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Working Toward a Good Life as a Cancer Survivor

A Longitudinal Study on Positive Health Outcomes of a Rehabilitation Program for Young Adult Cancer Survivors

KEY WORDS

Complex rehabilitation
 EORTC QLQ-C30
 Follow-up
 Health-related quality of life
 Longitudinal study
 Physical fitness
 Positive health outcomes
 Young adult cancer survivors

Background: Research on cancer rehabilitation targeting young adult cancer survivors (YACS) is limited, and little is known about the positive health outcomes of rehabilitation programs tailored specifically for this vulnerable group. **Objective:** The aim of this study was to investigate whether a complex rehabilitation program improved the health-related quality of life (HRQOL) and physical capacities of YACS. **Methods:** A longitudinal prospective study using Norwegian norm-based comparisons was conducted. Twenty YACS (24–35 years old) with different cancer diagnoses participated in a complex rehabilitation program lasting for 6 months, focusing on goal setting, exercise, psychoeducation, individual follow-up, and peer support. **Results:** Health-related quality of life was measured by EORTC QOL C-30 and the scores showed significant increases in overall HRQOL ($P < .005$ –.001) and all functional dimensions ($P < .001$ –.05) and a decrease in fatigue ($P < .000$ –.05) and effect sizes between 0.72 and 1.30. Significant changes occurred within physical fitness ($P < .005$), lung capacity ($P < .05$), and left-hand strength ($P < .001$), but not right-hand strength and body mass index, with effect sizes between -0.04 and 0.48. The values of HRQOL were stable after a 1-year follow-up. **Conclusions:** A complex cancer rehabilitation program especially tailored for YACS seems to build positive health outcomes such as HRQOL

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and physical capacity in a long-term perspective. The content and structure of the program were feasible with high compliance. The results underline the importance of targeting rehabilitation interventions to YACS in need after cancer treatment, acknowledging rehabilitation as a process that requires adequate time and follow-up. **Implications for practice:** Healthcare providers should be aware of YACS' symptom burden and monitor HRQOL and physical parameters to ascertain holistic cancer survivorship care.

Young adults (18–35 years of age) are a small group of cancer survivors with increased risks of physical and psychosocial late effects and morbidity that influence their long-term health and quality of life.^{1–4} Consequently, it is crucial that after treatment, the care of survivors is based on the provision of holistic rehabilitation services. It is important to teach young adult cancer survivors (YACS) to cope with long-term threats and to help them adopt positive health behaviors to achieve good long-term health and quality of life.^{1,5,6} Currently, rehabilitation services are not a common aspect of survivorship care, and research on cancer rehabilitation targeting YACS is virtually absent.⁵ As a result, we know little about the effects of complex rehabilitation programs on positive health outcomes such as quality of life and the physical capacity of YACS.⁵

■ Theoretical Framework

New theories of cancer rehabilitation take a health-promoting approach and build upon a bio-psychosocial and positive health concept.^{7–9} Within this perspective, rehabilitation is defined as an active, goal-oriented, and dynamic process of educating, enabling, and restoring physical, social, and psychological aspects to promote optimal functioning, autonomy, and health-related quality of life (HRQOL).^{7,8,10} Coping¹¹ and empowerment¹² are key factors within rehabilitation, whereby individuals work in partnership with their healthcare providers to master and gain control over issues that concern them and participate in decisions affecting their lives.⁸ Thus, there is an emphasis on positive health outcomes defined by the presence of particular qualities or attributes, and not merely the absence of disease or symptoms.^{7,9} Physical capacity and HRQOL are often mentioned as positive health outcomes and frequently identified as the ultimate aims of cancer rehabilitation.^{7–9} There is no established definition of HRQOL, but there is a general agreement that HRQOL is an individual-based, subjective, multidimensional concept that comprises physiological, psychological, and functional aspects of well-being.^{8,13,14} In line with this, the conceptual framework of Ferrell et al¹⁵ for cancer survivors states that specific concerns within each dimension may influence HRQOL. Although an individual's strengths and weaknesses in specific domains can be measured separately, the overall perception of HRQOL is a function of the combined contributions of all domains.¹⁵ Subsequently, rehabilitation efforts targeting the same concerns may improve the overall HRQOL, as well as the other dimensions.^{8,14,15} Physical capacity is commonly seen as a pos-

itive health indicator and an important factor for cancer control across the entire cancer experience. The Physical Exercise Across the Cancer Experience (PEACE) framework is an organizational model for examining physical exercise across the cancer journey.¹⁶ This framework, like research on cancer rehabilitation and survivorship,³⁰ underlines the importance of physical exercise after cancer treatment to build physical capacity through aerobic and muscle strength training. The recommended norm for physical activity for cancer survivors is at least 30 minutes of moderate activity for at least 5 days a week.^{16–18}

■ Previous Research

Several studies have documented that late effects of treatments and unmet needs negatively affect cancer survivors' HRQOL in a long-term perspective beyond the completion of therapy.^{19–21} Most of these studies target older cancer survivors, and we know little about the HRQOL of YACS.^{5,22} However, recent research has documented several factors specific for YACS that may contribute to decreased HRQOL and health. One element is that the cancer biology of YACS is unique, and the treatment is often intensive, multimodal, and lengthy.^{1,2} Moreover, YACS are in a vulnerable period of life, where cancer treatments interrupt the normal developmental and transitional processes.^{2,5} Research has also documented that YACS are at higher risk of life-threatening late effects^{3,4} and increased incidence of a multitude of physical and psychosocial problems compared with younger and older cancer survivors.^{1,4,5,23,24}

Research on cancer rehabilitation in general has been limited and, until recently, has focused primarily on deficits and single interventions targeting breast cancer survivors.^{25,26} Because the challenges of cancer survivorship are multifaceted, research on complex cancer rehabilitation is now warranted.^{10,25,27} Current research provides evidence that tailored physical activity, cognitive therapy (CT), psychoeducation, and peer support are important components of complex rehabilitation programs.^{10,27–29} Research has also revealed that physical capacity is crucial to long-term health and HRQOL for cancer survivors,^{25,30} and the positive effects of physical activity on HRQOL, fatigue, and distress are well established.²⁵ In addition, other interventions such as CT and psychoeducation have showed promising results on enhanced coping, empowerment, and HRQOL.^{19,25} We have not found research on YACS focusing on rehabilitation that aims to improve HRQOL and physical capacity. However, recommendations for cancer rehabilitation research suggest a

focus on prospective, longitudinal lifestyle interventions such as physical activity and psychoeducation to improve and sustain long-term health and HRQOL^{20,27,30,31} and to direct interventions to selected subgroups with the greatest needs, such as YACS.^{22,30,32}

Objective

The aim of this study was to measure if a complex rehabilitation program specially tailored for YACS improved positive health outcomes. Thus, the study's research questions were as follows:

1. How do the participants comply with the program?
2. Will participation in a rehabilitation program improve YACS' self-reported HRQOL at the end of the program and after 1-year follow-up?
3. Will participation in a rehabilitation program improve YACS' physical capacity at the end of the program?

