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Exercise rehabilitation study: qualitative findings

Title: Colorectal cancer survivors' exercise experiences and preferences: qualitative findings from an exercise rehabilitation programme immediately after chemotherapy.

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Abstract

Little is known about cancer survivors' experiences with and preferences for exercise programmes offered during rehabilitation (immediately after cancer treatment). This study documented colorectal cancer survivors' experiences in an exercise rehabilitation programme and their preferences for programme content and delivery. At the completion of 12-weeks of supervised exercise, 10 participants took part in one-on-one semi-structured interviews. Data from these interviews were coded, and themes were identified using qualitative software. Key findings were that most participants experienced improvements in treatment symptoms, including reduced fatigue and increased energy and confidence to do activities of daily living. They also reported that interactions with the exercise trainer and a flexible programme delivery were important aspects of the intervention. Most participants reported that they preferred having a choice of exercise, starting to exercise within a month after completing treatment, having supervision and maintaining a one-on-one format. Frustrations included scheduling conflicts and a lack of a transition out of the programme. The findings indicate that colorectal cancers experience benefits from exercise offered immediately after treatment and prefer individual attention from exercise staff. They further indicate directions for the implementation of future exercise programmes with this population.

Trial registration: ACTRN012606000395538

Key Words: Exercise, Rehabilitation, Colorectal cancer, Qualitative, Intervention

INTRODUCTION

The importance of exercise for cancer survivors throughout the cancer continuum has been well justified in numerous reviews over recent years (Courneya and Friedenreich 2007). However, certain points along the continuum have not been rigorously studied. One of these is the ‘rehabilitation’ period, the period immediately following the completion of cancer treatment (Courneya and Friedenreich 2007). Results from the few studies that have targeted cancer survivors when they were within 12 months of completing treatment suggest that exercise in this period is feasible and may provide both physiological and psychological benefits (Spence et al. 2009). Although the quantitative data from these studies provide evidence of potential benefits of exercise during rehabilitation, qualitative data on the perceptions of survivors about exercise and exercise programmes during this period is lacking. It is expected that insight into cancer survivors’ experiences with and preferences for exercise programmes developed for the rehabilitation period would allow for more refined tailoring of these programmes and would thus increase exercise uptake by cancer survivors during this period. Furthermore, one of the key benefits of qualitative research is its ability to highlight important issues, generate new hypotheses and to guide design of future interventions studies.

This article summarises the qualitative data collected from colorectal cancer (CRC) survivors at the conclusion of a one-on-one supervised aerobic exercise programme that was commenced within four weeks of completing chemotherapy. The aim was to understand participants’ experiences of the exercise programme and preferences regarding its content and delivery.

METHODS

Participants

Participants were CRC survivors who had completed adjuvant chemotherapy treatment within the previous 4 weeks. They were recruited through oncology and surgery clinics at local hospitals in Brisbane, Australia. The local university and hospital research ethics committees provided ethical approval. Patient inclusion criteria were: aged 18 to 75 years;

confirmed CRC (stage I-III), treated with surgery followed by adjuvant chemotherapy treatment; non-smoker (not having smoked during the previous 12 months); able to read, write and understand English; and willing and able to attend supervised exercise sessions three times per week for 12 weeks, with the intention of achieving 90% attendance. Patient exclusion criteria were: metastatic or incurable CRC; physical/psychiatric impairments that would seriously impair physical mobility; and known contraindications for exercise (as assessed by a pre-screening questionnaire modified from the Sports Medicine Australia Pre-Exercise Screening System 2005 (Norton and Sports Medicine Australia 2005)).

Intervention

The 12-week intervention consisted of three sessions per week of supervised moderate- to high-intensity aerobic exercise. A supervising exercise physiologist prescribed an individualized exercise prescription for each participant, based on a general prescription of 20-40 minutes of exercise at 40-80% of heart rate reserve. All sessions commenced with a 5-minute warm-up and concluded with a 5-minute cool-down, both of which consisted of aerobic exercise and stretching of major muscle groups. For the main session (20-40 minutes) participants had their choice of aerobic exercise/s (given the necessary resources were available and the exercise physiologist deemed the chosen exercise to be safe).

