Published in final edited form as:
Cancer Nurs. 2010 ; 33(6): E10–E17. doi:10.1097/NCC.0b013e3181db699d.

Lessons learned in the trenches: facilitating exercise adherence among breast cancer survivors in a group setting

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Abstract

Background—Improving effectiveness of group exercise counseling for breast cancer survivors is needed.

Objective—Describe clinical observations, with research and translation implications, derived during group exercise counseling for breast cancer survivors.

Intervention/Methods—While implementing group session components of an effective social cognitive theory-based exercise intervention, observations were made through verbal discussion with study staff, review of participant feedback, and prospective journaling by the group facilitator. The intervention has been implemented 11 times (i.e., 63 survivors; 66 group sessions). Thematic consistency, application to intervention goals and design, and implications were reconciled between two investigators.

Results—Breast cancer diagnosis was a strong source of commonality among group participants. Participant age, time since diagnosis, and expectation for group sessions (e.g., group support versus health education) hindered group commonality. Barriers unique to the breast cancer experience were infrequent but people-pleasing behavior was often identified as a barrier to adherence. Feeling at risk for cancer recurrence was a major concern. Some participants required referral for mental health evaluation for pre-existing conditions (e.g., depression). Although participants easily understood time management, application of other behavioral modification techniques was more difficult.

Conclusions—A breast cancer diagnosis alone is not sufficient for commonality among group members. Teaching time management and positive reframing is essential. Protocols for appropriate mental health referrals are needed.

Implications for Practice—Our observations will assist group leaders in enhancing group dynamics and addressing obstacles hindering counseling effectiveness. Moreover, our results suggest hypotheses related to enhancing behavior change in a group setting worthy of future study.

Keywords

oncology; physical activity; survivorship; social cognitive theory; health education

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Introduction

Encouraging breast cancer survivors to exercise regularly is important for reducing disease risk and improving quality of life [1–2]. Although multiple studies have reported important information about exercise preferences, barriers, and correlates [3–9], reflecting upon lessons learned when applying this information to intervention implementation is worthwhile for enhancing translation and dissemination. Group counseling provides the opportunity to efficiently deliver specific information about exercise adherence while tailoring recommendations to the individual needs of group participants. The open group discussion format expands a facilitator's understanding of recurring needs of the participating breast cancer survivors which improves the facilitator's effectiveness in future group sessions.

Discussion groups can have a dual focus of education and social support. For example, such groups can address exercise adherence by 1) problem-oriented focus on exercise behavior and benefits after breast cancer, 2) group support for changing self defeating behaviors, 3) growth-oriented perspective, and 4) facilitating discovery of internal sources of strengths [10]. The role of the group facilitator is to assist participants in reaching their personal goal of exercise through education and effective group interactions. In playing this role, facilitators must be alert to factors influencing group dynamics such as trust, commonality, personal awareness of emotional response to their cancer diagnosis, sensitivity to needs and feelings of others, willingness to let others know them, age differences, commitment to change, and expectations for group activities and goals. [10]

We have previously reported an intervention that effectively improved exercise adherence in breast cancer survivors (i.e., change in ≥ moderate intensity physical activity per week for the usual care group was −21.7 minutes versus 78.7 minutes for the intervention group 3 months after intervention completion; p=.01) [11–12]. In addition to individual exercise and counseling sessions with exercise specialists, 6 group sessions were included in the intervention because of the importance of social support as an exercise correlate among breast cancer survivors [4, 8–9]. The intervention group sessions were also designed to address social cognitive theory constructs (see description of theoretical framework below and Table 1). To facilitate intervention effectiveness when translating to other locations and to inform investigators planning group sessions as part of an exercise intervention for breast cancer survivors, this report aims to describe clinical observations made while providing exercise counseling for breast cancer survivors in a group setting during the original pilot testing of the intervention and ongoing studies initiated since pilot testing. Observations with research and translation implications are reported.

