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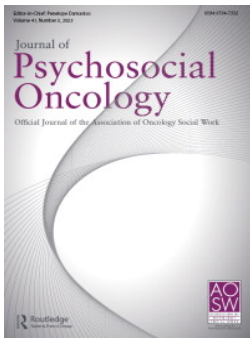
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Online cognitive-behavioral group intervention for young adult survivors of childhood cancer: a pilot study

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ABSTRACT

Background: Young adult childhood cancer survivors (YACCS) are a vulnerable group in need of psychosocial support, but tailored interventions are lacking.

Aim: To examine feasibility and satisfaction, and to explore preliminary effectiveness of an online group intervention (*Op Koers Online for YACCS*) aimed at teaching active coping skills and providing peer-contact, thereby reducing and preventing psychosocial problems in YACCS. The intervention is based on psycho-education, cognitive behavioral therapy, and aspects of acceptance and commitment therapy.

Methods: YACCS completed questionnaires pre- and post-intervention. Feasibility was based on attendance, drop-out, and an evaluation questionnaire was administered to assess satisfaction. Preliminary effectiveness was evaluated with the Mastery Scale, Illness Cognition Questionnaire, Distress Thermometer, Impact of Cancer - Childhood Survivors, and Pediatric Quality of Life Inventory. Preliminary effectiveness was investigated by testing differences on the psychosocial outcomes (coping and psychosocial wellbeing) between T0 and T1 within respondents, using paired samples *t* tests and Cohen's *d*.

Results: 10 YACCS participated in the intervention and completed all questionnaires. There was no drop-out; 90% of participants attended five out of six sessions. Overall, participants were satisfied with the intervention; 7.6 on a 0-10 scale. Distress (Cohen's $d=-.6$, $p=.030$) and feelings of helplessness (Cohen's $d=-.8$, $p=.001$) reduced from T0 to T1, while self-efficacy (Cohen's $d=.8$, $p=.013$,) improved. Other outcomes displayed small effects, but did not change significantly.

Conclusions: This first, small pilot study showed short-term decrease in distress and feelings of helplessness and improvement of self-efficacy. *Op Koers Online* was positively evaluated by YACCS and course leaders, filling a gap in psychosocial services for YACCS.

KEYWORDS

online cognitive-behavioral group intervention;
young adults survivors of childhood cancer

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ABBREVIATIONS: CCS: Childhood Cancer Survivor(s); YACCS: Young Adult Childhood Cancer Survivor(s); CBT: Cognitive Behavior Therapy; ACT: Acceptance and Commitment Therapy; DT: Distress Thermometer; MS: Mastery Scale; ICQ: Illness Cognition Questionnaire; IOC-CS: Impact of Cancer – Childhood Survivors; PedsQL-YA: The Pediatric Quality of Life Inventory Young Adults; HRQOL: Health-Related Quality of Life; CNS: Central Nervous System

Introduction

Thanks to significant medical advancements, most children diagnosed with childhood cancer now survive into adulthood.¹ As a consequence of intensive treatments, many childhood cancer survivors (CCS) are faced with long-term physical and some with mental health problems called late effects.^{2–7} Young adult childhood cancer survivors (YACCS) are potentially vulnerable for adverse psychosocial outcomes, because of the combination of their developmental (e.g. starting a career, living independently) and survivorship challenges, e.g. uncertainty about health and fertility, intimate friendships and sexuality, autonomy and work performance.^{8–10} Despite this pressing issue and current psychosocial standards of care recommending screening and psychosocial care for survivors,¹¹ psychosocial interventions specifically aimed at preventing or reducing psychosocial problems in YACCS are lacking.

Interventions tailored for YACCS could focus on teaching coping skills, so that YACCS are better equipped to deal with the challenges of survivorship and the demands of development in young adulthood. The disability-stress-coping model of Wallander and Varni (1998)¹² assumes that coping, known as the way people react to stressful situations, plays an important role in adaptation to disease. The model of Wallander and Varni (1998)¹² was adapted for the current study to explain outcomes for YACCS (Figure 1). Elements from known effective therapies such as Cognitive Behavior Therapy (CBT) and Acceptance and Commitment Therapy (ACT) could be used in psychosocial interventions for YACCS, as they aim to improve coping by targeting unhelpful cognitions that elicit negative feelings and behaviors. CBT is a widely used evidence-based method that focuses on identifying and challenging unhelpful thoughts in an effort to replace them with helpful ones.¹³ Cancer specific CBT-based interventions have been developed and evaluated and found effective in the past, for example for reducing fear of cancer recurrence in adults,¹⁴ and for persistent severe fatigue in CCS.¹⁵ A recent RCT of a CBT-based online group intervention for survivors of adolescent and young adult cancers, showed that participants