Assessment

Demographic characteristics were collected at the initial assessment. Following the collection of quantitative outcome data (data presented elsewhere) at the conclusion of the 12-week exercise programme, each participant took part in a one-on-one semi-structured interview with the study coordinator (RS, a doctoral student with training as an accredited exercise physiologist and experience in prescribing exercise for cancer survivors). The interview took approximately 1 hour and followed a structured set of questions and probing guidelines, which are shown in table 1. Questions were developed by RS in consultation with KH and WJB, who have doctoral degrees in physical activity and health-related fields and experience in qualitative data collection methods. Questions were adapted from those used in previous studies of exercise interventions in cancer survivors. Interviews were audio-recorded with permission of participants.

Data Analysis

The qualitative data from the interviews were transcribed verbatim and imported into QSR NVivo 8 qualitative software (QSR International, Melbourne, Australia). The data were first coded into categories representing each question asked, and then from each category, into major themes that emerged from the data. RS and KH jointly developed the themes and coded the data into themes. Next, RS reviewed all themes, merged those which overlapped, added major theme headings, and summarized the findings. KH reviewed the summary and confirmed that it represented the data. For the final step, a researcher who was not included in the data collection or analysis procedures (WB) reviewed the coding, themes, and summary report to confirm the trustworthiness of the conclusions. The qualitative results are presented as descriptive summaries supported and illustrated by quotes from the raw data. The identification number of the participant is given either before each quote or in parentheses following the quote.

RESULTS

Participants' Characteristics

All eligible patients who were referred to the study consented to involvement. Over an 18-month period 10 participants were recruited into the study (see table 2 for participant characteristics). Seven were male. Six were diagnosed with colon cancer and four with rectal cancer. Participants ranged in age from 42-74 years. Of seven participants who were employed, four were on sick leave at baseline; however, all returned to work during the intervention period. All participants had undergone curative surgery for colon or rectal cancer, and all had completed chemotherapy within 4 weeks of attending the baseline assessment.

Qualitative findings

Below we summarize the major themes that emerged from the week 12 interviews. Quotes are provided in text when brief quotes reflect the statements of most participants. Quotes about a theme are provided in boxes when longer quotes are more representative.

Improvements

Participants were asked to recall their expectations of the programme prior to starting it. Most reported that they had expected to improve their fitness, stamina or general wellness (both physical and mental), using phrases like ‘get fitter’ or ‘feel better’ to describe their expectations. Participant 01 elaborated by saying, “I didn’t want to continue feeling physically and mentally debilitated.” A number of participants mentioned that they had not given much thought to the outcomes of the programme. This is reflected in the statement by participant 10, who said, “I had limited expectations. I didn’t sit down to make a list of what I expected. I knew there would be benefits.”

All participants were asked to identify the improvements they received from the programme. Most said that an important benefit was an increase in their confidence to exercise and do activities of daily living, such as returning to work (see box 1a).

The main physical improvements reported may have influenced confidence levels. These were increased fitness and reduced fatigue levels. Every participant said that their fitness had improved, citing improvements in aerobic fitness, physical strength, and the ability to walk or run faster and for longer without tiring. A few of the older male participants expressed amazement that they were feeling fitter than they had in up to 20 years. Participant 07 said, “I’m fitter now than I have been for a long time”. A number of participants mentioned that flexibility was a valued benefit of the exercise sessions, although flexibility was not a focus of the study. It is likely that this was attained from the stretches that were included in the 5-minute cool-down at the end of each session.

Most participants also reported that the exercise helped them overcome the fatigue experienced after treatment and regain their pre-treatment energy levels, which, they said, was an important outcome for them. One participant commented:

08: The programme has definitely impacted my improved energy levels. I’m frightened to think what I would have been like by this stage if I hadn’t been coming and doing this hard training... I feel like I’d feel just as bad now [as at the end of treatment] if I hadn’t done something. I wouldn’t have the nausea and diarrhoea, but the fatigue and depression and all the rest.

However, on-going fatigue was reported by a number of participants, with some participants still finding they needed to nap during the day or that ‘the brain just switches off’ due to fatigue (participant 07).

All participants reported that the programme gave them a greater sense of health or well-being (see box 1b). This improvement was reported to be a strong motivator to exercise, as it contrasted with how they had felt during chemotherapy. There were a number of passionate comments about the programme helping participants to return to life and feel good again.

Most participants reported that an improvement in mental outlook was another important benefit. Participants said that having to get up in the morning to go exercise, getting a sense of achievement from being able to complete a task and having something other than their illness to focus on resulted in improvements in their mental health, including improved self-esteem and increased positiveness. Some participants reported that having to wake up earlier to go exercise had the extra benefit of helping them to develop healthy lifestyle habits.