Method

The study took place at the Red Cross Haugland Rehabilitation Centre (RCHRC) in Norway from January 2011 to January 2013. The RCHRC is a private rehabilitation center at the specialist level with contracted agreements with the official healthcare system. Participation in the study was free of charge for the YACS.

Design

A longitudinal, prospective design with a pretest and 4 follow-up tests was used. A Norwegian norm-based population and a European Organization for Research and Treatment of Cancer (EORTC) cancer population were used as comparison groups.³³⁻³⁵ This design is recommended for clinical research when it is not possible to establish a control group.³³ Figure 1 gives an overview of the entire design, intervention, and data collection of the study.

Recruitment, Eligibility Criteria, and Participants

As the difficulty of recruiting YACS into research¹ has been highlighted,³⁶ the recruitment was wide ranging and included hospital and primary healthcare nationally, brochures, and different Web sites. To ascertain the need for rehabilitation, an oncologist or a general practitioner made the referrals to the study.³⁰ The referrals were based on the patient's diagnosis and medical history and a holistic assessment of physical and psychological function. Only those who fulfilled the legal requirement for necessary healthcare and the following eligibility criteria were included in the study: YACS between 18 and 35 years of age who had completed primary cancer treatment within the previous 5 years, with any cancer diagnosis but with no current evidence of cancer, and with Norwegian as their main language. Of the 31 YACS referred to the study, 11 did not meet the eligibility criteria, and thus, 20 participants were included. All participants gave written consent. Table 1 presents the demographic and medical data of the sample. The Western Norway Regional Committee of Research and Ethics and the Norwegian Social Science Data Services approved the study.

Intervention

An interdisciplinary specialist team that was trained according to the intervention protocol conducted the intervention. The rehabilitation program consisted of 3 weeks of residential rehabilitation at the RCHRC with 1-week follow-up visits after 3 and 6 months. The program was structured around 6 core elements:

1. Setting individual goals^{8,37,38}: The participants set individual goals within the areas of self-care, productivity (work/study), and leisure (physical activity) to work toward during the rehabilitation process.
2. Physical exercise^{18,29,30}: Physical fitness, lung capacity, and strength of the participants were tested, and an individualized exercise program was compiled. Physical programs typically included 2 or 3 sessions every day, varying between individual

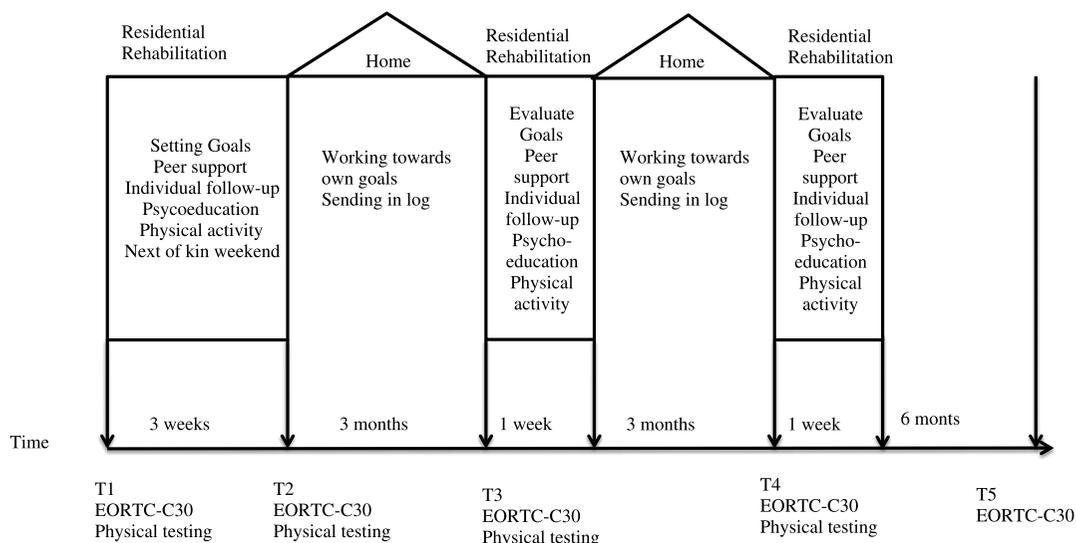


Figure 1 ■ Design of the rehabilitation program.

Table 1 • Demographic and Medical Presentation of Study Population (N = 20)

	n	Mean (SD), Range or %
Age, y	20	31.1 (3.9), 24–35
Gender		
Female	15	75
Male	5	25
Education		
Senior high school	6	30
University/university college	14	70
Social status		
Married/cohabitating	11	55
Single/divorced	9	45
Employment		
Working/study full-time	4	20
Working/study part-time	9	45
Full sick leave	7	35
Type of cancer		
Lymphoma	5	25
Gynecological	5	25
Breast	4	20
Testes	2	10
Colon	2	10
Sarcoma	1	5
Head and neck	1	5
Months since diagnose		24.6 (16.7), 4–71
Type of treatment		
Only surgery or chemotherapy	8	40
Multimodal treatment	12	60
Months of treatment		7.8 (6.8), 1–30
Months since treatment		16 (15.8), 1–66

workout and group sessions. The individual workout was based on Cybex workout units or Red Cord programs, supervised and followed up by physiotherapists. The group sessions typically focused on strength and physical fitness, coordination, body awareness, and relaxation. Each session lasted for 45 minutes, started with a warm-up, and finished with stretching and relaxation. To ensure that they continued with physical activity at home, the participants set goals for themselves and sent activity logs to RCHRC.

- Peer support^{1,2,5,8}: Within the structured rehabilitation program, the participants exercised and took all the psychoeducation sessions together. Furthermore, they lived together in a separate cabin, ate all meals, and spent most of their spare time with each other, thus facilitating a high level of interaction.
- Individual follow-up^{4,5,8,27,39}: Each participant received individual follow-up to attend to individual challenges or problems in a multidisciplinary way.
- Psychoeducation^{7,8,11,12,25,27,39}: The participants attended 7 psychoeducation sessions during their first stay (T1–T2). Each session lasted for 90 minutes and included teaching and discussions of relevant topics to increase the participants' knowledge of relevant cancer survivorship issues. The psychoeducation content is outlined in detail elsewhere.⁴⁰ Cognitive therapy¹¹ was used throughout all sessions as a tool to help them discover and cope with negative thoughts and emotions. At each follow-up week, the participants had 1 CT

session, focusing on the experiences they had while they were at home, and the challenges ahead.