Intervention theoretical framework and design

Health education interventions should be theory-based for optimal effectiveness [13]. Social cognitive theory constructs have been consistently identified as activity correlates in breast cancer survivors suggesting its usefulness in intervention design [8–9, 14–15]. Because self-efficacy (i.e., an individual's confidence in their ability to engage in a specified behavior) is the central construct in the social cognitive theory 16, our group discussions were designed to improve self-efficacy for overcoming exercise barriers. Because constructs other than self-efficacy warrant consideration in intervention design 13, the group sessions also addressed barriers interference, social support, observational learning (i.e., role models), exercise enjoyment, emotional coping, goal-setting, and expected exercise outcomes (positive and negative) and their importance. Constructs were addressed through group interactions, journaling, and education related to time management, stress management, and application of behavior modification techniques. Although this report provides clinical observations relevant to group counseling components of the intervention, we have provided a description of the

social cognitive theory targets and their magnitude of emphasis in the group and individual components of the intervention in Table 1. Additional intervention details have been previously reported 11−12. Small to medium effect size improvements in several of the targeted social cognitive theory constructs were found during pilot testing (manuscript submitted). Although these changes may be due to both group and individual counseling, Table 1 demonstrates that the group sessions were the delivery method for the majority of theory constructs targeted.

Methods

The BEAT Cancer intervention (Better Exercise Adherence after Treatment for Cancer intervention) is an exercise behavior change intervention which is based on the social cognitive theory (see description of theoretical framework above and Table 1) and includes individual and group sessions that taper the participant from a supervised to home-based exercise program 11−12. The previously described intervention 11−12 has been initiated with 63 breast cancer survivors in completed (i.e., 21 survivors) 12 and ongoing studies (i.e., 42 survivors). These 63 survivors represent 11 cohorts completing a total of 66 group sessions. Of the 63 survivors beginning the intervention, only 10% (n=6) have withdrawn before completing the intervention activities. Also, we have previously reported a group attendance rate of 98% in the pilot study 12. Participants have been sedentary or insufficiently active breast cancer survivors who have finished primary treatment for Stage I, II, or IIIA breast cancer. All group sessions have been lead by the same clinical psychologist (coauthor on this report) providing a unique opportunity to expand clinical awareness of the needs of breast cancer survivors seeking to increase their exercise adherence.

We provide a summary of our clinical observations, in an effort to disseminate the lessons learned while implementing the intervention. These observations were derived from three sources. First, verbal discussion with study staff occurred formally (i.e., open-ended request for feedback during weekly laboratory meetings and monthly exercise specialists' meetings) and informally (e.g., spontaneous feedback from study staff or exercise specialists which occurred in an ongoing fashion). Second, participants provided feedback formally (i.e., completed a written evaluation at the end of the intervention as previously described 12) or informally (i.e., made unsolicited verbal comments to staff, exercise specialists, or group facilitator that were then reported back to the principal investigator). Third, the following information and reflections were recorded by the group facilitator (clinical psychologist; coauthor on this report) in written journal entries within 24 hours after each group session: observations of group dynamics, unsolicited participant verbal comments, ideas for improving future group sessions (e.g., effective and ineffective strategies), and difficulties experienced along with potential solutions.

Of note, the significance of our observations was not identified until we initiated intervention implementation training materials for translation of the intervention to other sites. It was at that point that the investigative team realized that what we had learned by "trial and error" was currently not available in the medical literature and warranted dissemination by publication to other professionals in the field. Such dissemination would assist future group facilitators in enhancing group dynamics and avoiding obstacles and misconceptions which hinder the effectiveness of group counseling for behavior change. Furthermore, we realized our observations generated hypotheses related to the group process which could guide future researchers in the field. Because our observations represent a combination of multiple formal and informal sources rather than rigorous qualitative methodology, we have labeled our results as "clinical observations". The group facilitator and principal investigator for the trials using the intervention (coauthors on this report) met multiple times to review and discuss the information provided by the sources described above. These meetings were spent reconciling the observations for thematic consistency, application to the intervention goals and design, and

relevance to research and implementation implications. We acknowledge that this report is based on clinical experience rather than rigorous qualitative assessment methods (e.g., focus groups). Nevertheless, it is valuable and important for us to share what has been learned through clinical experience in our attempt to formalize what frequently occurs as a health care professional learns through the practice of their vocation. This information can also serve as the "qualitative" information that occurs when an expert draws on personal experience to enhance the training of individuals who will be implementing the intervention in future translational venues. Lastly, we do not aim to reiterate the vast knowledge currently available related to the leading of counseling groups [10] but focus our comments on issues specifically relevant to exercise counseling with groups of breast cancer survivors.

