

Program Proposal

Comprehensive Health and Wellness Program for Breast Cancer Survivors

Background:

This program, aimed at supporting and promoting health and quality of life in breast cancer survivors, will implement evidence-based program components in hopes to elicit long term health behavior changes in this population. This will be achieved via program elements including physical activity (walking and strength training components), lymphedema self-management training, a peer-based support group, and short educational sessions on common issues faced by women after breast cancer treatment. To measure the success of the program several outcome measures will be implemented to include the Disabilities of the Arm, Shoulder, and Hand Questionnaire (DASH), the World Health Organization Quality of Life-BREF (WHOQOL-BREF), and the 6 Minute Walk Test (6MWT).

Interventions:

Physical activity in the form of a walking and strength training program is an essential part of this community program because of the vast benefits, across physical and psychological health, that regular physical activity can have a positive impact on, especially for breast cancer survivors.¹ Lowered bone mineral density, weight management, and mental health concerns such as depression are common long term side effects after breast cancer treatment that may be positively impacted by incorporation of regular physical activity.² For many people, even without the added barriers related to breast cancer, establishing a regular physical activity routine can be a challenge at the individual, interpersonal, and community levels.³ Individuals may not have the knowledge or current motivation to implement a plan, the friends/family support to influence them, or a safe community space in which to participate in physical activity.³ Through participation we hope to create a safe space and a support group as well as instilling

skills and confidence that these women can carry with them beyond the completion of the program.³ The combination of both an aerobic and strength training components have been found effective in breast cancer survivors in improving physical fitness, levels of fatigue, and quality of life when compared to a control group that receive no physical activity instruction.¹ Additionally, depressive symptoms in breast cancer survivors were improved in groups participating in light to moderate intensity physical activity, further supporting the use of a walking program.⁴ By capitalizing on motivational factors such as social support and personal fulfillment, and reducing barriers such as ease of access we hope to improve upon participation and compliance of the physical activity portion of the program to make long term behavior changes.⁵

Lymphedema self-management education and training has been shown to be effective in reducing rates of lymphedema development in breast cancer patients.⁶ By reducing rates of lymphedema, breast cancer survivors experience improved quality of life and social and psychological well-being when compared to survivors who develop lymphedema.⁶ Compliance with lymphedema self-management techniques has been improved through the use of health belief model concepts to include establishing perceived benefits and perceived susceptibility in addition to education on techniques, which in turn reduced rates of lymphedema occurrence when compared to women who did not receive lymphedema management education.⁷ This education has been found to be effective when delivered in a group setting, making it an important and appropriate component of the program.⁸ By educating and providing training on how these women can mitigate the risk of lymphedema independently we are empowering them at the individual level to elicit behavior change through knowledge, skills, and confidence.³

Social support via peer support groups for women after breast cancer treatment has been found to be beneficial for this population, who have stated they had positive experiences in aspects of psychological, physical, and social health when taking an active part in these groups.⁹ When considering the social ecological model of health behavior change, by being able

to share their mutual experiences, support one another in recovery, and empowering one another these women are creating an interpersonal support group that the program hopes to foster in order promote and sustain behavior change and lasting relationships.^{3,9}

Educational portions of the program will benefit women at the individual level by providing knowledge as well as the interpersonal level by providing access to further resources or health professionals within their communities if further assistance is desired.³ Simple, brief education has shown to be effective in reducing rates of side effects of breast cancer treatment such as lymphedema self-management.⁷

Unfortunately, breast cancer and its treatment impact the whole person, across physical and psychosocial realms. By implementing a comprehensive program that targets several areas of health and wellness through utilization of theories within the health belief model and the social ecological model as discussed above, the program hopes to provide a holistic approach to support and health after the completion of breast cancer treatment.