- Next-of-kin weekend⁴¹: Next-of-kin were invited to a weekend at RCHRC during the participants' first stay. The purpose of this weekend was to allow next-of-kin to visit the participants, learn about the rehabilitation process, and meet others in the same situation.

Measurements

Demographic and medical data were collected from patient self-report.

Health-related quality of life was assessed by the EORTC Quality of Life Questionnaire C30, version 3.0 (EORTC QOL C-30). This is a self-administrated, cancer-specific, validated, and reliable instrument showing sensitivity to changes in clinical interventions with cancer survivors,^{3,34,42,43} including YACS.¹³ The EORTC QLQ-30 is used internationally, and reference data from several countries, including Norway, are established.^{34,42,43} Here, HRQOL is operationalized through a global health and quality of life scale (global HRQOL), 5 functional scales (physical function [PF], role function [RF], cognitive function [CF], emotional function [EF], and social function [SF]), 3 symptom scales (fatigue, pain, and nausea/vomiting), and 6 single-item symptom measures. All items are scored on a 4-point interval scale ranging from 1 ("not at all") to 4 ("very much"), except for global health and quality of life, which are scored on a 7-point interval scale ranging from 1 ("very bad") to 7 ("excellent").⁴³ In this study, only the results of the global HRQOL, the 5 functional scales (PF, RF, CF, EF, and SF), and 1 symptom scale (fatigue) are reported because these are the most relevant for YACS after treatment.¹⁹

Physical capacity was operationalized as physical fitness, lung capacity, and strength and body shape. Physical fitness was measured by the submaximal aerobic fitness test Astrand 6-minute Cycle Test. Heart rate was measured every minute while the participant pedaled continuously for 6 minutes, and the steady-state heart rate was determined.⁴⁴ Lung capacity, forced expiratory volume in 1 second (FEV₁), which is the maximal amount of air a person can forcefully exhale in 1 second, was measured by spirometer.⁴⁵ As a test of general muscle strength, a handgrip test was conducted, measuring maximum isometric strength of both hands and the forearm muscles with a dynamometer (Gripit).⁴⁶ To measure body shape, body mass index (BMI) was calculated by dividing the individual's weight (kg) by the square of their height (cm²).¹⁶ Physical exercise between the residential stays was measured by self-reports of time (minutes) and intensity (Borg's Ratings of Perceived Exertion).⁴⁷

Data were collected at 4 points: baseline (T1), after 3 weeks (T2), after 3 months (T3), and after 6 months (T4). In addition, EORTC QLQ-C30 data were collected after 1 year (T5) (see Figure 1).

Data Analyses

Data were analyzed by SPSS version 19. The EORTC QLQ-C30 items were transformed to scales ranging from 0 to 100.⁴³ A higher score on the global and functional scales indicates a

higher quality of life and a higher score on the fatigue scale indicates a higher level of fatigue. The results from the physical tests were converted to a percentage of the predicted normal score, considering gender and age, as well as adjusted for the dominant hand for the muscle strength tests.^{44–46} According to the manual, missing items of EORTC QLQ-C30 ($n = 3$) were calculated through the mean because at least half of the items on the scale had been answered.⁴³ Missing forms because of dropouts were coded as “missing” in the data set.⁴³ The Kruskal Wallis test showed no significant differences between the dropouts and those who completed the program at T1, T2, and T3, indicating that missing data did not seem to be a problem in this study.³³

Because the sample size was small ($N = 20$), nonparametric statistics were used to reduce the likelihood of type 2 errors.³³ A P value of <0.05 was considered statistically significant. Descriptive statistics were used to describe the characteristic of the participants and the different variables. The Wilcoxon matched-pairs signed-ranks test was used when testing the differences from baseline (T1) to each of the 4 posttests (T2, T3, T4, and T5) for the different dimensions of the EORTC QLQ-C30, lung capacity, muscle strength, and BMI.^{33(p473)} The power of change over time, effect size (d), was calculated by dividing the difference between pretest and posttest scores by the SD of the pretest score.¹⁴ The effect size was interpreted against Cohen criteria ($d > 0.20$ for small effect, $d < 0.50$ for moderate effect, and $d > 0.80$ for large effect).¹⁴ Spearman’s rank correlation was used to test the relationship between continuous demographic and medical variables,^{33(p488)} whereas the Mann-Whitney U test was used when the variables were categorical.^{33(p479)}

To compare the results of the EORTC QLQ-C30, we used the data of Hjermeid et al³⁴ from a Norwegian norm-based sample reporting no health complaints ($n = 631$, mean age 39.0 years). We also used EORTC’s norm group of cancer patients younger than 50 years.³⁵ According to the manual,⁴³ clinical significance may be interpreted as changes or differences in line with the following values: 5 to 10, little change; 10 to 20, moderate change; and greater than 20, large change.

■ Results

Compliance

Of the 20 enrolled participants, 17 completed the rehabilitation program (T1–T4). During the program, 3 participants withdrew because of breast reconstruction ($n = 1$ after T2), not being able to take time away from university/college ($n = 1$ after T2), and relapse of cancer ($n = 1$ after T3). At the 1-year follow-up (T5), 14 of the 17 participants who had completed the program returned the questionnaires. Study withdrawals at T5 were related to relapse of cancer ($n = 1$), sudden death in the immediate family ($n = 1$), and unknown ($n = 1$). The participants’ overall compliance with the different elements of the rehabilitation program was generally very high. The compliance is outlined in Table 2.

Changes in Self-reported HRQOL

There were no differences in the selected dimensions of EORTC QLQ-C30 based on medical or demographic variables at baseline. From baseline (T1) and throughout the program (T4), significant

 **Table 2 • Compliance to the Different Elements of Research and the Rehabilitation Program**

Compliance Within	Elements of Compliance	T1 (N = 20), n	T2 (N = 20), n	T3 (n = 18), n	T4 (n = 17), n	T5 (n = 17), n
Research	Physical testing ^a	20	20	18	16	Not included in the design
	Self-report EORTC QLQ-C30 ^b	20	19	18	17	14
The rehabilitation program	Physical activity ^c	20		18	17	
	Individual follow-up ^d	20		Only on request	Only on request	
	Psychoeducation ^e	20		18	16	
	Peer support	+		+	+	
	Next-of-kin weekend ^f	9		Not included in the design	Not included in the design	
	Sending in logs ^g				15	11
	Weeks reported on ^h			10 (6–14)	9 (2–12)	

The symbol + confirms peer-support, ie, that they met other cancer survivors.

Abbreviation: EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30, version 3.0.

^aNumber who completed physical testing.

^bNumber who filled out more than 95% of the questions in the questionnaires.

^cNumber who attended the scheduled hours of physical activity in accordance with the timetable.

