Factors That Affect Decisions About Physical Activity and Exercise in Survivors of Breast Cancer: A Qualitative Study

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Background. Exercise has many benefits for survivors of breast cancer, yet only half of this population regularly exercise. Fear has been identified as a barrier to exercise for people with neuromusculoskeletal conditions but has been minimally explored in women with breast cancer.

Objectives. The purposes of this study were: (1) to investigate factors that affected decisions about physical activity and exercise in survivors of breast cancer and (2) to determine whether fear was a factor.

Design. This investigation was a grounded-theory qualitative study. Qualitative data were triangulated with data from 2 quantitative scales that measured participants' beliefs about exercise and their activity levels.

Methods. Thirty-four survivors of breast cancer in 8 focus groups participated in semistructured interviews that were recorded, transcribed, and coded. Concept maps created for each group were merged to develop themes. Beliefs about physical activity and exercise were assessed with the Decisional Balance Scale. The Rapid Assessment of Physical Activity was used to assess behaviors regarding physical activity and exercise before and after the breast cancer diagnosis.

Results. Participants generally believed that exercise was beneficial (Decisional Balance Scale score: $\overline{X}=28.1$ [of a maximum score of 44], SD=7.6, range=10-43). Participants decreased the amount of physical activity or exercise during treatment but increased the amount of exercise beyond prediagnosis levels after treatment (Rapid Assessment of Physical Activity score: median=6, range=2-7). Three prominent themes described participants' behaviors regarding physical activity or exercise: values and beliefs about exercise, facilitators and barriers that were both similar to those affecting the general population and cancer specific, and lack of or inaccurate information about safe exercise.

Conclusions. Survivors who were active were not afraid to exercise. However, concern about lymphedema and knowledge about safe and effective exercise programs influenced choices regarding physical activity and exercise.

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Regular exercise and activity in survivors of breast cancer has been linked to reductions in cancer-related fatigue[1] and nausea symptoms,[2] improvements in immune system function,[3] and reduced rates of cancer recurrence.[4,5] Review articles[6,7] also have supported physiological and psychological improvements with exercise and activity, such as decreased anxiety[8] and improved cardiopulmonary function[9] and quality of life.[10] Additionally, moderate-intensity and vigorous recreational activity has been found to decrease the risk of breast cancer-related death,[11,12] and moderate activity has been found to decrease the risk of recurrence.[11] However, only half of survivors of breast cancer exercise; this rate is similar to that of the general population.[13] Many survivors who exercised before the diagnosis do not return to the same exercise level.[13-15]

Web-based resources available to survivors support the benefits of exercise for people living with cancer but, until recently, have failed to offer sufficient exercise program guidelines.[16] In an effort to fill this gap, a roundtable convened by the American College of Sports Medicine concluded that survivors of cancer should follow the 2008 Physical Activity Guidelines for Americans,[17] with adaptations based on treatment-related adverse effects.[18] Historically, survivors of breast cancer were advised to avoid or limit physical activity and resistance exercise because of the risk of developing lymphedema.[19] In a recent randomized controlled trial, however, Schmitz et al[20] found that a slowly progressive weight lifting program did not significantly affect the severity of lymphedema in survivors of breast cancer with lymphedema. Additionally, weight lifting reduced the number and severity of symptoms in the arm and hand, increased muscular strength, and reduced the incidence of lymphedema exacerbations. These recent findings need to be communicated to survivors to encourage regular exercise.

Fear has been identified as a primary barrier to physical activity or exercise (PA/E) and has been measured in people with a wide variety of neuromusculoskeletal conditions.[21-25] Fear was found to limit activities in people with osteoarthritis, even in the absence of significant radiological findings.[26] Piva et al[27] found that fear-avoidance beliefs and anxiety were associated with function and pain in patients with patellofemoral pain syndrome, although the physical impairments measured in the study, such as muscle strength and length, were not associated with function or pain. For people with musculoskeletal problems, identification of fear-avoidance beliefs and management of those beliefs during interventions can reduce fear and predict or improve outcomes.[25,28,29] Additionally, Houben et al[30] found fear of movement and injury in a general population without pain, a finding that emphasizes the importance of examining fear as a barrier to decisions about PA/E in people with cancer.

The awareness of fear as a barrier to movement is a nascent concept in oncology. Two studies addressed the concept of fear with different methods. Karadibak et al[31] used the Tampa Scale for Kinesiophobia to measure fear of movement before and after an intervention of complete decongestive therapy for 62 women with breast cancer-related lymphedema. They found a positive correlation between fear of movement and severity of lymphedema. They also found a decrease in Tampa Scale for Kinesiophobia scores and thus a decrease in fear after 12 weeks of treatment. Lee et al[32] used a survey to explore why women avoid strenuous arm activity after breast cancer surgery. They found that fear of lymphedema and lack of health care provider approval of arm exercises influenced women's intention to avoid strenuous activity. The variables distinguishing women intending to avoid strenuous activity from those not so intending included the extent of axillary surgery and the receipt of advice about arm care from a combination of sources, such as health care providers and the Internet. In these 2 studies,[31,32] participants were directly questioned about fears related to movement and developing or worsening lymphedema.

