
Understanding barriers to exercise implementation 5-year post-breast cancer diagnosis: a large-scale qualitative study

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Abstract

Due to the amount of literature supporting exercise participation after cancer diagnosis, there has been recent interest in barriers to exercise engagement among cancer patients. However, little is known regarding reasons why people choose to disengage and how this disengagement occurs over time. This study aimed to qualitatively study the perceived barriers to exercise implementation, 5-year post-breast cancer diagnosis. Eighty-three female breast cancer survivors participated in a one-to-one semi-structured interview, regarding their experience of exercise over the past 5 years following their original participation in a group-based structured exercise intervention after diagnosis (41 from intervention and 42 from original control group). The data were analysed using inductive thematic analysis. The findings included three main themes and several subthemes regarding the women's perceived barriers: psychological barriers (lack of motivation, fears, dislike of gym, not being the 'sporty type'), physical barriers (the ageing process, cancer treatment and other physical co-morbidities, fatigue and weight gain) and contextual and environmental barriers (employment, traditional female care-giving roles, proximity/access to facilities, seasonal weather). The findings add inductive support to the

current survivor health research advocating the use of activity immediately after diagnosis, as well as the need for tailored activity programmes in order to overcome potential obstacles.

Introduction

As the population of cancer survivors increases, there is a real need for interventions that reduce the negative physical and psychological side effects of diagnosis and treatment [1, 2]. Physical activity (PA) (Physical activity is defined as 'any bodily movement produced by skeletal muscles that results in energy expenditure'. 'Exercise' is defined as 'a form of structured physical activity with a specific objective of improving or maintain physical fitness or health' [3].) has been found across several studies to increase quality of life and alleviate 'treatment related burdens' [4, 5]. More specifically, weekly supervised exercise interventions (cardiovascular or resistance and strength training) are one of the most effective programmes for reducing depressive symptoms and increasing psychological well being within a breast cancer population [6–7]. Furthermore, regular activity participation can reduce the risk of developing several disorders such as obesity, cardiovascular disease, coronary heart disease, stroke, diabetes (type 2), osteoporosis,

certain sleep disorders, high blood pressure, certain cancers and even premature death [9].

In a large-scale randomized controlled trial, Mutrie *et al.* [10] reported immediate post-intervention (3 months) and long-term (9 months) physical and psychological benefits (e.g. shoulder mobility, positive mood) after the participation in a 12-week group aerobic exercise intervention for patients undergoing chemotherapy. In the subsequent 5-year follow-up, Mutrie *et al.* [11] found that women who were in the original intervention group (IG) maintained higher levels of positive affect and increased participation in leisure PA in comparison to the original control group (CG). Furthermore regardless of group allocation, the researchers found that those who maintained an active lifestyle over the 5 years had lower levels of depression and increased quality of life. Recorded explanations for these positive effects include (i) a healthy distraction, (ii) a productive (not passive) environment, (iii) a safe environment (expert instructor) with similar individuals, (iv) the participation in 'normal' activities, (v) the maintenance of weight and (vi) a reconnection to the body through exercise [12–14].

Despite PA being lauded as a healthy and safe activity to engage in after cancer diagnosis [15], few cancer survivors actually meet the recommended daily activity guidelines. The most recent study from the American Cancer Society's Study of Cancer Survivors (ACS SCS-II) showed that 37.1% of breast, 43.2% of prostate, 35% of colorectal and 29.6% of uterine cancer survivors met the recommendations of 150 min of moderate or 75 min of vigorous activity per week [16]. Similar results have been observed from large Canadian [17] and Australian [18] samples of cancer survivors and there is a clear decline in activity engagement post-diagnosis [19]. Breast cancer patients, in particular, have been found to list significantly more barriers to exercise participation than prostate cancer [20]. The barriers to exercise implementation amongst cancer patients have included nausea, pain and soreness, no time to exercise, lack of social support, fatigue, no cancer exercise expert, work and depression [1, 21]. Although valid reasons, it is

important to work to engage patients to participate in activity during their survivorship, as there have been links to reduced fatigue, enhance quality of life and reductions of depressive symptoms [22–25].

With high rates of depression within breast cancer survivors and a lack of activity in general, risk reduction is a key factor within this population [26, 27]. Furthermore, women are traditionally identified as an at risk population with lower levels of reported PA [28]. Thus as the rate of cancer survivorship increases over time [29] the need for long-term positive health behaviours becomes more and more crucial to survival.

