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ORIGINAL ARTICLE

'A good stepping stone to normality': a qualitative study of cancer survivors' experiences of an exercise-based rehabilitation program

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Abstract

Purpose Exercise-based rehabilitation is not routinely offered to patients. We explored the experience of cancer survivors completing an exercise-based cancer rehabilitation program with and without motivational interviewing.

Method A qualitative study using semi-structured interviews and thematic analysis was completed with a purposive sample of 26 cancer survivors ($n = 17$ female, $n = 18$ post-treatment) participating in cancer rehabilitation at a tertiary hospital. Interviews were recorded and transcribed verbatim. Coding was completed by two reviewers independently and confirmed by a third reviewer.

Results The main theme that emerged was exercise-based rehabilitation facilitated a return to normality after diagnosis which included positive changes in physical activity behaviour. Sub-themes were that rehabilitation is person-centred, challenges expectations, empowering and facilitated by expert staff. Common themes emerged whether participants received additional motivational interviewing or not. However, participants who received motivational interviewing were more likely to report feeling accountable for their physical activity levels. Transition to ongoing independent physical activity remained a challenge for some people who did not feel empowered or socially supported.

Conclusion Exercise-based cancer rehabilitation is important in facilitating 'return to normal' including increased participation in physical activity. To challenge expectations and to empower cancer survivors, rehabilitation programs should be person-centred and led by expert staff.

Keywords Cancer · Rehabilitation · Physical activity · Exercise

Introduction

Cancer rehabilitation assists people to improve their physical, social and psychological functioning and may guide positive health behaviour change [1]. With more people surviving cancer, there is a growing need for rehabilitation to address the psychological and physical impact of cancer as a chronic disease [2, 3]. Exercise-based rehabilitation improves outcomes including fitness, strength, fatigue and mood [4, 5]. Accumulating evidence suggests that increased levels of physical activity, as promoted by cancer rehabilitation, are associated with improved survival and prevention of recurrence [4, 6].

Quantitative data supports cancer rehabilitation, but less is known about the experience of survivors completing rehabilitation. Qualitative studies capture insights into benefits not detected by the limited outcomes represented in quantitative trials. A recent meta-synthesis of exercise-based cancer rehabilitation identified the importance of rehabilitation for continuity, reclaiming the body and preserving 'normal' life [7]. The review demonstrated the value of exercise for cancer rehabilitation, but it did not evaluate other components, like education and the multi-disciplinary team [8]. Moreover, only one of the included studies was delivered in a 'real-world' clinical setting utilising non-research staff [9]. As cancer rehabilitation is not routinely offered to cancer survivors [10], qualitative evaluation of cancer rehabilitation in a clinical context is required to facilitate research translation.

Increasing physical activity is an important goal of cancer rehabilitation given that most cancer survivors living in the

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community are inactive [11]. To date, there is little direct evidence describing the impact of cancer rehabilitation on physical activity levels. A review of exercise trials demonstrated that exercise alone was unsuccessful in changing physical activity behaviour of cancer survivors [12]. Theory-based interventions such as motivational interviewing may improve physical activity of cancer survivors [13, 14] but when combined with exercise, do not provide any additional benefit [15]. There is a lack of data demonstrating which components of behaviour change interventions are most important for improving physical activity [16]. Qualitative information about behavioural interventions may provide insight into the effectiveness of rehabilitation in addressing low levels of physical activity amongst cancer survivors.

The aim of this study was to explore the experiences of cancer survivors completing a hospital-based cancer rehabilitation program with and without motivational interviewing.

Method

Research design and theoretical framework

A qualitative study using a phenomenological approach was completed to explore the experiences of people attending cancer rehabilitation. This study was part of a clinical trial evaluating the effect of adding motivational interviewing to cancer rehabilitation (ANZCTR 12616001079437). Semi-structured interviews enabled participants to tell detailed stories about their experience and provide insights about their thoughts and feelings about rehabilitation [17]. The study was approved by hospital and university ethics committees, with all participants providing written informed consent.

