A focus group study exploring gynecological cancer survivors’ experiences and perceptions of participating in a RCT testing the efficacy of a home-based physical activity intervention

C. M. Donnelly · A. Lowe-Strong · J. P. Rankin · A. Campbell · J. M. Blaney · J. H. Gracey

Abstract
Purpose This study aims to explore gynecological cancer survivors’ perceptions and experiences following participation in a randomised controlled trial (RCT) testing the efficacy of a home-based physical activity behavioral change intervention (Donnelly et al., Gynecol Oncol 122:618–624, 2011).

Methods All participants completing a two-armed parallel RCT were invited to participate in the study (31/33) (Donnelly et al., Gynecol Oncol 122:618–624, 2011). Sixteen participants took part (16/31; physical activity (PA) group n=9, contact control (CC) group n=7). Four qualitative group interviews were conducted (focus group size 3–5). A structured interview guide was followed by an independent moderator. Groups were audio recorded, transcribed verbatim, and analyzed using the framework approach (Ritchie and Spencer 2001), a five-stage qualitative method of analysis.

Results One of the most unanimously perceived benefits of taking part in the programme regarded participants’ psychological well-being. Additional benefits included improved physical fitness and functioning. Important programme features included the weekly telephone calls from a physiotherapist, the patient–professional relationship, and goal setting. Participants’ own motivation and programme timing were also identified as important factors. Suggestions for improvements include: opportunities for social interaction with other gynecological cancer survivors and greater exercise choice.

Conclusion Findings suggest that women diagnosed with gynecological cancer perceive participation in physical activity as important and participation provides benefits in terms of psychological well-being and improved physical functioning. Support for continuation of many of the current features of the home-based programme was provided. Findings provide insight and rationale for the selection of components for future home-based physical activity interventions. Findings also support further research into the development of multidimensional interventions for the gynecological cancer population.

Keywords Physical activity · Cancer · Fatigue · Gynecological cancer

Introduction
The quantitative evidence base regarding benefits of physical activity for cancer survivors is increasing. A recent meta-analysis of controlled trials established small to moderate effects for physical interventions on physical activity levels, aerobic fitness, quality of life, fatigue, body weight, anxiety, and self-esteem during and post-anticancer treatment [1]. Despite the growing number of exercise intervention studies, relatively little attention has been paid to understanding experiences and perceptions of cancer survivors' taking part in these studies through qualitative study. Qualitative data in the form of interviews and
focus groups has the potential to yield rich data and important ideas for the development and evaluation of programmes [2].

Among the small number of existing qualitative studies, the benefits cancer survivors gain from participating in group-based physical activity programmes has been identified [3–5]. The existing literature does not include participants' perceptions and experiences of home-based exercise programmes despite population-based surveys highlighting the preference shown for home-based programmes among specific cancer populations [6, 7]. Home-based interventions represent an inclusive mode of programme delivery, facilitating the participation of both rural and urban cancer survivors. It also offers flexibility as to physical activity timing, duration, and frequency, important for participants who may be experiencing an array of acute and chronic side effects during and post-anticancer treatment.

The current physical activity intervention under qualitative investigation included exclusively gynecological cancer survivors, an understudied population within current physical activity trials. The physical activity intervention tailored to a mixed group of gynecological cancer during and post-treatment was facilitated from a regional oncology unit. It was a home-based, behavioral change, moderate-intensity physical activity intervention [8]. Its efficacy was tested within a recently published randomized controlled trial, of which the primary outcome was cancer-related fatigue. Results showed that the physical activity (PA) group reported significantly less fatigue post intervention and at follow-up compared to the contact control (CC) group [8].

Careful consideration was given to the components of the intervention based on exercise adherence issues reported within previous home-based trials [9, 10]. The designed intervention included exercise counseling strategies to promote physical activity and encourage behavioral change [11]. An initial consultation was conducted between individual participants and the intervention therapist [12], followed by weekly telephone contact from a therapist for 12 weeks, before a final consultation at 12 weeks. The programme also included self-monitoring tools such as an exercise diary and a pedometer and regular outcome assessments. The intervention, therefore, involved many different components, and as a result, to evaluate participants' thoughts on individual aspects was felt to be important.

It was the aim of this study to explore gynecological cancer survivors’ perceptions and experiences following participation in a randomised controlled trial (RCT) testing the efficacy of a home-based physical activity intervention. This is the first qualitative study involving gynecological women; therefore, establishing their reasons for taking part and overall thoughts on the programme will be highly informative for tailoring interventions to this population. Furthermore, as the first qualitative study evaluating a home-based intervention, establishing participants’ thoughts on the home-based nature and likes and dislikes of the individual programme components will be of interest in helping determine valuable components for inclusion in future programmes.