As of yet, there has only been quantitative/deductive research into the barriers of exercise engagement. Research has not yet included an inductive approach to data collection, on exercise engagement, following the 5-year anniversary. Understanding what maintains activity participation 5 years after treatment is an important avenue for research [30]. Furthermore, little research has followed cancer survivors from intervention during treatment to the 5-year follow-up in order to ascertain barriers to participation [11]. Emery *et al.* [31] indicate that the timeline and trajectory of activity participation have shown a curvilinear relationship with participants engaging in recommended levels from diagnosis to 18-month post and then slowly declining to 42 months, dipping below baseline levels [31]. Little is known about why activity participation follows a curvilinear relationship [6]. This research aimed to understand and add to the literature regarding barriers to clinical population engagement with exercise, utilizing a rare data set of cancer survivors 5-year post-treatment and engagement in an activity intervention [11]. This article aims to take the current research findings and determine what the perceived barriers to exercise are for women who have had breast cancer. Several studies have looked at predictors of long-term engagement from a quantitative perspective [31]. They found that poor physical health, depressive symptoms and lower emotional health-related quality of life (HRQOL) were associated with less PA. However, to our knowledge, no research has looked at barriers, over this period of time, from a qualitative perspective.

Method

Ethical approval was obtained by the University of East London and the University of Strathclyde.

Design

The researchers used a qualitative research design to elicit the understandings, experiences and voices of individuals (patients themselves) that are not traditionally heard in psychology [32].

Participants

Participants and background to original study

The original study focused on the benefits of PA as a rehabilitation strategy for women receiving treatment for breast cancer (physical and psychological) [9]. This study was the first randomized controlled trial exercise intervention conducted during cancer treatment. A total of 1144 women were approached during their chemotherapy/radiotherapy (January 2004–05). Pre-screening of 313 women (stage 0–III) excluded 110 due to ‘concurrent unstable cardiac, hypertensive, or respiratory disease; cognitive dysfunction; and already participating in regular exercise; 66 declined and 40 dropped out for ‘other reasons’. The final $n=203$, with age range of 29–76 years and a variety of occupational backgrounds and sociodemographic profiles. The 203 were randomly assigned to one of two conditions: IG and control. The intervention consisted of specially designed circuit classes (45 min) running 6 day a week and two evenings a week at eight separate leisure centres across the city of Glasgow. The participants were assessed at three time points (baseline, 12 weeks and 9 months) on a battery of tools [Functional Assessment of Cancer Therapy—General; Becks Depression Inventory, The Positive and Negative Affect Scale, body mass index (BMI), 7-day recall of PA (Scottish Physical Activity Questionnaire), performance in a 12-min walk test and score on a shoulder mobility test]. The original study results showed that the IGs had

improved functionally and psychologically at completion and 6-month follow-up [10]. Furthermore, qualitative inquiry found that the classes helped facilitate post-traumatic growth (the experience of findings positive benefits after trauma) via exercise environment and physical mastery/transformation of body [13, 14].

Procedure

After obtaining informed consent, the third author, a researcher at the University of Strathclyde, carried out a 15-min semi-structured research interview with 83 of the 87 (95% adherence rate) individuals who wished to continue as participants for the 5-year follow-up (four declined due to lack of time). The 83 were from both the original control ($n=42$) and IGs ($n=41$). The research interview used five open-ended questions (see Table I), confirming whether the participant was in the CG or the IG and then focusing on perceived benefits and barriers to exercise participation that the women had experienced over the 5-year period.

Participants were also verbally reminded of the anonymity of the research process, of their right to withdraw and details about how the data would be stored and used. Data were collected over a 1-year period (January 2010 until December 2010) at various local sports facilities across Glasgow, Scotland, where the original assessments had been carried out. The research interview was carried out after a set of physical and psychological measures were taken from participants as part of the 5-year follow-up to the original randomized control trial [10, 11, 13, 14]. The research interviews were recorded on an mp3 player and transcribed verbatim by a professional transcription service. Transcripts contained local accentuations and we used pseudonyms for research participants.