We undertook a qualitative approach that did not assume that survivors of breast cancer avoided strenuous exercise or had fear related to PA/E but allowed the concepts, if present, to emerge from the stories of the participants. Therefore, the purposes of this study were: (1) to investigate factors that affected decisions about PA/E in survivors of breast cancer and (2) to determine whether fear was a factor. We defined *physical activity*[33] as any movement that involved the use of skeletal muscle and raised energy expenditure above a resting metabolic rate and that did not have to reflect systematic, planned, or structured skeletal muscle activity of a specific frequency, intensity, duration, or mode; *physical exercise*[33] was defined as systematic, planned, or structured physical activity that involved a specific frequency, intensity, duration, or mode and that was performed regularly for the purpose of enhancing physical fitness.

Method

Individual biases of the investigative team members were discussed and incorporated into initial concept maps[34] describing the relationships between fear and PA/E. These individual concept maps were merged to illustrate the conceptual framework

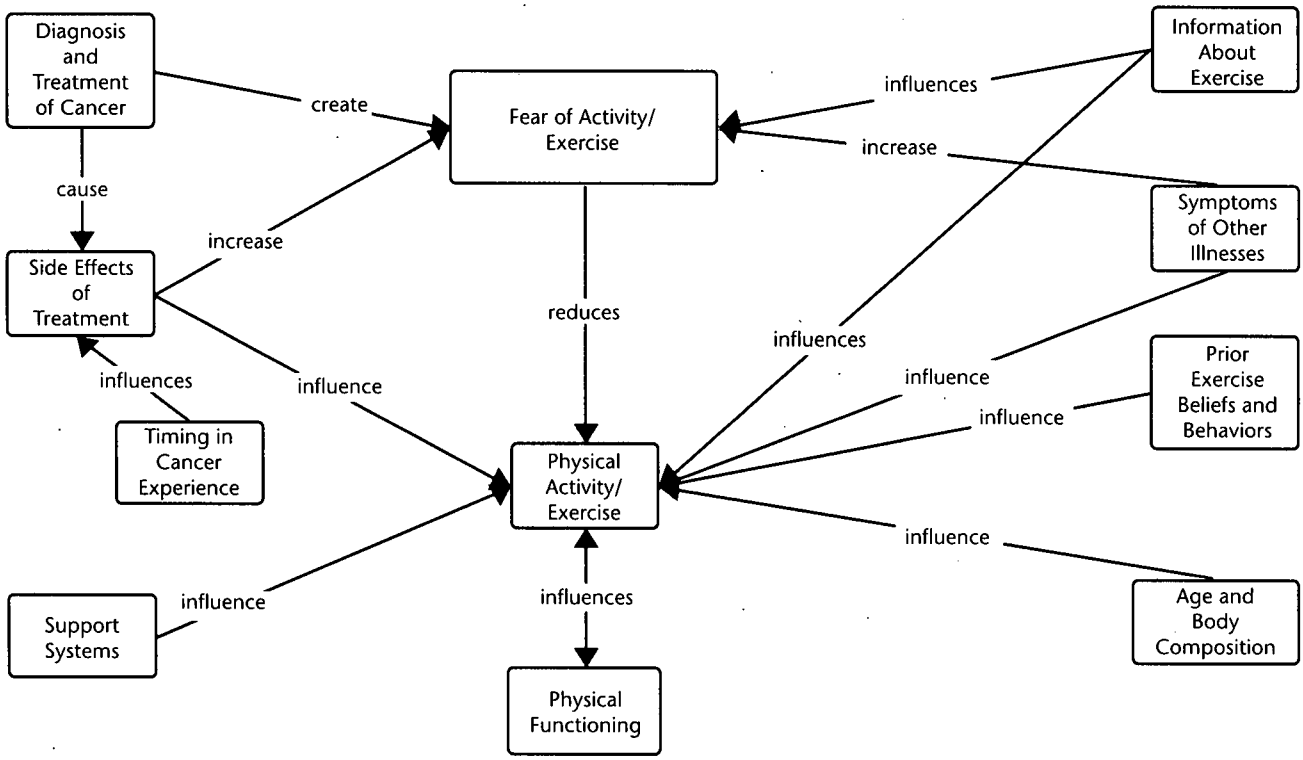

Figure 1.
Initial conceptual framework hypothesizing relationships between physical activity or exercise and fear before data collection.

for the study. We hypothesized relationships among fear of activity or exercise, PA/E, and physical functioning and potential influences on these 3 constructs (Fig. 1). In addition to the usual influences on behaviors regarding exercise, such as support systems, age, and body composition, we believed that the effects of cancer and treatment of cancer, the timing of exercise in the cancer experience, preexisting beliefs about exercise and behaviors regarding exercise, and the amount and type of exercise information available would affect the decisions of survivors of cancer regarding exercise.