Participants

Participants were recruited from a public, metropolitan outpatient cancer rehabilitation program between August 2016 and August 2017. The program comprised 1 h of exercise and 1 h of interactive education, including facilitated group discussion and activities on topics such as exercise, nutrition, relaxation and fatigue. The program ran twice-weekly for 7 weeks and was delivered by a multidisciplinary team comprising a physiotherapist, nurse, occupational therapist and dietitian. Participants were eligible to participate in the program if they were diagnosed with cancer and deemed medically fit to participate in exercise. Survivors could self-refer or be referred by a health professional. Participants were eligible to participate in this research if they attended the rehabilitation program and enrolled in an associated clinical trial. In the trial, participants were randomly allocated to standard rehabilitation or standard rehabilitation plus once weekly, physiotherapist delivered, motivational interviewing telephone calls. Participants were excluded if they could not speak conversational English or had a cognitive impairment as determined by the Short Portable Mental Status Questionnaire [18]. Participants were purposively sampled to reflect the diversity of people attending the rehabilitation program and recruited until data saturation was achieved.

Semi-structured interviews

Participants completed a 20- to 30-min interview, either in person at the rehabilitation centre or via telephone at the completion of the program. Participants were questioned about their thoughts and feelings, and barriers and facilitators to their rehabilitation experience. A flexible interview schedule was used, ensuring that appropriate topics were covered whilst allowing participants to discuss their experience in their preferred order (Table 1). Participants allocated to receive motivational interviewing were asked additional questions about the intervention. All interviews were conducted by the same independent researcher (MR) who was not involved in the delivery of therapy or administration of the rehabilitation program.

Data analysis

Interviews were audio-recorded and transcribed verbatim. Transcripts were de-identified and assigned a pseudonym to ensure anonymity. Transcripts were read line by line, independently by three researchers (AD, MR, NS) and coded using open coding (i.e. the codes emerged from the data) with NVivo (QSR International version 11) software. Codes were categorised and discussed on multiple occasions until consensus was reached on themes. Transcripts were re-read to selectively search for data related to the identified themes. A final list of themes including a main theme and sub-themes was formulated and transcripts re-read to ensure comprehensive analysis.

Trustworthiness

Several strategies increased the trustworthiness and rigour of the data [19]. Transcripts were sent to participants to be check for accuracy (member checking) and verify if they were an accurate reflection of the participant's experiences [19]. Credibility and reliability was ensured by having three researchers independently code and reflect upon the data to enable a comprehensive understanding of themes that emerged. Rich and thick descriptions were presented to enhance reliability, and generalisibility was supported by a detailed description of the program and participants. The research process was documented using an audit trail.

As the research process may be influenced by the researchers own experience [20], brief summaries of

Table 1 Interview schedule

Topic area	Sample questions
Oncology Rehabilitation Participants to discuss their overall experience with the Oncology Rehabilitation Program	Tell me about your experience with the oncology rehabilitation program … Prompts: anything that you liked/did not like about the program, about staff/disciplines involved, program content and duration. What did you find most helpful about the program? What did you think was least useful? How do you think could the oncology rehabilitation program be improved?
Identification of facilitators to participation in Oncology Rehabilitation Participants to discuss what motivated them to attend the program and any barriers to their participation.	Describe the reasons why you chose to attend the oncology rehabilitation program… What were the most important reasons for attending the program? Prompts: health benefits, recommendation from oncologist/other clinicians Tell me about any difficulties you had in taking part in the oncology rehabilitation program? Which difficulties had the greatest impact on your participation in the program? Prompts: time, transport, motivation, fatigue and symptoms
Motivational interviewing Participants to discuss how they perceived the motivational interviewing program (participants in the MI group only)	What information given was most helpful during the oncology rehabilitation program? Overall, what was your impression of the motivational interviewing calls during the program? What did you find most helpful about the motivational interviewing calls during the program? Prompts: person delivering them, content and additional support How could the motivational interviewing calls during the program be improved? Prompts: was there sufficient detail, content, clarity, relevance and importance? Is there anything else you would like to add about your experience with oncology rehabilitation program? (all participants)