Analysis

Inductive thematic analysis was used to produce a set of themes for participants’ perceived barriers to exercise participation (A separate paper focusing on

Table I. Interview schedule

1	Did you take part in the original intervention?
2	<ul style="list-style-type: none"> ● Have you kept exercising since your participation? If yes: <ul style="list-style-type: none"> ● How often? ● With whom? ● What barriers did you/do you have to overcome to continue exercising? ● Why do you still exercise now–5 years later? If no: What barriers in particular, have made it difficult to keep exercising?
3	What value (benefit) has exercise had in your life over the past 5 years?
4	Has this exercise experience influenced any other areas of your life?

the motivations and benefits of activity engagement is currently in preparation.) [31]. Thematic analysis was deemed more appropriate method for the design of the study than other qualitative methods of inquiry (e.g. interpretative phenomenological analysis) due to its flexibility and emphasis on nomothetic inquiry [32–35].

The analysis was conducted by the first author included several readings of the transcripts to become familiar with the text [33]. The researcher looked for major themes for barriers to exercise, beyond surface level interpretation, organizing the text into coherent sections (themes). The detail of analysis included line-by-line coding and then moving on to broader overarching themes to create the final master list (see Fig. 1) [33]. This systematic analytical process was done for all 83 participants and then combined to make a final group analysis Master List.

The rationale for combining both groups for the qualitative analysis stemmed from the fact that after the original intervention was complete, the CG was offered the programme; hence both groups were given the specific training. However, despite this, the researchers kept the group allocation identifiers to see if any difference emerged from data. Once the analysis was finalized, the second author reviewed the data for completeness, not convergence, reporting coherence in the data and the themes produced [34].

Results

General overview of activity participation 5-year post-breast cancer diagnosis

Half of the 83 women interviewed claimed that they were active (49.4%). Surprisingly, there was a clear difference between current reported levels of activity engagement depending on what group the women were originally allocated, with 63% ($n = 26$) of the original IG self-reporting as active versus only 35% ($n = 15$) in the original CG. Interestingly, a small percentage of the entire data set (<5%, $n = 4$) identified ‘No barriers’ to exercise participation. The qualitative findings support the quantitative findings noted in Mutrie *et al.* [11]. Overall, there were several notable differences in participant’s engagement with activity (see Table II) depending on their original allocation to either the CG versus IG. The authors felt that was important to reflect on these differences as they may demonstrate the influence of the timing of the intervention (immediately after diagnosis versus 6 months later) and subsequent activity participation.

For example, in terms of preferred methods of exercise (exercising alone, exercising with others or both) the original IG maintained a high level of autonomy, whereas the CG claimed that they preferred to exercise with others. This can and is argued to be due to the perceived safety of the original exercise classes which gave the women a sense of expertise, education and accountability during a particularly vulnerable time period [13]. This finding is interesting in relation to existing studies that report one major barrier to exercise participation for female breast cancer survivors is the lack of an exercise partner [20]. Interventions should focus on building autonomy and confidence can help counteract this barrier.

Despite there being latent differences in activity participation that was documented via the inductive thematic analysis, this article will review the entire data set ($n = 83$) and highlight the discrepancies in engagement when applicable. We will also report upon the motivators to engagement 5-year post-diagnosis, in a subsequent publication.

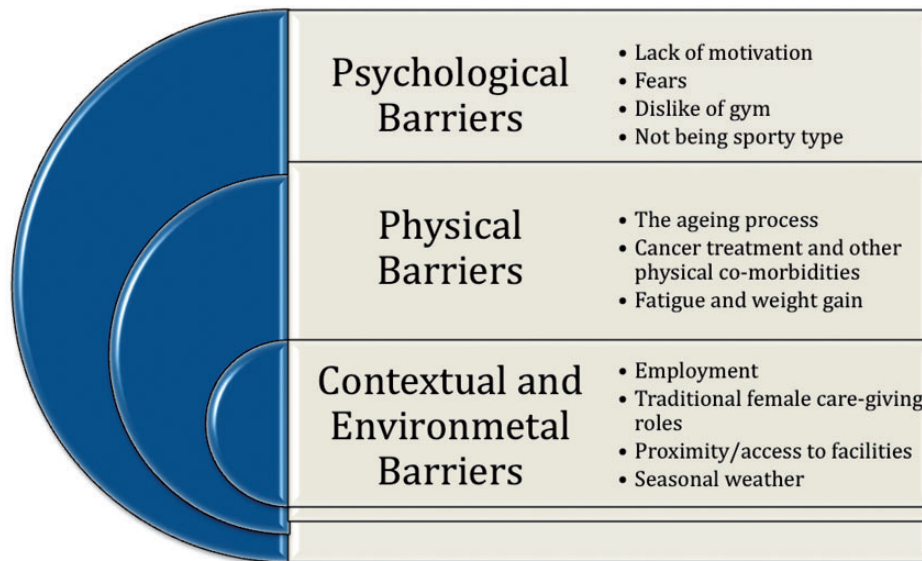


Fig. 1. Main themes and subthemes for barriers to exercise participation 5 years following a breast cancer diagnosis.

