and knew how to deal with me emotionally."
If you attended most of the Group Exercise Sessions (i.e., missed 10 sessions total or less), what motivated you to participate regularly?	"I looked forward to it. After you exercise, I always got this little energy - like a boost." "It was actually a lot of fun."	"Because of the way my body felt. I was losing weight. Then I got to a point where I wasn't losing weight, but I could see my waist coming back. Before I used to just walk. I even started running! I just had to keep moving."	"I knew I needed it and physically I needed to make sure I made a commitment to it for the health of my body." "I was toning up muscles and I needed to do that real bad."
If you attended most of the Support Group Sessions (i.e., missed 5 sessions or less), what motivated you to participate regularly?	"The ladies in my group. My counselor - she makes you want to come. She just helps you enjoy it and makes it easy to be there and want to be there. They became family."	"The support. I just wanted to be around them. It was kind of a break - a relief from my life and the cancer treatment. I just longed to be with them because they had become an integral part of my life - a part that I loved."	"The friendship, sisterhood of the group members and wanting to be with them and being comfortable to share my personal journey."

Overall Program Satisfaction: Overall, participants were satisfied with the program with nearly all respondents (n=14 out of 15 who completed the exit interviews) reporting that they would recommend the program to others when asked “Would you recommend this program to other breast cancer survivors? If so, why? If not, why not?”. One participant responded by stating “*Absolutely. The camaraderie that was developed between the survivors was awesome. The exercise was great for us...*”; and, another remarked “*Oh yes. I’m more motivated, uplifted. I feel better about myself.*” (Table 3). When asked about any specific concerns in participating in the exercise and support group portions of the program, very few (n = 3) expressed having any concerns about the exercise but, most (n = 11) expressed at least some initial apprehension about the support group. Participants credited the group counselor (facilitator) for making “*...it easy and really enjoyable to share...*” and for helping “*...us work through those (sad, depressing) moments*” and others felt that “*once I got to know people, it was easy*”.

Satisfaction with Facility and Personnel: Most (n = 12) indicated that they felt more comfortable about joining the program because the facility and personnel had experience with cancer patients. Example responses include the following: “*Yes, that was one of the points that won me over. I’m not sure if I would have enjoyed going to a hospital...*” and, “*...it was a big help. Being around people who knew what you were going through...*” (Table 3).

Motivations and Barriers to the Support Group: When asked “If you attended most of the Support Group Sessions (i.e., missed 5 sessions total or less), what motivated you to participate regularly?”, most (n = 11) participants cited the camaraderie forged as a primary motivating factor. One participant stated “*The friendship, sisterhood of the group members and wanting to be with them...*” and another cited “*I just wanted to be around them...I just longed to be with them because they had become an integral part of my life - a part that I loved*” (Table 3). When asked “If you missed a lot of the Support Group Sessions (i.e., missed greater than 5 sessions), what interfered with or prevented you from participating regularly?”, one participant cited issues with her general health and another participant indicated the barrier was related to her reconstructive breast surgery (which she decided to undertake after enrolling in the program).

Motivations and Barriers to the Exercise: When asked a similar set of questions regarding motivations and barriers to attendance to the group exercise sessions, most (n = 8) cited improvements in body composition, strength and function as a motivating factor with one participant stating “*Because of the way my body felt. I was losing weight. Then I got to a point where I wasn’t losing weight, but I could see my waist coming back. Before I used to just walk. I even started running!*” (Table 3). Others reported simply “*liking the exercise*” (n = 2) and having “*fun*” (n = 2) as motivating factors. Only one participant cited a barrier to participating regularly in the exercise sessions, which was due to having breast reconstructive surgery (after enrolling in the program).

Program Improvement Suggestions: Participants offered several suggestions for improving the program including more integration of medical professionals into the program to discuss side effects of treatments including hair loss, changes in skin, and lymphedema. In addition, participants suggested adding a nutritional component, at both the individual and group levels, to address general healthy eating (e.g., recipes, cooking demonstrations) and complementary alternative medicines (e.g., turmeric). In addition, participants expressed the desire to have more variety in the exercise, particularly related to the aerobic exercise (e.g., water aerobics, hula hoop, outdoor activities). They also thought more attention to individual fitness and functional levels as well as more frequent monitoring and progress reports would be helpful. Participants recommended that programs continue to be offered at community centers (like TGP) and to continue to offer transportation services to those in need.