Study Design

This investigation was a grounded theory qualitative study in which focus groups[35] and semistructured interviews were used as the primary data collection methods. The intent of a grounded theory study is to generate a general explanation of a process, action, or interaction shaped by the views of representative participants.[36] In grounded theory, an inductive, systematic approach to data analysis is used to explain behavior. Because fear was a relatively unexplored concept with regard to decisions about PA/E in women living with breast cancer, we believed that grounded theory was the best approach. We selected focus groups to allow conversation, agreement, and disagreement among participants to further elucidate the fear concept, if present. Qualitative data were triangulated in an analysis with data from 2 quantitative scales that measured participants' beliefs about exercise and their activity levels. Triangulation provided a more comprehensive description of the participants in our study.

Participants

Survivors of breast cancer who were currently exercising or had never exercised on a regular basis were recruited from a Midwestern medical center through posted flyers, physicians, and other health care providers. Participants could be in treatment or beyond treatment and with or without lymphedema. Inclusion criteria for the participants included being a woman and being 18 to 80 years of age. Exclusion criteria were metastatic disease and pregnancy. Sixty people were screened, and 42 agreed to be scheduled for focus group sessions. People who did not participate were not interested or were not available for the scheduled focus group sessions. Participants were scheduled as they responded to the recruitment efforts. Of the participants who were scheduled, 8 did not attend the assigned focus group sessions and were not available for rescheduling. Because demographic

Table 1.
Demographics of 34 Participants in 8 Focus Groups[a]

Characteristic	Value
Age, y, $\bar{X}$ (SD)	56.9 (9.7)
Body mass index, kg/m^2, $\bar{X}$ (SD)	25.7 (5.6)
Months after treatment, $\bar{X}$ (SD)	56.3 (66.7)
No. of nodes removed at surgery, $\bar{X}$ (SD)	1.2 (2.6)
Race/ethnicity (n=33)	
African American	3
Hispanic	1
White	29
Cancer stage (n=32)	
0	1
I	18
II	8
III	5
Treatment	
Lumpectomy	21
Mastectomy	13
Chemotherapy	19
Radiation	30
During treatment	4
After treatment	30
Lymphedema present	5
Currently exercising	29

[a] Values represent number of participants, unless otherwise indicated.

data were collected at the time of the focus group meetings, information about people who did not participate was not available. We ultimately enrolled 34 participants across 8 focus groups consisting of 2 to 6 participants. Although efforts were made to recruit participants both during treatment and after treatment, most of the participants were months or years beyond cancer treatment. Five participants had lymphedema, and 29 were currently exercising at some level (Tab. 1). All participants provided written informed consent.

Quantitative Data Collection

To describe levels of physical activity, participants completed the Rapid Assessment of Physical Activity (RAPA),[37] reflecting their levels of activity both before diagnosis and at the time of our study. The RAPA is a descriptive scale that was developed to assess and monitor aerobic, strengthening, and flexibility-promoting activities of adults older than 50 years of age. This scale met our needs with regard to age and activities that were measured. Part 1 of the RAPA (RAPA 1) consists of 7 hierarchical questions about the frequency and level of intensity of physical activity. Part 2 of the RAPA (RAPA 2) consists of 2 additional questions pertaining to strengthening and flexibility-promoting activities. Responses are dichotomous (yes/no). The RAPA 1 is scored from 1 to 7 (1=rarely engage in any physical activity; 7=engage in 20 minutes of vigorous activity 3 or more days per week). A participant's score is the highest numbered item with an affirmative response. The RAPA 2 is scored on the basis of whether a participant engages in strengthening activities, flexibility-promoting activities, or both. The RAPA was shown to have good criterion validity and good predictive properties for identifying adults who did and adults who did not meet the Centers for Disease Control and Prevention-recommended physical activity standard of 30 minutes of moderate activity 5 days per week or 20 minutes of vigorous activity 3 days per week.[38] Reliability data are not available.