Table II. Notable differences in activity engagement between original intervention and control group 5-year post-cancer diagnosis

Intervention group	Control group
More aware of importance of exercise to health and well being	Understood importance but not to same extent as intervention group
More knowledgeable in how to exercise safely	Felt lost as to how to start exercising safely
More self assured in engagement in different types of activity (weights, classes)	Discussed lower levels of self efficacy
Integrated exercise into lifestyle	More likely to be at ‘contemplative’ stage of change
More likely to be ‘gym goers’	More likely to be ‘walkers’

Barriers to PA participation

Figure 1 illustrates, in detail, the common barriers for the entire data set ($n = 83$). Our findings of barriers to exercise implementation support previous research [9, 20] whilst also including more specific components, such as contextual and environmental barriers. The results demonstrated three main themes and several sub-themes in relation to the barriers of activity participation including: psychological barriers (lack of motivation, fears, dislike of gym, not being the ‘sporty type’), physical barriers (the ageing process, cancer treatment and other

physical co-morbidities, fatigue and weight gain) and contextual and environmental barriers (employment, traditional female care-giving roles, proximity/access to facilities, seasonal weather).

Psychological barriers

Lack of motivation. A common generic barrier to exercise cited throughout the interviews was lack of ‘willpower’ or laziness. The women discussed how ‘life got in the way’ and that sometimes they were just lazy. Others simply did not like exercising.

I haven't done anything, I haven't been active at all. I lack motivation. I can't be bothered. (Alison, IG)

But I think why I'm very lazy about doing it, is although I know I should do it- take more exercise, whether it's going to the gym or whether it's walking or swimming or whatever it is, I can't say I feel this wonderful burst afterwards and feel really good afterward as lots of people say they do. You know they think, that was a real effort to go there but I feel better for it. And I didn't lose weight when I was going to gym, I didn't get more toned as I hoped I would and I think that's why I got very disheartened. (Bridgette, CG)

I just get bogged into life and I feel I have to deal with that. And then the exercise bit just gets left. (Caroline, IG)

For those who previously exercised, this lack of motivation, following cancer, had a negative impact on their sense of self and confidence.

I just always, I feel a bit disappointed in myself that I haven't kept up the amount of exercise that I did because even now sometimes I see women out running you know, and they're obviously training for the 10 K and all that, and I think, if I'd just kept it up I could still be doing that. Not necessarily running, just walking fast... so I'm a bit disappointed in myself so I really know that I really need to do more so that I'll feel better. (Dorothy, IG)

Fears. Several perceived safety dangers with engaging with activity were barriers to implementation such as fear of being attacked as well as slipping in poor conditions and injury. As the original CG was more likely to engage in outdoor activity, this theme was more salient, although not isolated, to this group.

The walking is so nice in the parks—you'd rather do that with somebody else at night so

the barrier would be if you've not got somebody to do that with you. You maybe do it during the weekend because it's busy and it's kind of safer to do it...it's not so bad then. (Eloise, CG)

The severe winter that we had with the frost on the ground—I have to [walk] before I start work in the morning which means half seven in the morning, not a lot of folk around. I'm nearer 70 than 60 and if I'd fallen, I'd have perished. (Noreen, IG)

Dislike of gym. The most notable differences between the original allocation groups surrounded their preferred method of activity engagement, with the CG preferring walking ($n = 19$) versus the gym ($n = 1$) and the IG reporting the opposite pattern: walking ($n = 9$) versus gym ($n = 20$). For many of the participants (especially the original CG), there was an overall dislike of the gym and its environment. Reasons varied from disengagement to lack of privacy to more detrimental issues such as lack of proxy efficacy (e.g. 'participant's belief in their leader's capabilities') [36]:

I just hated the gym. I never enjoyed it [...] but the honest truth is I didn't feel any better for it... I decided I would just go as a casual member and of course, that was the death of it, wasn't it because I never went back after that! (Bridgette, CG)

The Wii Fit—it suits me better because I can do it in my house. I don't have to go out and go to a gym and once I'm finished I can just jump into the shower, whereas when I was at the gym, I didn't like the shower there. So I would go straight into my car, drive home and then go into the shower at home. (Grace CG)

I did actually go to a gym [once the treatment finished] and I explained the sort of problems that I still have and asked could they tailor something for me—and they were very good—except when I was in a big group and they were all asking us to do the same thing and when I sort of went 'I can't actually do

that', I kinda got chivvied. Rather than saying, 'Well, why don't you try that?', I felt as though I was obliged to do things, which at the time, I can do, but I know that the following day, I'm gonna be in pain. So I stopped going to the gym. (Heather, CG)

Not being the 'sporty type'. Many of the women did not identify psychologically with 'having a sports persona', which seemed to have a knock on effect with regard to structured exercise uptake. These women tended to identify as novice to intermediate exercisers, and had already subsumed this 'not sporty' identity.