Clinical observations

Our comments are organized into general observations relevant to building the effectiveness of the groups involving breast cancer survivors followed by lessons learned related to each of the specific group session topic areas. Details related to the content of each group session are provided with the clinical observations to improve understanding of how observations related to specific session content. A summary of the lessons we have learned has been provided in Table 2 with more detailed comments provided below.

General observations

Each intervention cohort of group participants was unique due to differences in individual participant needs and expectations. For example, group participants with a more recent breast cancer diagnosis seemed to express a higher level of grief (or sense of loss) with greater need for (and benefit from) group support. In contrast, enhancement of group participation and benefit for participants with a more distant history of breast cancer diagnosis (e.g., ≥1 year) appeared to require exploration of their own denial of need for support and encouragement to provide support to more recently diagnosed women. Therefore, knowing time since diagnosis assisted the group facilitator in enhancing individual participation, group participation benefit, and emotional well-being. Because of the broad age range for breast cancer survivors receiving the intervention [e.g., 36 to 68 in the pilot study 12], it is relevant that the older survivors often seemed more open to group interaction than the younger participants.

With regard to expectations, some participants viewed the group sessions as opportunities for support without an expectation for learning, whereas others expected to receive information without group support activities. Because group sessions included both specific curricular information (e.g., didactic information) and group sharing, it was imperative that these expectations be understood and reconciled with group activities throughout the intervention to maximize the group counseling benefit.

It appeared to us that participants benefitted more from "case-based" provision of didactic material rather than a traditional slide presentation. Although a specific curriculum was necessary to standardize information delivery, asking discussion questions provided relevancy to the information provided. This also built group bonding as group participants became more comfortable sharing about "safe" or impersonal topics. Nevertheless, written information was provided as resources which the group participants could refer to during and after the group sessions.

The group facilitator spent time during each group session encouraging group participants to provide an update on their current needs and expectations in an effort to facilitate continued improvements in bonding, sharing, and personal insight. Most group participants seemed to enjoy sharing their experiences related to their breast cancer and efforts to increase exercise adherence. Although this sometimes occurred spontaneously, the group facilitator would ask

about this specifically at each session, if necessary. In addition to emotional well-being, this activity appeared to enhance reciprocal determinism with improvement in self-efficacy as participants reviewed their personal exercise adherence success (mastery experiences) and the success of other group participants (social modeling) [16]. Nevertheless, such sharing occasionally lead to recommendations by group participants to change intervention group format, focus, or information. Although we initially attempted to respond to this feedback mid-intervention, this "fractured" the flow and intent of the intervention. Therefore, we learned that facilitators should treat this feedback with respect and empathy while postponing changes in response to valid feedback until the next intervention implementation.

With regard to logistical issues, several different conference rooms of varying sizes and seating arrangements were used based on availability. It is not unexpected that that smaller rooms with sitting around a table rather than in a classroom setting facilitated group sharing. We also learned that more frequent scheduling of the initial groups (e.g., the first 3 sessions were held weekly with the remaining 3 groups held every other week) facilitated trust building among the group participants. Lastly, we learned it was important to reinforce and model regular group attendance, starting on time, and finishing within the allotted time.

Introduction (Group session #1)

The introductory session focused on intervention goals, exercise safety, importance of confidentiality, and initiating the process of "getting to know each other". As mentioned above, identification of differences in the individual group participants' needs and expectations by the group facilitator was quickly added to the introductory session during pilot testing. We learned that the first session was crucial to participants and the group facilitator "getting to know each other". This interaction enhanced group support throughout the intervention by providing the group facilitator with the necessary understanding of individual participant differences while appearing to facilitate important emotional bonding among the group participants. In our experience, potential differences included variable family dynamics, breast cancer side effects, preexisting psychiatric conditions, and prior physician counseling about exercise after breast cancer diagnosis. Moreover, honest sharing of deep personal experiences during the introductory session seem to facilitate the trust, social support, and identification with other participants (i.e., observational learning) needed to enhance group dynamics [10]. We felt this was important for our intervention because social support is a significant exercise correlate 8–9, with subjective norm being especially important among breast cancer survivors 4. Therefore, the introductory session was important for laying the foundation for the recurring theme of trusting relationships and supportive networks encouraged during all subsequent group sessions.