^dNumber who met scheduled appointments with specialist in rehabilitation medicine, physiotherapist, nurse, nutritionist, and social worker.

^eNumber who attended all 7 sessions at T1 to T2 and 1 session at T3 and T4.

^fNumber who had visits from next-of-kin and attended this program.

^gNumber who sent in log from homestay between T2 and T3 and between T3 and T4.

^hNumber of weeks between the residential stays were between 12 and 14 weeks.

Table 3 • European Organization for Research and Treatment of Cancer (EORTC) Mean Changes From Baseline (T1) to T2, T3, T4, and T5 and Comparison With a Norwegian Healthy Population and a Cancer Population

	At start, T1 (N = 20)	After 3 Wk, T2 (N = 20)	After 3 Mo, T3 (n = 19)	After 6 Mo, T4 (n = 17)	After 12 Mo, T5 (n = 14)	Reference Data	
						Norwegian Population, Healthy (N = 631) ^a	Cancer Patients <50 y (N = 5237) ^b
Global HRQOL	53.8 (17.8)	69.7 (13.7) ^c	69.7 (15.5) ^d	72.1 (16.4) ^c	74.4 (17.7) ^d	76.8 (9.8)	61.4 (23.4)
Functional Scales ^c							
Physical Functioning	75.7 (16.9)	85.6 (12.4) ^f	87.0 (8.2) ^c	86.7 (12.5) ^f	92.0 (9.2) ^d	93.1 (5.8)	80.2 (20.8)
Role Functioning	46.7 (29.9)	71.9 (24.9) ^c	67.5 (29.6) ^c	72.5 (25.6) ^c	73.3 (33.8) ^f	86.3 (9.9)	68.6 (31.7)
Emotional Functioning	60.4 (23.9)	77.2 (16.9) ^g	75.9 (19.8) ^f	82.4 (18.1) ^d	79.8 (17.5) ^d	82.5 (7.1)	69.2 (24.4)
Cognitive Functioning	54.2 (28.0)	72.8 (14.9) ^d	73.7 (19.5) ^d	76.5 (24.3) ^c	71.4 (25.7)	88.1 (5.9)	82.9 (21.6)
Social Functioning	37.5 (28.0)	69.3 (29.5) ^g	67.5 (28.0) ^g	74.5 (28.9) ^c	75.0 (26.8) ^c	87.4 (8.4)	72.1 (29.5)
Symptom Scales ^h							
Fatigue	62.8 (26.1)	47.9 (27.3) ^f	36.8 (23.1) ⁱ	37.3 (19.6) ^c	34.1 (24.0) ^d	28.0 (9.6)	33.9 (26.1)

Data are presented as mean (SD).

Abbreviation: HRQOL, health-related quality of life.

^aNorm data from Norwegian norm population with no health complaints by Hjermstad et al.³⁴

^bEORTC norm for cancer patients with mixed cancers younger than 50 years (EORTC 2008).

^cDifference from baseline and actual time, Wilcoxon matched-pairs signed-ranks test: $P < .005$.

^dDifference from baseline and actual time, Wilcoxon matched-pairs signed-ranks test: $P < .01$.

^eA higher score indicates a higher function.

^fDifference from baseline and actual time, Wilcoxon matched-pairs signed-ranks test: $P < .05$.

^gDifference from baseline and actual time, Wilcoxon matched-pairs signed-ranks test: $P < .001$.

^hA higher score indicates higher symptom.

($P < .05$ –.001) increases occurred in overall HRQOL and all functional scales (PH, RF, EF, CF, and SF), as well as a decrease in fatigue ($P < .5$ –.000) (Table 3). Thus, the main increase ($P < .05$ –.01) in the EORTC QLQ-C30 dimensions occurred from T1 to T2, where the differences on the scales were between 9.9 and 31.8 points. These values were relatively stable across time (T3, T4, and T5), but there was a further significant ($P < .05$)

decrease in fatigue from T2 to T3. These results are illustrated in Figure 2.

According to Cohen criteria, the effect sizes (d) within the program (T1–T4) were large, as all dimensions scored over 0.80, except for PF, where the effect was moderate ($d = 0.72$). The effect sizes of the program are illustrated in Figure 3. From the end of the program (T4) to 1-year follow-up, there was no

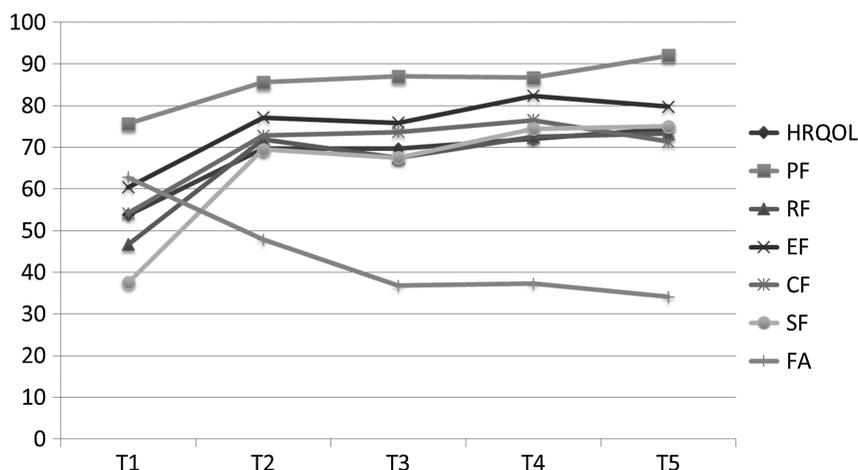


Figure 2 ■ Mean changes in selected European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30, version 3.0 (EORTC QLQ-C30) scales within the program (T1–T4) and 1-year follow-up (T5).

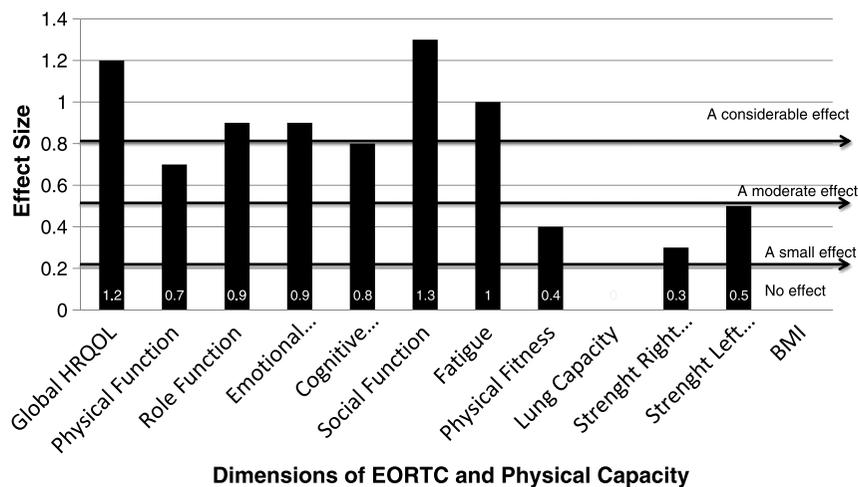


Figure 3 ■ Effect size of European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 version 3.0 (EORTC QLQ-C30) and physical capacity within the rehabilitation program (T1–T4, n = 16).

further effect within SF ($d = 0.08$), CF ($d = -0.10$), RF ($d = 0.04$), and EF ($d = -0.06$), a small effect within PF ($d = 0.40$), and a moderate effect in HRQOL ($d = 0.70$).