Participants' beliefs about regular exercise were measured with the 16-item Decisional Balance Scale,[39] which is used to examine beliefs about the benefits of and barriers to regular exercise. On the basis of pilot data, we modified the response categories from rating the importance of items to rating the level of agreement (1=strongly disagree; 5=strongly agree). Summing 10 positive-belief items creates the "pro" subscale score (possible range=10-50); summing 6 negative-belief items creates the "con" subscale score (possible range=6-30). The Decisional Balance Scale score is the difference between the pro and con subscale scores and can range from −20 (10 minus 30) for someone with markedly negative beliefs to 44 (50 minus 6) for someone with markedly positive beliefs. Thus, higher scores represent a more positive attitude toward exercise. This scale exhibited evidence of construct validity by discriminating between survivors of breast cancer who were sedentary and those who participated in regular exercise. Survivors who were sedentary identified more negative-belief items than survivors who exercised regularly.[40] The alpha coefficient of internal consistency for the modified scale was .78.

Qualitative Data Collection

Before collecting qualitative data, research team members held "practice interviews" until they felt comfortable with the questions and the process. Eight focus groups met for 2-hour sessions that were audiotaped and transcribed. For each focus group, 1 researcher was the primary interviewer, and the second researcher managed the recording equipment and took field notes on the process and content. A semi-structured interview guide (Appendix) of open-ended questions provided both structure and flexibility during the interview. The interviewers did not specifically ask the participants whether they were afraid to engage in PA/E until the end of the interview. This decision was made purposefully to decrease potential bias in our results and to allow the concept of fear, if present, to emerge from the stories of the participants. Focus group sessions were conducted until data saturation was reached, that is, until similar stories were heard from new participants.[35] When similar themes emerged in subsequent focus group sessions, recruitment was discontinued.

Data Analysis

Quantitative data were analyzed with descriptive statistics, and the results were triangulated with the results of the qualitative analysis. Qualitative data analysis began as interviews were transcribed and involved the iterative process of constant comparative analysis.[36] Constant comparative analysis is especially suited for grounded theory studies because the data, in the form of transcripts from interviews of the participants, are coded, compared, integrated, and delimited in the process of formulating a theory to describe behavior.[41] This process ensures that the final themes are a good fit, truly grounded in the data.

Table 2.
Rapid Assessment of Physical Activity (RAPA) and Decisional Balance Scale Results

Assessment	Value
RAPA score, median (range)	
Before cancer diagnosis	5 (3–7)
Current	6 (2–7)
Strengthening exercise, % of participants performing	
Before cancer diagnosis	50.0
Current	58.8
Flexibility-promoting exercise, % of participants performing	
Before cancer diagnosis	52.9
Current	67.6
Decisional Balance Scale[a] score, $\bar{X}$ (SD), range	28.1 (7.6), 10–43
"Pro" subscale score	42.2 (5.7), 28–50
"Con" subscale score	14.1 (4.4), 7–34

[a] The "pro" subscale represents positive beliefs, and the "con" subscale represents negative beliefs.

Analysis of the focus group transcripts began with open coding[42] of the text to characterize the statements made by the participants. These coded statements were grouped into categories, creating code books[43] of data and identifying the frequency with which the categories were discussed across the focus groups. Concept maps[34] were created to visualize the relationships among the coded categories. At least 2 investigators developed individual concept maps for each focus group. The individual concept maps were combined across investigators and across groups so that, in the final analysis, we used a single consensus concept map to develop themes. A narrative summary of the concept maps was sent to the participants for feedback. Finally, a consultant on the project who had not participated in data collection or analysis reviewed the transcripts, concept maps, and narrative summary. Efforts to ensure the trustworthiness of the analysis included the identification of biases of the investigators, peer review by the researchers of code books and concept maps, member checks, and external review of the final themes.

Role of the Funding Source

This study was supported by grant 1229 from the Oncology Section of the American Physical Therapy Association. The funding source had no role in the study design; data collection, analysis, and interpretation; or writing of this report.

Results

Quantitative Results

The median RAPA 1 score before diagnosis was 5 of 7 (range=3–7), which described vigorous activity for less than 20 minutes per day or 3 days per week. After treatment, the median RAPA 1 score was 6 of 7 (range=2–7), which described moderate activity for at least 30 minutes per day, 5 or more days per week. Fourteen participants did not change their levels of activity after treatment; 12 increased and 8 decreased their levels of activity after treatment. The RAPA 2 scores indicated that 50% of the participants engaged in strengthening exercises before diagnosis, and this proportion increased to about 59% after treatment; about 53% of the participants engaged in flexibility-promoting exercises before diagnosis, and this

proportion increased to about 68% after treatment (Tab. 2). Although biased toward vigorous exercise, each of the focus groups contained both participants who were active and participants who were less active.

