Determinants for Exercise Adherence and Maintenance for Cancer Survivors: Implementation of a Community-based Exercise Program. A Quality Feasibility Study

Maria Ranes (maria.ranes@helse-bergen.no)
Haukeland Universitetssjukehus Avdeling for kreftbehandling og medisinsk fysikk
https://orcid.org/0000-0001-9153-6553

Tor Helge Wiestad
Haukeland Universitetssjukehus Avdeling for kreftbehandling og medisinsk fysikk

Inger Thormodsen
Haukeland University Hospital: Haukeland Universitetssjukehus

Cecilia Arving
Uppsala University: Uppsala Universitet

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Abstract

Purpose

Research verifies that physical exercise plays an important part in recovery after cancer treatment. Despite this knowledge, multiple studies have shown that maintaining a physically active lifestyle after cancer is challenging. There is a need for effective implementation of exercise programs for cancer survivors in community care, with focus on exercise adherence and maintenance. This qualitative descriptive feasibility study explores experiences from the implementation of a four-month community-based exercise program for cancer survivors after completion of rehabilitation in the specialist health care service.

Methods

Focus group interviews of fourteen cancer survivors after completing Rehabilitation: Physical activity and Coping, feasibility study. Data were analyzed using the systematic text condensation method.

Results

The category *determinates for exercise adherence and maintenance* added four subcategories: peer-support, environment, structure and knowledge.

Conclusions

A social and supportive exercise environment is important for exercise adherence and maintenance among cancer survivors. This knowledge can be useful in the further work with implementing high quality community-based exercise program for cancer survivors.

Introduction

Cancer survival rates have increased considerably due to better treatment and earlier diagnosis (1). Despite improved survival, cancer survivors report reduced physical function, poorer mental health and well-being post-treatment, compared to persons without a cancer history (2). Cancer treatment is known to cause late effects, such as increased risk for cardiovascular disease, diabetes, lung disease, osteoporosis and musculoskeletal conditions (3), in addition to hormonal disorders, fatigue, pain, neuropathy and impaired memory, concentration and planning ability (2). These late effects might affect a patient's relationships, working life, finances and the ability to undertake daily activities (4). A growing body of research draws attention to the benefits of physical exercise (PE) among cancer survivors. After treatment, PE contributes to increase physical and mental health, and for some cancer diagnoses, improve survival outcomes (5–7). In addition, facilitated PE can shorten the time between recovery and return to work and optimize work performance (8). Despite these benefits of exercise for cancer survivors, it is difficult for survivors to maintain being physical active after cancer treatment (9, 10). Lack of support, information and recommendations from health care professionals, treatment side effect, lack of time and

motivation, feeling uncomfortable in a fitness center due to changed appearance and physical level after treatment are common barriers due to reduced PE levels post treatment (11, 12). However, cancer survivors show a high level of interest in participating in health promoting exercise programs and exercise interventions (6, 13, 14), but adherence to exercise program and maintenance after interventions seems to be challenging (15, 16). Exercise adherence and maintenance is affected by multiple factors including sociodemographic, physical and medical variables (17). Health behaviors theories can improve understanding of the dominant mechanisms behind adherence to exercise programs (18). Social Cognitive Theory-based interventions demonstrate an improved health behavior in cancer survivors, and self-efficacy appears to be the variable most strongly associated with positive behavior change for PE (19, 20). Further, social rewards, offers of encouragement and assistance in monitoring exercise progress are important aspect of social support to consider when developing exercise intervention strategies (13). In 2006, Hewitt (21) described cancer care from specialist to community health service as *lost in transition*, and to date the transition to community services remains a problem among cancer survivors (22). Community-based exercise groups for cancer survivors of mixed diagnoses and ages are safe, show physiologic and psychosocial benefits and it is a valid setting to improve survivor care and promote adherence to PE (23–25). However, implementation of exercise interventions in real-world setting is challenging (26). There is a need for qualitative research to understand the contextual dimensions of group-based exercise for cancer survivors, which may be of importance in the application, implementation and dissemination of community-based exercise programs in clinical practice. Thus, the aim of this study is to explore how cancer survivors experienced a four months community-based exercise program.