Fatigue was significantly ($P < .05$), strongly, and negatively correlated (ρ between -0.47 and -0.87) to all the other dimensions of EORTC QLQ-C30 at all points of measurements (baseline, T2, T3, T4 and T5), except for CF at T1 and T2 and EF at T2, T4, and T5.

The study participants scored substantially lower (22.1–49.9 points) at baseline than the healthy normal population did,³⁴ where SF, RF, and fatigue showed the highest differences (Table 3). The participants also scored between 4.5 and 34.7 points lower on all dimensions than the cancer population did³⁵ at baseline. Here, SF, fatigue, and CF showed the highest differences. After completing the program (T4), these differences had decreased substantially related to the normal population (0.1–13.8 points). At the end of the program (T4), the participants scored higher than the cancer population did on all dimensions, except for CF (6.4 points lower) and fatigue (3.4 points lower). At 1-year follow-up, the participants scored closer to the normal population (1.1–16.7 points lower) and higher than the cancer population did in all dimensions, except for CF (11.5 points lower) and fatigue (1 point lower).

Changes in Physical Capacity

Results from the objective tests on physical fitness, lung capacity, muscle strength, and BMI are summarized in Table 4. The participants' physical fitness was 78.9% at baseline and thus substantially lower than that of the normal population (>90%), regardless of age and gender. The participants had a significant ($P < .01$) increase in physical fitness from baseline to T2, but no further significant increases were observed at T3 or T4. At T3, the participants' mean score was closer to that of the normal population, but a small nonsignificant decrease occurred from T3 to T4.

The participants' lung capacity (FEV₁) was 83.7% at baseline and within the lower range of that of the normal population (>80% by age and gender).⁴⁵ There was a significant ($P < .05$) increase in FEV₁ from baseline to T3.

The participants' muscle strength was within the range of the normal population at baseline. The results indicated no significant increase in right-hand strength from baseline to T2, T3, or T4. There was a significant increase in left-hand strength from baseline to both T3 ($P < .05$) and T4 ($P < .01$).

The participants had a mean BMI of 26.1 kg/m² at baseline, indicating slight overweight. There was a slight but nonsignificant decrease in BMI at the end of the program (T4).

The effect sizes of the physical parameters within the program (T1–T4) were small for left-hand strength ($d = 0.47$), physical fitness ($d = 0.42$), and right-hand strength ($d = 0.32$), but there was no effect on lung capacity ($d = 0.00$) and BMI ($d = -0.04$) (see Figure 3).

The results from the participants' logs indicated that they continued with physical activity while they were at home between the residential stays (Table 5). The mean value for physical activity between T2 and T3 was 276 minutes/week, divided into 4 sessions with a mean intensity of 14 on Borg's scale.⁴⁷ Between T3 and T4, the mean value for physical activity was 231 minutes/week, divided into 4 sessions with a mean intensity of 14 on Borg's scale.

There were no differences in physical outcomes at baseline related to demographic or medical parameters, except for BMI. Here, the male participants scored significantly higher ($P < .05$) than the female participants did. Body mass index was also negatively correlated to physical fitness ($\rho = -0.48$, $P < .05$). Furthermore, there were no significant correlations between the physical parameters and the different dimensions of the EORTC QLQ-C30 at baseline, except for a significant negative correlation between physical fitness and fatigue ($\rho = -0.47$, $P < .05$).

Discussion

To our knowledge, this is the first study to report on a complex rehabilitation program tailored for YACS, focusing on positive health outcomes such as quality of life and physical capacity. The participants reported significant increases in global HRQOL

Table 4 • Changes in Physical Parameters During the Program From T1 to T4

Measure of	Measurement	Baseline (T1) (N = 20)	After 3 Wk (T2) (N = 20)	After 3 Mo (T3) (n = 19)	After 6 Mo (T4) (n = 17)	Norm Reference
Physical condition	Astrand 6-min Cycle Test (%) ^a	78.9 (19.4)	86.3 (17.3) ^b	88.8 (18.5)	86.7 (20.0)	>90%
Lung capacity	FEV ₁ , % ^c	83.7 (11.2)	85.2 (8.5)	86.7 (8.0) ^d	85.5 (10.0)	>80%
Muscle strength	Hand-grip (%) ^c					>90%
	Right max	103.1 (17.6)	105.2 (16.6)	108.4 (18.0)	106.6 (17.5)	
	Left max	101.9 (18.5)	105.4 (18.4)	112.4 (22.0) ^d	109.3 (15.8) ^f	
BMI	BMI ^g	26.1 (4.2)	26.1 (4.2)	26.2 (4.5)	25.7 (3.9)	18.5–24.9

Data are presented as mean (SD).

Abbreviations: BMI, body mass index; FEV₁, forced expiratory volume in 1 second.

^aPhysical condition was measured by Astrand 6-minute Cycle Test and expressed as a percentage of predicted normal considering gender and age.

^bSignificant difference between T2 and T1 using Wilcoxon signed-ranks test: $P < .005$.

^cLung capacity (FEV₁) was measured by spirometer and expressed as a percentage of predicted normal considering gender and age.

^dSignificant difference between T3 and T1 using Wilcoxon signed-ranks test: $P < .05$.

^eMuscle strength was measured by hand-grip test and expressed as a percentage of predicted normal considering gender and age.

^fSignificant difference between T4 and T1 using Wilcoxon signed-ranks test: $P < .01$.

^gBMI was calculated as follows: weight (kilograms) divided by the square of height (meters squared).

and in all the functional dimensions and a decrease in fatigue within the program. These values were relatively stable at 1-year follow-up. The effect sizes for the EORTC QLQ-C30 dimensions within the program were generally large. Furthermore, significant changes occurred in physical fitness, lung capacity, and left-hand strength, but no changes in right-hand strength or BMI. The effect sizes of the physical parameters ranged from moderate to no effects. In addition to a low dropout rate and a high level of compliance to the program, these results indicate that the program was feasible for YACS with different cancer types after completing cancer treatment.