Methods

Design

To address the study aim, an exploratory, descriptive qualitative design was employed, with focus groups used as the data collection method. All participants completing participation in the RCT [8] were invited to take part. The RCT was a two-armed parallel trial, involving a PA and a CC groups. Participants assigned to the PA group took part in a 12-week, home-based, moderate-intensity, physical activity behavioral change programme, including home-based walking and strengthening exercises. The intervention included two physical activity consultations and weekly telephone calls from a physiotherapist. For further details on the intervention, see Donnelly et al. [8] and for programme components, see Table 1.

The CC group also received weekly phone calls for the duration of the intervention to match the frequency of telephone contact between both study groups. No advice was provided to the CC group on changing their activity levels. To provide a purpose to the weekly telephone contact with the CC group, the Rotterdam Cancer Symptom Checklist was completed during the call [13]. This 39-item measure covered four domains, including psychological and physical symptom distress, activity levels, and overall global quality of life [13]. Ethical and research governance approval were obtained from the Office for Research Ethics Committees Northern Ireland and the Belfast Health and Social Care Trust.

Participants and recruitment

Upon completion of final trial outcome assessments, participants from both study arms (n=31/33) were invited to take part in the focus group study. The trial’s contact control participants were not a usual care group, having received weekly telephone contact during the intervention, therefore they were included within the focus group study to explore their reasons for taking part and their thoughts on the weekly telephone contact. Invitation letters were sent via post and followed up by a telephone call from the project investigator (CMD). Interested participants were provided with a letter detailing the date, time, and venue of the focus group. Reminder letters were sent 2 weeks prior to the focus group, with written consent obtained on the day of the focus group.

Sixteen participants took part in one of four focus groups representing 52 % (16/31) of eligible trial participants [8]. Group size ranged from three to five (PA group, n=9; CC group n=7). Participants have a mean age of 55 years (range 38–78). The study was equally representative of women with ovarian (n=8) and endometrial/uterine cancer (n=8). The majority of the sample had cancer stages I and II (stage I, n=10; stage II, n=4; stage III, n=2). Nine participants had completed treatment during the trial.
Focus group sessions

Each session was facilitated by an experienced female moderator who had no previous contact with participants within the trial. A notetaker was also present to observe nonverbal communication and emerging themes [14]. The moderator followed a questioning guide based on the research team’s own research aims and questions from similar qualitative studies (see Table 2) [2–4]. Open-ended questions were used [15] and the moderator stressed her neutrality by wishing to explore both positive and negative experiences of taking part. Each group lasted approximately one and a half hours.

Data analysis

All focus groups were audio recorded. Recordings were transcribed verbatim (CMD) and transcriptions were independently reviewed by the moderator and notetaker to verify their accuracy [16]. Data was analyzed by the project investigator (CMD) using the five-stage ‘Framework’ approach [17]. This approach was developed in the context of conducting applied qualitative research, which is distinguished from basic or theoretical research through its requirements to meet specific informational needs and for its potential for actionable outcomes [17]. Stages of analysis included: (1) familiarization, (2) thematic framework development, (3) indexing, (4) charting, and (5) mapping and interpretation. The first stage involved repeated listening and reading of the transcripts in order to become familiar with the data. From this, notes were taken on the recurrent themes and issues that emerged as important to the respondents. In the second stage, notes from stage one were used to identify key issues and concepts, leading to the creation of a thematic framework from which the data could be sorted. During the third stage, the thematic framework was systematically applied to the data. To complete this, all transcripts were read and information relevant to each index heading was copied to build a descriptive textual-based system for each heading.