Methods

This qualitative, descriptive study used focus group interviews to explore participants' experiences of the transition from rehabilitation within specialist health care (hospital) to an exercise program in the community health service (municipality). The study was a part of the *Rehabilitation: Physical activity and Coping – feasibility study* (RPAC-FS), which assessed a four months group-based exercise intervention for cancer survivors. RPAC-FS was a collaboration between Haukeland University Hospital, the University College of Western Norway and the municipality of Bergen.

Participants

Participants who had completed a rehabilitation program of up to six months at The Cancer Center for Education and Rehabilitation (CCER) during May and June 2019 were eligible for inclusion in RPAC-FS. The participants had to be resident in the municipality of Bergen, be able to understand and express themselves in Norwegian and have no cognitive disorders or severe emotional instability. Further, they had to be able to perform basic activities of daily living and have no comorbidity that might hamper physical exercise (e.g. unstable angina, severe heart failure, severe chronic obstructive pulmonary disease, orthopedic conditions and/or neurological disorders). Twenty cancer survivors were informed verbally and in writing about the RPAC-FS and asked to participate, all agreed. All participants received a

written invitation to participate in a focus group interview. Fourteen of the participants consented to join the focus group interviews post-intervention. Six declined, due to the timing of the interviews.

Exercise intervention

The RPAC-FS lasted from August 2019 to December 2019. The intervention consisted of an organized, group-based exercise program twice a week, with 10 participants in each group and supervised by a physiotherapist. Each session duration was 60 minutes, including 20 minutes endurance and 40 minutes strength exercise. The endurance exercise was performed as intervals on an optimal training apparatus and consisted of five of the following intervals: two minutes of high-intensity exercise (instructed to achieve 15 to-17 on the Borg scale) (27) and one minute moderate-intensity (Borg scale 12 to-14). The Borg scale has a scoring range from minimum 6 to maximum 20. The strength training consisted of the following nine strength exercises; leg press, lateral pulldown, leg extension, shoulder press, chest press, glute bridge, plank, diagonal raise and sit ups. Each strength exercise was performed in three sets, with ten repetitions per set. The intensity corresponded to 7–9 on the Omni scale of resistance exercise (28). The Omni scale range from 0 (extremely easy) to 10 (extremely hard). After each exercise session, the participants registered their perceived exertion in a personal logbook.

Data collection

Post-intervention in January 2020, two focus group interviews were completed with seven participants in each group; participants of the same exercise group were placed in the same focus group. A semi-structured focus group guide included the following topics: The exercise program, instructors, work and everyday life, late effects and transition from specialist to community healthcare services. The interviews took place at CCER and lasted for 90 minutes. They were sound recorded and later transcribed verbatim. Two co-researchers (TW, CA) led the focus groups. Baseline characteristics of focus group participants were collected from Chalder Fatigue Questionnaire and a study-specific questionnaire, and medical history was obtained with permission from participants' medical journals at Haukeland University hospital (**Table 1**).

Table 1 Baseline characteristics of participating subjects (n = 14). Data are presented as frequencies and percentages in parenthesis unless otherwise stated*

Analysis

Systematic Text Condensation (STC) was used to analyze the transcribed data (29). STC is a descriptive and explorative method for thematic cross-case analysis of different types of qualitative data. The method is a 4-step analysis (**Table 2**).

Table 2 Performance of the 4-steps analysis

Results

The participants expressed that taking part in community-based exercise was important in order to maintain exercise, be more self-reliant, increase their physical capacity and improve mental health after rehabilitation in the specialist healthcare service. The analysis shown determinants affecting willingness to adhere to the exercise program and maintain PE after rehabilitation in the specialist health-care service (**Fig. 1**).