These results are in line with earlier studies reporting that multidimensional cancer rehabilitation programs generate positive health outcomes such as quality of life and physical capacity.^{25,28,29,48} However, this study lacked a control group and included a relatively small sample of YACS. Thus, the findings cannot be generalized to the entire population of YACS.³³ Furthermore, it cannot be definitely concluded that the intervention caused the improvements. Nevertheless, in the following sections, we will argue that the beneficial effects cannot simply be attributed to passage of time but are likely to be related to the intervention. These results may then shed light upon some important factors that might promote positive health outcomes for YACS.

Needs and Timing

Recent research has identified YACS as a vulnerable group of cancer survivors in need of follow-up and rehabilitation to build

capacity for long-term good health and quality of life.^{1,3,5,21,23} The results from this study seem to confirm this picture, as the participants scored lower at baseline compared with studies of older cancer survivors.^{32,48} The participants also reported a large impact on HRQOL at baseline compared with the Norwegian norm population³⁴ (22.1–49.9 points lower).⁴³ On the other hand, they scored relatively similar to the cancer population in global HRQOL, PH, and EF (<10 points) but scored even lower in RE, CF, and SF.⁴³

Previous research has found that fatigue and distress are significant contributors to decreased HRQOL, a measure often underestimated by healthcare providers.^{13,21,24,25,28,30,48} These findings seem to be in line with the results from the present study. The participants reported a high level of fatigue compared with the norm population and the cancer population (Table 3). In addition, there were high correlations between fatigue and the various dimensions of HRQOL throughout the program. According to Ferrell et al,¹⁵ a problem within 1 dimension, here fatigue, can affect the overall HRQOL as well as the other dimensions.

It can be argued that the present sample was biased toward self-selection, representing highly impaired YACS. The sample had an overrepresentation of women, but the prevalence of cancer among young adults in Norway is higher in women than in men.⁴⁹ The sample was, however, representative of both cancer diagnoses and age distribution within this specific group of cancer survivors.⁴⁹ On the other hand, several researchers explain low outcome effects on HRQOL by baseline levels

Table 5 • Physical Exercise at Home Between the First and Second Restay (T2–T3) and Between the Second and Third Restay (T3–T4)

	Weeks Reported	Physical Exercise, Min/Wk ^a	Amount of Exercises per Week	Perceived Exertion per Exercise ^b
Between T2 and T3 (n = 15)	10.7 (2.6)	276.2 (115.5)	4.1 (1.1)	13.8 (1.1)
Between T3 and T4 (n = 11)	9.0 (3.0)	231.4 (104.1)	4.1 (2.1)	13.8 (1.8)

Data are presented as mean (SD).

^aBased on self-report log of minutes per exercise.

^bPerceived exertion was measured by the Borg scale: 6 to 9, 20% to 50% effort (very light); 10 to 14, 55% to 75% (somewhat hard); and 15 to 19, 80% to 100% (hard to very hard).

comparable with the general population norms, consequently underestimating intervention effects.^{32,50} Thus, there is a new recommendation to target participants in cancer rehabilitation on a needs-based approach requiring a physician's clearance or prescreening for participation, rather than a "take all comers" approach.^{30,32,50} This was done in this study, as a physician's referral was required to confirm the participants' need for rehabilitation in accordance with legal rights for necessary healthcare.

Research has documented lack of knowledge in survivorship care, particularly in YACS,^{5,6,24} along with a limited focus on follow-up and rehabilitation.^{1,6,24} Within both the Cancer Control Continuum³¹ and the PEACE framework,¹⁶ rehabilitation and health promotion are included in the phases after completion of cancer treatment. This is in line with Courneya and Friedenreich,¹⁶ who recommend that the period of rehabilitation and health promotion should start 3 to 6 months after treatment, when the acute effects of medical treatments have dissipated and the person is attempting to resume normal activity. In contrast to this, several studies of cancer rehabilitation have evaluated "mixed" groups of cancer survivors, both undergoing treatment and having finished treatment, which may have affected the results.^{30,48,50} Consequently, Speck et al³⁰ underline the importance of having the Cancer Control Continuum and PEACE framework to guide cancer rehabilitation research, allowing for greater specificity in evaluating interventions. Thus, the participants in this study had all completed treatment within the last 16 months. Research has revealed that improvement in the first year after cancer treatment is especially important to avoid a prolonged experience of poor HRQOL.^{19,20,21} The participants' low baseline levels of HRQOL may therefore indicate that their natural recovery was unsuccessful and that their need for rehabilitation had not been acknowledged early enough to prevent severe impact on HRQOL.²⁴ Furthermore, these results demonstrate the importance of being aware of YACS HRQOL throughout cancer treatment as well as in survivorship care. Screening of HRQOL may thus be a tool to detect areas of resources as well as areas in need of follow-up.

In this study, the participants scored lower than the norm population in HRQOL. They also scored lower or within the lower range of normal for physical capacity. Here, HRQOL was self-reported and the physical parameters were objective tests. One may therefore claim that the objective tests gave a more reliable and "true" picture of the YACS' present situation. In contrast, it may be argued that the low HRQOL scores indicate that the participants perceived themselves as worse than they really were. Research has revealed that YACS compare their present situation with how they used to be before cancer treatment.^{6,24} In line with this, Davis⁸ explains decreased HRQOL as a difference between individuals' hope and expectations in their life. On the other hand, the physical tests in this study were short and intensive, with a maximum of 6 minutes.⁴⁴ These tests may then not reflect the respondents' existent fatigue, as they were able to perform for a short time but experienced fatigue over a long time.²⁴ Furthermore, the objective tests were isolated physical parameters, whereas the HRQOL measures give a picture of the different dimensions in relation to each other.^{8,14} In line with the findings from this study, other studies have

found modest correlations between the dimensions of HRQOL and physical parameters, indicating that physiological parameters and perceptual ratings are relatively independent.¹³ Katz et al¹³ argue that HRQOL measures are not proxies for physiological parameters but rather provide a more comprehensive evaluation of patient functioning across multiple life domains, and therefore, they are both needed.

Based on the discussion above, it seems likely that this study's sample was tailored to a needs base, as all the participants were in the same phase of rehabilitation. Furthermore, the self-reported HRQOL results and the objective physical tests may be seen as more complementary than overlapping. All these factors may thus be important to explain the positive results of this study.

A Real Change or Improvement With Time?

The results indicated significant increases in both HRQOL and some of the physical parameters within the program. The effect sizes in the different dimensions of HRQOL were, in general, high, with smaller effect sizes within physical capacity. For the HRQOL dimensions, the values were rather stable at 1-year follow-up.