Journaling was introduced during the introductory group session (and reinforced throughout the intervention). By recording successes in overcoming exercise barriers and exercise benefits personally experienced for later review and by dealing with emotional influences on behavior, this activity targeted emotional well-being, self-efficacy, reciprocal determinism, and perceived barriers. We learned that participants respond with different levels of enthusiasm for keeping a hand-written journal with some women choosing to use the computer to journal or choosing not to keep a journal at all.

Time and stress management (Group session #2)

Group discussions related to time and stress management consistently revealed that many breast cancer survivors participating in the intervention did not spend time caring for their own health because they were too busy caring for others. The group facilitator learned the importance of consistently assisting participants in obtaining personal insight into this possibility. Sessions focused on helping participants understand that they are better able to help

others if they care for themselves (including making time for regular exercise) and they have the right to assert their needs and express when expectations are unfair or excessive. Also relevant, exercise adherence was reframed as mandatory rather than optional.

Traditional time management skills and stress relieving techniques were taught. Exercise goal setting was also mentioned and the concept of behavioral antecedents (see below) was introduced. These activities addressed the following social cognitive theory constructs: perceived barriers related to lack of time, emotional well-being related to stress, barriers self-efficacy, goal setting, and environment related to antecedents. We learned that at least one group participant during each cohort eventually revealed a need for professional services from a mental health professional, usually for depression. Therefore, the facilitator has remained alert to this possibility and we have developed a referral protocol for such participants.

Perceived barriers (Group session #3)

Lack of time was the most frequent and consistent exercise barrier discussed in the group setting. In addition to traditional time management techniques such as making a “to do” list (including prioritization) and scheduling exercise sessions ahead of time on a personal calendar, the group facilitator had to identify and address personality characteristics. Our impression was that many of the breast cancer survivors who struggled with lack of time were “people pleasers” who were unable to set clear boundaries. In choosing to use their time for exercise, several attitudes were noted. First, participants sometimes behaved a certain way (i.e., chose not to exercise) because they were “rule followers” who thought they had to act a certain way and did not realize they had a choice about how to spend their time. This attitude was often based on considering others’ needs above their own needs to an extreme. As a result, participants were counseled that they deserved to take time to exercise but, more importantly, if they chose to exercise they would be healthier and better able to care for the needs of others. Interestingly, barriers specifically related to breast cancer (e.g., lymphedema, fatigue, and joint pain) were less frequently mentioned. Fear of exercise and negative outcome expectations were addressed in this session. Also, the concept of antecedents was revisited and participants were encouraged to identify positive outcome expectations (currently experiencing and expected), consider ideas for setting up a personal support system (i.e., social support), and choose enjoyable physical activities.

Role model speaker (Group session #4)

To provide observational learning and improve self-efficacy (i.e., vicarious experience), a breast cancer survivor who exercised regularly was invited to participate in the group discussions during session #4. These speakers were routinely well-received by participants. The most frequent questions/concerns raised for the role model speaker focused on their personal experience with breast cancer treatment and side effects. This implied a participant interest in comparing her personal experience with others. For example, did they get the same treatment and have the same side effects? Is there something else that someone is doing that they should be doing to improve their chances of survival? Our sense was that participants wanted to be sure they were doing all they could possibly do by comparing their own experience with someone who had lived longer since their breast cancer diagnosis.

ABC sessions/behavioral modification (Group session #5)

Behavioral modification was taught using the ABC format described by Watson and Tharp 17. Specifically, “A” refers to antecedents (setting events to cue and facilitate behavior), “B” refers to behavior (actions, thoughts, and feelings that allow practice of new behaviors and removal of distractions and obstacles), and “C” refers to consequences (reinforcements) [17]. Because several key concepts relevant to behavioral modification had been mentioned in preceding discussions, a more formal discussion with assembling and refining concepts into a

more complete personal application was done. The need to reframe cognition with positive self-talk (i.e., affirmations) and view exercise as mandatory rather than optional was reviewed and reinforced in this session. Assisting group participants to articulate a personal behavioral modification plan for enhancing exercise adherence required avoidance of psychological "jargon" while linking behavioral modification to time management activities. In other words, participants appeared more familiar with the concept of time management but struggled with conceptualizing behavioral modification techniques unless they were combined with time management activities learned and practiced in the earlier group sessions. For example, scheduling exercise sessions on the calendar is both an antecedent and a time management activity 17. Similarly, having participants develop contingency plans for unexpected scheduling conflicts is also an antecedent. Another challenge to articulating the behavioral modification plan was the fact that not all group participants enjoyed writing out their thoughts and plans.