researchers' backgrounds are provided. The principal researcher (AD) is a physiotherapist employed by the cancer rehabilitation program and was responsible for delivering the exercise groups and motivational interviewing intervention. The researcher who conducted the interviews and assisted with analysis (MR) is a social worker not involved with the cancer rehabilitation program. Researchers NT, NS and CP are physiotherapists working in an affiliated university with experience in qualitative research.

Results

Twenty-six participants (17 women) were approached to be interviewed and all agreed to participate (Table 2). Fourteen participants (54%) received motivational interviewing in addition to the rehabilitation program. Eight participants (31%) were receiving cancer treatment at the time of their interview. No participants made changes to their transcripts during member checking.

Common themes emerged irrespective of whether participants were allocated to the experimental or control group. Situations where participants described perceptions specific to motivational interviewing are described in relation to the associated theme.

Table 2 Participant demographics

	N (%) or mean (SD)
Sex-female	17 (65)
Age	59 (13)
Work status	
Not working	16 (62)
Employed, not working	5 (19)
Currently working	5 (19)
Diagnosis	
Breast	13 (50)
Prostate	4 (15)
Lymphoma	5 (19)
Gynaecological	2 (8)
Pancreas	1 (3)
Kidney	1 (3)
Metastatic disease	12 (46)
Receiving active treatment	8 (31)
Received motivational interviewing	14 (54)
Total	26 (100)

Main theme: rehabilitation helps participants regain normal

Participants described their primary motivation for attending cancer rehabilitation as facilitating return to normal functioning. Participants reported a loss of identity and physical function resulting from cancer treatment that impacted their quality of life.

'I needed to do something to get me out of my funk and get my life back, just get me back …' (Jessica, age 36, breast cancer).

For participants, regaining normal encompassed physical and psychosocial goals including the ability to complete everyday activities, socialise and re-establish routine. Return to work was described by those employed at diagnosis.

Rehabilitation was perceived as an opportunity for support to regain physical ability, confidence and motivation to return to pre-morbid activities and make lifestyle changes related to weight loss and physical activity.

'… it was a good stepping stone back to some sort of normality after all sort(s) of institutionalising, having chemo, going to hospital all the time …' (Wendy, age 62, non-Hodgkin's lymphoma).

Sub-themes

Four sub-themes emerged: rehabilitation is patient-centred, and includes essential elements; rehabilitation challenges expectations; rehabilitation is empowering; and rehabilitation is facilitated by sensitive, interested, expert staff (Fig. 1).

Rehabilitation is patient-centred, and includes essential elements

Participants spoke about how individualisation of rehabilitation was important. Individual tailoring and supervision by staff reinforced participants' sense of safety and confidence to exercise.

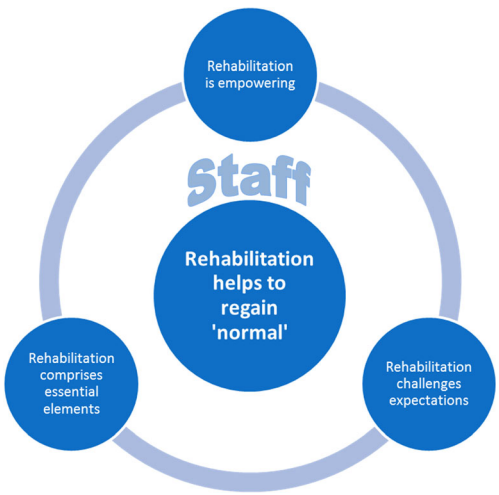

Fig. 1 Relationship of themes

'… I've joined gyms before and they just chuck you on the machine, you have to run on the treadmill like crazy … everything was taken into consideration […] wrote a special program for me and I improved!' (Natalie, age 57, breast cancer).