Discussion

We found that our 20-week exercise and support group

intervention in African-American BCa survivors conducted in a community setting led to a clinically relevant improvement in overall QoL and a statistically significant decrease in depression scores and, significant improvements in strength, fitness and C-peptide levels as reported previously [1]. The patient interviews presented in this report suggest that this program was well accepted by the women who enrolled and, the qualitative analyses of these data support the improvements found in the quantitative scores for quality of life.

Most RCTs evaluating the effects of exercise in cancer survivors, particularly BCa survivors, following the completion of treatment have found significant improvements in overall QoL [12,13,34]. In our study involving African-American BCa survivors who completed surgery, chemotherapy and/or breast irradiation, we found a clinically relevant improvement in overall QoL using the FACT-B scale, which was supported by the qualitative analysis of the exit interview data in that participants reported feeling “*more motivated and uplifted*” and were “*enjoying*” and “*having fun*” in the program. Our findings contribute to the small but growing body of evidence that lifestyle interventions in African-American BCa survivors improve quality of life. In our program, we found a statistically and clinically relevant improvement in QoL. Other small pilot studies observed improvements in QoL but these were not statistically significant [15,35]. Interestingly, a large, prospective multi-ethnic cohort study has recently shown that African-American BCa survivors that meet the recommended levels of physical activity have improved QoL [36]. As only a small percentage of African-American BCa survivors (only 12.3% in Northeast Ohio [11]) are meeting current exercise guidelines, programs encouraging physical activity at recommended levels will help improve QoL in African-American BCa survivors.

Although the effects of exercise on depression in cancer survivors has been less consistent, a recent meta-analysis reported that 3 RCTs in BCa survivors had significant improvements in depression using the BDI-II scale. In our study of African-American BCa survivors, we also found a significant improvement in depression scores. Addressing depression in cancer survivors may be particularly important because the depression itself can create a barrier to participating in physical activity [37,38] and, possibly other healthy behaviors; therefore, lifestyle programs designed to address depression are likely to create synergistic, sustained improvements in depression and other lifestyle factors such as physical activity.

Furthermore, we found a significant improvement in self-reported minutes of moderate and strenuous exercise using the LSI after the intervention compared to baseline. Although none of our patients had reported engaging in strenuous activity at baseline, on average, they reported in engaging in about 40 minutes/week of strenuous activity and about 100 minutes/week of moderate activity after the intervention. A structured dietary component was not included in our intervention; however, we found a non-statistically significant increase of about 2 servings per day in fruit and vegetable consumption and, a non-statistically significant increase in diet related self-efficacy using the WEL scale [30,31], which appeared to be driven, at least in part, by a significant improvement in the social pressures domain. Although the support group did not focus on eating behavior, this change in eating behavior self-efficacy may have been driven by the general interactions of the support group but, a larger trial involving separate arms for exercise and the support group would be needed to better understand these suggestive effects.

We found that distance to the exercise facility, baseline depression scores and baseline BMI were significantly different between adherence groups with increased distance from the facility, higher baseline BMI and higher baseline depression scores observed in those who attended less than 70% of the exercise sessions. Longer distance to the facility is a known barrier to participation in exercise programs [39,40]. In our study, five patients (23%) utilized the transportation services provided to attend exercise and support group sessions (99 total roundtrips) as well as baseline and EOI testing (11 total round trips) which enhanced adherence. Depression has been shown to be associated with decreased physical activity and may also be a barrier

Table 4: Summary of Strategies Recommended for Future Lifestyle Programs in African-American Breast Cancer Survivors