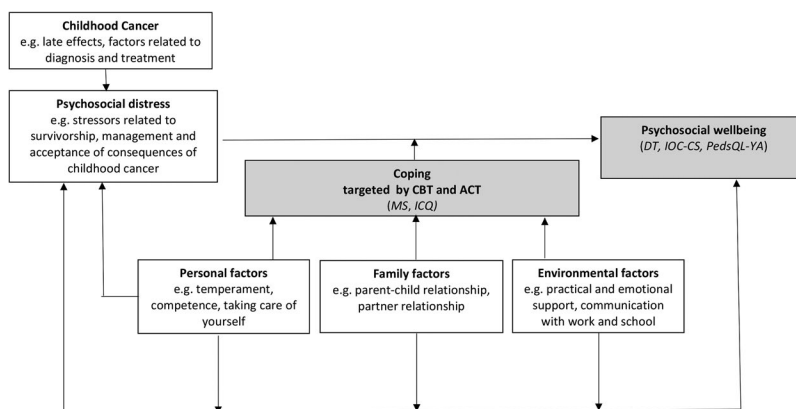


Figure 1. Conceptual model: adapted version of the disability-stress-coping model of Wallander and Varni (1998)¹² to explain psychosocial wellbeing of young adult survivors of childhood cancer. CBT Cognitive Behavior Therapy; ACT Acceptance and Commitment Therapy MS Mastery Scale; ICQ Illness Cognition Questionnaire; DT Distress Thermometer; IOC-CS Impact of Cancer – Childhood Survivors; PedsQL-YA Pediatric Quality of Life Inventory for Young

in the intervention used more CBT skills than a peer support and waitlist control group, indicating that conveying the principles of CBT is possible with such an intervention.¹⁶ ACT is a third wave CBT that focuses on acceptance of thoughts and situations to reduce the impact of unhelpful thoughts on daily life. ACT includes various techniques, such as value elicitation which encourages participants to discover and live by their values even when faced with challenges.¹⁷ Specifically, ACT could be useful for YACCS because they are confronted with situations that cannot be changed. Components of ACT can teach YACCS to cope with such situations.

E-health interventions can make psychosocial interventions more accessible and less demanding while connecting to the online world of young people today.^{18,19} It eliminates logistical barriers such as travel time and distance. These barriers apply especially for CCS because they are living all over the country.^{20,21} In addition, online therapy may be more cost-effective than face-to-face therapy, especially when delivered in a group since that allows therapists to use their time on several patients simultaneously.^{22–24} Finally, group therapy gives participants an opportunity to share experiences with peers which was previously suggested to be beneficial for mental health.^{19,25–27}

Op Koers (English *On Track*) is a program of CBT and ACT-based face-to-face and online group courses developed at the Emma Children's hospital in Amsterdam, The Netherlands. Op Koers aims to prevent and/or decrease psychosocial problems in children with chronic illness, including cancer, their siblings and parents through improving coping with current or future challenges of the illness. A Dutch chatroom intervention for adolescents and young adults with depressive symptoms, called Master Your

Mood Online, showed effectiveness in reaching the target group and in reducing depressive symptoms and anxiety.^{28,29} The first online module of Op Koers was developed by combining the technology and successful format of Master Your Mood Online with the content of the Op Koers program.

Op Koers courses have shown promise with regard to teaching coping strategies and improving psychosocial outcomes in pilot studies among various populations and in a randomized controlled trial (RCT) among children with a chronic illness and their parents.^{30–34} After adjustment of the content, to specifically fit the developmental and survivorship needs of YACCS, while using the components of CBT and ACT as in the previously developed courses, Op Koers has potential to fill the current gap in interventions for this population.

This study evaluates the first experiences with Op Koers Online for YACCS, an online group intervention, by examining feasibility and satisfaction with the content, the course leaders and the technical aspects of the intervention, and exploring preliminary effectiveness. Psycho-education, elements of CBT with influences from ACT, and peer support could help YACCS to cope with the challenges of survivorship they faced or will face in future, and prevent and/or decrease psychosocial problems.

Materials and methods

Design and procedure

This study was a pilot of the group intervention Op Koers Online for YACCS, conducted between February and June of 2019. Participants completed a set of paper-pencil questionnaires 1-4 weeks before (T0) and 1-4 weeks after (T1) the intervention to explore preliminary effectiveness. To examine satisfaction, they completed an evaluation questionnaire at T1. Additionally, the intervention was evaluated in person with the participants as part of the sixth course session and with course leaders in an evaluation meeting (Figure 2). Participants provided written informed consent and the Medical Ethical Committee of the University Hospital Utrecht reviewed this study (case number 18/256).

Participants

Participants (N=151) in a study about the psychosocial well-being and need for psychosocial support for YACCS⁸ (aged 18-30, age at diagnosis ≤ 17 years and time since diagnosis ≥ 5 years) were asked whether or not they would be interested in an online group course for YACCS. A total of 40 (opt-in rate 26.4%) reported to be interested and were invited to