These results are considerably higher than those reported in other studies of cancer rehabilitation.^{10,19,48,50} Thus, some may wonder about the differences between the effect sizes of HRQOL and the physical parameters. According to Crosby et al,¹⁴ these differences must be seen in connection with the baseline values because improvements are greater for individuals who have lower scores at baseline, which was the case for HRQOL, and somewhat lesser for higher baseline, as for the physical parameters.

The largest significant changes in the HRQOL dimensions (see Figure 2) and physical fitness occurred during the first residential stay (T1–T2), whereas the significant changes in the other physical parameters occurred after 3 months (Table 4). These results may support the suggestion that the improvements were related to the intervention, and not the passage of time. Theories of empowerment and coping highlight that empowering and developing coping skills are dependent on being in a setting that facilitates interaction, authentic coping experiences, social modeling, social support, as well as knowledge.^{11,12} The results then may indicate that a residential stay of 3 weeks can be important to initiate the rehabilitation process.

Rehabilitation is defined as a process over time.⁸ The results illustrate this point as outlined in Figure 2. Whereas the main effects occurred from T1 to T2, there was a steady increase onto T3, T4, and to some extent, onto T5. The participants' physical parameters were within or close to the norm at the end of the program (T4), and they scored higher than the cancer population did in most of the HRQOL dimensions. In addition, they scored closer to the mean of the norm population than the cancer population did in global HRQOL, PF, and EF, indicating recovery.¹⁴ However, in the other dimensions (RF, CF, SF and fatigue), they scored closer to the mean of the cancer population, indicating that fatigue was still a problem.

Theories of rehabilitation stress that processes of change are in need of both time and follow-up.⁸ New research also documents that cancer survivors are in need of survivorship care and follow-up, especially the YACS.^{5,6,39} In line with this time and

process perspective, the results from this study may indicate that the restays and professional follow-up were important elements of the rehabilitation program. This is supported by Hauken et al,⁴⁰ who found that YACS highlighted multidimensional follow-up over time as 1 of the most important factors for reaching their rehabilitation goals and increasing participation in all areas of life.

Previous research has found limited durability of beneficial effects in HRQOL and physical capacity from rehabilitation interventions over time. However, most of these studies had short interventions and did not include a 1-year follow-up.^{10,19,25} In contrast, the findings from this study indicate that the improvements in HRQOL were maintained or even slightly improved at 1-year follow-up (Figure 2 and Table 3). Here, the participants were closer to the normal population (1.1–16.7 points lower) and scored better than the cancer population did in all dimensions, except for CF (11.5 points lower) and fatigue (1 point lower). These results indicate an improvement related to the program.^{14,43} The small to moderate effect sizes from the end of the program (T4) to the 1-year follow-up also support that the main improvements seem to be related to the intervention. The increases in outcomes after the intervention may be related to the possibility that the participants could cope with and had more control over their cancer related challenges and were thus empowered.^{11,12} This is supported by a previous study wherein YACS stated that they were not fully rehabilitated at the end of the program but could continue with the rehabilitation process by themselves because they knew how to cope and in which direction to continue.⁴⁰

Because this study included a small sample size and no control group, several efforts were made to establish valid results.^{14,16,34} To reduce the likelihood of type 2 errors,³³ we used an instrument (EORTC QLQ-C30) with established validity and reliability. Furthermore, the same person conducted the objective measures of physical parameters under the same conditions each time. The intervention was standardized, theory based, and supervised to secure that all the participants got the same program.³³ Furthermore, the study had several points of measurement, which also enhances the validity.³³ In analyzing the data, nonparametric tests were used and the significance level was set to $P < .05$, and a number of variables known to be associated with HRQOL were controlled.³⁴ All these efforts indicate that the results are valid. Furthermore, Gray³³ argues that finding large effect sizes within a small sample indicates that the changes cannot simply be explained by selection errors. Based on the arguments outlined above, it seems plausible that the beneficial changes in HRQOL and physical parameters are not simply attributable to the passage of time but are likely to be related to the intervention.

Which Elements Were Important?

Even if complex rehabilitation is warranted, it may not be possible to determine the effects of the individual elements of the program on the outcomes.^{20,25,32} This criticism affects this study as well. However, combining the results with theory and earlier research may offer some indication for important core elements of complex rehabilitation programs tailored for YACS.

SETTING INDIVIDUAL GOALS

According to theory and definitions of rehabilitation, rehabilitation is a goal-oriented process.^{8,10,31} Applying this theory into clinical practice, research has documented that assisting cancer survivors in setting achievable goals supports the process of health restoration and leads to improved outcomes.^{8,37,38} In line with this, Hauken et al²⁴ found that YACS expressed that setting specific goals helped them to structure, motivate, and take responsibility for their rehabilitation process. The results revealed high goal achievement and increased participation and satisfaction in all areas of life. The experience of coping and control seemed to mediate the goal-oriented process.⁴⁰ It therefore seems plausible to argue that setting individual goals within different areas of daily life may help YACS to specify and direct their efforts in the rehabilitation process and build coping capacities.

PHYSICAL EXERCISE

Physical activity is the single most studied element in cancer rehabilitation, showing physiological and psychological benefits in addition to reducing cancer recurrence risk and mortality.^{25,30} Research has shown that YACS are interested in programs targeting physical activity, that they prioritize physical goals but are in need of physical activity interventions to meet public guidelines.^{36,39,40} It seems that the results from this study fit into this picture: Significant improvements and large changes occurred within global HRQOL and all the physical and psychological dimensions of HRQOL, as well as a reduction in fatigue and significant improvement in physical fitness. These results may be explained in accordance with Ferrell et al,¹⁵ who state that an intervention directed to 1 dimension, in this case physical activity, may also have positive effects on the other dimensions. Given this study's results together with the high compliance (>95%) to the exercise sessions, it seems that the content and conduct of physical activity in this program were relevant, feasible, and effective for YACS. Another important finding is that the participants continued with physical exercise between the residential stays at a surprisingly high level considering their reported fatigue at both T3 and T4 (Tables 3 and 4). In fact, physical activity with a mean value of 231.4 minutes in 4 sessions a week indicates physical activity in excess of the guidelines for physical activity for cancer survivors of at least 150 minutes a week.¹⁶ Furthermore, a perceived mean intensity of 14 using the Borg scale indicates 75% effort and a level expected to be effective in improving physical capacity and to give positive health effect.^{18,47} Thus, it may be suspected that the participants overreported their activity in the logs sent to the rehabilitation center. This is not very likely because the logs were filled out in a very detailed and specific way. The participants also knew that they would be tested on the restays and that cheating in the logs would most likely have been discovered. Thus, these results indicate that even fatigued cancer survivors can follow physical exercise guidelines when they get a safe and tailored exercise program.³⁰ This also highlights the importance of healthcare providers focusing on and establishing physical activity guidelines throughout the treatment, which may prevent decreases in physical capacity and HRQOL.¹⁶