I'm not sporty, so I'm not particularly active. I mean I would go for a walk about a few times a week but that's about as far as it goes. (Isla, CG)

I'm not particularly interested in exercise and I'm not a tennis or a badminton or a golfer or a bowling player. I say this because my husband is very sports oriented and I'm not. I wish I were but I'm not! And at my age, I think I have to be honest with myself and say, I'm never going to be able to use a sewing machine, I'm not going to take up sport! (Jacqueline, IG)

Physical barriers

Ageing process. As discussed earlier, the majority of breast cancer diagnoses is within females over the age of 50. By the time the 5-year follow-up occurs, many are dealing with co-morbid issues caused not only by the cancer treatment but also by the ageing processes as well. This barrier was present throughout the majority of the participants' narrative.

I don't know whether it's to do with the diagnosis or to do with the change in your body because of what we've been through or whether it's an age thing. I think I've probably aged ten years. I think I feel ten years older than I should do. Because I have suffered joint problems and things through the

medication... I am not back to where I was but then I'm six years older as well. (Kelly, IG)

I still like to walk... still try to do one or two wee sit-ups and different things [but] I'm not as supple as I used to be bearing in mind that I'm nearly 62, so I'm not as young as I was then... The maturity you get, the wee kinds of niggles and pains, the osteoarthritic type things coming along... (Linda, CG)

Cancer treatment and other physical co-morbidities. Following surgery, cancer patients tend to report numbness of nerves, shoulder stiffness and lymphodema [31]. These participants reported that pains and aches in their body sometimes prevented them from exercise. The presence of such issues inhibited the women from properly engaging in exercise over the previous 5 years.

I think as time went on, I did have kinda medical problems. So, bit by bit, I did give practically all my exercise up [...] I just didn't want to. It was just, I ended up, with quite bad depression—I still am suffering now. I'm still on medication, but I was really, really, pretty bad and I just didn't even want to do anything. But, it was a conjunction with operations and a series of different operations for my reconstruction that literally went wrong every time. I ended up with different infections and them leading on to other things and then all my skin dying away, and just a catastrophe. (Mary, IG).

I had my breast off, I had to go through a year later for another operation and it was, you know, you're all kind of sore and tense [...] plus the fact that the chemotherapy affected the nerve in my feet, so I didn't have the strength in... I didn't have the feeling in my feet. (Noreen, IG)

Fatigue and weight gain. The women felt that a lack of energy (due to treatment or surgery) [37, 38] and increased weight gain was a barrier to exercise participation. Lack of activity has been linked to

increases in weight during treatment [39] and this was especially influential during their treatment.

I just couldn't, I had absolutely no energy and also when my blood was very low, I had no energy to do anything. I could hardly drag one leg after the other but that has been you know, not all the time. That's just been at times when I've not been very well. (Penny, IG)

Quite lethargic actually and I know that I've put on a bit of weight, I definitely have but I'm definitely going to be addressing that because I really am very uncomfortable with the extra weight and the lack of exercise. I really do feel it. I just feel that I've not got as much energy. Whereas I feel when you're doing regular exercise, you definitely do have more energy for things. (Dorothy, CG)

Contextual and environmental barriers

Several contextual and environmental barriers were mentioned with regard to inhibiting exercise participation. Work commitments, as well as simple 'life duties' (care-giving in traditional female roles) seemed to hinder even the best of intentions.

Employment. Returning to work was a major time and energy guzzler with regard to enabling activity participation. Long hours, late days and shift work forced women to make 'priorities' which meant that exercise activity was put on the back burner. Mix this time drain with the common treatment side effect of fatigue [38] and the effects are cumulative.