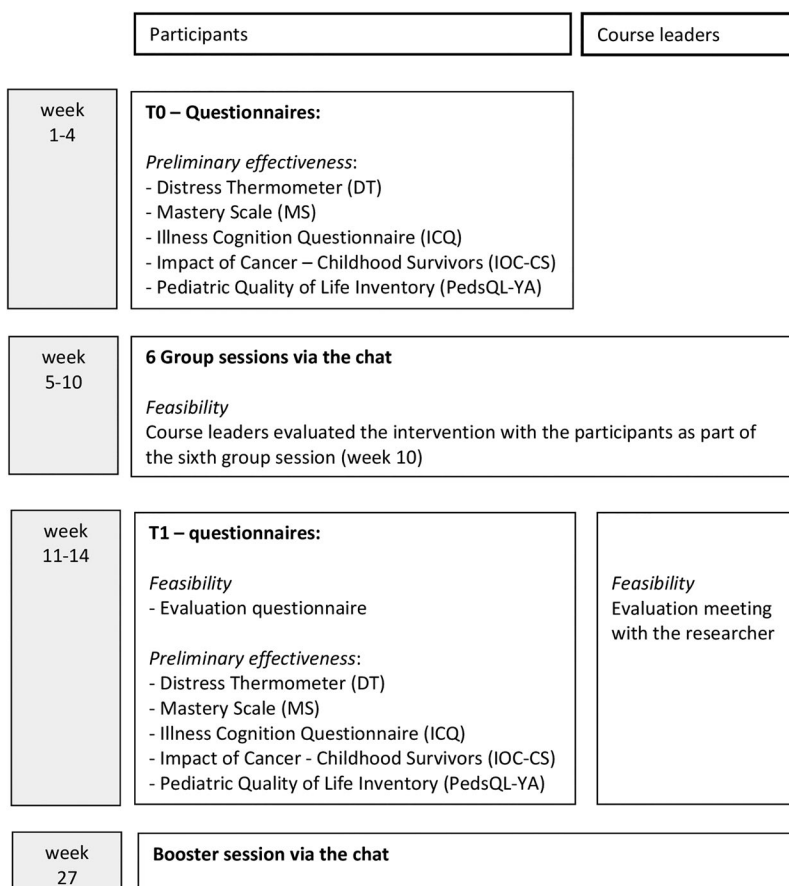


Figure 2. Design of the pilot study Op Koers Online for YACCS.

participate in the pilot study. In the end, a total of 13 YACCS wanted and were able to participate in the pilot study. Others replied they were too busy at the moment or not available at the times suggested for the intervention. A few YACCS were no longer interested to participate or did not reply.

We offered the course at two different times, one during the day and one during the evening. Three out of the 13 YACCS could not participate because the time at which the intervention groups would take place was not appropriate for them, or participation was not possible because the group had already reached the maximum group size of six YACCS. Ten YACCS were included in this pilot study (enrollment rate 25%). One group contained four and the other six participants. The researchers and/or course leaders did not intervene in the assignment of participants to groups, which was completely based on scheduling and availability of the participants.

Exclusion criteria for this pilot study were a cancer diagnosis in the past three years, current treatment for cancer, or severe psychological

problems (clinical depression, severe PTSD, etc.). These were assessed during the intake via telephone by asking “Did you receive a diagnosis of cancer in the past three years or are you currently being treated?” and “Do you currently suffer from mental health problems, or did you receive a mental health related diagnosis in the past?”. One participant mentioned a PTSD diagnosis, but no current complaints of heightened arousal, nightmares or spontaneous flashbacks. No participants were excluded as a result of the screening.

Intervention

Op Koers Online is an online group intervention aimed at teaching active coping skills, e.g. cognitive restructuring and relaxation, and providing peer contact. It has a generic approach improving coping with current or future challenges of illness and survivorship, and preventing or decreasing psychosocial problems, e.g. (health) anxiety or difficulties in (family) relationships and friendships. Op Koers makes use of the basic principles of CBT. In order to explain the basic principles of CBT, course leaders use the “thinking-feeling-doing model”, with focus on restructuring negative thoughts about the disease, e.g. opinions of others, not being able to participate in activities with peers, and thereby increasing coping skills.¹³ Furthermore, psycho-education is used (through, among others, psycho-educational texts, informative videos and group discussions), and reinforced and practiced through exercises such as role-play in the face-to-face sessions and games in the online sessions. Also, components of Acceptance and Commitment Therapy (i.e. living your values) are used.¹⁷ Finally, providing this intervention in a group of peers is expected to contribute to improving coping skills.³⁵

A preliminary outline for Op Koers Online for YACCS was based on topics from the available literature about YACCS’ challenges and their psychosocial well-being as well as on a previous study from the authors into YACCS’ need for psychosocial support.³⁶ To validate the content of Op Koers Online for YACCS, two focus groups were organized. One focus group (N=7) was held with health care providers (HCP) involved in survivorship care and with survivor representatives from the Dutch parent and survivor association. Another focus group was held with five YACCS who had participated in the previous study about need for psychosocial support. During the focus groups, the preliminary content of Op Koers Online for YACCS was presented and participants were asked to respond to the topics meant to be included in the intervention as well as to mention any topics they missed. Because the preliminary content was mostly in agreement with the input of YACCS and HCP, the course was finalized by grouping the discussed predefined topics into topics for the six sessions:

1) introduction, 2) “my body”, 3) “my family”, 4) “friendships and relationships”, 5) “school, work, future”, 6) “looking back and evaluation”.