PSYCHOEDUCATION

Research within cancer rehabilitation indicates that both psychoeducation and use of CT are important elements of complex cancer rehabilitation.^{25,27,39} The theoretical base of psychoeducation and CT is to empower individuals by providing them with knowledge and decision-making skills that are important in enabling them to cope with their present health situation.^{7,8,11,12} Thus, the tailored psychoeducative program focusing on relevant aspects of YACS such as exercising and how to handle fatigue and return to work/studies may explain some of the positive improvements on the typical psychological dimensions such as CF and EF, as well as the other dimensions (Table 3 and Figure 2). These results are also in line with the framework of Ferrell et al¹⁵ indicating that psychoeducation may increase function in all dimensions. Furthermore, these results are also supported by a previous study wherein the participants reported that the psychoeducation provided them with new insight important for their control and coping.⁴⁰

INDIVIDUAL FOLLOW-UP

Rehabilitation is an individual process.⁸ Research has demonstrated that YACS have multifaceted challenges and needs in survivorship, emphasizing the importance of basing the rehabilitation process on individual needs.^{4,5,27,39} The participants' individual needs were addressed in several ways in this study. First, the participants had individual appointments with different cancer rehabilitation specialists, including a physician, a physiotherapist, a nurse, a nutritionist, and a social worker, for a holistic appraisal of needs. All participants attended all appointments, indicating that they found these relevant (see Table 2). The individual perspective was also apparent in the setting and follow-up of personal goals, physical testing, and tailoring and supervision of the exercise program, as well as related to the participant logs. Therefore, it seems likely that the participants' individual needs were identified, which also may have affected the different dimensions of HRQOL¹⁵ in a positive way.

PEER SUPPORT

Even if rehabilitation is defined as an individual process,⁸ empowerment¹² and cognitive theory¹¹ identify social support as an important factor in facilitating coping and control and, thus, HRQOL. Some studies have reported that YACS experience an impaired social life after cancer treatment related to late effects and a lack of understanding from their surroundings.^{5,24} The results from this study are in line with these findings, as the score in SF was the lowest at baseline and the one with the highest improvement at the end of the program (Table 4). Earlier research provides strong evidence that peer support is especially important for YACS.^{1,5,22} Cancer in young adulthood is rare, and the outpatient regimens of most treatments leave most YACS with limited peer support during treatment.^{2,24} The participants in this study interacted closely at the rehabilitation stays. They participated in most of the elements of the program together, and they lived, ate, and spent their spare time together. The sharing of experiences from both

the cancer journey and the rehabilitation process most likely facilitated close interaction. Previous research has also shown that peer support between cancer survivors has given positive effects on psychosocial function and HRQOL, as well as fostered supportive exchanges and empowerment.⁴¹

NEXT-OF-KIN WEEKEND

Contrary to the findings from the other elements of the program, no impact from the next-of-kin weekend can be substantiated, as compliance with this element was only 45%. However, this result may reflect the vulnerability of YACS related to their period of life.⁵ Some participants did not want their parents to be involved in their rehabilitation process, regardless of whether they lived with their parents or lived alone; some had only recently formed a relationship with a partner and found it difficult to invite them; and the partners of others who had small children experienced practical difficulties in participating.

Even if it is plausible to assume that most of the individual elements of the program accounted for some of the improvements in both HRQOL and physical capacity, it is more likely that the combination of these elements facilitated the positive changes. As the challenges of cancer survivorship are complex, rehabilitation must also be complex. According to the multidimensionality of the definitions of both rehabilitation⁸ and HRQOL¹³ and to the framework of HRQOL and survivorship of Ferrell et al,¹⁵ it is likely that the different elements had different significance for the YACS based on their individual needs. According to Davis,⁸ the different elements in the intervention may also have facilitated more congruence between the participants' hope and expectations and their actual life and thus promoted their HRQOL.

Norway, like several Nordic countries, has an official healthcare system and formal legislation to secure rehabilitation needs.¹⁰ This implies that there are limited financial implications for YACS to participate in rehabilitation programs, and health insurance is not required.¹⁰ However, the situation is not the same in other countries, where such rehabilitation programs may be unaffordable for YACS because they lack health insurance. Nevertheless, the results from this study seem to point out several important elements of rehabilitation targeted to YACS. These elements may also be effective in other countries and can be implemented in other clinical settings such as primary healthcare as well as in follow-up clinics.

■ Conclusions and Implications for Clinical Practice and Research

The findings of this study seem to confirm previous research showing YACS to be a vulnerable group of cancer survivors with highly affected HRQOL and impaired physical capacity. The results showed significant increases and large improvements in the different dimensions of HRQOL, as well as significant increases within physical capacity during the program. The participants' HRQOL was close to the norm population at the end of the program and at 1-year follow up. These results suggest that a complex cancer rehabilitation program especially tailored

for YACS may be important in building positive health outcomes, such as HRQOL and physical capacity, over time. Important elements of such a program seem to include setting individual goals, physical exercise, peer support, psychoeducation based on CT, and individual follow-up. The main changes within this study occurred within the program, mainly from T1 to T2. These results suggest that a residential rehabilitation component may be of importance to initiate the rehabilitation process but still acknowledge that cancer rehabilitation is a process requiring time and professional follow-up.

The findings outlined in this study are of significance to clinicians, as healthcare providers should be aware of the symptom burden and HRQOL of YACS throughout the cancer journey. Monitoring YACS' own perceptions of their HRQOL and symptom burden can help patients to communicate concerns to healthcare providers that might not be otherwise discussed. Although not all YACS will need complex rehabilitation, screening for HRQOL may be valuable for detecting resources and a tool to provide holistic survivorship care. Furthermore, screening for HRQOL (and especially fatigue) seems to be a tool for discovering those in need of special medical attention and complex rehabilitation interventions. The results also pinpoint the importance of including multidimensional interventions to improve HRQOL and physical activity into survivorship care. Awareness of the same elements in the period of cancer treatment may also be beneficial to prevent decrease in HRQOL and physical capacity for YACS.

Because this study's sample size was small, the results cannot be generalized to the entire population of YACS. However, this study represents a promising starting point for cancer rehabilitation interventions for YACS. Further research should try to illuminate the use of regular screening of HRQOL as well as physical capacity to identify YACS in need of complex rehabilitation based on cutoff values. Complex cancer rehabilitation should target YACS in need, with a suggested start of the rehabilitation phase 3 to 6 months after treatment. Furthermore, randomized controlled trial studies should be conducted to see if the considerable improvements within HRQOL in this study could be confirmed by larger representative samples. Important areas to focus on are the content and structure of the rehabilitation program. To understand the rehabilitation process of YACS better, explorative and qualitative studies within this field are highly warranted.

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