Participant 06 said,

“Sometimes I would struggle to get here [to the exercise sessions], but then afterwards I would feel so much better, even going back to work I noticed I was more alert after exercise and more focussed...It improves the emotional side too, getting out and doing something and proving that you can.”

As the quote above mentions, participants also reported improvements in mental outlook from the sense of achievement they got from pushing themselves and being able to do more each week (see box 1c). This was especially important in that some participants found their achievements in the programme a way of taking control of something after having so much done for or to them during treatment.

Some participants found the discipline of having to meet someone on a regular basis helped them to develop a regular exercise schedule that they hoped that they could maintain. Others mentioned being more intentional than they had in the past about being physically active or eating better, which may explain the weight changes reported by some participants.

Another reported benefit was the knowledge gained from the programme. Participants reported that they learned the importance of exercise for health and, more specifically, they learned to use training techniques, such as measuring and modulating exercise intensity. A number of participants had no previous exercise knowledge. For example, participant 09 said,

“I’ve never done exercise like this before in my life. I always thought that doing the housework was enough. I didn’t realise that I had to get my heart rate up and that I

needed to be puffing. I thought doing the housework at home was enough. I didn't know.”

Most and least enjoyable aspects of the programme

Supervised delivery of the exercise sessions made key contributions to participants' enjoyment of them. Participants reported that they enjoyed the regular social contact with the trainer and the rapport that developed (see box 2). They particularly appreciated having the one-on-one exercise sessions personalised to their needs, including: having the sessions modified when they were experiencing side-effects from the chemotherapy treatment; being allowed choice in the time, place and type of exercise for exercise sessions; and the use of an acceptable and appropriate exercise intensity. This is well summarised by the following quote:

02: You made it at a time that was convenient for me. You started at a pace that was comfortable and progressed from there. And I really enjoyed walking as opposed to other exercises, so it fitted really well for my personal taste.

Participants also reported that they appreciated the trainer holding them accountable to complete each session and pushing them to improve their performance. Most participants believed that they would have had difficulty in maintaining a regular exercise schedule without the accountability provided by the trainer. Some participants reported the accountability to be an enjoyable aspect of the programme, while others reported both positive and negative feelings towards being held accountable by the trainer (08: “it's [accountability's] a good thing and a bad thing.”). However, the participants agreed that “the routine” and “the hard work” of the programme were necessary for them to improve. One participant reported that the supervised format was problematic because it was difficult to arrange the supervised sessions around his work travels; however, overall he felt he needed the commitment of a supervised programme (06). Another participant found the supervised format and encouragement of the trainer to be very important but identified a need for transition out of the programme so that the benefits (e.g. social support and motivation) did not stop abruptly at its completion (09).

Programme preferences (e.g., content and delivery)

Participants preferred choice in the type of exercise they did for the programme. For example, one participant (05) stated an interest in swimming while another (10) said, unprompted, “I wouldn’t have wanted to swim. You would have lost me if I had to do that.” Overall though, most participants preferred walking. As participant 01 said, “I loved our walks. I don’t think I would have liked anything else as much.” However, some participants preferred exercising at gyms where they had a selection of machines. Other participants preferred gym sessions because the ambient temperature was regulated (i.e., air conditioning was important in summer) and they could easily regulate their intensity. For example, participant 03 reported, “I could feel my muscles working harder in the gym... [it] was less convenient but I felt it was worthwhile. It was something different and I felt like I was working more consistently.” Quite a few participants would have liked to do resistance training in addition to aerobic training, because they still felt weak, primarily in their arms or abdominal areas. However, some of these participants thought it was better to first regain the aerobic fitness they had lost during chemotherapy.

Participants were asked to consider possible variations to the programme, such as whether they thought they could have started it during chemotherapy or whether they would have preferred a group or unsupervised format. Although participants were biased by the format of the programme they had experienced, their comments provide additional insights into preferences that could inform development of future interventions. Most participants reported that they would prefer initiating an exercise programme within 2-4 weeks of completing chemotherapy (see box 3a). They suggested a short period of time to recover from the immediate effects of the last chemotherapy dose, but they felt it was important to enrol in a programme before ‘life moves on’ and the motivation was lost (06). Other reasons for preferring this timing included that the programme was ‘a goal to look forward to’ during treatment (06), or they wanted to ‘get on with things as quickly as possible’ (03). Two participants reported that 2-3 months after treatment might have been a better time to start to exercise, because they would have liked more time to recover. These participants did note the importance of maintaining ‘regular contact so that the patient does not lose motivation or commitment’ between finishing treatment and the scheduled start of the programme (10). When the participants were asked whether they thought they would have been able or willing to start it during treatment, opinions were divided (see box 3b). Half reported that they could have done a modified version of much lower intensity during treatment, as long as it was