Figure 1 The category and subcategories resulted in determinants for a successful implementation

Determinates of exercise adherence and maintenance

The category *determinates of exercise adherence and maintenance* and subcategories *knowledge* and *structure* resulted in essential determinates such as *safety* and *self-efficacy*. The social aspect of group exercise with *peers* gave rise to a favorable *environment* for the survivors. They described a sense of *fellowship* and *belonging*, which gave the participants *encouragement* to exercise adherence and maintenance. They looked forward to each session, and the analysis did not identify any barriers of a community-based exercise program for cancer survivors.

Even though I think it's a long distance, and silly to go to xx when I don't live in the direction, with rush traffic and all, I still think it's worth prioritizing, because I think those four months have lifted me further with regards to how I feel and now I can stand on my own two feet. (Gr.1, 58)

Peer-support

Exercise with other survivors, peer-support, encouraged the participants to join the exercise program. The sense of fellowship provided accountability for participation and effort. They described that being in similar situations, with a common goal to increase physical capacity post cancer treatment, was an advantage. They discussed how they would sometimes feel different to people who do not have a cancer history. Together with peers, they experienced a shift of focus from disease to health promotion. Disease was rarely mentioned during the exercise sessions, although they did feel comfortable talking to each other about cancer related issues. Peers promote a caring environment, where participants motivated and supported each other, especially when a member had a bad day in terms of side effects and ailments. Humor was frequently used to cope with late effects. According to the participants, a group size of ten was perfect. A higher number of participants could have led to poorer exercise quality and group dynamics, due to less encouragement and a lesser sense of group belonging and unity.

(..) It's a one thing that we're pushing each other, but another thing is that we have gotten to know each other well enough to see if the other person is having an off day. It's not just about being considerate, but about looking after the other (…)(Gr.2, 60)

Social environment

The participants agreed that social aspects were of great value. They mentioned that the physical aspect of exercise was a part of the motivation for being physical active; the social environment of exercise was

equally, if not more, important.

The group discussed the psychosocial perspective in terms of sharing a cup of coffee and a chat, and expressed that they would have liked a common place to sit for talk to each other before or after exercise. They remembered the conversations around the coffee table during previous rehabilitation session at CCER as positive and useful. The social environment led to a sense of belonging and community, which filled a void and improved their mental well-being, and they felt better prepared to tackle the bad days.

You found a community. I was worried about going because I didn't want to be reminded… You know, I hated my cancer. But then I found this amazing group! With you, and the coffee table, and it became the highlight of the week! (Gr.1, 51)

Before start of intervention, the instructor had an assessment interview with each participant. This background knowledge made it possible to individualize the content and intensity of the exercise program, based on their fitness level. The group trusted the instructions they were given, and that their workload was suitable for them, and highlighted the importance of individually tailored exercise to feel safe and seen for their physical challenges after treatment. Generally, the participants were negative about membership at a fitness center. Due to insufficient hygiene at public gyms, absence of group dynamics and/or the lack of an instructor. Furthermore, they described fitness centers as an impersonal and lonely environment, and the exercise generic for their needs after cancer treatment. The group could possibly imagine fitness centers as an option, provided they had one or more exercise partners and an instructor during the first sessions.

Structure

Group-based exercise appointments promoted commitment to another person and increased the participants' sense of responsibility for adherence to the program. Fixed exercise sessions also enabled them to move any confliction appointments to prioritize the exercise sessions and provide a structure of their daily life. This also meant more predictability for family members and employers. Structure was important in order to return to normal routines, implement daily activity and reduce inactivity. Structure influenced increased self-efficacy for the cancer survivors.

It affects us mentally that we have a set appointment Tuesday and Thursday. It's not a fitness center… a gym where we can just say: "I can't really be bothered today". Because we're a group (…) And being made to go because you have appointment with someone. (Gr.2, 56)

Work active participants, full time or part time, found the days when they combined work and exercise, hard. They experienced cognitive deficits at work, impaired in concentration and reduced ability to multitask, caused by cancer treatment. Some working survivors described an understanding support from their employer including agreements to facilitate exercise during working hours. Others, whose employers did not offer such support, reported that they were more tired. Even so, working survivors were unsure how much the exercise had affected their ability to return to work.