1. Offer programs at community centers (e.g., The Gathering Place) not at hospital-based centers
2. Provide both exercise and support group programs
3. Provide group exercise to enhance social support but maintain attentiveness to individual comorbidities as well as individual fitness, functional and strength levels
4. Provide a variety of different aerobic (e.g., dance, hula hoop) and resistance training exercises
5. Provide nutritional and clinical counseling in the support group to better address dietary, complementary alternative medicine and treatment side-effect issues
6. Provide frequent updates on progress in strength, fitness, function and body composition
7. Offer transportation services for those in need
8. Provide training, as needed, to ensure the entire program team is knowledgeable of and sensitive to the particular needs of African-American breast cancer survivors

to exercise in BCa survivors [37,38]. Depression poses an interesting challenge in exercise trials because, although exercise is known to improve depression in cancer patients [41], depressed patients may be the most non-adherent to the intervention but, in our study, baseline depression scores were, on average, in the normal range. Perhaps, though, this emphasizes the need to screen for depression at baseline and, to specifically target these conditions as part of the intervention strategy to enhance participation. Being obese is also a barrier to exercise [42] and, obese African-American BCa survivors have reported participating in fewer minutes of physical activity per week (100 min/wk) compared to non-obese African-American BCa survivors (150 min/wk) [43]. However, very little is known regarding how obesity affects adherence in supervised exercise trials focusing on African-American BCa survivors. Taken together, our findings suggest that future lifestyle interventions should develop specific strategies to enhance adherence in African-American BCa survivors, particularly those who are obese and mildly depressed.

We provide a summary of our suggestions for consideration in future programs based upon the patient interview responses and our insights from administering the program (Table 4). The patient interviews in our study suggest that future programs should be conducted in community-based settings and the support group program should include participation by clinicians and nutritional counselors to better address concerns with side effects and complementary and alternative medicines. In addition, future programs may benefit from tailoring to individual desires of African-American BCa survivors regarding the types and variety of activity rather than trying to standardize these aspects. In addition to these insightful suggestions made by our participants, we believe that ensuring the entire study team is knowledgeable of and sensitive to the unique needs of African-American breast cancer survivors is key to enhancing the overall success of the program.

Our study has several limitations. We had a small sample size which limited our power to observe statistically significant changes and, we conducted many exploratory analyses and did not correct for multiple testing; therefore, our significant findings, particularly those from the subgroup analyses, could be due to chance. In addition, we conducted the program over a single 20-week period and we did not have a control arm so it is possible that the changes observed in self-reported measures of QoL, depression and other outcomes may be explained by contextual or other factors not directly related to the participant's engagement in the program. However, because we observed an average attendance of 70 percent for the 20-week intervention and because our results are consistent with previous exercise trials in Caucasian and minority breast cancer survivors [12,44,45], we believe the statistically significant results we found were indeed driven by the intervention program.

In summary, our preliminary results suggest that conducting lifestyle interventions in African-American breast cancer survivors in a community setting is feasible and may improve quality of life. Our participant interviews provide additional support for these quantitative results and provide insights to motivators, barriers and improvements to enhancing adherence to an exercise and support group program. Providing community-based and culturally sensitive lifestyle programs to African-American breast cancer survivors may improve their quality of life and, may, ultimately, improve their overall survival. Although further and more definitive research is required, the current study lends insight for improving future programs.

Acknowledgements/Funding

This work was supported, in part, by the American Cancer Society (ACS) [IRG-91-022-18 to N.L.N.], the National Institutes of Health (NIH) [NCI K07CA129162 and R01CA175100 N.L.N.; U54 CA116867 to N.A.B.; R01MD0009699 to CO], the Susan G. Komen Breast Cancer Foundation, Career Catalyst in Disparities Award [KG100319 to C.O.], the Ellison Medical Foundation [AG-SS-2420-10 to N.A.B.] and, the Behavioral Measurement Core of the Case Comprehensive Cancer Center [P30CA43703].

Human Subjects

All procedures performed in the studies involving human participants were in accordance with the ethical standards of the University Hospitals Institutional Review Board.

