

## Experiences of Breast Cancer Survivors Participating in a Tailored Exercise Intervention –A Qualitative Study

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**Abstract.** *Aim: The aim of the study was to investigate how tailored exercise is experienced by cancer survivors. Patients and Methods: Twenty-five breast cancer survivors who were recently treated with systemic adjuvant treatments attended tailored exercise classes as a part of a randomized controlled exercise intervention study (Breast Cancer and Exercise, BRES). Focus group discussions with a median of four (range 3-6) participants in each group were conducted to capture their individual experiences of their course of illness, taking part in the exercise trial, the personal meaning of tailored exercise classes and the group. Results: Attending the intervention in which the focus of attention was on physical rehabilitation was highly valued, since the participants experienced both improved physical fitness and improved coping. Due to altered physical appearance and poor physical fitness, the participants felt that tailored exercise for patients with breast cancer reduced their barrier to start exercising. Peer support from the group was valued, especially that of sharing experiences, receiving psychological support and gaining a sense of normality. A sense of mastery over their disease through participating in the intervention, i.e. better psychological functioning and improved mood, was a consequence of better physical fitness and of meeting other breast cancer survivors. Also participating in the study per se increases a sense of comfort and security with extra medical examinations and follow-up. Conclusion: Participating in the tailored exercise*

*group for breast cancer survivors helped patients gain a sense of mastery, restoring their self-esteem and constructing a meaning for their cancer experience and its impact on their lives.*

The rehabilitation needs for breast cancer survivors have increased significantly over the past decades in line with improved survival. Many survivors experience prolonged adverse physical and psychological effects such as fatigue, vasomotor symptoms and psychosocial distress (1, 2). Exercise seems to be a feasible and well-tolerated strategy for ameliorating breast cancer survivor's physical and psychological problems (3-9).

There is a growing body of evidence suggesting that physical exercise is an effective intervention to improve quality of life (QoL) (5, 7, 9) and fatigue in patients with breast cancer and survivors (3, 10-13). Participating in exercise programs after breast cancer treatment has been also reported to lead to improvement in body image (14, 15) and feeling of sexual attractiveness (16). It has also a positive effect on functional quality of life, anxiety and self-esteem (17). Despite the known benefits of exercise, physical activity levels fall significantly for many women after a diagnosis of breast cancer and also remain low after treatment completion (18, 19). However, women treated for breast cancer are in general motivated to restart physical activities after cancer treatment and to exercise (20).

Relatively little attention has been attributed to the subjective experiences of patients participating in breast cancer-tailored exercise programs. Most of the research carried out is quantitative and uses predetermined scales, rather than capturing the experience of the illness and rehabilitation as a whole. It is not yet very well understood which factors influence this population's willingness to participate in physical activities and how exercise contributes to the adjustment process during cancer rehabilitation.

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The breast cancer and exercise (BREX) study is a large open prospective randomized clinical trial of physical exercise shortly after adjuvant treatment of breast cancer. The primary objectives of the BREX study are to investigate the effects of exercise intervention on QoL and bone health (21, 22). In the present study, an attempt was made to capture the individual experiences of cancer survivors attending an exercise intervention tailored for patients with breast cancer. The aim was to increase our understanding over the factors through which exercise influences the adjustment process during cancer rehabilitation.

## Patients and Methods

Participants in focus groups were recruited from the BREX trial (23). The BREX study is an open prospective multicenter phase III randomised trial with Finnish patients with breast cancer aimed at investigating physical training as a rehabilitation of the patients. A total of 500 women aged from 35 to 68 years with newly-diagnosed invasive breast cancer who had been treated with adjuvant chemotherapy or radiotherapy within four months (or started endocrine therapy no more than four months earlier) were included in the study. Patients not capable of training, such as women with other serious illnesses, were excluded. The adjuvant treatment was carried out according to clinical guidelines. Patients who were randomized into the exercise group participated in a 12-month supervised exercise intervention. Training included a guided aerobic exercise session once a week (the effective part being either step aerobic or circuit training in alternate weeks in small training groups of 5-15 participants) and similar home exercise sessions three times-a-week. The follow-up is 10 years, including measurements of weight, height, body mass index, fat percentage, bone mineral density, cholesterol, glucose and insulin, physical fitness tests (2-km walking test, figure of eight running test) and questionnaires for quality of life. The recruitment process and the exercise program of the study have been reported in more detail elsewhere (23, 24).