flexible in both the exercise prescription (for weeks when treatment was making them feel especially sick) and the scheduling (to fit around treatment and possible periods of incapacity). The other half believed that they would not have been able to, because of the presence of symptoms (diarrhoea, nausea and constipation) or because chemotherapy required all their time and physical and emotional energy. However, almost all participants reported that they would have benefited from an exercise programme during chemotherapy, including feeling better at the end of treatment than they had.

When asked to consider supervised *group* sessions, most participants discussed possible benefits, such as these sessions being cheaper to run and providing more social support. Some participants suggested they would have valued a group with whom they could share the experience, and others reported that they had not felt a need for or had not wanted additional social support. Although some would have considered enrolling in group sessions, all participants preferred individually supervised sessions (see box 4a). The reported reasons for this preference included: the flexibility in scheduling sessions at a convenient time and place, personal attention, the opportunity to learn about and discuss exercise-related issues one-on-one, and not having to walk at someone else's speed. Suggestions for making a group programme more accommodating to the needs of each participant included holding individual sessions for the first 4-10 weeks and then transitioning into group sessions, or having small groups of 3-5 people of similar fitness. When asked whom they would prefer to have as members in group sessions, most participants said they would prefer other cancer survivors, or at least other people who have recently had a "life threatening condition" (01). When asked to consider an unsupervised programme, participants reported a preference for a supervised format, given the importance of having someone to hold them accountable and keep them motivated. Some recounted the low levels of confidence they had at the start of the programme, and the need for support from a trainer to boost their confidence (see box 4b). A few reported that they may have been agreeable to enrolling in an unsupervised programme, but they preferred supervision.

Exercise post-programme

All participants were regularly active at the time of the interview as all had regularly attended the exercise sessions for the study. All participants also reported that they intended to continue to exercise after study completion. Most planned to incorporate strength training into their exercise routine, as well as to maintain or increase their level of aerobic exercise.

One participant acknowledged that it would be hard to maintain the same frequency and intensity of exercise without being accountable to an exercise trainer. Participant 06 identified a similar concern, saying, “I know it will be hard to fit around work, I’m thinking about getting a personal trainer once a week to keep me on track”. All other participants reported specific plans for the frequency, intensity and mode of exercise they planned to do for the future. However, they did not mention strategies for overcoming any barriers to exercising that might arise.

DISCUSSION

To our knowledge, this is the first study to qualitatively explore the experiences and preferences of CRC survivors taking part in an exercise programme during the rehabilitation period (immediately after completing treatment). Previous studies have collected qualitative data about cancer survivors’ experiences with exercise outside the rehabilitation period (Adamsen et al. 2004; Stevinson and Fox 2006; Emslie et al. 2007; Korstjens et al. 2008; Anderson et al. 2009). The current study provides insight into CRC survivors’ experiences of a 12-week supervised exercise programme and their preferences for content and delivery.

Participants identified numerous improvements that they attributed to participation in the exercise programme. These included reduced fatigue and increased confidence, physical functioning, mental outlook, exercise participation, and knowledge about exercise. The ability and confidence to do activities of daily living and to return to work were of particular importance to participants. These benefits are similar to those identified in other qualitative analyses of exercise interventions that recruited cancer survivors during treatment, in the rehabilitation period (Stevinson and Fox 2006; Anderson et al. 2009), or at approximately one year or more post-treatment (Korstjens et al. 2008). Stevinson and Fox (2006) also noted improvements in physical functioning, resulting in improved ability and confidence to do more activities of daily living (Stevinson and Fox 2006). Promoting increases in ability and confidence to do activities of daily living may, therefore, be useful in marketing exercise programmes to cancer survivors in the rehabilitation period.

Participants also appreciated the sense of achievement and opportunity to take control over their recovery. Likewise, Stevinson and Fox (2006) found that participants appreciated the

opportunity to feel that they were being proactive during the rehabilitation period. This may also be a useful angle in marketing similar programmes.