The mean Decisional Balance Scale score (of a maximum score of 44) was 28.1 (SD=7.6) (Tab. 2). The mean pro subscale score (of a maximum score of 50) was 42.2 (SD=5.7), and the mean con subscale score (of a maximum score of 30) was 14.1 (SD=4.4). The scores reflected that most, but not all, of the participants believed that exercise was beneficial. Triangulation of these data with qualitative data helped to describe the current activity levels and beliefs about exercise of the participants in our study.

Qualitative Results

Three prominent themes that described participants' behaviors regarding PA/E emerged: values and beliefs, facilitators and barriers, and lack of information.

Values and beliefs. Participants valued exercise for commonly accepted reasons, such as improved health and personal appearance. As 1 participant stated:

> I think, not even because I'm a breast cancer patient, but I think for your whole body and your mind, you just have to keep moving. I think once you sit down, you get sedentary and then the whole body sort of gets lazy. . . . I try to walk, take the bus more and walk from the furthest point in the parking lot, just little mindful things to keep a little bit more motion in my life. (Group 1, participant 5)

Participants also believed that exercise would prevent recurrence of their cancer and increase their immune responses to fight disease. As noted by 2 participants:

> I understand that being physically fit will reduce the likelihood of a recurrence, so that's a huge motivator. (Group 5, participant 3)

> I believed that exercise built up my immune system. (Group 5, participant 6)

Participants did not always like to exercise but still appreciated the value of exercising. As 1 participant remarked:

> Before I was diagnosed with breast cancer I had to admit that I hated to exercise. But I have started exercising every morning for about an hour . . . and I hate every minute of it, but I know it's good for me. (Group 7, participant 6)

Facilitators and barriers. Survivors experienced facilitators of and barriers to exercise and activity that were similar to those experienced by the general population, such as convenience, social support, time, and musculoskeletal pain. Echoing a common barrier to exercise, 1 participant stated:

> I need a class. I need that social aspect to it. I need a class that is at a nice time of the day for me to go. (Group 2, participant 5)

In contrast, some participants described too much support from family and friends as a barrier to activity because they were encouraged to rest and prevented from doing regular household chores. As 1 participant stated:

> My immediate family has become so concerned about me that they try to do things for me instead of letting me do them. (Group 4, participant 3)

Survivors also experienced specific cancer-related barriers, such as fatigue, neuropathy, joint pain, and poor body image, which affected their decisions about exercise. Two participants' comments typified cancer-related barriers:

> Chemotherapy came and I did experience fatigue . . . so that stopped me from doing a lot of things. (Group 8, participant 1, during treatment)

> I was really working out quite a bit before the diagnosis, but during treatment I became very inactive. (Group 5, participant 3)

Lymphedema emerged as a cancer-related barrier that produced fear and concern in the participants and affected their decisions about PA/E. As 1 participant stated:

> But I was also afraid of doing those exercises because of the fear . . . of lymphedema . . . . So I think there's a piece of me that's always a little bit concerned about what I can do with my right side and what kinds of exercises I should be doing. (Group 3, participant 1)

Echoing this fear, another participant stated:

> Well, definitely, I was afraid of getting lymphedema after I read all those booklets from the American Cancer Society. Several times, when something went wrong, I would ask my primary [physician] if I had lymphedema because I was getting really nervous about getting that. (Group 6, participant 1, during treatment)

Participants did not understand why some survivors developed lymphedema and others did not, and this confusion contributed to their fear. They told stories about how other survivors had developed lymphedema, and the causes appeared to be random. As 1 participant stated:

> I sort of don't even know why it happens to people 5 and 10 years later. Friends will tell me, "Well, I was lifting"—a lot of times it was yard work, dragging mulch—but, why mulch and not a suitcase? I mean, I'm so perplexed by it, and I'm totally perplexed as to where I would go if it were to occur. (Group 1, participant 6)

Because most of the participants believed in the benefits of exercise, as indicated by the Decisional Balance Scale scores, they continued to perform regular exercise with modifications. Several participants limited the amount of weight that they lifted in daily activities or avoided resistance exercise in their workout routines because of fear of injury to the involved arm. As noted by 1 participant:

> Right after my surgery, I was afraid to pick up my grandbaby. Not that I was worried about dropping her, but I felt that she might have been too heavy for me. (Group 4, participant 3)

Fear of lymphedema and injury contributed to self-imposed barriers and modifications to PA/E. Participants addressed PA/E with cautious confidence. As 1 participant stated:

> I pretty much would do whatever I wanted to do. I don't think that I feel like I have any limitations. I do occasionally worry about putting weight on my left arm, but for the most part, I would do anything. (Group 3, participant 4)

Cancer-related barriers led to self-imposed limits in daily activities and exercise routines. Some survivors learned to "listen to their own bodies" to determine how much activity or exercise they should perform. Within these limitations, they managed to do what needed to be done in their daily lives. As 1 participant remarked:

> I think because my husband doesn't do a lot, . . . if I don't do it, no one's going to do it so I have to do it. But that's a good thing for me. (Group 1, participant 3)

Lack of or inaccurate information.