The intervention contains six consecutive weekly 90-minute sessions, and a 90-minute booster session after three months. Sessions are led by two psychologists (course leaders). Course leaders were trained and followed a detailed manual that was reviewed by the psychosocial staff of the Princess Máxima Center beforehand.

The sessions take place in a secure chatroom. The chatroom offers no video or audio communication, in order to allow participants to take their time thinking about their response and remain anonymous. Participants (min. 3, max. 6 in a fixed group) log on to the Op Koers website (www.opkoersonline.nl) on a personal computer or laptop to see their personal environment, from which they can enter the chatroom, submit homework assignments, and view psycho-educational texts.

Each session follows a similar structure. Firstly, the group discusses their experiences since the last session. After that, the homework exercises are discussed; YACCS can share their answers or ask questions to each other or the course leaders. Then, the majority of the time is spent on the topic of the session. To discuss this topic, the course leaders ask questions about that topic to be answered by the YACCS and discussed in the group. The course leaders moderate the discussion, answer questions, and keep an eye on chats from YACCS that can be used for a teaching moment, e.g. about cognitive restructuring, relaxation, living your values. To close the session, YACCS are reminded of the homework for next week and there is time to ask questions that were left unanswered during the session.

Before the intervention, each participant had a 45-60 minute intake with one of the course leaders over the telephone. During the intake, the intervention was discussed, and also YACCS' employment and/or education and living situation, childhood cancer history, survivorship care, late effects, and coping with late effects in daily life. Also, the interviewer screened for exclusion criteria.

After each session, participants gain access to homework and psycho-educational texts, which is meant to consolidate the knowledge and skills from the completed sessions and prepare for the next session. The educational texts were composed by psychologists of the Princess Máxima Center, who had knowledge of and experience with CBT and ACT, and who were familiar with the psychosocial consequences of childhood cancer. All homework and information remain accessible for the duration of the course. [Table 1](#) provides a global overview of the topics and used therapeutic techniques, homework exercises, and psycho-educational texts for

Table 1. Overview of Op Koers Online for YACCS sessions.

Session	Topics	During session	Homework	Psycho-educational texts
Introductions + CBT-model	<ul style="list-style-type: none"> Introduction to the course, each other and the CBT-model "thinking-feeling-doing". 	<p>Cognitive restructuring:</p> <ul style="list-style-type: none"> Text and information by course leader/information screen Video "thinking-feeling-doing model" Exercises with the CBT-model <p>Peer support:</p> <ul style="list-style-type: none"> Group discussion based on questions from the course leader 	<ul style="list-style-type: none"> Practice with the CBT-model, application to self and others. Finding information 	<ul style="list-style-type: none"> The CBT-model Disability
My body	<ul style="list-style-type: none"> Physical late effects Finding information 	<p>Cognitive restructuring:</p> <ul style="list-style-type: none"> Discussing home exercises <p>Psycho-education:</p> <ul style="list-style-type: none"> Text and information by course leader/information screen <p>Peer support:</p> <ul style="list-style-type: none"> Group discussion based on questions from the course leader 	<ul style="list-style-type: none"> Coping with late effects Finding information Practice with CBT-model 	<ul style="list-style-type: none"> Late effects Reliable information Independence from parents
My family	<ul style="list-style-type: none"> Impact childhood cancer on family life 	<p>Cognitive restructuring:</p> <ul style="list-style-type: none"> Discussing home exercises <p>Psycho-education:</p> <ul style="list-style-type: none"> Text and information by course leader/information screen <p>Peer support:</p> <ul style="list-style-type: none"> Group discussion based on questions from the course leader 	<ul style="list-style-type: none"> Leisure activities with others Talking to brothers/sisters about illness and late effects Practice with the CBT-model, application to self and family members Dealing with impact of own disease on family members Complimenting others Writing "your story" Deciding when to disclose illness history Thinking error "mindreading" 	<ul style="list-style-type: none"> Impact of childhood cancer on brothers and sisters Complimenting others Thinking errors Finding distraction or relaxation
My friendships and relationships	<ul style="list-style-type: none"> Telling others about childhood cancer Impact of childhood cancer on current friendships and relationships 	<p>Cognitive restructuring:</p> <ul style="list-style-type: none"> Discussing home exercises <p>Psycho-education:</p> <ul style="list-style-type: none"> Text and information by course leader/information screen <p>Peer support:</p> <ul style="list-style-type: none"> Group discussion based on questions from the course leader 	<ul style="list-style-type: none"> Complimenting others Thinking error "mindreading" 	<ul style="list-style-type: none"> Talking about childhood cancer Friendships after childhood cancer Assertiveness Creating a common vision in a romantic relationship

(Continued)



Table 1. (Continued).