Outcome Measures:

The DASH is regularly used in studies for women after breast cancer and has been validated as a convenient and reliable tool in this population to assess upper extremity disability.¹⁰ Upper extremity disability is common in breast cancer survivors due to treatment, surgery, and common side effects such as lymphedema.¹⁰ The DASH includes functional activities of daily living important to quality of life and participation.¹¹ The DASH is appropriate for this program as it will capture the impacts of strength training, lymphedema management, and establish a baseline of appropriate UE activities for individual participants as we move through lymphedema self-management and UE strength training/stretching activities.¹⁰

The WHOQOL-BREF is being used to assess quality of life because it encompasses several of the important components of the program to include social support, self-esteem, and participation in recreational activities.¹² This will serve as a starting point to assess a participants baseline before participation in the program as several of the interventions (peer support,

physical activity, education) may influence a participant's perceived quality of life over time.¹²

The WHOQOL-BREF has been deemed accurate in assessing quality of life in women with breast cancer when compared to other common quality of life outcome measures.¹³ When considering making long term behavior change it is essential that we consider and measure factors included within the WHOQOL-BREF such as mental health and social relationships, as these play a key role in health behavior integration. For example, when considering the Health Belief Model, self-efficacy or the belief in one's ability to perform a health behavior is an essential factor to creating real change, and through the WHOQOL-BREF we can better understand a participant's current level and readiness for change, and how it evolves over the course of the program.¹⁴

Finally, the 6MWT will be included to establish a baseline of aerobic capacity for participants, as well as inform the instructor on safe parameters for the walking portion of the program.¹⁵ As these women may have just concluded their cancer treatment they may be experiencing fatigue, weakness, and reduced endurance.¹⁶ As a result, a 6MWT should be performed not only to establish a baseline to improve upon throughout the program, but to confirm a participants ability to safely take part in the walking portion of the program.

Program Goals:

1. In 6 months, at the completion of this community-based program, participants will have a higher mean score (improvement of at least 1 point from initial baseline assessment) in at least 2 domains of the WHOQOL-BREF, indicating improvements in quality of life across the domains of physical health, psychological, social relationships, and or environment; indicating that the program has provided positive, holistic opportunities for participant growth.¹²
2. In 6 months at the completion of this community-based program, participants will at least maintain, if not improve, their overall DASH score from initial baseline

- assessment, indicating that program components to include education, strength training, and or self-management topics mitigated the development of secondary complications common to breast cancer survivors such as lymphedema or functional weakness.¹¹
3. During the last 4 weeks of the 6-month program participants will indicate via weekly physical activities logs that they are meeting at least 80% of the recommended walking (or other preferred method of physical activity) and strength training guidelines for adults (180 minutes/week), as the program aims to elicit long term adoption of these health behavior changes outside of the program.
 4. At the completion of the program at least 75% of participants will have stayed enrolled within the program to 6 months, and have attended at least 75% of all sessions, indicating that program participants appreciated the personal value of the program, as well as appropriate management of potential barriers to participation in a community-based program.⁵

Methods:

This community-based program for breast cancer survivors will be delivered 3 times per month for 6 months, ideally starting in January, with a potential second session beginning in June. Location of the program may be dependent upon the community and available community spaces - for the initial program plan it will be set to take place In Jacksonville, North Carolina, with hopes to expand to other communities in the future. Spaces such as community recreational facilities, schools, or churches may be utilized, as timing, funding, and permission allows. In Jacksonville the program will ideally team up with the City of Jacksonville Parks & Recreation department to rent out a room within their recreational facilities (such as the Jacksonville Commons Recreation Complex) where education, peer support group, and strength training could take place. For the walking portion this can take place either in the double court gym, or on the ¼ mile walking loop in the front of the building, dependent upon

weather. If the city was not willing to sponsor the program and offer it at one of their 5 recreational centers, these spaces can be rented out for private, nonprofit, and commercial events for a range of \$20 to \$60 per hour, which would need to be considered in the program budget, funding, and cost for participation as well as future evaluation of the program and its use of resources.¹⁷

Recruitment will take place in the 4 months leading up to the start of the program. The facilitator of the program will work to build relationships with local oncologists, physicians, physical and occupational therapists, pharmacists, etc. to promote the program and encourage them to refer and educate their patients on their options for support within the community. Flyers will be posted at local oncology centers and the program will be promoted on the City of Jacksonville's website within their 'Programs' offered. Ideally the program would like to enroll anywhere from 5-15 participants.