Initially the return to work was very difficult and exhausting, so my social activity if you like, exercise classes and things, dropped off. But that, I think in the main was the struggle to get back to work and then to get back to full-time work, was just so exhausting there was absolutely no room for anything else. (Tara, IG)

Because I'm working all week, I'm trying to catch up with things at the weekend so you don't always have the time and you've

shopping to do and obviously you want to go and meet a friend or something like that, so you don't always have the time to go out [walking]. (Rachael, CG)

Traditional female care-giving activities.

Twenty percent ($n = 17$) of the data set reported traditional 'female' roles as potential interferences in their participation in activity. These included women reporting partner and 'motherly' duties, running of the household, raising children and taking on positions as caregiver to ageing parents and ill spouses. The traditional female care-giving activities were a significant factor in whether or not the women prioritized activity within their daily life.

It was very important to me, when I was diagnosed, my children were young and I realised that really, in the pecking order of things, quite naturally as a mum, you come last. (Diana, IG)

I have very good reasons why I don't do things... just particular lifestyle pressures and different family commitments [care giving] over the intervening five years have made it a very busy time without a lot of personal time available. (Beth, IG)

I used to cycle, maybe cycle down the bank-side and back round the canal, it was about five miles. But then when my husband took ill, I was frightened I might fall off and did any damage because I'm responsible, you know, for looking after him, so the bike's up the creek! [The exercise class] was ten o'clock in the morning and wasnae suitable really because it meant I was just getting him up and the carers were just going away and I was going out—anything after nine o'clock wastes the rest of your day. That's what finished the aerobics. (Andrea, CG)

But the trouble is you get home, you have your tea, you've got to sort the boys dinners out, and do your ironing, by the time you've done that your, you can't be bothered going to the gym, you know? (Freya, IG)

Proximity and/or access to facilities. Some of the women reported exercise classes not being conveniently timetabled or close to home, thereby restricting their likelihood in engaging in activity.

Two of the Pilates classes were through the day and one of them was in Largs. So the drive to Largs, then an hour's exercise and I was exhausted—it was really, really taking it out of me, it was just too much. I wasn't happy about it but there was nothing I could do round about it. Something had to go. (Ethel, CG)

Again, lack of proximity to convenient, safe and accessible activity venues is a key barrier to exercise uptake [40, 41]. Research into the aesthetics and convenience of the gym (e.g. showers, towels, soap) and how this affects likelihood of attendance is an area of interest for future research. Of course, with additional 'perks' comes additional costs, which can hinder uptake in the first place.

Individuals who are dealing with injuries due to treatment place high levels of importance on post-operative privacy [12]. In addition, cancer patients find it difficult to access and engage in 'healthy oriented' environments that do not take into account disabilities.

Well it's been extremely variable (laugh) as I suppose most people would say. But I did feel, you know, the classes were a great way to get you started. The difficulty was finding other classes where they didn't go (gasps) when you said you know 'I've got lymphodaema' and 'oh well you mustn't do that then'. (Francine, IG)

Access to gyms was not only depended on proximity but financial costs, which deterred some of the women from attending. The women reported that the expense of gym memberships would hinder their activity participation.

I used to go to the gym but it's partly the cost of that that's putting me off to be honest. So if I think I can do other things like work in the house, in the garden, it's still exercise [and]

I'm getting the benefit from it at the same time. (Gaby, IG)

Well I just feel it's a good way of exercising without going to the gym- because I got fed up doing that. When I was having my chemotherapy, the hospital, they have their own gym, so I was going there sort of two and three times. The sort of paid membership that I had at the Holiday Inn, it wasn't working out, it was just costing me too much money, for what? I wasn't really getting an awful lot out of it. (Harriett, CG)

Seasonal weather. The most frequently reported barrier to activity participation was the weather with 48% of the entire data set ($n=40$) reporting 'bad' weather as a major factor in inhibiting activity participation. This barrier could simply be a unique factor to west of Scotland, which has 1000–3500 mm/annum of rainfall per year (UK average = 500 mm) [42]. However, due to the lack of engagement with the gym environment (and therefore protection from the environment), this theme was most predominant in the CG:

Winter comes and you just don't do anything. (Grace, CG)

Oh I feel miserable! I hate the winter. Hate it with a vengeance. I really do! And I hate the wind and I hate the rain. I do, I do! (Imogen, CG)

So I do a lot of exercise in my life anyway... well apart from during the winter. (Joanne, CG)

Nice days you may have three-three walks a day but bad weather you would- you were struggling to go out for one walk. (Karen, CG)

Discussion

The findings from this large-scale qualitative research project reported three main themes and several subthemes regarding the women's perceived barriers to exercise engagement over the 5-year

post-participation in a randomized controlled trial that evaluated the benefits of supervised exercise. These themes included psychological barriers (lack of motivation, fears, dislike of gym, not being the 'sporty type'), physical barriers (the ageing process, cancer treatment and other physical co-morbidities, fatigue and weight gain) and contextual and environmental barriers (employment, traditional female care-giving roles, proximity/access to facilities, seasonal weather).