Session	Topics	During session	Homework	Psycho-educational texts
My education, work and future	<ul style="list-style-type: none"> • Support system in the context of education, work and future plans • Trouble at work/school • Reactions from others regarding childhood cancer • Contact with school or employer • Ambitions for the future 	Cognitive restructuring: <ul style="list-style-type: none"> • Discussing home exercises Psycho-education: <ul style="list-style-type: none"> • Texts and information by course leader/information screen Peer support: <ul style="list-style-type: none"> • Group discussion ACT (value-driven living): <ul style="list-style-type: none"> • Texts and information by course leader/information screen • discussing home-exercises 	<ul style="list-style-type: none"> • Writing down your support system • Difficult questions about history with childhood cancer • Practicing the CBT-model in the context of work or school • Value-driven living (ACT) 	<ul style="list-style-type: none"> • Asking for help and getting help • Looking for a job • Studying with a disability • Formulating ambitions • SMART
Looking back	<ul style="list-style-type: none"> • Complimenting each other • Looking back at course • Evaluation 	Peer support: <ul style="list-style-type: none"> • Group discussion based on questions from the course leader 	N.A.	N.A.
Booster session	<ul style="list-style-type: none"> • Looking back at course elements • Evaluation 	Peer support: <ul style="list-style-type: none"> • Group discussion based on questions from the course leader 	N.A.	N.A.

CBT: cognitive behavior therapy, ACT: acceptance and commitment therapy.

each session. For the exact content of our intervention, the manual is available on request from the corresponding author.

Measures

Satisfaction: After the intervention, an evaluation questionnaire was used to assess satisfaction with the content, the course leaders and the technical aspects of Op Koers Online. Participants were asked to give the course an overall grade (1-10). Furthermore, they were asked to indicate how much they agreed with statements on a 5-point Likert-scale, see Table 2. In addition to the questionnaire, YACCS’ input from session 6 as well as input from an evaluation meeting with the course leaders was used to find specific points for improvement.

Sociodemographic characteristics: YACCS were asked to report their date of birth, gender, marital status, number of children, employment, and educational level in a questionnaire.

Table 2. Feasibility of Op Koers Online for YACCS (N = 10).

How do you feel about the following components? %(N)					
Duration of sessions	<i>Too short</i>		<i>Good</i>		<i>Too long</i>
	10(1)		80(8)		10(1)
Number of sessions	<i>Too few</i>		<i>Good</i>		<i>Too many</i>
	60(6)		40(4)		0 (0)
Group size	<i>Too small</i>		<i>Good</i>		<i>Too large</i>
	10(1)		80(8)		10 (1)
How do you feel about the homework exercises? %(N)					
Quantity	<i>Too few</i>		<i>Good</i>		<i>Too many</i>
	0(0)		70(7)		30(3)
Difficulty	<i>Too easy</i>		<i>Good</i>		<i>Too hard</i>
	0(0)		90(9)		10(1)
Usefulness	<i>Not useful</i>		<i>Somewhat useful</i>		<i>Useful</i>
	30(3)		70(7)		0(0)
Would you recommend this course to others? %(N)					
<i>Certainly</i>		<i>Probably</i>	<i>Maybe</i>	<i>Probably not</i>	<i>Certainly not</i>
50(5)		30(3)	20(2)	0(0)	0(0)
Indicate how much you agree with the following statements %(N)					
	<i>Completely disagree</i>	<i>Disagree</i>	<i>Nor agree, nor disagree</i>	<i>Agree</i>	<i>Completely agree</i>
I could follow the sessions well	0(0)	0(0)	10(1)	40(4)	50(5)
I could express myself well in the chat	10(1)	0(0)	20(2)	30(3)	40(4)
During the sessions, I was (mostly) able to say what I wanted to say	0(0)	0(0)	20(2)	60(6)	20(2)
I found the course instructive	0(0)	0(0)	20(2)	60(6)	20(2)
Do you use something you have learned in the course in your daily life? %(N) (missing data = 1)					
	<i>Yes</i>			<i>No</i>	
	78(7)			22(2)	

YACCS: young adult childhood cancer survivor(s).

Medical characteristics: Data about the diagnosis and treatment of the initial cancer as well as recurrences was obtained from the Dutch LATER registry, which contains detailed information about diagnosis and treatment from the medical files of Dutch CCS.

Coping

Sense of control over changes in life: The Mastery Scale (MS) is a seven-item questionnaire measuring sense of control over changes in life.³⁷ Every item is a statement to which a respondent can respond on a 5-point Likert scale from 1 “totally agree” to 5 “totally disagree”. Higher scores indicate higher sense of control. A total score is calculated (5-35). Internal consistency of the MS is sufficient with Cronbach alpha .79.³⁸

Illness cognitions: Cognitions about childhood cancer were measured using the illness cognition questionnaire (ICQ). YACCS responded to 18 statements on a 4-point Likert scale to indicate how much they agreed with the statement from 1 “not” to 4 “completely”. The ICQ has three scales: Helplessness, Acceptance, and Perceived disease benefit. Higher scores indicate higher levels of the constructs (6-24). The ICQ has good psychometric properties, with Cronbach alpha ranging from .84 to .91.^{39, 40}

Psychosocial wellbeing

Distress: Distress was measured using the Distress Thermometer (DT).⁴¹ The DT is a thermometer (0-10) on which CCS can indicate their overall distress (physical, emotional, social, as well as practical). Higher scores indicate more distress. The DT is a quick screening tool that accurately identifies distress in CCS.⁴²