Participants were generally positive about their experiences with the exercise sessions. Most reported that interactions with the trainer were the most enjoyable aspects. Encouragement and rapport with trainers have previously been highlighted as important aspects of exercise interventions (Stevinson and Fox 2006; Anderson et al. 2009). However, in contrast to previous results, participants in our study stated a strong preference for one-on-one versus group exercise sessions. Participants' preferences are, however, likely to be guided by their personal experience in the type of programme they are offered: the three studies in which participants reported a preference for groups were group-based (Stevinson and Fox 2006; Korstjens et al. 2008; Anderson et al. 2009). Cancer survivors in these studies reported that "contact with fellow cancer survivors" (Korstjens et al. 2008) was very important, although some did have trouble with the inconvenience of the session location (Stevinson and Fox 2006) or challenging social situations (Korstjens et al. 2008). When asked to consider group exercise sessions, some participants in our study liked the potential for increased social support, but thought that the benefits of the one-on-one format were greater.

In a study of exercise preferences of cancer survivors, Jones and Courneya et al (2002) concluded that that cancer survivors have varied exercise counselling and programming preferences, with, for example, some preferring a supervised programme and others preferring telephone- or mail-based counselling. Although participants in the current study stated a preference for the one-one-one, supervised sessions, they preferred to be given choices in the types of exercise they did. It would appear therefore that some element of choice is important if participants are to initiate and continue with an exercise programme. As in previous studies (Irwin 2009), walking was the preferred type of exercise, with only a few preferring exercise equipment at a gym. Some would have liked to do resistance training as well. Resistance training is increasingly being included in exercise interventions for cancer survivors; however, only 4 of 10 studies of exercise in the rehabilitation period have included resistance training (Hayes et al. 2003; Hutnick et al. 2005; Thorsen et al. 2006; Hsieh et al. 2008).The participants in our study had undergone surgery prior to chemotherapy. Consequently, they were at least 6 months post-surgery and they had no treatment-related contraindications to resistance training. We would recommend combining aerobic exercise with resistance training in future programmes for similar populations.

Challenges of the programme included the scheduling of sessions around work travel and the 'abrupt' withdrawal of the trainer at the programme's completion. These could be addressed through a more flexible delivery of the programme. For example, small group sessions could be offered after the initial one-on-one delivery, or participants could be partnered with exercise 'buddies'.

This study intentionally focused on exercise during the rehabilitation period, with all participants commencing the programme within 4 weeks of completing chemotherapy. Overall, participants were supportive of offering it at this time. Most agreed that starting to exercise during treatment would have been challenging although about half of them said a modified programme during treatment could have been beneficial. Qualitative data from a previous study suggest that the side effects during treatment affect adherence with an exercise programme, but that involvement is still possible (Anderson et al. 2009). As in our study, participants in that study reported that the optimal time to start to exercise required a balance between having recovered from the most debilitating side effects of treatment while not having lost the motivation present at the conclusion of treatment. This is in contrast with the results of a large survey of breast and prostate cancer survivors, who preferred to exercise at or soon after diagnosis (Demark-Wahnefried et al. 2000).

The main limitations of this study were the sample size and the participant composition. As in previous qualitative studies of exercise and cancer survivors, difficulties with recruitment resulted in a small sample. As a result, meaningful comparisons between subgroups, such as between the sexes, was not feasible. Thus, we chose to focus on commonalities across all participants. Furthermore, as participation was intentionally limited to CRC survivors within 4 weeks of completing chemotherapy, the findings only apply to this cancer population and period on the cancer continuum. Another limitation is that the trust and rapport that developed with the trainers may have led participants to believe that what they did in the programme was the 'best' format, and thus their preferences may have been influenced by their experience in the program. Also, because the interview occurred after completing the programme, there is the potential for recall bias in responses to the question about their expectations prior to commencing the intervention. In future studies this issue should be avoided by collecting data on participant expectations at baseline.

Also of note is that some participants' comments appeared to be overly positive. One explanation is selection bias, as participants were volunteers who were motivated to participate in the exercise program. Although only one participant reported that he had been regularly active at baseline, it is possible that others had had some experiences with exercise programmes earlier in their lives which made them more likely to be positive about the programme. A second explanation is interviewer bias. Participants' positive attitudes may have been a result of having the interviewer (RS) also serve as the trainer to four of the 10 participants. To decrease the potential of this bias, RS used a standard interview protocol for all participants, and asked questions designed to elicit comments on both positive and negative aspects of the program. Moreover, participants were asked to provide full and frank answers to the questions, and those who had not had contact with the interviewer as their trainer were no less positive about the programme or their trainer. It would have been preferable to have an independent interviewer, but this was not feasible in this research setting. Furthermore, based on results of other qualitative studies with cancer survivors (Stevinson and Fox 2006; Korstjens et al. 2008; Anderson et al. 2009), it seems that participants are typically positive about exercise programmes.