Knowledge

According to the participants, basic knowledge concerning effect of PE and benefits from PE during and after cancer treatment, which the participants had previously acquired at CCER, was an essential factor for exercise adhere and maintenance. Additional, the instructors' exercise knowhow and their knowledge about the survivors' cancer diagnose and their need for facilitation resulted in a safe exercise environment. During the intervention, they improved their knowledge about exercise mechanisms and benefits from exercise. They were now confident enough to adjust and increase the intensity to fit their capacity. They were grateful for the new knowledge they had acquired through explanations, instructions and their own experiences. According to the participant, generally low activity levels among cancer survivors could be explained by reduced knowledge concerning PE and the benefits of exercise in their particular situation.

We know that exercise is good for us in the long run. As far as I am concerned, this exercise had been essential for how I feel today. And I just have to keep going whether I want to or not. I see others who can't get started and have a negative attitude towards exercise. (Gr.2, 58)

Discussion

The present, qualitative feasibility study explored how cancer survivors experienced a four-month community-based exercise program after completing rehabilitation in specialist health care. Taking part in community-based exercise was important in order to maintain exercise. The analysis show factors affecting willingness to adhere to the exercise program and maintain PE after rehabilitation in the specialist health-care service. Peer-support and knowledgeable instructors, as well as the social and structural aspect of group exercise were essential determinates for exercise adherence and maintenance. They missed a place to get together either before or after exercise sessions, e.g. a coffee table; this could brought the group closer and improved exercise adherence and mental wellbeing.

Generally, cancer survivors report maintenance of exercise after treatment as challenging, and there is a need for implementation of exercise program in community setting for this population (16, 26). The design of an exercise program can be essential for a successful implementation of exercise among cancer survivors. Peer support provided by groups have shown assists transition to independent exercise from hospital-based rehabilitation (30). As indicated by our results, peer support may be a potential, favorable facilitator for the maintenance of exercise after rehabilitation. Exercise with peers can help preserve a normal identity and escape the otherwise dominating patient role, change survivors' mindset, promote more positive outlook life and gaining psychosocial support (16, 31). Participants in the present study stressed that the group size must not be too large to enable appropriate monitoring and promote friendship and solidarity. They felt that a small group size prevented dropouts. A potential drawback when interacting with other cancer survivors is the risk of feeling overwhelmed by the reminder of your own cancer disease and mortality. However, the participant in this study rarely mentioned their cancer diagnosis or illness during exercise sessions. They focused on opportunities and not limitations. In

relation with a meta-study, which recognized the importance of replacing disease-focused follow-up care with wellness-focused survivorship care (13). The sense of fellowship and understanding by peers, the participants experienced the peer support during training sessions as encouraging and motivated them to achieve a higher intensity and maximized their benefit.They also helped regulate each other's intensity, when their exercise partner had a bad day and/or lack of energy. Because they can recognize themselves in how the other is feeling, based on the same experience in cancer history.

Survivors have different needs for PE after cancer treatment, depending on factors like age, diagnosis and comorbidity, and as such require flexibility in the exercise program. Untailored exercise programs contribute a reason to reject exercise among patients with cancer (12). A systematic review suggests substantial greater benefit in a supervised exercise group compared with an individual setting, which is explained by higher level of safety, exercise options, motivation and support (32). Person with cancer history may experience more barriers than the general population; a social environment and a sense of affinity with peers, as well as attractive and easily accessible exercise opportunities may be determinants that are more important for cancer survivors compared to the general population. The group in this study wished for a place to sit down after exercise to take a cup of coffee and converse with their peers. Similarly, other survivors have expressed that more time to debrief after classes would help to overcome emotional challenges (31). At this stage of understanding, we believe an environment that attends to both physical and psychological factors is a central element when implementing exercise for survivors, the social aspect can involve improved exercise behavior. The participants in this study described a flexible program where the instructors offered alternatives exercises that allowed all participants to complete the workout. Pre-intervention the instructors performed an individual interview with each participant to get background knowledge about cancer history, physical fitness level, possible late effects and/or comorbidities. This gave survivors a sense of confidence in the instructors, which increased their willingness to push their limits under instruction. The sense of empowerment, self-efficacy and increased confidence resulted in a positive and motivational attitude to exercise, which is known to strengthen exercise adherence (33).