Impact of cancer: The Dutch IOC-CS is a survivor-specific questionnaire about perceived impact of childhood cancer.^{8,43} It includes five scales measuring positive impact and six scales measuring negative impact (Table 3). Survivors respond to statements on a 5-point Likert scale from 1 “none at all” to 5 “very much”. Higher scores indicate more positive or negative impact. The original version has good psychometric properties.⁴³ Cronbach’s alphas in a previous study with Dutch YACCS ranged from .59 to .92.⁸

Health-related quality of life: The Pediatric Quality of Life Inventory Young Adults (PedsQL-YA) measures HRQOL. The PedsQL-YA has four scales: Physical, Emotional, Social, and Work/School functioning, a total scale and a Psychosocial Summary Scale combining emotional, social, and work/

Table 3. Preliminary effectiveness: Coping and psychosocial wellbeing of YACCS after versus before the intervention “Op Koers Online for YACCS” (N=10).

	before		after		<i>t</i>	<i>Cohen's d</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>		
Coping						
Mastery scale	20.1	4.1	22.8	2.3	3.1 ^a	.8
Illness cognition questionnaire						
Helplessness	10.4	2.2	8.7	2.2	-5.1 ^b	-.8
Acceptance	18.2	3.1	19.1	3.2	1.5	.3
Perceived disease benefit	19.6	3.0	19.6	3.9	.0	.0
Psychosocial wellbeing						
Distress thermometer	5.1	2.0	3.7	2.6	-2.6 ^a	-.6
IOC-CS						
<i>Positive impact of cancer</i>						
Body/Health	3.5	.5	3.7	.5	1.6	.4
Talking with parents	3.5	1.0	3.3	1.1	-1.4	-.2
Personal growth	3.1	.5	3.2	.7	1.8	.2
Health literacy	3.5	.8	3.7	.7	1.4	.3
Socializing	3.6	1.0	3.8	.7	1.2	.2
<i>Negative impact of cancer</i>						
Life challenges	2.3	.8	2.3	.7	.0	.0
Thinking/Memory problems	2.5	.6	2.4	.6	-1.3	-.2
Financial problems	1.5	.7	1.6	.8	.6	.1
Sibling concerns	3.1	1.2	2.7	1.2	1.3	-.3
Relationship concerns	2.6	.5	2.5	.5	-1.6	-.2
PedsQL (total score)						
Physical	76.1	10.5	76.0	10.2	.0	.0
Emotional	76.9	17.9	78.1	16.7	.5	.1
Social	71.0	22.0	69.5	18.3	-3	-.1
Work/school	79.5	11.1	79.5	7.9	.0	.0
Psychosocial	76.5	17.6	75.5	17.9	-2	-.1
Psychosocial	75.7	12.3	74.8	10.4	-2	-.1

^aSignificant at $\alpha = .05$.

^bSignificant at $\alpha = .01$.

YACCS: young adult childhood cancer survivor(s). IOC-CS: impact of cancer – childhood survivors.

school functioning. Higher scores indicate better HRQOL (0-100). The PedsQL-YA has good psychometric properties and a Dutch young adult reference group is available.⁴⁴ Internal consistency of the PedsQL-YA was satisfactory ($.80 \leq \alpha \leq .92$) in a previous study with Dutch YACCS.⁸

Statistics

All statistics were performed using IBM SPSS Statistics version 26. Descriptive statistics were used to create an overview of participants' characteristics. Feasibility was assessed using attendance rates, and descriptive statistics were used to assess satisfaction.

Preliminary effectiveness was investigated by testing differences on the psychosocial outcomes (coping and psychosocial wellbeing) between T0 and T1 within respondents, using paired *t*-tests. For all tests, α was set at .05. Cohen's *d* was calculated to assess the effect size of the differences between T1 and T0. To check whether the results were confirmed by nonparametric tests, additionally, we conducted the Wilcoxon signed-rank test.

Table 4. Characteristics of participants (N = 10).

	Mean \pm SD (range)	% (N)
Socio-demographic		
Age (years)	25.1 \pm 4.5(18.3-30.1)	
Sex (female)		60 (6)
Partner		
Yes		30 (3)
No		70 (7)
Employment status		
Paid occupation		50 (5)
No paid occupation		50 (5)
Educational attainment ^a		
Low		10 (1)
Middle		50 (5)
High		40 (4)
Current education (N = 4) ^a		
Low		0 (0)
Middle		25 (1)
High		75 (3)
Medical characteristics		
Age at diagnosis	12.0 \pm 5.2 (3.8-17.4)	
Time since diagnosis	13.1 \pm 2.8 (7.2-16.4)	
Diagnosis		
Hematologic cancers		80 (8)
CNS tumors		0 (0)
Solid tumors		20 (2)
Recurrence		40 (4)
Treatment ^{b,c}		
Surgery		60 (6)
Chemotherapy		100 (0)
Radiotherapy		60 (6)
SCT/BMT		20 (2)

^aCategories: low = primary education, lower vocational education, lower and middle general secondary education; middle = middle vocational education, higher general secondary education, pre-university education; high = higher vocational education, university.