One facilitator will be needed to run the program, however additional help and expertise would be favorable whenever possible. Ideally, this facilitator will be a healthcare provider within the community with a background in topics such as physical activity, lymphedema, and nutrition – such as a physical therapist or nurse. This use of a healthcare provider may also facilitate connections with other healthcare providers within the community who may be working with the target audience and serve as a referral source. All educational materials will be generated before the start of the program, with a facilitation guide for the facilitator to follow each week for the given topic and activities. Despite this, it would be ideal for a healthcare professional with a background and general knowledge in these topics to lead sessions, answer questions, and refer to additional resources if needed.

Overall there are 4 activities that will take place at each of the sessions – an educational portion, a peer support group, strength training, and finally a walking portion, each of which will be described in further detail below. Sessions are designed to take ~1 hour and 30 minutes, and will be held on weeknights 3 times throughout the month for 6 months. Feedback may be

taken from participants at the start of the program to plan future meetings if flexibility on date/time is an option, however facility rentals and facilitator scheduling will ultimately determine dates and times. The program will be offered in the evenings (likely about 6:30) to accommodate work schedules and potential for traffic to mitigate as many of these common potential barriers to participation as possible.⁵

The educational portion of the program will consist of a 15-minute topic, which may be covered over the course of several sessions if needed. Topics may include but are not limited to: lymphedema self-management, the importance of and recommendations for physical activity, weight management, nutrition, pain neuroscience, and mental health. All of the topics will be covered as a general overview, with additional community and national resources provided if participants wish to seek out additional assistance. A facilitation guide will provide the facilitator with all of the information they need to cover throughout the session to encourage comprehensive, accurate, and reproducible sessions that can be evaluated and adapted over time as needed. At the start of the program, participants will be able to rank the topics most relevant to them, as there will be some room for flexibility within the program if a facilitator and group feels that additional time may be better spent on one topic over another to meet individual group needs.

The peer support group portion of the session will last for ~20 minutes each session, and can be carried over into the walking segment for continued conversations if needed/wanted. The facilitator will simply serve as a guide to intervene when needed to initiate conversations or topics, as this portion is aimed at fostering a feeling of community among these women, building upon the interpersonal factors of the Social Ecological Model that influence health behaviors.¹⁸ The goal of the support group portion is to empower, allow mutual sharing, assist in moving on, and to create a support group within these women's local communities that they can continue to turn to and rely on for years to come. Facilitators may guide conversations by asking questions such as, 'can you each share a bit about what has been the hardest part of your survivorship

journey', or 'what have been some of your most valuable resources since your breast cancer diagnosis?' but ultimately participants should be interacting with, learning from, supporting, and sharing with one another.

The strength training portion of the session will be ~15 minutes, and will not require any equipment other than a chair to increase feasibility and carryover at home as well as decrease program costs/logistics. These 15 minutes will serve as an educational time for how to appropriately perform exercises plan for the following week on how to utilize these exercises to meet their physical activity goals. Each week participants will be asked to track their general physical activity, as class time alone will not allow them adequate time to meet guidelines. These strength training sessions may serve as a template or tools for exercises they can be performing at home on their own time. Exercises will be provided to the facilitator, who should be able to teach and assist participants in tasks such as: squats, sit to stands, lateral walking, upper extremity active range of motion, bridges, wall push-ups, etc.. Through improvement of individual factors in the Social Ecological Model, the program hopes to instill long term health behavior changes through empowerment, education, and instilling confidence in these women during sessions to carry through once at home.¹⁸

Finally, the walking portion of the session will provide ~30-minutes of cardiovascular exercise to work towards improvements in meeting physical activity recommendations. Women will be asked to walk at a brisk but comfortable pace, as walking at a moderate intensity, when performed in conjunction with strength training, has shown to improve physical health, fatigue, depression, and quality of life in women after breast cancer treatment.^{1,4} The walking portion will take place in an area that allows women to walk laps (ex. track, gym, parking lot, short walking path), rather than a long trail, in order to allow women who require breaks or walk at a slower pace to remain safe and engaged with the group and allow the facilitator to ensure safety of all members at all times. Again, physical activity will be tracked throughout the week to assess if participants are meeting physical activity recommendations that cannot be attained during