Elements of the program that were not individualised, such as the education sessions, appeared less important. They preferred interactive sessions including group discussion or practical sessions such as meditation and relaxation.

'Some of it [the education] wasn't relevant but then there were people in different stages so it mightn't have been relevant for me 'cause I've finished my treatment but other people were still going through it.' (Jessica, age 36, breast cancer).

Social interactions were reported as another essential element. They described the program as 'fun' and the importance of shared experience which created a positive atmosphere. Social support assisted some participants in transitioning to independent physical activity after the program.

'you realise other people are the same … or worse off … so it was really good to just feel that you weren't the only one.' (Christine, age 54, breast cancer).

'I've never kept up with exercise like that, I'd normally drop out week three … but the people in it made it really fun … So and I meet 'em now to all go to the lake [to walk].' (Jessica, age 36, breast cancer).

Participants described their hesitation when commencing rehabilitation. Timing of program commencement and patient readiness were essential for successful engagement with the program.

'… (nurse) had contacted me previously but it just wasn't the right time... I think it was the third time he had contacted me I went yeah, this is actually perfect timing, I'm ready.' (Nadia, age 46, metastatic breast cancer).

Participants discussed how they felt there was poor awareness of cancer rehabilitation in the community. They commented on the need for promotion of rehabilitation, particularly by oncologists.

'I only found out about it by chance … I went for nearly 18 months of treatment and there was no indication that this is existed.' (Andrew, age 70, metastatic prostate cancer).

Rehabilitation challenges expectations

Participants' hesitation in joining the program appeared related to their preconceived ideas about rehabilitation. Participants related rehabilitation to going to a gym or support group. Participants talked about their surprise at the positive experience, challenging their preconceptions.

'I was afraid to be in the group of people who has you know [cancer] … but then I found out that it's very helpful … it wasn't something like, oh we're going to die tomorrow.' (Hazel, age 68, metastatic endometrial cancer).

Furthermore, participants described unexpected outcomes of rehabilitation, where benefits of rehabilitation reported differed from participants' initial goals. For example, most participants reported that they were initially attending to improve fitness or lose weight. However, they described gaining psychosocial support through peers and staff.

Rehabilitation is empowering

Participants portrayed rehabilitation as an opportunity to gain control over their health. They described learning valuable information during the program relating to managing different aspects of their health.

'I wanted to improve my outlook on life, to fight my condition with exercise as well as drugs … so that it'd give me a better quality of life.' (George, age 68, metastatic prostate cancer).

Participants reported improvements in strength and fitness which empowered them to be active, through completing everyday tasks and returning to work. Participants were surprised at their physical capabilities and perceived their participation in rehabilitation as motivating.

'to know that I could go for a walk and I wasn't going to collapse and die somewhere … I didn't even consider that was an option...' (Katrina, age 53, metastatic breast cancer).

Participants described better awareness about the benefits of rehabilitation and how this gave them a sense of control. This, in combination with a newfound physical capability resulted in participants feeling empowered to be active outside of rehabilitation. This transition to ongoing physical activity was facilitated when participants initiated their own strategies to be active.

'I can walk in the supermarket and do my shopping without crying! If I park my car, I used to find the closest parking … I'm getting to know, I can park anywhere and walk.' (Natalie, age 57, breast cancer).

Participants who received motivational interviewing in addition to rehabilitation reported a change in their mindset towards physical activity. They described how the motivational interviewing calls were a reminder of why they should exercise, and helped put physical activity to the forefront. Participants also talked about how the calls provided continuity, an opportunity to problem solve and kept them accountable for their physical activity plans.

'Before I started this course, I would no more exercise than fly to the moon … now (I'm) walking and shadow boxing and everything …! ' (George, age 68, metastatic prostate cancer).