^bMore than one category possible.

^cTreatments for primary tumor and (if applicable) recurrence(s).

CNS: central nervous system.

Results

Sample characteristics

Ten YACCS (mean age = 25.1, 60.0% female) participated in this pilot study. There were two group courses, one with four and one with six participants. Sociodemographic and medical characteristics of participants are displayed in Table 4.

Feasibility and satisfaction

Attendance logs showed that of the ten participants, 90% attended at least five out of six sessions and the drop-out rate was 0%.

Results from the evaluation questionnaire (Table 2)

On average, YACCS rated the intervention a 7.6 (range 7.0-8.0) on a 0-10 scale. Most YACCS indicated that they implemented at least one thing

they learned during the course into their daily lives. YACCS most often mentioned implementing the “thinking-feeling-doing model.. Most participants would certainly (N=5) or probably (N=3) recommend the course to others. YACCS were mostly positive about their experiences with the intervention.

In terms of points for improvement, the number of six sessions was not enough according to 60% of YACCS. Also, participants were not all satisfied with the homework. Even though 70% thought that the quantity of the exercises was good, and 90% agreed that the difficulty of the exercises was good, no participants considered the exercises to be useful.

For more details see [Table 2](#).

Results from the evaluation during the sixth session

The group with six participants mentioned that there was often not enough time to discuss topics as thoroughly as they would like. YACCS indicated that to solve this problem, they would rather have had more sessions than longer sessions, as they expected that longer sessions would be unattainable in terms of energy and attention.

Results from the evaluation session with course leaders

In a separate evaluation meeting, course leaders, who were mostly positive about the intervention, agreed that a group of six was too large to thoroughly discuss certain topics. Furthermore, conversations were slower than expected, due to the fact that the group was often waiting for someone to type a message. Lastly, homework was often not completed by all participants, which made plenary discussion of the homework exercises more difficult.

Preliminary effectiveness

Participants' distress (DT, Mean_{T0}=5.1, Mean_{T1}=3.7, $p=.030$, Cohen's $d=-.6$) and feelings of helplessness (ICQ, Mean_{T0}=10.4, Mean_{T1}=8.7, $p=.001$, Cohen's $d=-.8$) reduced significantly from T0 to T1, while their self-efficacy (MS, Mean_{T0}=20.1, Mean_{T1}=22.8, $p=.013$, Cohen's $d=.8$) improved. Impact of cancer (IOC-CS) and HRQOL (PedsQL-YA) did not change significantly. See [Table 3](#) for all outcomes. The results were confirmed by the Wilcoxon signed-rank test.

Discussion

Op Koers Online for YACCS was positively evaluated by both YACCS and course leaders in this first, small pre-post-test, pilot study. Attendance was

high but the enrollment rate indicated that an online intervention does not fit all YACCS. Participating YACCS rated the intervention satisfactory in terms of their user experiences with the chat box as well as the content, and most YACCS reported that they implemented the main CBT skills in their daily lives. The pilot study showed promising results shortly after the intervention regarding distress, illness-related helplessness and self-efficacy. This could indicate that YACCS feel more prepared to deal with challenges, which fits well with the learning goals that the course aims to fulfill through the combination of CBT, ACT, peer support, and psycho-education.

Besides the significant results, a few small to medium effects that were not significant stood out: increase of acceptance, perceived positive impact of cancer on one's body and health, and health literacy, as well as decrease of concerns about the impact of cancer on siblings. These results align with the use of ACT and topics discussed during the sessions "my body" and "my family". However, to be able to draw sound conclusions about effectiveness of the intervention, results should be replicated in a RCT, with sufficient power and measuring also effects on the long term.

The preliminary, short-term results of this small pilot study are in line with the results of Op Koers Online in adolescents treated for cancer or with a chronic illness, and in their parents.^{30,31,33} Like the present study, the recently published RCT about Op Koers Online for parents, which offers CBT to another adult population in a similar manner as Op Koers Online for YACCS, found a significant decrease of helplessness. Furthermore, a significant increase of acceptance was found in parents, while the present study found a trend toward significance.

Although there was no drop-out in this pilot and attendance was high, adherence to the homework exercises was low. This is unfortunate, because the psycho-educational texts and the homework exercises are core components of CBT and low adherence could jeopardize the effectiveness of the intervention. It is a weakness of the study that we did not instruct the participating YACCS about the use of the psycho-educational reading material. Nevertheless, most YACCS reported that they used the "thinking-feeling-doing model" into daily life, indicating that repeatedly addressing CBT principles during the sessions was probably sufficient to achieve retention. This result is in line with the short-term results of a recent RCT of Recapture Life, an Australian online group intervention for survivors of adolescent and young adult cancers, showing that participants have adopted CBT-skills over the course of the intervention.¹⁶ Because of the low adherence and limited perceived usefulness, the homework exercises will be revisited while further developing Op Koers Online for YACCS.