Table 1 Components and content of the behavioural change PA intervention

<table>
<thead>
<tr>
<th>PA consultation</th>
<th>Introduction:</th>
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<tbody>
<tr>
<td></td>
<td>• Potential benefit of PA during and after anticancer treatment</td>
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<td>• Current and past PA levels discussed</td>
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<td>• PA guidelines outlined</td>
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<th>Aspects of the programme explained:</th>
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<tr>
<td>• How to warm up and cool down after PA</td>
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<td>• How to be PA at moderate intensity (Borg Scale 12–13)</td>
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<td>• Strengthening exercises guidelines</td>
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<td>• First week’s goals agreed</td>
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<th>Behavioral change strategies discussed:</th>
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<td>• Pro’s and con’s of exercising</td>
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<td>• PA barriers</td>
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<td>• Self-efficacy to exercise</td>
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<th>Participants provided with:</th>
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<tr>
<td>• Information booklet</td>
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<td>• Exercise diary</td>
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<td>• Pedometer (Digi-Walker SW 701, Yamax Corporation)</td>
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<th>Weekly telephone calls</th>
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<td>• PA levels discussed and recorded</td>
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<td>• PA barriers identified and discussed</td>
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<td>• Suitable PA goals agreed for the week ahead</td>
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<td>• RSCL completed</td>
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<th>Final consultation</th>
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<td>• PA levels and barriers throughout the programme discussed</td>
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<td>• Benefits of PA and PA guidelines restated</td>
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<tr>
<td>• PA goals for month ahead agreed</td>
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<td>• Longer term PA goals agreed (six monthly and yearly)</td>
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<td>• Relapse prevention strategies discussed</td>
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<td>• Self-efficacy to exercise examined and discussed</td>
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<th>Follow-up calls</th>
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<td>• Current PA levels and barriers recorded and discussed</td>
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<td>• PA goals agreed for the month ahead</td>
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<td>• Final follow-up call</td>
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<tr>
<td>• Progress during PA programme outlined</td>
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<td>• Long-term goals discussed</td>
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<td>• Relapse prevention strategies emphasized</td>
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Table 2 Overview of the questioning guide for physical activity participants

<table>
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<th>Questioning guide</th>
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<td>Physical activity group</td>
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<tr>
<td>• Reasons for taking part</td>
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<td>• Overall thoughts of the programme</td>
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<td>• Programme likes and dislikes</td>
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<td>• Barriers and motivations to physical activity</td>
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<td>• Thoughts regarding individual components of the programme</td>
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<td>• Perceived benefits</td>
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<td>• How to improve the programme</td>
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<td>• Appropriateness of the timing of the programme</td>
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<td>• Future physical activity intentions</td>
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<th>Contact control group</th>
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<tr>
<td>• Reasons for taking part</td>
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<td>• Thoughts on being randomized to the CC group</td>
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<tr>
<td>• Positive and negative aspects of being a CC participant</td>
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<tr>
<td>• Activity levels during the programme</td>
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<tr>
<td>• Participants views on PA services for women diagnosed with gynecological cancer</td>
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<tr>
<td>• Preferences for programme type and timing</td>
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PA Physical activity, RSCL Rotterdam Symptom Checklist
The fourth stage involved producing a summary of the respondents’ views or experiences under each heading. During the final stage, charts were reviewed systematically in order to detect patterns or associations within the data.

The moderator and notetaker subsequently reviewed the thematic frameworks and resulting interpretations and met CMD to discuss alternative interpretations, and a consensus was reached. Themes from individual sessions were issued in writing to each participant for their information and verification.

Results

Reasons for participation

Results showed that across all four focus groups and with the majority of participants, there was initially a strong desire to be randomized to the PA group, highlighting the perceived importance of physical activity for women diagnosed with a gynecological cancer.

[P1: and you knew it was a random thing and I was thinking, please let me be in the group that was going to be phoned.]

Participants’ reasons for wanting to take part included: to feel better, increase energy, decrease fatigue, and change body shape. For other women, participation was based on reasons beyond those associated with physical activity. For one lady, the programme was described as a stepping stone back to ‘normality.’ Additional reasons included participating in research to help others.

[P14: and we have quite a few grandchildren and that was my aim, to get myself fit again so that I could look after my grandchildren…]

Theme 1: Range of benefits

Findings suggest that participants experienced a number of benefits linked with taking part in the study. This emerged as a key theme throughout the focus groups, interestingly, both in the PA and CC groups. Benefits were discussed spontaneously by participants in relation to their overall thoughts of the programme and to what they liked most about taking part. Reported benefits could be considered within two main categories, including benefits associated with participation in physical activity and additional benefits that were experienced through the social interaction with the study’s health professionals (see Fig. 1). Benefits associated with participation in physical activity included increased activity levels, improved physical functioning and physical fitness, and improved psychological well-being. The latter, in particular, appeared to have vital relevance for participants, being the most consistently discussed across all four focus groups. Further benefits were reported in terms of fatigue and body shape. However, there was also strong negative emotion reported by some participants regarding increased weight gain experienced during the study.

Subtheme: Physical activity-related benefits

Activity levels While there was a strong sense for the majority of women in the PA group that they had led previously active lives, most were not currently active at the time of invitation into the study. However, as a result of participation, positive changes on their activity levels had occurred. Importantly, for a number of participants, the programme overcame barriers by encouraging them to exercise despite how they were feeling and regardless of the season.