'I was reminded of why I was attending the course and the long-term benefits associated with increased levels of activity and fitness … that combined with the accountability.' (Michael, age 45, Hodgkin's lymphoma).

However, despite an overall change in the importance placed on physical activity by participants, some described uncertainty about how to continue exercise once the program was completed and desired future follow-up sessions to check their progress.

'The difficulty for someone who's just finished the program is maintaining it … it might be scope for some follow-up after it's completed just to see whether we've dropped the ball entirely.' (Michael, age 45, Hodgkin's lymphoma).

Some participants, particularly those who missed sessions or had metastatic disease, reported that they wished the program could be longer. Difficulty transitioning to ongoing physical activity was described by people who felt they had unachieved goals by the completion of the program.

'since I finished the program I think I got a little bit of a lapse backward … it was a very well designed program … but unfortunately, it did improve me but the main aim hasn't been achieved …' (Jack, age 79, metastatic prostate cancer).

Rehabilitation is facilitated by sensitive, interested, expert staff

Participation in the program appeared to be influenced by staff support. Participants described how staff expertise made them feel safe to exercise.

'there was that level of trust because you're medical people rather than a gym … I felt confident that I wouldn't get pushed into doing something that would be bad for me …' (Wendy, age 62, non-Hodgkin's lymphoma).

Many participants reported that they completed regular physical activity prior to cancer diagnosis. However, they were unsure how to re-engage in physical activity post-diagnosis. Participants enjoyed the multidisciplinary mix of staff and spoke of being progressed in a gradual way.

'I'm a big swimmer so I'd gone back in the pool and kind of overdid it and felt really unwell so I needed the guidance … with people who know about oncology … in a way that I was able to take risks but it was in a safe way.' (Nadia, age 46, metastatic breast cancer).

Patient-staff rapport was seen as critical to facilitating participants' engagement in rehabilitation. Participants discussed the value of staff who were interested in their needs and sensitive to their emotions.

'[The staff] approached everything with humour and a gentleness that recognised that we all had different levels, different expectations and abilities, and it was always done in such a respectful way so, from the moment I walked in I felt really welcome and embraced.' (Nadia, age 46, metastatic breast cancer).

Discussion

Cancer rehabilitation was described as a positive experience that helped people regain a sense of normality after cancer

diagnosis. Rehabilitation facilitated return to normal through expert staff, patient empowerment, challenging patient expectations and patient-centredness. Rehabilitation also impacted physical activity behaviour. Transition to ongoing participation was facilitated when participants felt equipped with skills to change their physical activity levels. However, transition remained difficult for others. Motivational interviewing was described as enhancing knowledge and accountability which assisted the transition to independent physical activity. Our data, collected in a clinical setting, are consistent with a meta-synthesis review of predominantly laboratory-based studies [7]. Our study adds to this literature by explaining how cancer rehabilitation helps patients 'return to normal'. Person-centred rehabilitation facilitated by expert staff helped challenge expectations and empowered cancer survivors.

This study provided insight into what makes cancer rehabilitation effective. A group environment facilitated by expert staff using a patient-centred approach contributed to the positive experience. Groups alleviate negative feelings and normalise the cancer experience [21, 22]. This is noteworthy given that cancer is associated with significant psychological distress [23]. Group cohesion can predict adherence, attitudes and efficacy related to exercise [24], with exercise facilitating group cohesion superior to other exercise styles [25]. Groups provide opportunities for modelling, persuasion and feedback which enhance self-efficacy [26, 27], and peer support provided by groups assists transition to independent physical activity from hospital-based rehabilitation [28]. Socially supportive leadership of groups including encouragement, reinforcement and interest in participants [27] enhance enjoyment of exercise [29] and impact physical activity behaviour [30]. Staff interactions have been described as influential in creating positive experiences of rehabilitation in other contexts [31, 32]. Group dynamics and staff leadership are, therefore, important considerations when designing cancer rehabilitation programs.