CONCLUSION

Exercise programme content and delivery methods vary substantially across studies, even within the small number of studies of exercise rehabilitation for cancer survivors (Spence et al. 2009). This study summarised the experiences of CRC survivors in a supervised one-on-one exercise intervention post-treatment and indicated the aspects of its delivery and content that participants preferred. Although it is likely that participants' preferences were biased by having experienced only one format, the study provided an insight into CRC survivors' attitudes towards exercise programmes post-chemotherapy. These results can inform development of future exercise rehabilitation programmes for CRC survivors and other cancer survivors (see recommendations in table 3).

Conflict of interest statement

None of the authors have any financial or personal relationships with other people or organisations that could inappropriately influence this work.

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Table 1. Interview questions and probing guidelines^a

Enjoyment:

What improvements did you expect to see from the programme?

What improvements or changes have you noticed since starting the programme?

Prompt: (eg. weight, mood, sleep, appetite, fatigue)

Improvements:

What have you enjoyed most about the ImPACT Programme?

What have you enjoyed least about the ImPACT Programme?

Do you feel that you are better equipped or more confident exercising on your own than you were before?

Programme Preferences (e.g. content and delivery)

Do you think you would have been willing or able to do a similar programme during treatment?

When do you think the best time to start a programme like this is?

Prompt: At a certain time after or during treatment?

Would you have preferred a different type of exercise programme- for example: gym based, treadmills/weights, swimming, water aerobics? If yes, what?

Would you have preferred a group setting with other cancer survivors? Why/ why not?

Would you have preferred a group with people recovering from various health problems? Why/ why not?

Would you have preferred a group of the general population? Why/why not?

Would you have preferred to have been taught about exercise and had help setting goals by a professional, but then done the exercise on your own, where ever it was convenient? If so: How much contact? What type of contact?

General:

Would you recommend a similar programme to others going through chemo? Why/why not?

Is there anything about the programme that you think we could improve or that we should change?

Is there anything else you would like to tell us about your experience in the programme?

Do you plan to exercise on your own now that you have finished the program? If yes: What do you plan to do?

^a Questions are not presented in the order they were asked. They have been re-ordered in this table to reflect the major themes of the responses.

Table 2: Participant characteristics

I D	Sex	Age	Diagnosis	Stage of disease ^a	Chemo ^b	Employment	Sick Leave at baseline	BM I	PA level at baseline ^c
1	Female	55	Colon	C	Folfox	Full-time	Yes	34.6	Sporadic
2	Female	42	Colon	B	Folfox	Home duties	NA	19.3	None
3	Male	74	Colon	B	Folfox	Retired	NA	24.4	Regular
4	Male	67	Colon	C	5FU	Retired	NA	23.0	Sporadic
5	Male	63	Colon	C	Folfox ^d	Full-time	No	27.0	Sporadic
6	Male	42	Rectal	C	Camp- tosar	Full-time	No	27.9	Sporadic
7	Male	60	Rectal	B	Folfox	Full-time	No	25.2	Sporadic
8	Male	63	Colon	B	Folfox	Full-time	Yes	29.2	None
9	Female	47	Rectal	C	Folfox	Part-time	Yes	28.2	None
10	Male	65	Rectal	C	Folfox	Part-time	No	29.2	Sporadic

5FU: Fluorouracil.

^a Stage of disease at diagnosis, reported as Dukes Stages A-D. ^b Chemotherapy protocol – all protocols were fortnightly for approximately 6 months and commenced approximately 4-6 weeks after surgery. ^c Participants were asked to categorise their physical activity level at baseline as ‘none’, ‘sporadic’ (<3 sessions/ week) or ‘regular’ (≥3 sessions/ week). All participants were regularly active at the time of the interview because they had been engaged in regular sessions for the programme. ^d Participant 6 completed 8 treatments of Folfox followed by 4 treatments of Folfiri.

Box 1. Identified improvements

A. Confidence

01: The ImPACT Programme helped me to think I was fit enough to go back to work which was very important to me.

02: It showed me that I could do exercise and get up early and that it didn't make me feel tired for the rest of the day.

07: It builds confidence and shows that life can return to normal.