The group appreciated the instructors' ability to communicate their knowledge concerning exercise, techniques, benefits and effects of the exercise. Increased knowledge fostered autonomy, competence and relatedness, and participants found their own motivation and experienced empowerment. In addition, knowledge can influence current beliefs and attitudes, such as a change in attitude to enjoy and wish to maintain exercise habits (20). Studies demonstrate that reduced knowledge and lack of information about exercise is a barrier to being PE (11, 12). Survivors are concerned about overdoing PE, and breast cancer survivors experienced conflicting information concerning exercise from health care professionals. Additionally, an overload of information on the internet, myths and misconceptions were barriers to performing exercise (11). This emphasizes the importance of conveying information in an understandable and appropriate way.

Survivors can struggle with establishing balance between building capacity and participation in various areas of life after treatment (34). Exercise sessions at regular times gave the participants potential to

store structure to everyday life after a long time in the “cancer bubble”. Planned group exercise provided a sense of commitment, influence and self-worth, and motivated them to get out of the house. Similarly, Midtgaard (35) found that fixed appointments for exercise sessions and programs help survivors rebuild structure in everyday life, and create a normal context and enable the survivor to re-establish confidence in their own body and physical potential. We believe exercise routines can provide the survivors with a focus on constructive action to improve their health and a sense of competence and increased confidence at a time when life offers a variety of challenges (eg. return to work, socialization, late effects). Therefore, community-based exercise routine has to enroll immediately post-treatment (36). For many people, exercise maintenance requires a change of behavior. According to Social cognitive theory (SCT), human behavior, personal and environmental factors influence each other in the outcome of health behavior (20). The participant experienced the group-based exercise program generated positive encouragement and a sense of obligation to daily exercise task, and improved their self-efficacy. Performing PE and work on the same day had appeared too energy consuming for the survivors. Groeneveld (8) recommend the employer to have a close collaboration with the clinical setting. Communication with employers is beneficial if it is regular, positive, respectful, personal compassionate and helpful (37).

Strengths and limitation

The findings of this feasibility study are limited by a small sample size. On the other hand, this study represent diverse population of participants across sex, age, physical fitness, education, working status, cancer diagnosis and received treatment. Two of the six participants who declined the interviews, was the youngest people participating in the exercise program (39–44 years). They would have brought the study useful information of their experiences as young cancer survivors’ parents to young children. Performing analyses in collaboration with another researcher can create an analytical space with several nuances (29). The researcher group consisted of two nurses and two health and fitness consultants, all with expertise and experience in cancer care and rehabilitation. The nurses had previous experience and knowledge regarding the qualitative research method. The fact that the researcher group had different education, experience, knowledge and perspectives within the main theme of cancer care and rehabilitation, adds strength to the study. A general limitation of qualitative research is the inability to generalize results to all cancer survivors, as people may experience their own situation differently depending on their context. However, this feasibility study reveals possible determinates that promote exercise adherence and maintenance for cancer survivors.

Conclusion

Through this study, knowledge that can be useful in further efforts to implement high quality community-based exercise programs was uncovered. Further, a strengthen collaboration between health services is needed for development of a successful and sustainable delivery of community-based exercise program for cancer survivors.

Declarations

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Conflicts of interest The authors declare that they have no competing of interest.

Availability of data and material N/A

Code availability N/A

Authors' contributions All authors contributed to the study conception and design. THW and CA performed the material preparation and data collection. MR did the analysis and wrote the manuscript. All authors commented on previous versions of the manuscript, and read and approved the final manuscript.