The impact of these findings has several implications on the current understanding of barriers to long-term exercise participation within cancer populations as well as the advancement of cancer care. For example, the observed lack of motivation reported here has been found to be the biggest psychological barrier to exercise participation among cancer patients, and these results further support the need to address this apathy within lifestyle programmes after cancer diagnosis [20].

Furthermore, whilst research into the influential impact of the environmental aesthetics of the exercise environment is scarce [5, 9], the study's results showed a severe distrust of outdoor activities if completed in inconvenient and isolated areas and if there was a perceived likelihood of injury and harm to personal safety. These findings add to the growing research on understanding fear barriers to exercise participation, such as a lack of accurate and tailored information (safety in structured programmes) [5]. In terms of long-term protection from these fears, Loprinzi *et al.* [43] found that individuals with higher levels of self-efficacy predicted engagement in activity 6 months post-activity interventions. Linked to this, these participants' dislike of the gym could be linked to a lack of environmental mastery [40] as individuals who perceive the gym as an uncomfortable and unwelcoming space report feeling threatened and out of their comfort zone, thereby reducing the ability to experience positive emotions even in group exercise [44]. Furthermore, the perception of 'not being the sporty type' is rife among women [9], with research showing reduced activity participation in women in relation to their male peers [however explanations as to why this occurs vary from psycho-social (self-presentation) to more

environmental/biological (parental) influences]. Physical education programmes should aim to clarify that exercise participation does not need to be of vigorous intensity, as walking and moderate intensity exercise have comparable benefits to intense activity (e.g. positive effects on cardio vascular disease and diabetes) [4].

The physical barriers participants described add new evidence of cancer context-specific barriers to exercise participation. As patients grow older, the likelihood of survival after diagnosis reduces and likelihood of reoccurrence increases [45]; therefore, maintaining a physically fit body is important to breast cancer survivors. Despite older women reporting higher levels of HRQOL regardless of activity levels [46], increasing age and a high BMI can be a negative influence on promoting physically active behaviours in older women. Engaging in exercise has been found to reduce fatigue as well as cause significant improvements in BMI, body weight and physiological output [1, 8]. Some researchers have posited that exercise may increase survival rates however being overweight at the time of diagnosis and weight gain after diagnosis has been linked to poorer survival. Thus, control of weight gain is an important element of cancer survivorship [47].

Furthermore, chronic pain is a common side-effect of cancer treatment [45, 48] and exercise is an important counteraction against the pains, stiffness and lymphedema (swelling due to a blockage of the lymph vessels) [10]. Researchers have found that there is a relationship between treatment type and activity participation 5-year post-diagnosis, with patients who have received chemotherapy increasing activity levels up to 18 months and then slowly declining, versus patients who have not received chemotherapy peaking at 3 years and then declining.

This study also reflects upon novel contextual and environmental barriers for cancer patients that have not been highlighted within the mainstream literature. The risk of unemployment following cancer diagnosis is now dissipating, with a large proportion of survivors returning to the workforce [49]. These women reported issues with transitions back to work and this is a new direction of survivorship research. These findings show the difficulties of maintaining a

holistic and healthy lifestyle with the demands of returning to work. Although employment can create a sense of meaning and purpose as well as increase self-esteem among survivors [50], the psychological and social benefits of occupational rehabilitation should not outweigh nor counteract the physical benefits of exercise activity.

Additionally, the negative impact of *traditional female caregiver roles* was an unexpected, but strong feature in these women's narratives. Although gender and family dynamics have changed over the past 50–60 years [51], the women interviewed took on the burden of traditional familial duties. The World Health Organisation (WHO) reviewed PA levels in women and found that women were hindered by gendered cultural 'stereotypes' (e.g. homemaker) that restricted their freedom to engage in activity [49]. Furthermore, women tend to earn on average less than men, which puts financial pressure on their budget and likelihood to uptake memberships [52].