The local Ethical Committee of Helsinki University Hospital approved of the focus group study protocol (Dnro 269/E6/05) and written informed consent was obtained from all participants before the interview. Twenty-five women volunteers included in the BREX study exercise group participated in the focus group sessions. They were contacted by a researcher by phone who gave the information and sent the information consent form. Each woman participated in one of seven focus groups, with an average of four women in each group (range 3-6). Each focus group was established from the participants of the same training group of the BREX study. The different training groups had trained together 4-11 months at the time of the interview. The focus groups were facilitated and all group discussions were lead by the psychologists. One co-researcher also attended the focus groups and took notes of the discussion. As the groups were set up, the women were reminded of the purpose and background of the BREX study. After explanation of the study and assurance of confidentiality, verbal consent was ascertained before audiotaping. All focus group recordings were transcribed verbatim. The duration of the focus group interviews ranged from 55 to 76 minutes, the mean length was one hour.

The focus groups were guided by a semi-structured schedule the domains of which are presented in Table I. There was also an

Table I. *Interview domains.*

Course of illness, treatments and illness experience
Experiences of taking part in the exercise trial
Personal meaning of the exercise tailored to breast cancer patients
Personal meaning of the group
Reasons to continue taking part in the trial
Barriers to start exercise after treatment
Participant's view of personally meaningful outcomes of exercise

opportunity for the participants to raise other related topics which were important to them.

A phenomenological research method was chosen to interpret the qualitative data (25). The method comprises four essential steps: i) The investigator reads the entire description to obtain a general idea of the whole statement. By thoroughly reading and rereading each interview file the researcher acquires an idea of the women's experience. ii) Discrimination of meaningful units within the psychological perspective and with focus on the phenomenon being investigated. It is impossible to analyze the entire interview file simultaneously; it must thus be broken down into manageable units. The meaningful units in this phase of study were first relatively broad and followed the broad areas of the interview. The researcher repeated this phase many times and, as a result, the meaningful units that emerged as a consequence of the analysis sharpened and narrowed. iii) Transformation of the participants' everyday expressions into psychological language. These transformations were necessary because we wished to elucidate the psychological aspects in depth. iv) Synthesis of transformed meaningful units into a consistent statement. The investigator and the co-investigator performed the analyses.

## Results

The mean age of participants was 54 (range=43-67) years. The survivors were very sure about participating in the BREX study and in the tailored exercise classes. They were willing to discuss their cancer and their experiences regarding training. They felt that through participation in the study, they gained multiple benefits. In addition to free supervised training classes once-a-week for one year, they had extensive medical examinations and a closer follow-up at the University hospital. They also valued the fact that they contributed to the development of new interventions for patients with breast cancer, and that in the future other patients might profit from their experience.

*Impact on physical appearance and fitness.* Since the majority of patients were treated after surgery with chemotherapy and postoperative radiotherapy, they suffered from alopecia and had scars. Some patients also felt that they looked very ill. These changes in appearance were for many patients a barrier to joining ordinary group exercise. The patients felt that the tailored intervention for breast cancer

survivors only helped them to join an exercise group. One of the reasons that reduced the barrier was the knowledge that their changed appearance was a common issue in the group. They felt that it was easier not to wear a wig when exercising and have a shower after exercise, since there was no need to explain their appearance. They felt relieved that nobody stared or felt sorry for them because of their illness.

*"I hate to be the one that people look at. Or they try not to look, but they'll look anyway. (Makes me always think how retarded people feel when people... ) You know, when you walk by and you just notice that eyes are staring"*.

It was also helpful to deal with hair loss through sharing experiences and jokes.

*"Although I wasn't bothered by the fact that I had no hair, but if I had gone to an open exercise class, I'm sure others would have noticed, you know, what kind a lezzie is that, shaved all her hair with a razor. You don't feel like that, that you'd need to explain to anybody why you have short hair. Or just recently we had such a laugh when we were noticing, that oh yeah, your hair has grown that much and look how your hair curls"*.