Ethics approval: The study was performed in line with the principles of the Declaration of Helsinki. The Western Norway Regional Committee of Research and Ethics South East (Ref NO: 2019/620) granted ethical approval for the research.

Consent to participate and for publication Informed consent to participate and for publication was obtained from all individual participants included in the study.

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Tables

Due to technical limitations, table 1 and 2 is only available as a download in the Supplemental Files section.

Figures

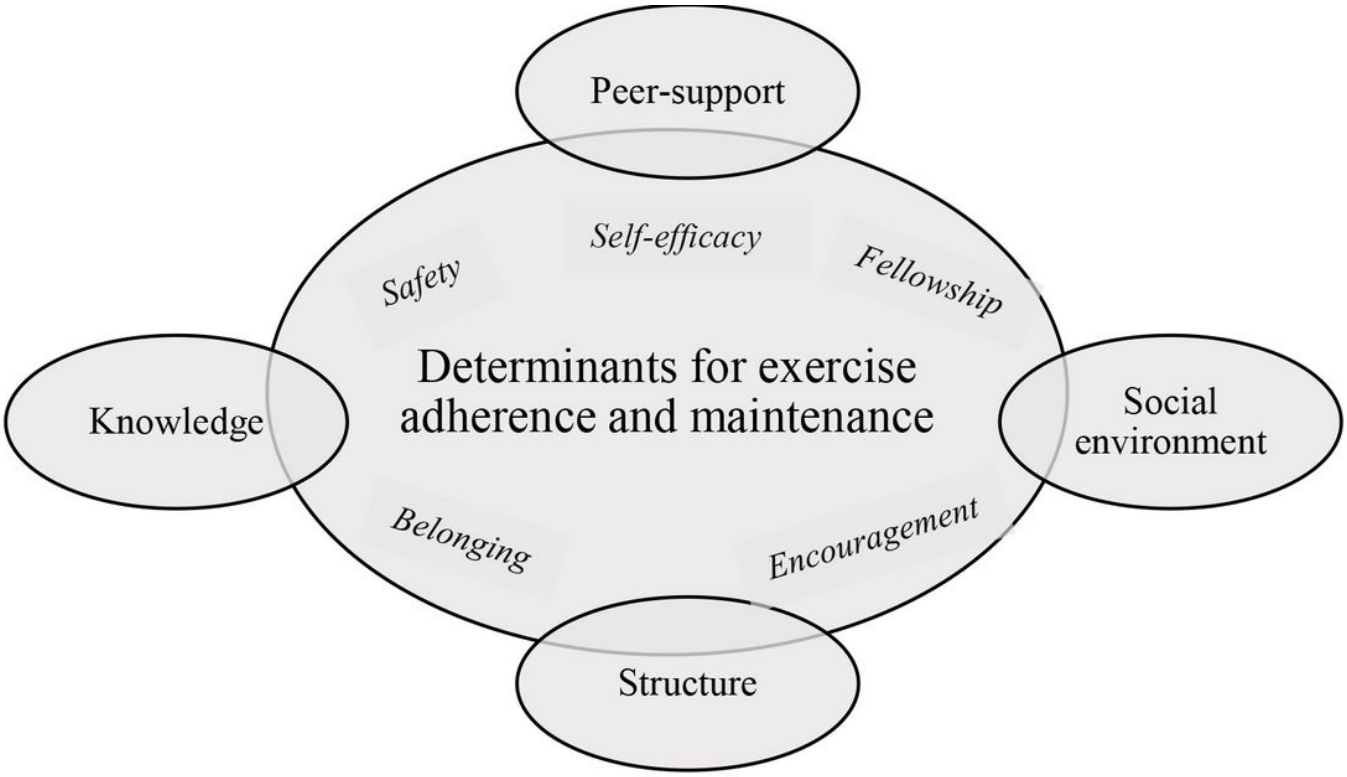

Figure 1

The category and subcategories resulted in determinants for a successful implementation

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- CArving.pdf
- IThormodsen.pdf
- Table1.pdf
- MRanes.pdf
- THWiestad.pdf
- Table2.pdf