Participants believed that guidelines from health care providers about lymphedema and about safe and effective exercise parameters were insufficient. Lack of information and misinformation about lymphedema for those seeking guidance about the management and prevention of lymphedema contributed to the fear of lymphedema. As 1 participant said:

> I'm so perplexed about lymphedema. . . . The surgeon [said,] "this is not my problem," and the radiation oncologist [said,] "this is not my problem . . . (Group 1, participant 6)

Participants found conflicting information from health care providers, the Internet, and stories about other survivors. As 1 participant stated:

> I got a lot of information from my doctors encouraging exercise, definitely. But also from the Internet I sought out information on my own. But a lot of times I felt that there was a conflict. Information from the Internet and from pamphlets and other resources made the risk of lymphedema seem huge, and I felt that my surgeon really downplayed it and said, "No, no, no, you're really not at risk," so I felt there was some conflict in the information I was getting. (Group 4, participant 4)

Guidelines regarding weight lifting, when given, were not consistent among participants, as indicated by several comments:

> Soon after my surgery the surgeon said that I could not lift more than 5 pounds on that side, and I never quite understood if that was permanent or temporary. . . . (Group 6, participant 1, during treatment)

> I was told that I could only lift 10 pounds. (Group 2, participant 2)

> They did warn me not to lift more than 20 pounds. (Group 2, participant 6)

Participants wanted safe and effective exercise guidelines from health care providers who understood the risk of the development of lymphedema. As 1 participant stated:

> None of the medical people that I'd gone through . . . gave me any advice as to physical exercise or activity. None of them! I did it all from my friends on the Internet, I did research, or I went to the library and tried to find the information on my own. (Group 3, participant 5)

Another participant also expressed a desire for more specific guidelines:

> I thought twice [about exercise] because I wasn't sure if my body was ready to exercise. And I definitely wanted to be not just doing it on my own, but I felt like I wanted to have an expert to help me through it, either to help train me or whatever, so I would be as safe as possible. (Group 7, participant 4)

Figure 2 shows a concept map that graphically describes the 3 themes and the interactions among the themes that affected participants' decisions about PA/E: values and beliefs, facilitators and barriers, and lack of or inaccurate information. We initially believed that preexisting beliefs about exercise and support systems would influence behaviors regarding exercise (Fig. 1). Most of the survivors in the present study were active exercisers before diagnosis, and we believe that their previous exercise influenced their return to previous levels of activity after treatment. We found that support systems were generally facilitative but could be a barrier to activity, such as when a family protected a survivor. We thought that side effects of cancer treatment would increase fear of PA/E. We found that side effects of treatment, such as fatigue and neuropathy, decreased activity because of physical constraints but not because of fear. Fear of lymphedema, which was not identified in our initial concept map, is a new finding of the present study. We believed that lack of information about exercise would influence fear and potentially reduce the amount of PA/E. The survivors expressed a