[P9: It definitely helped me too, I think it was a great motivation and it gave you the incentive to walk no matter how bad you were feeling. Although the days I got treatment I wouldn’t have gone out, but the day after that, I was on my bike, so, it was really good]

[P6: And I mean like come January, February, March you don’t feel like going, whereas with being on the programme I thought well you have to go]

Encouragingly, a number of participants reported that they were still regularly active despite a sense that they were...
not as active as during the programme. For a number of participants in the CC group, the study had a positive influence on their activity levels.

**Physical fitness benefits** Relating to activity levels, participants in the PA group reported improved physical fitness or functioning. Some participants reported feeling fitter compared to other cancer patients they knew. Participants also found that increased activity levels translated into making day to day activities easier, with one participant indicating that she felt fitter than she was before her cancer diagnosis.

[P6: It just got you out, mmm just really that it did get you out into the fresh air and it kept you fitter; you know, I find even going up and down stairs pretty easy whereas other people I have been talking to, that weren't on the programme didn't find it easy going up and down stairs and things like that. But I do definitely think the walking helped me.]

[P6: I know another girl who went through the same operation as me, and she's younger than me, she's only 54, and she can't put one foot in front of the other; but she went home and her husband looked after her, she couldn't get up to make a cup of tea now P9: That's right, I met up with one like that too, she did nothing, she stayed in bed all day, she never got out of the bed, and I said to her, “it's going to be hard for you when you try and get back up again P6: But we had to go out.]

[P1: that you could, you know, actually, probably, I'm fitter now than I was before all this happened.]

**Psychological benefits** The vast majority of PA group participants identified psychological benefits linked with participation, and these were mentioned recurrently throughout the groups. Participants' explanation provided a number of mechanisms for this. For some, physical activity was distracting from thinking about the cancer diagnosis and its consequences. Being physically active also provided acute benefits in terms of mood, and for some, the programme was thought to prevent depression. In addition, other participants reported experiencing a sense of achievement from exercising and increased activity levels.

[P2: I think I would have got depressed if I didn't have Caroline (therapist) phoning and giving me all them exercises to do.]

[P3: Hmm, so you know, so, umm, it lifted my spirits to be out, you know, out to get that thing, to go out and have your walk and do that bit of exercise in the house and things like that, you know.]

Additionally, for participants in the CC group, there was a strong sense that physical activity was important for psychological health.

[P11: I always felt great after walking somewhere or after doing something. You do feel better.]

[P14: and I really do feel exercise can help you get better quicker.
P15: Mentally and physically.]

[P10: I think it is twofold, it's not just about the exercise, it's about your mood and if you're exercising a wee bit more, you're a bit more active, your mood will lift a bit more, and it also takes you out of thinking about it all the time and you feel like you're achieving something and it's like, for me, it was very important to feel like I was doing something to get myself well again. Do you know what I mean? So, it's part of the psychological journey as well, you know]

[P14: You do feel as though you're much more able to cope because, physically, your, your level of. I can't even think of the word I'm trying to use but your level of exercise and your physical ability has improved and that helps you.
P16: Yes P14: To cope with other things.]

**Fatigue benefits** For some participants' benefits in relation to fatigue were reported. One participant reported how exercise had an acute effect on her tiredness with agreement from other participants. She outlined that physical activity changed the type of tiredness from a lethargic feeling, which was perceived as negative, into an exercise-induced tiredness that was positively perceived. It was, however, noted by some that fatigue was still present. Additionally, for one participant, exercise helped with fatigue by improving her sleep quality and for participants in the control group, the reenergizing effects of exercise were also felt.

[P1: I distinguished between, good tiredness and bad tiredness. The bad tiredness was the result of your illness and your treatment, were you get so lethargic. The good tiredness was when you've been out and you've been walking or exercising.]

**Body shape changes** Outcomes in relation to weight and body shape resulted in mixed outcomes and strong emotions. A number of participants across both groups had gained weight and expressed strong disappointment at this. For others, objective changes in body shape were experienced, while some believed physical activity was helping to rectify negative changes in their body shape.
[P2: But I just blew out after I had the surgery. I just blew out completely. So doing that there kind of helped me to get back into my way of going again.]

[P14: Whenever I came up to see Janine (outcome assessor) and in this I will be honest, I cried bitterly the whole way home. I really did. I was so devastated and gonked. I don't know, as I said, I never went into this to be a diet. I went for the exercise, to get myself back up there and I did, I cried the whole way down that motorway. I think about (place name), I, kind of, they dried up and I got home and that night, I was, oh, by evening, oh, what is wrong with me and all this. I got up the next morning and I thought about it and I said, well, I never went to it to lose weight and I had to look at it again and I never went to it for to lose weight. I went to increase my energy levels and I've done that.]