An effort to raise awareness of exercise benefits (i.e., consequences) was also made and participants were asked to articulate and focus on these benefits. The outcome expectations and exercise benefits often mentioned by participants included less fatigue, a feeling of accomplishment, increased enjoyment of exercise, and greater feeling of control (e.g., felt like they were doing something to improve their health). Because enjoyment is a consistent and strong correlate of exercise [18], it is noteworthy that the increased feeling of enjoyment was reported by some participants as being due to learning how to exercise (e.g., "learned what to do"). Lastly, some group participants doubted the current epidemiologic data supporting a reduction in breast cancer risk with regular exercise because they personally knew women who had developed breast cancer or had a recurrence in spite of exercising regularly. This appeared to limit the motivational impact of this potential benefit. We learned from this response that helping women understand the concept of risk reduction was important for understanding the benefits of exercise.

Wrap-up/wellness session (Group session #6)

The final session was spent reviewing material and topics covered in the previous group sessions. Priority was given to the review of final exercise goals (i.e., addressed social cognitive theory construct of goal setting), effective adherence strategies (i.e., self-control and performance), and outcomes experienced from regular exercise participation (i.e., positive and negative outcome expectations). We learned that this session was important for closure among the participants because it provided an opportunity for participants to ask questions of the group facilitator and enhanced potential future exercise social support through the voluntary exchange of contact information among group participants.

Discussion

Clinical experience with 63 participants in 66 counseling group sessions designed to improve exercise adherence in breast cancer survivors has taught us valuable lessons (Table 2) with several key lessons warranting specific comment. Although breast cancer itself is a strong source of commonality among group participants, group facilitators may need to address other areas of diversity, such as age and expectations for the group interactions. Also, basic concepts related to group dynamics, participant coping styles, and exercise adherence (e.g., barriers) are applicable to breast cancer survivors but facilitators should be alert to aspects unique to the cancer survivor experience (e.g., treatment side effects, fear of not doing enough for their health). Related to the emotional impact of a cancer diagnosis, participants may require referral to a mental health professional for diagnosis and management of underlying conditions such as depression and facilitators should be familiar with appropriate protocols for making these referrals. Lastly, teaching participants to apply behavioral modification techniques can be

challenging due to participant difficulty understanding the concepts and/or resistance to keeping written journals or modification plans.

With regard to group dynamics, the group process was similar to other groups who are highly committed to the process because they feel "at risk" [10]. The group participants interest in ensuring that they are doing all they can do to reduce their disease risk (including exercise), is consistent with the "teachable moment" for health behavior change after a cancer diagnosis [19] and the frequent belief among breast cancer survivors that exercising regularly would help them “gain control of my cancer and my life” 5 and “change the course of cancer” 14. It also suggests that the Health Belief Model 13 may warrant further study as a potentially appropriate framework for interventions aimed at cancer survivors. Also, similar to that described in other populations 10, group dynamics were influenced by the wide age range and sensitivity to others needs (e.g., talking too much). Although these factors can be overcome by an attentive and astute group facilitator, our experience reinforces the need to be on the alert for these issues. The general concepts of group dynamics also suggest that the high level of commitment to the process found among the participants [e.g., 80% in the contemplation or preparation stage of change 12] may have contributed to our intervention success.

With regard to social cognitive theory constructs, our experience is consistent with prior studies suggesting the importance of social support and subjective norm in exercise behavior, especially in breast cancer survivors [4, 8–9]. The support of others in the group was important for helping participants feel as though they were not alone in their fear and struggle to live their lives after their cancer diagnosis. Related to exercise barriers, the most frequent barriers were not specific to the breast cancer experience probably because participants were not currently receiving primary treatment nor did they have more severe disease symptoms and treatment side effects that may be expected with certain cancer types, such as head and neck [20–21]. Facilitators of groups involving cancer survivors at risk for more severe side effects should be familiar with potentially unique or more frequent barriers. Lastly, participants may view population-based epidemiologic data as invalid based on a single personal, individual experience. Therefore, a reduction in cancer risk can be a motivating benefit but it requires that participants understand the concept of relative risk.