The women valued the size of the groups that was only 10-15 patients and the fact that they were about the same age. The importance of exercising with women with similar experiences was emphasized, since they felt that they did not need to take into account other people when they were undressing, dressing or taking a shower after the exercise. It was important that the group was only for breast cancer patients.

*"Well I'm not worried, what do I look like. But you know, others feel uncomfortable and there are unnecessary questions. Just like in our apartment building's common sauna. And you don't know any of them that closely"*.

After their treatment, the women experienced reduced physical activity and their physical fitness was poor. Many patients were surprised that the rehabilitation had been so slow and that feelings of fatigue were still present.

*"Well I was in a really bad shape to start with. I had no energy, I probably was the worst one in the start. Then during the summer I got slowly fitter. Now in the Autumn I've really noticed it. It's like I've gotten fitter, but the chemotherapy treatments did make me feel really bad and tired for a long time"*.

*Value of the intervention and tailored exercise program per se.* After treatments, patients often feel very weak and

vulnerable. After surgery, some of the patients felt uncertain regarding what kind of exercise is safe. They understood the importance of the physical activity and wanted to do the right things. Therefore they emphasized the importance of having a skilled instructor. They appreciated the fact that the instructor understood issues crucial for recovery from breast cancer. They felt safe to exercise, because they could trust that the movements they were asked to do were suitable for them. They felt that they did not need to explain why their physical performance was so poor nor why their movements were restricted.

*"I felt it was really important that we are instructed to do exercises that suit us. I'm really careful about how my hand and spine works and moves. I didn't know how much strain I could put on it. And how much I can stretch it"*.

Women expressed the desire to switch identity from being a breast cancer patient to being a healthy woman again. Participating in the tailored-exercise group helped them to gain normality because they felt that they were not treated like patients. They appreciated the fact that the instructor tailored the classes so that the activity was manageable; however, they also valued that she made them exercise intensely, like healthy persons. They felt normal, since in this group, they felt that limitations were allowed.

*"But you don't get the feeling that here you are ill. I think it's really well planned. All the exercises and everybody know how fit they are and do everything according to how they feel that day"*.

When the patients finish their cancer treatments, they often have remaining symptoms and illness-related feelings. Many of them felt left alone after active treatment. There was also a fear of recurrence; therefore, they felt safe to be followed up for 10 years.

*"Then there was this funny thought I had when the treatments were over, that I didn't feel safe, thinking that now I'll be left on my own and alone with this scary thing...Here's an opportunity to get some peer support and then there are these examinations. It felt safer although it might not be"*.

Participating in the BREX trial also meant that the patients had more detailed medical follow-up's, extra laboratory and medical examinations, and unlimited access to the University Hospital's Oncology Department. Some participants viewed the BREX participation as an opportunity for additional medical care since they were monitored very closely. This seemed to help patients adjust psychologically and to feel more confident through gaining more control over a possible recurrence of their illness.

*“I knew that in that study they would do examinations I wouldn’t otherwise go to. So I got tests done like bone density that wouldn’t have been done on me otherwise. I thought it was great. They took all x-rays and all examinations They took good care of me and I felt safe”.*

**Influence on QoL.** The cancer experience often undermines one’s sense of control over one’s body and over life in general. Exercise had significant impact in gaining control over one’s body. Most patients felt that their physical fitness was impaired due to cancer treatments, especially after chemotherapy. Physical recovery was very rewarding. Many patients felt that their physical fitness first was so poor that they should not attend regular exercise groups. They felt gratified when they noticed their physical fitness increase.

*“You feel kind of clumsy and slow after the treatments. I’m not the same as I was before and don’t know if I ever will be. But I’ve gotten better, I don’t break into sweat quite as easily as in the beginning! During the year you’ve noticed that you’re developing and have already developed”.*

One of the most important benefits was more increased well-being and increased energy levels. The patients emphasized how much better they felt after exercise. When they noticed that their physical fitness was getting better and feelings of fatigue were not that predominant, it further motivated them to exercise. This was an important part of re-gaining well-being.

*“I was in a really bad shape, somehow really tired. I feel so much better after I’ve started exercising. It really makes a difference”.*

A sense of mastery over their disease through participating in the exercise was fulfilled also through gaining better psychological functioning and improved mood. The patients felt that this was consequence of better physical fitness and of meeting other patients.