Subtheme: Additional benefits

Aside from benefits that were directly attributable to participation in physical activity, a number of additional benefits were identified by participants in the CC group in relation to the programme and the contact with health professionals. For some ladies, the contact with a health professional provided an avenue to discuss feelings or symptoms that they preferred not to burden or constantly burden family members or friends with.

[P11: No, I found it really therapeutic. You know, I mean you're diagnosed with cancer, you have to accept OK we're going down this road now, you're going to hospital, getting all your treatment and then for being in this study this was another thing, I just viewed it as another thing that is going to help me through it and for getting phone calls, it was just fantastic. It was another avenue for me to offload all these feelings because my poor family had listened to so much and you felt nearly guilty, you know, saying the same thing over and over and over and over, again, and this was another person that I could say it to, you know, who wasn't emotionally involved and you get all of this off your chest and then say bye bye and that's was OK so...]

For one participant, completing a cancer-specific symptom checklist was useful in helping decrease her anxiety by normalizing symptoms. For another participant, the contact was important as it made her aware that there were other ladies going through similar experiences. Finally, for one lady, the contact helped with the void after treatment, with the regular contact being described powerfully as a ‘lifeline.’

Theme 2: Important programme features

The study highlighted a number of key features of the programme that helped in creating the subjective and objective benefits outlined. Some of the important features were inherent in the programme design, including the weekly phone calls and the home-based nature of the programme. However, other significant features included the issue of programme timing, participants’ own motivation, and the patient–professional relationship that developed. Figure 2 serves to represent important programme features.

Weekly telephone calls

The weekly phone calls to participants were designed with the aim of encouraging behavioral change within a home-based programme. However, participants’ thoughts regarding this element could not be predicted. Fortunately, results showed that participants perceived this positively and regarded it as a critical element of the programme. The calls, it appeared, created an accountability to exercise that was appreciated by participants.

[P7: And I found it helpful that they kept in touch with you.]

[P2: The phone calls motivated you. When Caroline (therapist) phoned me.]

[P8: Well I think now someone on the phone now, can be stimulating.]

Even for participants within the CC group, the calls appeared to motivate.
so I devised my own programme to get myself back, trying to, I think you have to exert energy to get energy and I know that, so I knew I needed to increase it a bit to get my energy back up but it was good because I was motivated more by the study like Caroline (therapist) ringing every week so that motivated me a bit more to try and get my exercise back up again so that was good.

There were a number of practical aspects relating to the calls that participants felt were important. This included their weekly regularity, which mattered to both physical activity and control participants. A set day and time for the call was also remembered and liked by participants in both groups. Further confirmation of participant's appreciation for the calls was indicated by participants who said they missed the calls after the trial had ended.

Patient–professional relationship and contact

While the role of the professionals and the relationship between participants was never directly enquired about, it emerged as a key theme when evaluating the programme. It appears that contact with the therapist established a relationship that was important to the success of the programme. This relationship, it appears, created an extra motivation to exercise.

More as a friend, wasn't she? (referring to the therapist)
P1: Exactly. That's what my husband said. It's like your friend phoning you today or whatever, you know.
That was it. That was how she was perceived, you know.
P2: It wasn't just somebody doing their job.
P1: No.
P2: I think that's what helped too.

And you build up a relationship with Caroline (therapist) you know
P12: You do
P10: You do.

Key attributes linked with the professionals included understanding and flexibility, with advice to work within limitations or barriers considered particularly important. Furthermore, not to be forced to exercise was important. However, a negative aspect to the patient–professional relationship was highlighted by one participant who felt she had let the therapist down, and one other participant mentioned guilt would have been experienced if you had not exercised.

Yes, I was glad to take part in it as well. I was in the year of treatment and everything, like, you know, whenever I was asked, when I was up getting my check up or whatever. So yeah, I was glad but (laugh) I felt like I've let Caroline (therapist) down a bit because I've had put weight back on again.

Feedback and goal setting

Participants in both the PA and the CC group indicated they liked the 12-min walk test. In particular, any feature in which participants could see they had improved as well as any features that helped set measurable goals was beneficial. Seeing improvements in the 12-min walk test provided participants with encouragement to continue to exercise. Furthermore, seeing improvements was psychologically beneficial by providing clear evidence to participants that they were recovering.

I think when you go to the hospital the first time and you do that walking test, it motivates you to go out because you know you have to try and do better.]
P6

I really found the contact and just the encouragement from the girls and when you did come up here and met them and they did your height, your weight and saw how fast you could walk or whatever and, I found that a real encouragement because each time I did it I was able to walk that little bit further and that little bit faster and I really do feel exercise can help you get better quicker.