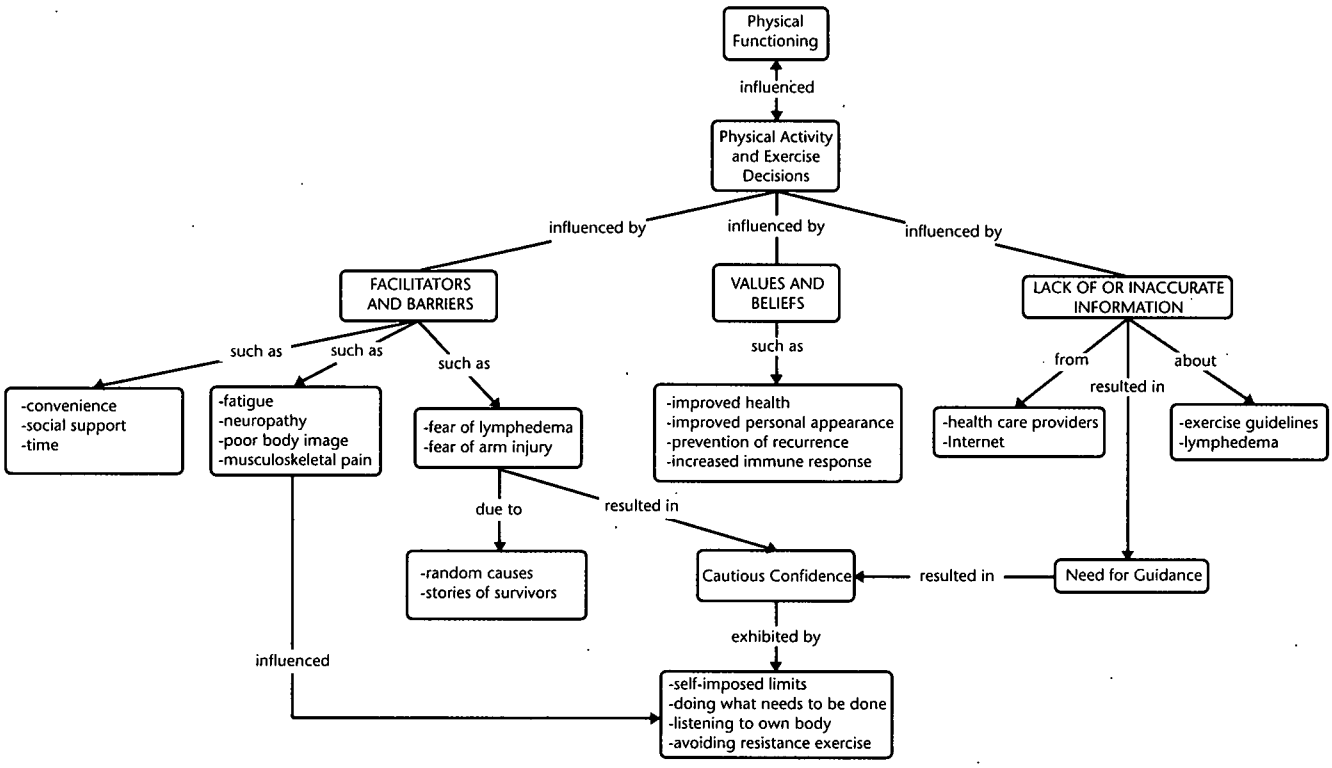

Figure 2.
Final conceptual framework illustrating 3 themes that influenced decisions about physical activity or exercise in survivors of breast cancer. Uppercase type indicates major themes.

need for more information about safe and effective exercise programs and more knowledge about the prevention of lymphedema. In our original concept map, fear was positioned as a primary issue reducing PA/E, resulting in a decrease in physical functioning. In the final analysis, fear of PA/E did not emerge as an issue in survivors who were active. However, we did find that fear of developing lymphedema was a cancer-related factor that affected participants' decisions about exercise and influenced their physical functioning.

Discussion

We explored feelings about exercise in a group of survivors of breast cancer who were physically active. We found that side effects of cancer treatment, such as fatigue, neuropathy, body image, fear of injury to the involved arm, and fear of lymphedema, contributed to barriers to exercise. Despite these barriers, most of the participants valued exercise for improved overall health and prevention of recurrence. However, the participants still expressed a desire for more specific guidelines about safe and effective exercise programs from health care providers.

We wanted to know whether fear was a factor that influenced participants' decisions about PA/E. Although not fearful of exercise, the participants did express fear of lymphedema. They expressed various levels of understanding of lymphedema and believed that it happened randomly, fueling their concern about what they could do to avoid lymphedema. This concern led to self-imposed barriers to PA/E, included protecting the arm at risk, avoiding certain exercises, and changing the way in which items were lifted or carried. Participants approached PA/E with cautious confidence. Some participants were able to "listen to their own bodies" and found strategies to become confident by testing limits through trial and error. Others were more cautious and limited by their fear. Within the self-imposed boundaries, the participants managed to do what needed to be done in their daily lives. Most of the survivors who were active found ways to overcome their concern about lymphedema to engage in a regular exercise program.

The RAPA data indicated that the participants were slightly more active after treatment. Although the participants reported that they increased their levels of activity after treatment, many reported that they had decreased their levels of activity during treatment. Participants

changed both the amount and the type of exercise after their cancer experience, with about 20% adding strengthening or flexibility-promoting activities that they had not engaged in before treatment. Triangulation of RAPA data with qualitative data indicated that the participants were confident in range-of-motion and aerobic exercises, often because they were given specific guidelines about how to perform these exercises from their physician or physical therapist during treatment.

Participants wanted more information about lymphedema and about safe resistance exercise practices. Lack of information and misinformation included the anecdotal stories told by others as well as conflicting information from health care providers. Physicians, physical therapists, personal trainers, and print and Internet sources provided information about lymphedema and exercise. Interestingly, some participants became fearful of lymphedema as a result of their newly found knowledge, in contrast to those who were ignorant of lymphedema and had no reason to develop fear. In a recent qualitative study of 12 survivors, Larsson et al[43] found a strong motivation to remain at or return to normal physical activity after breast cancer surgery. They emphasized the role of physical therapists in providing information about PA/E, encouragement, and motivation to empower survivors to return to normal activity.[44] Additionally, Lee et al[32] concluded that health care providers need to update information about strenuous arm activity on the basis of current research; that the risks associated with arm exercise need to be balanced with the benefits of arm exercise, and that information about lymphedema should be targeted to high-risk populations.