To advance the effectiveness of group sessions for enhancing exercise adherence among breast cancer survivors, future research should evaluate the impact of matching participants on factors, such as age, in addition to a breast cancer diagnosis. Because preferences and expectations differed among group participants and preferences may influence an individual’s response to an exercise intervention [22], the influence of preferences and expectations for group interaction and activities such as journaling are worthy of investigation. Also important is the influence of coping styles and personality types on many of the participants’ struggle to adopt a physically active lifestyle. Although personality may influence exercise adherence in cancer survivors [23–24], the impact of “people pleasing” behaviors on lifestyle adherence in cancer survivors is an understudied area that warrants further attention.

Importantly, the group session appeared to be a useful way to provide health education with social support. Group facilitators should identify expectations and should avoid using the term “support group” which suggests an exclusively supportive group focus without educational intent. Facilitators should also be sensitive to unique situations, coping styles, and the fact that a breast cancer diagnosis alone may not be sufficient for group commonality. Demonstrating personal relevance is important especially when applying behavioral modification techniques. Lastly, a protocol for assisting the occasional participant who may need a mental health referral is necessary.

Acknowledgments

We acknowledge that this report is based on clinical experience rather than rigorous qualitative or quantitative data. Nevertheless, our observations further expand our understanding of the clinical realities of effectively assisting breast cancer survivors in adopting an exercise program. Our observations also suggest several worthwhile research and translational implications that can contribute to future efforts to improve the health and well-being of the breast cancer survivors.

Grant support: This report was supported by the Southern Illinois University School of Medicine Excellence in Academic Medicine Award (#E200634), Brooks Medical Research Fund, SimmonsCooper Cancer Institute 2008 Developmental Cancer Research Award in Translational Science, and Memorial Medical Center Foundation and Regional Cancer Center. Dr. Rogers and Dr. Vicari are supported by the National Cancer Institute Grant CA 136859-01. Dr. Courneya is supported by the Canada Research Chairs Program.

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Table 1

Social Cognitive Theory Intervention Targets for the Group and Individual Components of the BEAT Cancer Intervention (magnitude of emphasis indicated by number of asterisks).

Social Cognitive Theory Target	Group Components Only	Individual Components Only
Barriers Self-Efficacy	***	*
Task Self-Efficacy		***
Barrier Interference	***	***
Social Support	***	
Outcome Expectations	***	*
Value (Outcome Importance)	***	
Enjoyment	**	
Fear of Exercise	*	**
Role Model	**	
Exercise Partner	**	

Table 2

Summary of Session Content and Lessons Learned for the Group Session Components of the BEAT Cancer Exercise Behavior Change Intervention for Breast Cancer Survivors.

Group	Content	Lessons learned
General	N/A	• Determine time since diagnosis and age • Clarify expectations for group experience • Use case-based format • Encourage sharing of progress at each session • Avoid format changes mid-intervention • Use smaller room with table • Shorter time intervals between groups facilitates group dynamics
Session #1	Intervention Goals; Exercise Safety; Confidentiality; Getting Acquainted; Journaling	• Determine individual differences and expectations • Initial interaction is critical for facilitating emotional bonding, trust, and social support • Prepare for varying responses to journaling
Session #2	Time Management; Stress Management; Introduction to Exercise Goal Setting and Antecedents	• Too busy helping others may be a barrier • Reframe exercise as mandatory • Have a protocol for mental health referral
Session #3	Perceived Barriers; Outcome Expectations; Social Support Outside of the Group Setting; Exercise Enjoyment	• Time management is critical • Survivors may be “people pleasers” • Barriers may or may not be cancer specific • Identify personal social support for exercise • Review antecedents • Encourage identification/ review of positive outcomes • Advise to choose physical activities they enjoy
Session #4	Role Model Speaker	• Well-received by survivors • Discussion may focus on cancer diagnosis and treatment experience rather than exercise • Survivors may fear they are not doing enough for their health
Session #5	Behavioral Modification Techniques and Personal Plan	• Incorporate time management concepts • Avoid psychological “jargon” • Encourage use of affirmations • Reinforce positive outcome expectations • Discuss the meaning of disease risk reduction because survivors may know a regularly exerciser who developed breast cancer
Session #6	General Wellness; Final Question and Answer Period; Review; Closure	• Allow a final chance to ask questions • Survivors may wish to exchange contact information and/or arrange future exercise partnerships