B. Health and well-being

01: The programme works like a 'walking stick'. It helps you get over the hump of treatment and sick life...It gave me a sense of well-being and I think this is a big motivator for most people in this situation.

05: I would recommend that [a programme like this] should be mandatory. It makes you live again.

C. Sense of achievement

01: I saw it as a way of taking control over getting better.

04: There were a couple of times I thought I couldn't do [a session], but I kept on going because I wanted to try and do it and then I had a sense of achievement.

06: [I liked] getting out and doing something and proving that you can.

Box 2. Most enjoyable aspects of the programme

Supervised delivery of programme

01: [I enjoyed] the commitment and routine that it provided – I wouldn't have done it otherwise.

06: It was good to have someone to push you.

09: I was so low, so weak, so low self-esteem. If it were not for my trainer - who so

understood my disabilities, both physical and mental - I would not have initiated any sort of exercise or well-being programme of my own accord due to my weak physical and mental position. The personal contact, the motivation, the encouragement... has been so wonderful.

Box 3. Preferred time (in relation to treatment) to start programme

A. How long after treatment?

07: Treat it as the next stage in treatment... you are generally on a high after finishing treatment and to keep momentum the programme should start just after treatment.

08: I started 3 weeks after [treatment finished] and I think that was the best time. I was feeling sorry for myself, I had the nausea, the diarrhoea, I couldn't be too far away from a toilet. That started to get better after those 3-4 weeks. I was quite comfortable to start then – to be away from the toilet! I think the sooner you get into it the better – just long enough to get over the nausea and diarrhoea.

B. During treatment?

01: Maybe. Perhaps walking a little would have stopped the fatigue... I think an exercise programme would have been good and I like to think I would have done it – but perhaps I wouldn't have!

02: Maybe I could have done it... [but] I think it would have been really hard to schedule because I never knew how I would feel.

06: At times I might have been able to do limited sessions... not on chemotherapy days but on the good days in the breaks in between.

04: Trying to do an exercise programme around the weekly ordeal [of chemotherapy] would have been too hard for me.

05: During treatment I would have thrown up or had gastro problems. I needed all my mental and physical capacity just to keep going during treatment... I couldn't have done exercise.

Box 4. Preference for one-on-one supervised sessions

A. Considering a supervised *group* programme

04: If it was flexible time-wise it wouldn't have worried me, but being one-on-one has certainly benefited me. I find that in groups you tend to hold back a little bit when the trainer isn't talking to you.

06: I think early on it's probably more important to be one-on-one and then later on once you know what you need to do then the group programme would be ok... early on I think you need the extra attention.

09: I wouldn't have minded an extra person or two, but I really enjoyed the one-on-one. I really think it was the best thing. I wouldn't have minded talking to other people about their experiences with cancer.

B. Considering an *unsupervised* individualised programme

03: I wouldn't know how hard to push myself [without a supervising exercise physiologist]

05: I don't think you'd work as hard or as well [without a supervising exercise physiologist], especially early on when your motivation and confidence are lower.

06: Maybe a mixture [of supervised and unsupervised sessions] would have worked... I think I'd have struggled if I'd just been given the programme and sent off on my own. I think maybe seeing someone just once a week would be enough for me – knowing I was being checked up on.

09: No. [Without supervision] I wouldn't have done it, definitely!

Table 3: Recommendations for future programmes in similar populations

Recommendations
To promote the programme, inform cancer survivors that the programme may lead to increases in energy levels, confidence to do exercise and return to work and improvements in mental outlook.
Offer supervision for at least some of the sessions during the rehabilitation period. In these sessions trainers should aim to help survivors gain confidence in their ability to exercise safely, teach the survivors to modify their exercise prescriptions when experiencing treatment-related side effects, as well as provide the survivors with accountability and motivation.
Offer one-one-one sessions with a trainer early in the programme with a focus on developing survivors' exercise knowledge, skills and confidence.
Transition to small group or unsupervised sessions of 2-3 survivors after 4 weeks (or as appropriate) if this is more feasible financially or if a survivor wants long-term social support.
Offer optional prescriptions for unsupervised sessions for participants who have to miss supervised sessions (e.g. due to work or family commitments), but ensure follow-up with participants to maintain the safety of the exercise prescription and optimise accountability.
Prescribe an exercise programme that builds participants' confidence by slowly increasing the level of exercise intensity and duration and optimise on the sense of achievement felt by participants as they reach new goals.
Provide choice of exercise modality to allow for exercise preferences (e.g. walking, running, bushwalking, swimming, dancing) and special requirements (e.g. colostomy bag, requiring close proximity to toilet facilities, existing injuries). Access to gym facilities may be important to overcome barriers such as weather or safe environments for exercise.
Include resistance training as a part of an exercise programme.
Aim to enrol participants to commence the programme within 1-3 months of the final chemotherapy session to optimise on the momentum present at the completion of treatment. If participants cannot commence the programme within the first month then regular contact

should be made with the participant to avoid the loss of motivation.