Programme timing

Timing emerged as an important theme throughout the focus groups in relation to the benefits participants experienced and their ability to take part. Interestingly, participants' opinions on whether the programme would be better during or following treatment varied. For a number of physical activity participants, it was important to exercise during treatment, with the benefits they experienced being directly linked to the timing of intervention. Similarly, for some participants in the CC group, exercising during treatment was important. However, it was felt that it will depend on the treatment and the extent of side effects experienced.

My treatment was October and I didn't finish my treatment, like I had 18 days of chemo and then I had 3 weeks off and then I had 30 sessions of radiotherapy and 2 of brachytherapy so if you take all that there you have sat about too long.
P6

Yes, it depends on the treatment you're getting. I think you are on another level. Well, actually, I think if even if you start really gently during treatment, it is probably a good idea, you know, just something very gentle because it depends, but it depends how sick you are. If you're sick you're not going to want to go out
and do stuff, you know, so, but something really, really gentle that you could do. Like a lot of those things and you can do in the house, you know, so even to start thinking about it…]

For a number of participants who participated in the intervention post-treatment, they expressed that they would not have wanted or been able to exercise during treatment; in this case, the majority of participants were referring to radiotherapy. The daily travel required and pelvic symptoms experienced presented as major barriers. In addition, one participant who began the intervention during chemotherapy considered that, in hindsight, she would have preferred to exercise after treatment, in particular, a month following chemotherapy.

[**P5:** Whenever you're getting all that treatment and you're going to hospital all the time and I had to get radiotherapy as well which was every day running... You couldn't have done that exercise programme when you were in the middle of it.]

[**P7:** I suppose it depends on everybody because I really enjoyed the programme but I think I would have enjoyed it more had I started it after my treatment was finished because I was so sick during my treatment. I probably would have had more benefit out of it, if I had started it after my treatment was finished because I suppose everybody is different but because I was so sick.]

**Internal motivation**

Participants' own motivation also emerged as a subtle but nonetheless important factor linked with the success of the programme. While it was not explicitly mentioned in all focus groups, participants' initial reasons for taking part allows for such a conclusion, given that all participants perceived benefits of exercise and wanted to experience them.

[**Moderator:** Can I just ask you, what did motivate you to exercise at home?  
**P7:** I think it was because, obviously, I wanted to exercise, because I felt as if I was getting bigger. I thought I'm going to have to do something because you know, because I need my mind lifted. You know, I thought, it's something different, it lifts your mind and, you know, it took your focus away from your illness  
**P9:** Yeah definitely.]

**Programme type**

Regarding the programme type, it was felt that a home-based programme was most suitable, as while participants expressed a desire for contact with other cancer survivors, the difficulties of organizing and attending a group-based intervention made it seem unappealing for both rural and urban participants.

[**P1:** But for somebody to tell me when I am going through what I was going through like could you come up next week and do stretching exercises or something I would probably have said no, I don't feel up to it and you wouldn't know till the day whether you could go or not, you know.]

**Theme 3: Ways to improve the programme**

Participants were asked how the programme could be made better for other women in the future; this question and questions regarding programme dislikes provided a number of areas where the programme could be improved. This included the need for greater exercise choice, inclusion of abdominal strengthening exercises, and opportunities for social interaction with other gynecological cancer survivors.

**Greater exercise variety and choice**

While walking suited the majority of participants, two participants suggested greater variety would improve the current programme. This was felt to be important as for one participant, walking got particularly monotonous.

[**P5:** The only problem was, you know, the walking just got too monotonous and too boring, you know. Well, if she could have said, like, do a half hour's walk, go for a swim, or instead of doing half an hour's walk, you know, go to a yoga class, you know, there are other forms of exercise apart from just walking.]

**Abdominal strengthening exercises**

Specific exercises to strengthen the abdominal area were also considered important.

[**P7:** find that the exercises were great but the one I didn’t mention to Caroline and Janine both (therapists) I would have found exercises for your tummy better, if you know what I mean, if we could have had more of those]

**Social interaction**

Across all four focus groups, participants spontaneously shared and compared their cancer experiences, discussing how they initially coped with their diagnosis, symptoms they experienced, and their experiences of medical services received. Within these short discussions, there was evidence of the support the women provided to each other by
affirming what participants were doing to help themselves and sympathizing with the situations of others. Furthermore, across all focus groups, participants reflected and agreed how it was nice to have the opportunity to share experiences and hear how other women were coping. These findings alone highlight the value of social interaction with other cancer survivors. However, group physical activity was not recommended as a way to facilitate such contact. Suggestions were, however, made that this could be facilitated via group consultations or meeting other participants at regular intervals, such as during outcome assessment attendances or by telephone contact.