References

- Nock NL, Owusu C, Kullman EL, Austin K, Roth B, et al. (2013) A Community-Based Exercise and Support Group Program in African-American Breast Cancer Survivors (ABCs). *J Phys Ther Health Promot* 1: 15-24.
- Siegel R, Ma J, Zou Z, Jemal A (2014) Cancer statistics, 2014. *CA Cancer J Clin* 64: 9-29.
- American Cancer Society (2011) Cancer Facts and Figures for African-Americans 2011-2012. Atlanta, GA: American Cancer Society.
- Cuyahoga County Board of Health (2012) The Cuyahoga County Comprehensive Cancer Report of 2011; A Detailed Look at Cancer Incidence and Mortality Data from 2002-2006.
- Ademuyiwa FO, Groman A, O'Connor T, Ambrosone C, Watroba N, et al. (2011) Impact of body mass index on clinical outcomes in triple-negative breast cancer. *Cancer* 117: 4132-4140.
- Stolley MR, Sharp LK, Wells AM, Simon N, Schiffer L (2006) Health behaviors and breast cancer: experiences of urban African American women. *Health Educ Behav* 33: 604-624.
- White A, Pollack LA, Smith JL, Thompson T, Underwood JM, et al. (2013) Racial and ethnic differences in health status and health behavior among breast cancer survivors--Behavioral Risk Factor Surveillance System, 2009. *J Cancer Surviv* 7: 93-103.
- Weaver KE, Foraker RE, Alfano CM, Rowland JH, Arora NK, et al. (2013) Cardiovascular risk factors among long-term survivors of breast, prostate, colorectal, and gynecologic cancers: a gap in survivorship care? *J Cancer Surviv* 7: 253-261.
- Germine BB, Mishel MH, Alexander GR, Jenerette C, Blyler D, et al. (2011) Engaging African American breast cancer survivors in an intervention trial: culture, responsiveness and community. *J Cancer Surviv* 5: 82-91.
- Hair BY, Hayes S, Tse CK, Bell MB, Olshan AF (2014) Racial differences in physical activity among breast cancer survivors: implications for breast cancer care. *Cancer* 120: 2174-2182.
- Thompson CL, Owusu C, Nock NL, Li L, Berger NA (2014) Race, age, and obesity disparities in adult physical activity levels in breast cancer patients and controls. *Front Public Health* 2: 150.
- Fong DY, Ho JW, Hui BP, Lee AM, Macfarlane DJ, et al. (2012) Physical activity for cancer survivors: meta-analysis of randomised controlled trials. *BMJ* 344: e70.
- Speck RM, Courneya KS, Mâsse LC, Duval S, Schmitz KH (2010) An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *J Cancer Surviv* 4: 87-100.
- Ashing-Giwa K, Rosales M (2012) Recruitment and retention strategies of African American and Latina American breast cancer survivors in a longitudinal psycho-oncology study. *Oncol Nurs Forum* 39: E434-442.
- Stolley MR, Sharp LK, Oh A, Schiffer L (2009) A weight loss intervention for African American breast cancer survivors, 2006. *Prev Chronic Dis* 6: A22.
- Paxton RJ, Nayak P, Taylor WC, Chang S, Courneya KS, et al. (2014) African-American breast cancer survivors' preferences for various types of physical activity interventions: a Sisters Network Inc. web-based survey. *J Cancer Surviv* 8: 31-38.