session time. This tracking over time will allow participants to set graded goals (for example increasing walking time each week) and these improvements or goals met should be acknowledged by the facilitator (tracking forms collected each month or every 3rd session) in order to create a sense of achievement – these strategies have been found to be the most effective behavioral change strategies in increasing physical activity among cancer survivors.¹⁹ The aerobic and strength training components of the program hope to utilize aspects of the Social Cognitive Theory to influence long term adoption of these health behaviors, to include self-regulation through weekly log monitoring and goal setting, observational learning by participating with their peers, psychological determinants through improving self-efficacy, and finally dismantling environmental barriers by providing them with tools to achieve regular physical activity behaviors such as at home body weight exercises.²⁰

At the initial session, 3 months, and at the completion of the program (6 months), participants will be asked to complete a 6-minute walk test and the DASH and WHOQOL-BREF Questionnaires – to save times these final two self-report outcome measures may be completed outside of the session. Additionally, participants will be asked for general feedback at the 3- and 6-month mark to better assess the program and areas in need of adjustment to best meet participant needs in the future. The midpoint data collection will allow the facilitator to assess participant progress thus far, consider feedback, and collect data for future evaluation.

Program Evaluation:

In order to assess program goals, all outcome measures will need to be assessed at the start of the program to establish baselines, at the 3-month midpoint to ensure progression towards goals and potential needs for adjustment, and finally at the 6-month completion of the program to assess overall outcomes and attainment of the program goals. Additionally, a weekly physical activity log will be completed by participants either in an online forum, or by hand to track general physical activity throughout their week. The program will only be meeting 3 times per month, allowing time for introduction to physical activity concepts, but not to carry out

weekly recommendations. This will also allow for assessment of the physical activity program goal for participants (#3). Attendance will be kept throughout the duration of the program to assess follow-up and potential drop outs, as well as number of sessions attended (program goal #4). These measures and documentation are extremely important, as effective program assessment cannot take place without available data in order to evaluate and critique a program in a meaningful and comprehensive way.²¹

As indicated in the Wurz et al. study, there may be many barriers, as well as motivators, that influence a breast cancer survivors participation in a community-based physical activity program.⁵ If participation or recruitment is found to be an issue for the program, feedback on these barriers and motivators from not only those women within the program, but those who decided against participation is essential to effectively determine what changes need to be made to eliminate barriers - for example moving locations or times of sessions.^{5,21}

Especially for the initial program implementation, and likely several subsequent times the program is administered this evaluation is essential to determine if program elements are being implemented as intended, if their implementation is effective, and if overall the program is meeting, or working towards meeting program goals.²¹ This program involves several elements, to include peer support, physical activity, and education sessions, and so evaluation of each of these components, as well as adjustments will likely be needed to best meet the needs of this population.²¹ While the program is in its very early stages, setting clear focuses for evolution, such as, 'are the appropriate targets being reached', or 'are walking program or educational elements being administered as intended' may help to guide early evaluation.²¹

For a community-based program such as this aimed at changing long term health behavior habits around physical activity and symptom management for breast cancer survivors, one of the primary stakeholders we need to engage are those affected – the survivors we are attempting to enroll.²¹ By demonstrating the evidence or results for the program to these stakeholders during recruitment, as well as actively engaging them in the evaluation process

through regular feedback hopefully we can better structure and continue to progressively evaluate and adapt the program over time.²¹

Conclusion:

Care and support for breast cancer survivors should extend well beyond their treatment, as the effects of this disease and its impacts on the whole body may last for years to come.²² Through implementation of this community-based program we hope to give these women the opportunity to improve not only their physical health, but provide education for management common long-term side effects related to breast cancer and create a peer support system within these women's communities. Through a comprehensive approach this program intends to bridge the gap between active breast cancer treatment, and the millions of women living within the United States after treatment with little to no support that could benefit from improve physical, social, and mental health.²³ As discussed throughout this proposal, interventions included within the program are supported by evidence to improve the quality of life, physical health, social support, among other benefits in women after breast cancer treatment. As numbers of breast cancer survivors in our country increase and as medical advancements in the treatment of breast cancer improve²⁴— so should our support for these women after the completion of their primary treatment through implementation of community-based programs such as this.

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