The Decisional Balance Scale scores reflected the fact that most of the participants believed that exercise was beneficial. Courneya et al[45] found similar positive expectations for exercise in a group of 52 survivors of early-stage breast cancer. More than 90% of the participants believed that exercise would improve their energy levels and well-being.[45] In the present study, triangulation of Decisional Balance Scale data with qualitative data revealed that support from family and friends, making a financial commitment (eg, buying a gym membership), and convenience and timing of exercise opportunities encouraged the participants to engage in regular exercise. In the study of Courneya et al,[45] 100% of the participants believed that family, friends, and health care providers would be supportive of an aerobic exercise program. Participants in the present study mirrored those in the study of Courneya et al[45] in valuing support; however, our findings reminded us that although support is good, too much support can hinder activity.

We believe that data saturation was reached in our sample; that is, we interviewed enough participants to hear similar stories.[35] A strength of the present study—from a qualitative perspective—is the emergence of fear or concern about the development or worsening of lymphedema as a factor in decisions about PA/E in survivors of breast cancer who were active. If survivors who were active were fearful, this concern might be even more pervasive in survivors who were less active. Fear of the development of lymphedema was also found in the preintervention-postintervention design used by Karadibak et al[31] and in the survey design used by Lee et al.[32] These 3 studies support each other in the need to further address the role of fear of lymphedema in survivors' decisions about PA/E.

The present study also had limitations. Participants chose to be part of focus groups in response to posted flyers and contact with health care providers and might have been more committed to exercise than other survivors. Participants were from 1 Midwestern metropolitan area because of the need to travel to participate in focus group sessions, and no attempt was made to stratify by socioeconomic status. The fact that participants were asked to recall PA/E levels before treatment both in focus group sessions and in completing the RAPA raises issues about inaccurate recall and potential recall bias. Finally, few participants were currently in treatment because of difficulty in recruiting this population. However, the stories of participants in treatment, such as decreasing PA/E during active chemotherapy and radiation, matched the recalled stories of participants who were months beyond treatment.

Our findings invite further exploration of factors that influence decisions about PA/E in survivors of breast cancer. The absence of fear of PA/E in the present study might have been attributable to the participants in our sample who were active. Because those participants were not representative of the norm,[13-15] it would be interesting to repeat this study with a population that is less active to determine whether the same or different themes emerge. Even participants who were active expressed concern about the development of lymphedema. Because the present study included only a few participants with lymphedema, targeting this population could identify factors that affect decisions about PA/E in women with breast cancer–related lymphedema. We initially supposed that timing in the cancer experience would affect behaviors regarding PA/E. The small number of participants in treatment

did not allow this concept to be fully addressed.

In summary, participants in the present study were generally active, and many maintained or increased their levels of activity and exercise after treatment. We found that participants' choices regarding PA/E were influenced by their values and beliefs about exercise, by facilitators and barriers that were both similar to those affecting the general population and cancer specific, and by lack of or inaccurate information about safe exercise. Although we did not find fear of PA/E in participants who were active, those participants expressed concern about the development or worsening of lymphedema, and that concern affected choices regarding PA/E. Physical therapists need to be aware of potential facilitators of and barriers to exercise in survivors of breast cancer so that interventions and patient education can be individualized and goal directed. Providers should be educated about the importance of exercise and safe and effective PA/E parameters on the basis of current evidence about the safety of resistance exercise in survivors of breast cancer.[20,46] Studies then should be done to assess the effectiveness of such educational programs for both providers and survivors.

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Appendix.

Semistructured Interview Guide Used for Focus Groups

Physical Activity Questions

1. Describe your physical activity level before diagnosis, during your treatment phase, and how it is now.
2. Where did you get information about physical activity?
3. How has this information affected your physical activity decisions?
4. How has support from others affected your physical activity?
5. What makes it easy for you to do your physical activities?
6. What makes it hard for you to do your physical activities?
7. How confident are you that you can do regular household or work activities?

Physical Exercise Questions

1. Before your breast cancer experience, describe any regular exercise you were doing.
2. Did your exercise routine change during your active treatment?
3. Describe any regular exercise you are doing right now.
4. Tell me more about any differences in your exercise level now and what it was before your diagnosis.
5. Where did you get information about exercise?
6. How has this information affected your exercise decisions?
7. How has support from others affected your exercise following your diagnosis?
8. How important is exercise to you?
9. What makes it easy for you to exercise?
10. What makes it hard for you to exercise?
11. How confident are you that you can do regular exercise?
12. Has body image ever been an issue in your decision to exercise?
13. Have you ever felt that exercise could negatively affect you?
14. Have you ever been afraid to exercise?