*“During the summer my physical condition was at its worst, but when you come here and see that you have the energy to do lots of stuff and are feeling well, that lifts your spirits. So carry on. When you notice that you are able to do more, so why not”.*

**Peer support.** Peer support was one of the main benefits and it had many different aspects. This tailored exercise program offered support from others in the same situation. The group was important in gaining and sharing information on cancer, on treatment and on side-effects, as well as practical information on where to get help if needed. It provided a reference point for evaluating one’s own physical health.

The patients had lots of questions concerning their illness and side-effects, however being no longer in active treatment, they had nobody to ask. Therefore the peer support received from other members of the exercise group was important and relieving.

*“I’m under the impression that if you ask any doctor at the cancer clinic, it’s just normal in your conditions. That’s all. So then it feels normal when 10 others have something similar. Then you believe it, I do anyway”.*

Peer support was also important for gaining a sense of normality. In their normal life, e.g. at their workplace, the patients were often asked how they felt, if they were OK. In this situation, when they were in the transition phase towards being healthy again, these questions reminded them of the illness experience. They did not want to carry a cancer stigma. They appreciated the fact that when they attended the group they were left in peace. There was no need to ask “how are you” or “how do you feel”, since there was a common understanding of the cancer-related feelings. They felt that in this group, talking about the illness was optional since the main focus was on exercise. Hence, the group was somewhat paradoxically also seen as a chance to forget their illness for a while.

*“I’m so sick of everybody at work asking how am I doing. I can’t forget it. This group doesn’t ask me all the time how I’m doing. That’s a really good thing. They know without asking how I’m doing”.*

On the other hand, since the reference group was other women who had had the illness experience they could all gain a sense of normality. They could talk about the illness very honestly and freely without feeling somehow weird, and they did not have to feel shame when they talked about cancer. They viewed themselves as one of those suffering from cancer and knowing that the illness experience was a part of their life.

*“And nobody pays any attention to the fact that the illness is talked about. And it’s not like everybody would start listening to what they are talking about... And I got annoyed when everybody kept saying that wow you look good. I said, do I need to crawl here on my hand and knees to make you happy. They were all always really surprised”.*

The women often felt that their loved ones also had difficulties facing their cancer. They felt that they could not burden their relatives and friends too much by talking about their cancer experience. They felt that people without similar experience could not understand their need to talk. The exercise group was a platform for them to talk about the

illness and there was no need to hurry up and assume a sense of wellness. They felt that most other people believed that the experience is over when the treatments are over.

*"I feel like, that I've talked so much about my illness that everybody is a bit like ... (laughing)... 'why don't you become healthy every now and then'"*.

The patients were living in a transition phase between being a patient and being a healthy woman again. They had finished their cancer treatments and were regarded as healthy, and yet they suffered from many long-term side-effects from treatments, such as poor physical performance, alopecia, hot flushes and insomnia, and many of them had feelings of depression. They also experienced anxiety about their uncertain future. These were negative consequences of breast cancer and treatment. Some women felt that this group reminded them about their cancer. Attending the exercise group had an important impact in the transition from sick patient to healthy woman.

*"Maybe this year is pretty good after all. But this group takes me back to cancer. Now I feel like that phase is over. At least sometimes it feels like, that you don't think about it that often. When you say to the others somebody always says something, that they've been to the doctors and experienced this and that. This reminds you. That maybe it's a good time to stop, because you need to look forward to and live your life"*.

A re-appraisal of life and search for meaning was expressed through thoughts about what had been the overall impact of the illness and that of participating in the tailored exercise interventions. Participants expressed a re-appraisal of their life due to illness. Participating in the exercise intervention had an impact on their changes in lifestyle; for many patients, the main change was not to prioritize work as high as before.

*"I feel the time is good because then I couldn't stay at work all hours. It was a really good thing for me, that I have to leave and I will do so on other days as well. I'm not gonna stay there and be some working hero"*.

The group was seen as a useful forum to make new friends. The patients also developed new, positive cognition regarding their illness and relating to the exercise intervention.

*"I've noticed that my spirits are clearly better than they were at some stage. But it's hard to know what it all comes down to. When I was working at one point I was really stressed out and all. Maybe it's because of this disease you have had to start finding different positive things that has gotten my spirits up generally as well"*.