Moreover, for these women, weather was a massive barrier to activity engagement, especially for those who were non-gym goers and relied on the outdoors. In a large-scale, longitudinal study, both prostate and breast cancer patients cited 'bad weather' as one of its top three barriers to exercise [20]. Interventions that address the lack of motivation during seasonal bad weather would be useful, especially as novel 'green exercise' research shows enhanced psychological benefits to engaging in exercising 'outdoor' (natural) versus 'indoor' environments [41, 53].

Finally, the three main themes that emerge from the analysis of these data correspond with the ecological model of factors that influence various health behaviours such as PA. The ecological model suggests that there will be individual, interpersonal, organisational, community and public policy levels of influence [54]. We have shown from this qualitative data that these factors also influence women's ability to take part in regular activity during 5 years following participation in an exercise focussed intervention study. Whilst many of these women were able to maintain activity levels, particularly those in the IG, we learned from these data that there were

many barriers. At the individual level (e.g. lack of motivation, not being the 'sporty type', the ageing process and the effects cancer treatment), at the interpersonal level (e.g. traditional female caregiving roles), at the level of organisations and communities (e.g. where these exercise opportunities are provided such as leisure services and proximity and access to these opportunities), we have identified issues that face many women who find it difficult to be active. The factors that services might be able to influence, such as ease and cost of access and promoting activity in a way that does not suggest women have to be 'sporty' to engage, are particularly important in order to make regular PA a more realistic choice for women who have been diagnosed with breast cancer. Finally, with reference to the ecological model, we note that there are few policies that are relevant to encourage the provision of exercise for cancer patients. We acknowledge that policy alone cannot overcome the other levels of the model but it has an influence throughout and without it there will be limited awareness of the benefits of exercise and there will only be *ad hoc* provision of services that support PA for cancer patients [54].

Conclusions

The limitations of the study centre around the lack of time for depth of information coverage. Although the time was brief (15 min), the researchers believe that sufficient data were generated over the 83 participants' accounts of activity participation 5-year post-intervention. Furthermore, despite the potential limitation of utilizing only one author for the data analysis, further validation of the study is demonstrated through the authors adherence to Yardley's [55] principles for quality in qualitative research; including 'sensitivity to context', with the inclusion of up to date, relevant literature; 'commitment to rigour' with several of the researchers engaging in the methodological process and continued discussion/reflection on the data provides; 'coherence and transparency' by providing vivid and supportive data from a range of participants and 'impact and

importance' by providing the following suggestions for applications and future research:

- (i) All PA programmes for breast cancer survivors should include a psycho-educational component on self-regulation (willpower) and self efficacy (mastery) in order to address pervasive issues such as lack of motivation and lack of confidence in engaging with exercise activity and service provision should attempt to increase access and to minimize perceptions that being 'sporty' is a prerequisite of involvement.
- (ii) Surgeons, oncologists and clinical nurse specialists can also play a crucial 'gateway' role in providing education on benefits of activity participation after cancer diagnosis, as even the use of standard public health recommendations for PA has been found to have long-term effects on activity engagement [56, 57]. As per our findings, some participants feel that exercise had been part of their 'prescribed recovery programme' then they would have been more likely to engage with it.
- (iii) In terms of future research, it is plausible that the results may have naturalistic generalization to other cancers as Ottenbacher *et al.* [20] found that prostate and breast cancer patients, despite gender and age difference, reported similar barriers to exercise implementation, thus there is a need to stretch beyond a purely breast cancer focus [30].

Furthermore, there appeared to be some differences at this 5-year follow-up between the two original group allocations, with the original IG identifying themselves as more active versus the original CG (also shown in the quantitative results), as well as maintaining higher levels of autonomy and diversity in choice of activity engagement. These findings concur with the quantitative results in Mutrie *et al.* [11] thus providing additional evidence for the long-term benefits of the original exercise intervention. These differences can be explained by the safety of the original exercise classes which gave the women a sense of expertise,

education and accountability during a particularly vulnerable time period [12,13]. The findings also add to the current survivor research that supports the use of activity immediately after diagnosis, as well as the need for specially tailored activity programmes in order to overcome potential obstacles.

In conclusion, there appears to be generic and cancer specific barriers to long-term activity engagement following diagnosis and treatment. The results offer suggestions for future research to tailor interventions as well as reflect upon optimum intervention timelines. Our results support and help explain the quantitative findings from the longitudinal pragmatic randomized controlled evaluation project [11]. Above all, we have presented the barriers to long-term activity engagement during cancer survivorship from a real-world, participant perspective.

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Conflict of interest statement

None declared.

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