[P14: I don't know. From a distance point of view, at times, it could be hard to get a group together; but having said that, it has been absolutely fantastic to come today and to meet other people in a similar situation so it's really a two-edged sword and I don't know what the answer is for that. Yet, I feel, the support of other people in the same situation means an awful lot and you see what level other people can do things like that, so from a group, yes, that would be fantastic but from a distance point of view and a time point of view I find that might be hard. Maybe if you could get together, you know, once a month and do the rest at home or once in two months but it would just be, it's the contact and support of other people that I think is most important.]

Theme 4: Need for information

Within all four focus groups, there was a recurring theme regarding the need for information in terms of activity levels and safe and unsafe activities. In relation to this, current practice was very often discussed and it appears that the timing of information is often inappropriate for patients who were sometimes coming to terms with bigger issues such as their newly confirmed diagnosis of cancer. In addition, how the information is provided appears inadequate.

[P1: And the thing is I don’t think you realise, you know, you’re so glad to get out of hospital you don’t think at the time what you need to ask and there is no follow up afterwards.]

[P15: Although she (the physiotherapist) came in the morning after the surgery, I was no more interested in it.]

Discussion

The aim of this study was to explore participants' perceptions and experiences of participating in a feasibility trial involving a 12-week home-based exercise programme. Primarily, participants' reasons for taking part and perceived benefits highlight the perceived importance of physical activity for gynecological cancer survivors. A study exploring the lived experiences of exercise for women with breast cancer recorded strongly comparable findings [18]. Within both studies, the importance of exercise in promoting aspects of recovery and regaining normality in the women's lives emerged.

In relation to the perceived study benefits, psychological benefits were the most consistently reported. This emerged for both physical activity and contact control participants. Interestingly, participants who took part in this study were drawn from a sample were the majority had minimal or mild levels of depression [8]. Participants could, therefore, represent individuals who have subthreshold levels of depression, for which it is suggested physical activity is beneficial [19]. If the intervention improved mental health significantly to prevent depression, this represents significant personal and societal gains. By reducing psychological morbidity, the need for further interventions, including general practitioner (GP) visits, pharmacological treatment, and counseling are reduced and importantly, the participants' functional capacity in terms of family roles and ability to return to work is improved. Therefore, investigating potential longer term benefits such as a reduction in health care utilization and a decreased time taken to return to work should, therefore, be considered important outcomes for future interventions involving this population.

Findings support the continuation of many of the current features of the intervention, including its home-based design and weekly telephone contact. Additional features, not inherent in the design that emerged as important, should also be considered, including timing and internal motivation. The appropriate time for participants to begin a physical activity programme post diagnosis created conflicting views between participants but ultimately emerged as an important factor. In summary, the variation in opinion suggests that it is perhaps inappropriate to specify an ideal time for providing a physical activity intervention for all participants and that a decision regarding programme initiation should be carefully considered based on individual preferences, demographic variables, and a professional assessment of symptom severity.

The weekly phone calls emerged as a key aspect of the intervention, encouraging exercise participation among the majority of physical activity participants and some contact control participants. Participants in both groups highlighted that the regular nature of the calls, a familiar day, time, and therapist were all important aspects associated with the weekly phone calls. The significance of the regularity of the calls has been supported by research that found that people who received weekly calls were more likely to walk regularly than people called every 3 weeks, even if the call was simply to ‘touch base’ [20]. The weekly phone calls seemed to create an accountability to exercise, linked with a rapport that was built up with the contacting therapist. Rapport, defined as the relationship a therapist and patient
establish, is built on trust and mutual respect [21]. It is suggested that if a strong therapeutic relationship is established, the behavior change process is more likely to succeed [21]; indeed, the current study's findings support this. Patient views highlight that therapists' listening skills and interest in participants were an important basis for the development of a therapeutic relationship; this is also supported by literature [22], highlighting the importance of basic skills health professionals may take for granted but should or do habitually engage in.

Other features that were appreciated by participants included aspects of the programme that helped participants see physical improvements including the 12-min walk test. Seeing improvements appears to have provided further encouragement to exercise and for some, created a strong sense of achievement, importantly contributing to feelings of physical and psychological well-being. Understandably, this may be important for women following a cancer diagnosis, extensive surgery, and debilitating anticancer treatments. Furthermore, recognizing physical improvements may be connected with a sense of 'going forward' from a cancer victim to a cancer survivor as suggested by Hennessy et al [18].