## Discussion

In the present study, we investigated the experiences of and meanings attributed to attending a supervised exercise intervention tailored to breast cancer patients shortly after cancer treatments *i.e.* during the rehabilitation period. After breast cancer treatments, women face the transition from being ill to being healthy again. This has both physical and social implications, such as cutting the close ties to the hospital and the healthcare system, and returning to work. Nevertheless, after treatment, many patients still have long-term side-effects such as alopecia, fatigue, insomnia, menopausal symptoms and depression (26); their recovery is not yet complete.

The BREX study's tailored intervention in which the focus of attention was on physical rehabilitation was very valued, since patients experienced both improved physical fitness and improved coping. We previously reported the improvement in physical activity and performance of the BREX study participants and the significant correlation between increased physical activity and improved QoL (21). During the rehabilitation period *i.e.* during the first year after the treatments, spontaneous recovery is significant. All kinds of physical activity are related to improved physical fitness and QoL (21). However, because of the altered physical appearance and poor physical fitness after the treatments, the participants of the exercise group felt that the tailored exercise solely for breast cancer patients helped them to join the exercise group. The knowledge that their changed physical appearance was a common issue in the group and there was no need to hide their illness or explain why their physical performance was so poor was especially helpful. They also felt that the skilled instructor made them train in a way that was suitable and effective for them. They appreciated the fact that the instructor understood issues crucial for the recovery from breast cancer.

The physical exercise was a central part of the rehabilitation, but important benefits were also attributed to the group as source of practical and psychological support that helped these women get a new grip on their lives. Peer support had many important dimensions, especially regarding sharing experiences and of gaining sense of normality. By comparing their experiences they felt that the side-effects that they experienced were normal in this phase of rehabilitation. They felt that they received psychological support from others. When these women thus had a reference group consisting of other breast cancer survivors they had no need to hide their illness and their feelings relating to having had breast cancer. Simultaneously, they felt no need comment on it either; they were left in peace, both from feelings of being an alien and of the intrusion of healthy people's well-meaning concern. The supportive atmosphere of the exercise group also helped them to re-appraise their

lives in terms of, *e.g.* the positive influence their illness experience had had on their priorities.

It should be noted that the patients who participated in the BREX study (and thus had passed its exclusion criteria) were younger and healthier than patients with breast cancer in general (23). Secondly, the participants had a markedly positive attitude towards exercise in general and the present intervention. Therefore the findings probably tell mostly about the gains these women had. Thirdly, being included in a clinical trial may have influenced their view on rehabilitation and their motivation for training, since the inclusion in the study actually brought multiple benefits in terms of medical examinations at the university hospital and a closer follow-up program. It is therefore possible that the dominant perception of the exercise intervention as something very positive may be biased and influenced by the comfort and security of the other 'fringe benefits'. Another caveat is that participating in the intervention study gave the feeling of contributing to the development of a new intervention for patients with cancer and thus a new meaning for participating.

Our findings are, however, in line with the theory of cognitive adaption by Taylor (27). Participating in the BREX trial helped the patients to gain a sense of mastery, since they shared information with other survivors. The group also helped to restore self-esteem. The group was a reference group for being healthy again and the women could also make downward comparisons to other survivors, more recent in recovery than themselves. The group also helped them to elaborate on the personal meaning of their cancer experience and its impact, since they were able to compare their experiences in the past and present. Our findings are in line with those of Hennessy *et al.* who demonstrated that breast cancer survivors valued exercising in a group context (28). Group exercise helped them feel less isolated as they shared the experience with other cancer survivors. It was also found that exercise facilitated the patients' physical and psychological recovery and helped them to regain a sense of normality. In another qualitative study, Emslie *et al.* found that setting up classes solely for women with breast cancer helped reduce gender-related barriers to physical activity, such as difficulties in prioritizing exercise over caring roles and worries about changed appearance (29).

In conclusion, the present study's findings suggest that a tailored physical exercise intervention can have multiple benefits and offer important support for breast cancer survivors in their transition from life as a patient to life as a survivor. Focus on physical exercise in a group of peers made it possible for our study sample – paradoxically – to both share the experience of illness and forget all about it, since it was not an individually defining feature within the group. This may have facilitated personal reflection, leading to the positive re-appraisals of life reported by the patients.

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