17. Swank AM, Hagerman P (2010) Resistance training strategies for individuals with cancer. *Resistant Training for Special Populations*. Clifton Park, NY, DELMAR Cengage Learning 305-324.
18. Schmitz KH, Courneya KS, Matthews C, Demark-Wahnefried W, Galvão DA, et al. (2010) American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Med Sci Sports Exerc* 42: 1409-1426.
19. Shapiro JP, McCue K, Heyman EN, Dey T, Haller HS (2010) A naturalistic evaluation of psychosocial interventions for cancer patients in a community setting. *J Psychosoc Oncol* 28: 23-42.
20. Cella DF, Tulskey DS, Gray G, Sarafian B, Linn E, et al. (1993) The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol* 11: 570-579.
21. Webster K, Cella D, Yost K (2003) The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcomes* 1: 79.
22. Beck AT, Steer RA, Brown GK (1996) Beck Depression Inventory. 2nd ed. San Antonio TX, The Psychological Corporation, Harcourt Brace Jovanovich.
23. Buysse DJ, Reynolds CF 3rd, Monk TH, Berman SR, Kupfer DJ (1989) The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. *Psychiatry Res* 28: 193-213.
24. Carpenter JS, Andrykowski MA (1998) Psychometric evaluation of the Pittsburgh Sleep Quality Index. *J Psychosom Res* 45: 5-13.
25. Godin G, Jobin J, Bouillon J (1986) Assessment of leisure time exercise behavior by self-report: a concurrent validity study. *Can J Public Health* 77: 359-362.
26. Thompson FE, Subar AF, Smith AF, Midthune D, Radimer KL, et al. (2002) Fruit and vegetable assessment: performance of 2 new short instruments and a food frequency questionnaire. *J Am Diet Assoc* 102: 1764-1772.
27. Garber CE, Allsworth JE, Marcus BH, Hesser J, Lapane KL (2008) Correlates of the stages of change for physical activity in a population survey. *Am J Public Health* 98: 897-904.
28. Marcus BH, Selby VC, Niaura RS, Rossi JS (1992) Self-efficacy and the stages of exercise behavior change. *Res Q Exerc Sport* 63: 60-66.
29. Pinto BM, Rabin C, Papandonatos GD, Frierson GM, Trunzo JJ, et al. (2008) Maintenance of effects of a home-based physical activity program among breast cancer survivors. *Support Care Cancer* 16: 1279-1289.
30. Clark MM, Abrams DB, Niaura RS, Eaton CA, Rossi JS (1991) Self-efficacy in weight management. *J Consult Clin Psychol* 59: 739-744.
31. Clark MM, Forsyth LH, Lloyd-Richardson EE, King TK (2000) Eating self-efficacy and binge eating disorder in obese women. *J Appl Biobehav Res* 5: 154-161.
32. Mott RW, Dishman RK, Trost SG, Saunders RP, Dowda M, et al. (2000) Factorial validity and invariance of questionnaires measuring social-cognitive determinants of physical activity among adolescent girls. *Prev Med* 31: 584-594.
33. Eton DT, Cella D, Yost KJ, Yount SE, Peterman AH, et al. (2004) A combination of distribution- and anchor-based approaches determined minimally important differences (MIDs) for four endpoints in a breast cancer scale. *J Clin Epidemiol* 57: 898-910.
34. Irwin ML (2012) Benefits of Aerobic and Resistance Exercise in Cancer Survivors. In Berger NA, Steindorf K, Ulrich C, eds. *Exercise, Energy Balance and Cancer*. New York, Springer.
35. Spector D, Deal AM, Amos KD, Yang H, Battaglini CL (2014) A pilot study of a home-based motivational exercise program for African American breast cancer survivors: clinical and quality-of-life outcomes. *Integr Cancer Ther* 13: 121-132.
36. Smith AW, Alfano CM, Reeve BB, Irwin ML, Bernstein L, et al. (2009) Race/ethnicity, physical activity, and quality of life in breast cancer survivors. *Cancer Epidemiol Biomarkers Prev* 18: 656-663.
37. Rogers LQ, Vicari S, Courneya KS (2010) Lessons learned in the trenches: facilitating exercise adherence among breast cancer survivors in a group setting. *Cancer Nurs* 33: E10-17.
38. Rogers LQ, Markwell SJ, Courneya KS, McAuley E, Verhulst S (2011) Physical activity type and intensity among rural breast cancer survivors: patterns and associations with fatigue and depressive symptoms. *J Cancer Surviv* 5: 54-61.
39. Daly J, Sindone AP, Thompson DR, Hancock K, Chang E, et al. (2002) Barriers to participation in and adherence to cardiac rehabilitation programs: a critical literature review. *Prog Cardiovasc Nurs* 17: 8-17.
40. Schutzer KA, Graves BS (2004) Barriers and motivations to exercise in older adults. *Prev Med* 39: 1056-1061.
41. Mishra SI, Scherer RW, Geigle PM, Berlanstein DR, Topaloglu O, et al. (2012) Exercise interventions on health-related quality of life for cancer survivors. *Cochrane Database Syst Rev* 8: CD007566.
42. Ball K, Crawford D, Owen N (2000) Too fat to exercise? Obesity as a barrier to physical activity. *Aust N Z J Public Health* 24: 331-333.
43. Paxton RJ, Taylor WC, Chang S, Courneya KS, Jones LA (2013) Lifestyle behaviors of African American breast cancer survivors: a Sisters Network, Inc. study. *PLoS One* 8: e61854.
44. Greenlee HA, Crew KD, Mata JM, McKinley PS, Rundle AG, et al. (2013) A pilot randomized controlled trial of a commercial diet and exercise weight loss program in minority breast cancer survivors. *Obesity (Silver Spring)* 21: 65-76.
45. Winzer BM, Whiteman DC, Reeves MM, Paratz JD (2011) Physical activity and cancer prevention: a systematic review of clinical trials. *Cancer Causes Control* 22: 811-826.