TABLES:

Table 1: Interview questions and probing guidelines

Table 2: Participant characteristics

Boxes 1-4: Additional participant quotes

Table 3: Recommendations for future programmes in similar populations

References

- Adamsen, L., Midtgaard, J., Andersen, C., Quist, M., Moeller, T. & Roerth, M. (2004) Transforming the nature of fatigue through exercise: qualitative findings from a multidimensional exercise programme in cancer patients undergoing chemotherapy. *European Journal of Cancer Care (English Language Edition)* **13**, 362-70.
- Anderson, A. S., Caswell, S., Wells, M., Steele, R. J. & Macaskill, S. (2009) "It makes you feel so full of life" LiveWell, a feasibility study of a personalised lifestyle programme for colorectal cancer survivors. *Supportive Care in Cancer*, 25 Jun 2009 Epub.
- Courneya, K. S. & Friedenreich, C. M. (2007) Physical activity and cancer control. *Seminars in Oncology Nursing* **23**, 242-52.
- Demark-Wahnefried, W., Peterson, B., McBride, C., Lipkus, I. & Clipp, E. (2000) Current health behaviors and readiness to pursue life-style changes among men and women diagnosed with early stage prostate and breast carcinomas. *Cancer* **88**, 674-84.
- Emslie, C., Whyte, F., Campbell, A., Mutrie, N., Lee, L., Ritchie, D. & Kearney, N. (2007) 'I wouldn't have been interested in just sitting round a table talking about cancer'; exploring the experiences of women with breast cancer in a group exercise trial. *Health Education Research* **22**, 827-38.
- Hayes, S., Davies, P. S., Parker, T. & Bashford, J. (2003) Total energy expenditure and body composition changes following peripheral blood stem cell transplantation and participation in an exercise programme. *Bone Marrow Transplantation* **31**, 331-8.
- Hsieh, C. C., Sprod, L. K., Hydock, D. S., Carter, S. D., Hayward, R. & Schneider, C. M. (2008) Effects of a supervised exercise intervention on recovery from treatment regimens in breast cancer survivors. *Oncology Nursing Forum* **35**, 909-15.
- Hutnick, N. A., Williams, N. I., Kraemer, W. J., Orsega-Smith, E., Dixon, R. H., Bleznak, A. D. & Mastro, A. M. (2005) Exercise and lymphocyte activation following chemotherapy for breast cancer. *Medicine and Science in Sports and Exercise* **37**, 1827-35.
- Irwin, M. L. (2009) Physical activity interventions for cancer survivors. *British Journal of Sports Medicine* **43**, 32-8.
- Jones, L. W. & Courneya, K. S. (2002) Exercise counseling and programming preferences of cancer survivors. *Cancer Practice* **10**, 208-15.
- Korstjens, I., Mesters, I., Gijzen, B. & van den Borne, B. (2008) Cancer patients' view on rehabilitation and quality of life: a programme audit. *European Journal of Cancer Care (English Language Edition)* **17**, 290-7.
- Norton, K. & Sports Medicine Australia (2005) *Sports Medicine Australia (SMA) pre-exercise screening system 2005*. Sports Medicine Australia, Canberra.
- Spence, R. R., Heesch, K. C. & Brown, W. J. (2009) Exercise and cancer rehabilitation: A systematic review. *Cancer Treatment Reviews*, 3 December 2009 Epub.
- Stevinson, C. & Fox, K. R. (2006) Feasibility of an exercise rehabilitation programme for cancer patients. *European Journal of Cancer Care (English Language Edition)* **15**, 386-96.
- Thorsen, L., Nystad, W., Stigum, H., Hjermsstad, M., Oldervoll, L., Martinsen, E. W., Hornslien, K., Stromme, S. B., Dahl, A. A. & Fossa, S. D. (2006) Cardiorespiratory fitness in relation to self-reported physical function in cancer patients after chemotherapy. *Journal of Sports Medicine and Physical Fitness* **46**, 122-7.