The primary theme was that cancer rehabilitation helped participants return to normal. This idea is supported by quantitative data that supervised exercise-based cancer rehabilitation programs restore function and quality of life [33]; improvements participants identified as helping facilitate 'normality'. Participants described positive changes to their wellbeing regardless of whether they were receiving cancer treatment or not. This is contrary to the expectation that people in rehabilitation who are receiving treatment experience more barriers to participation due to the acute side effects of treatment than those post-treatment [34]. However, whilst all participants described rehabilitation helping them return to normal, the transition to ongoing physical activity after rehabilitation was challenging.

It should be considered that normal life frequently does not include regular participation in physical activity. There is no difference between moderate to vigorous activity levels of cancer survivors and those without cancer, with only 8% of people in both groups' meeting physical activity recommendations [11]. This is problematic given that high levels of physical activity are associated with lower rates of recurrence and improved survival [4]. However, participants of cancer rehabilitation who were empowered, socially supported and had perceptions of their ability challenged described intentions to continue being active after rehabilitation. When participants were not empowered, they were more likely to express concerns about transitioning to independent physical activity in the community.

Transition to ongoing physical activity is a common challenge during rehabilitation, and relies on linking rehabilitation to community-based exercise through four distinct phases: rehabilitation, condition-specific exercise, fitness and physical activity [35]. Cancer rehabilitation addresses the first two phases and provides a positive environment that improves function and presents opportunity, motivation and capability to perform physical activity which influences physical activity behaviour [30, 36]. When rehabilitation is finished, further support to build efficacy for physical activity is needed, particularly for those who are not supported or empowered. Structured transitions to community-based exercise, with ongoing peer support and monitoring, may help the transition to regular physical activity [28].

In this study, themes were similar irrespective of whether participants received motivational interviewing. However, motivational interviewing was described as an acceptable, non-intrusive and efficient way to raise awareness, accountability and problem-solve barriers to physical activity. Motivational interviewing may assist transition to ongoing physical activity after rehabilitation for those who have difficulty. Motivational interviewing can improve physical activity by 37% in long-term cancer survivors [37]. It may be a cost-effective way to supplement traditional rehabilitation to facilitate behaviour change in patients who find this transition difficult. This needs to be explored in future studies.

Strengths and limitations

The study was conducted using rigorous design that contributed to the trustworthiness of the findings. Purposive sampling ensured that people with different cancers were represented. Data collection continued until data saturation and member checking ensured credibility, dependability and trustworthiness of results. Analysis was completed by three reviewers independently, thereby reducing bias in the interpretation of findings. A limitation is the inability to generalise results to all cancer survivors participating in rehabilitation, as people may experience their own situation differently depending on their context. This is a limitation of qualitative research. This study was embedded within a randomised controlled trial which may further limit generalisability as participants who had an interest in increasing their physical activity may have been

more likely to participate. However, our sample was drawn from a clinical population and we had a high recruitment rate. Therefore, people from a diverse range of backgrounds and ages, including those with early and advanced cancer, were included in our study. We were also conscious of the Hawthorne effect, where participants allocated to the intervention may view their experience more positively. To counter this, we interviewed participants from both the experimental and control groups of the trial. Further, the rehabilitation program in this study represents just one type of rehabilitation model. There may be differences in health literacy and socioeconomic status of participants in public compared to fee-for-service programs. However, our findings are consistent with a previous meta-synthesis [7].

Conclusion

Cancer rehabilitation was a positive experience that facilitated patients return to normal. It challenged expectations and empowered patients. Successful programs can promote psychosocial health and ongoing physical activity. Rehabilitation should be patient-centred, include group interaction led by expert staff, be flexible and align with patient readiness to participate. There remains a gap between rehabilitation and ongoing participation in community exercise which could be explored in future studies.

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Compliance with ethical standards

The research team have full control of all primary data. The journal will be unable to access the data as it involves individual transcripts of participants, as per our ethical approval.

Conflict of Interest The authors declare that they have no conflicts of interest.

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