While this study provides some important new insights, there are limitations to consider. Caution is warranted when drawing conclusions from this pilot study as there were only ten participants, who were recruited after showing interest to participate in the intervention in the questionnaire of the previous needs assessment study. Explorative comparison of the YACCS that were interested to participate to those who were not, revealed that interested YACCS reported poorer psychosocial functioning. Additionally, the prior needs assessment study found that YACCS with worse psychosocial outcomes reported more support needs.³⁶

Furthermore, there was no control group and only short term effects were measured in a small sample. Another matter of concern is the choice of the outcome measures. The operationalization of potential intervention effects into outcomes, and thereafter, finding sound measures (questionnaires), are crucial but often problematic. Therefore, a pilot study provides opportunity to explore and find appropriate outcome measures. On second thoughts, we considered it not realistic to expect short term improvement in generic HRQOL in the YACCS who participated in Op Koers. While Op Koers for adolescents with chronic illness appeared to improve HRQOL in a pilot study³⁰ and a RCT,³⁴ eight weeks and six months after the intervention respectively, we did not find improvement in HRQOL one to four weeks after Op Koers Online for YACCS. However, for future more rigorous and longer-term evaluation studies, we still consider HRQOL an important outcome.

While the study design was sufficient to answer the research questions in this pilot testing phase, further evaluation is necessary in order to draw conclusions about the effectiveness and feasibility of the intervention. While our study design could raise concerns for bias, nevertheless, the results seem to indicate that self-referral to low-threshold interventions such as Op Koers Online are appropriate for a subset of YACCS and may achieve improvement.

No CNS-tumor survivors participated, so we cannot generalize the findings from this pilot to them. Survivors of CNS-tumors are at risk for poor outcomes after childhood cancer,^{4,9,45-49} but Op Koers Online could be less appropriate for survivors with neurocognitive deficits, due to the high speed of the chat conversations at times.

Survivors in this pilot study varied from 18 to 31 years in current age and from 3 to 17 years in age at diagnosis, but we did not experience this to be a barrier in conversations between the YACCS. The content of Op Koers Online focuses mainly on experiences that YACCS have in their current life that may be related to their childhood cancer history. By centering each session around each survivor answering questions from their own experience, course leaders fostered an environment where

differences and similarities between survivors could be discussed in a safe and supportive manner.

With Op Koers Online for YACCS, we can now offer a first psychosocial intervention to YACCS receiving survivorship care in the Netherlands. The intervention fills a gap because to date no psychosocial intervention for YACCS was available in the Netherlands. Op Koers Online for YACCS made use of an existing platform and format that has previously shown positive results in various other patient populations.^{30,31,33} Researching the needs of YACCS and pro-actively asking YACCS for input have allowed us to create an intervention that matches what YACCS need and want in a psychosocial intervention.³⁶ It is important to note that Op Koers can't be classified as targeted CBT or ACT, and that an online group intervention does not fit every YACCS. Survivorship care should include a wide range of psychosocial care, so that tailored care can be delivered to YACCS.

Op Koers Online was designed as a chatroom intervention because at the time of development of Op Koers Online, video conference calls were not very common in the Netherlands. Since the first development of Op Koers Online in the early 2000s, e-health has become more popular and technological advancements have changed the way in which e-health interventions are delivered to patients. Although previous experiences with Op Koers Online as a chat box intervention were positive for most participants (e.g. anonymity), it could be time to explore more modern delivery methods such as video conferencing software or Voice over IP (VoIP). Therefore, we are now experimenting with a video call format. Notably, this pilot study took place before the COVID-19 pandemic. As the use of e-health has increased and evolved during the pandemic, Op Koers Online may now match even more closely with the demand for innovative e-health care.

Op Koers Online for YACCS shows promise, but continuous development could help make the intervention more effective and more fitting to the needs of YACCS. All points of improvement from the present study will therefore be taken along in developing the next version of the intervention. Op Koers Online for YACCS is not suitable for YACCS with severe mental health problems. Therefore, survivorship care clinics should still offer or refer to more intensive and personalized psychosocial support for YACCS.

Conclusions

The first pilot study of Op Koers Online for YACCS was evaluated positively by both YACCS and course leaders. Short term results of this small

pilot showed decrease in distress and feelings of helplessness and improvement of self-efficacy. The intervention fills a gap in psychosocial services for YACCS during survivorship care. Points of improvement for the intervention include reducing the number of participants per group, revision of the homework, and adding one or more sessions.

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Authors' contributions

Loes M.E. van Erp participated in performance of the research, data analysis, writing of the paper.

Heleen Maurice-Stam participated in research design, performance of the research, data analysis, writing of the paper.

Laura R. Beek participated in performance of the research, writing of the paper.

Leontien C.M. Kremer participated in performance of the research, writing of the paper.

Jaap G. den Hartogh participated in performance of the research, writing of the paper.

Marloes van Gorp participated in data analysis, writing of the paper.

Gea A. Huizinga participated in research design, performance of the research, data analysis, writing of the paper.

Martha A. Grootenhuis participated in in research design, performance of the research, data analysis, writing of the paper.

Conflict of interest

The authors report there are no competing interest to declare.

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Availability of data and material

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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