In relation to how the current programme can be improved, a number of subthemes emerged; in particular, the benefits of social interaction with other women diagnosed with gynecological cancer. While the benefits of social interaction during group exercise have been strongly portrayed in other qualitative work [3–5], the impracticality of exercising together, i.e., due to travel and establishing a suitable time, meant group exercise was not preferred by participants within this study. However, it was suggested by participants' social interaction could be facilitated within a home-based programme through conducting group consultation or more informal opportunities to meet throughout the intervention. The most appropriate way to facilitate this should be established. In relation to this, a behavioral change intervention by Rogers et al. [23], which included both individual and group sessions for breast cancer survivors, stated that participants felt individual sessions were most valuable, indicating both group- and individual-based consultations may be required to facilitate social interaction while maintaining personalized discussions within a home-based programme [23].

The psychological benefits contact control participants outlined that were not associated with participation in exercise suggested a very relevant area of further research. The reported benefits that were linked with the weekly phone contact from a therapist, where participants had the opportunity to offload feelings and informally discuss concerns, such as medical, social, or emotional issues, identified an unmet need for psychosocial support and multidimensional sources of information for the gynecological cancer population.

The RCT and qualitative benefits associated with physical activity ultimately highlight the important role physical activity may play within multidimensional programmes by its ability to address both physical and psychosocial outcomes. However, it should be established if the inclusion of additional programme components could further improve outcomes. The work by Steinga et al. [24], who conducted a study to establish the precursors to domain-specific quality of life in colorectal cancer survivors, suggests in terms of supportive care interventions, an integrated approach is required including symptom management, psychosocial and lifestyle variables, or health behaviors [24]. In particular, the significance of weight management for the women in this study highlights that the additional health behavior change component such as diet would be of interest for the gynecological cancer population, as has already been emphasized in a study by Beesley et al. [25].

A Queensland-based study, which attempted to identify the prevalence and correlates of unmet needs within the gynecological cancer population [26], identified the most common unmet needs including help with fear about cancer spreading (17 %) and uncertainty about the future (14 %). It has been suggested that social cognitive approaches may help a patient deal with cancer threat appraisal and how patients think about their cancer in relation to themselves, their social attachments, and their future [24], and therefore, such an approach could also be integrated into multidimensional programmes for gynecological cancer survivors. Recently, Hawkes et al. [27] tested the feasibility and short-term effectiveness of a multidimensional study for colorectal cancer survivors. The intervention included strategies such as: moving on after cancer, living with uncertainty, relaxation training, managing fatigue and symptom management, physical activity, healthy eating, and weight management. These components may have more to offer the gynecological cancer population than an exercise programme alone.

**Study limitations**

The greatest limitation of this study is that due to the study's small sample size, theory saturation, whereby no new information is gathered and groups become repetitive, was not achievable. However, repetitive themes emerged across the focus groups allowing greater confidence in the findings. It must also be considered that the sample was not wholly representative of all gynecological types and stages such as women with cervical cancer.

However, every effort was made to maximize the reliability of findings. Firstly, the vast majority of participants who took part in the RCT [8] were invited to participate in the study, and over half of trial participants took part,
including 65 % of physical activity participants. The focus
group sessions were conducted by an experienced indepen-
dent researcher, using a structured question guide for con-
istency. The framework approach [17] represents a
structured method of analysis with full review of all data.
The review of the thematic framework and emergence of
themes by two independent researchers ensured results were
not based entirely on a single and possibly biased interpre-
tation. Emerging themes from each session were also sent to
participants to verify their accuracy.

Conclusion

This is the first qualitative study evaluating gynecological
cancer survivors' views of a physical activity programme. Additionally, it is the first qualitative study to evaluate cancer
survivors' experiences within a home-based exercise
programme. Participants' reasons for taking part and perceived
benefits highlight that participation in exercise is perceived as
important for gynecological cancer survivors and can produce
benefits in terms of physical and psychological well-being.
Psychological benefits were consistently reported and
appear to have vital relevance for women following a
diagnosis of gynecological cancer. Weight management
is also a highly relevant issue; therefore, interventions
capable of producing positive outcomes in these areas
should be investigated. Participants' experiences and opin-
ions support the home-based mode of delivery and continuation
of many of the current programme features including
weekly phone calls with professional contact, goal setting,
and feedback. The importance of the programme timing and
participants' own motivation should also be considered in the
development of future interventions. The current programme
could be improved by providing opportunities for social
interaction with other gynecological cancer survivors. Further research regarding multidimensional sources of information
relevant to gynecological cancer patients should be investigated.

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