

# ‘It made me think a little different’ a qualitative study of young adult cancer survivors’ experiences of cognitive therapy in cancer rehabilitation.

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## Abstract

Young adult cancer survivors (YACS) have increased risk for psychosocial late-effects. Cognitive therapy (CT) aims to enhance coping in survivorship, but research of CT interventions and how YACS experience these lacks. This study’s aim was to explore YACS’ experiences of CT in a rehabilitation program. A phenomenological-hermeneutical design was used, including semi-structured interviews of 17 YACS who completed a rehabilitation program.

Two main themes and three corresponding subthemes emerged: The first theme, «CT as a tool», was elaborated by the subthemes «education and practicing», «follow-up» and «internalization». The second theme, «the perceived usefulness of CT» was clarified by the three subthemes «changed thought patterns», «insight and acceptance» and «handling a new life-situation».

The participants experienced CT as a useful tool in their rehabilitation process that changed their thought patterns and helped them getting insight and acceptance as an important basis to handle their new life-situation.

**Keywords:** Young adult cancer survivors, cognitive therapy, cancer rehabilitation, qualitative method

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## Introduction:

Young adult cancer survivors (YACS) are a small and understudied group of survivors, with specific challenges related to their vulnerable period of life, and their increased risk for morbidity and long-term effects (Albritton et al., 2006; Institute of Medicine, 2013). There is a research gap in survivorship-care for YACS, especially related to rehabilitation (Hall et al., 2012; Institute of Medicine, 2013). Cognitive therapy (CT) is seen as a promising intervention for enhancing coping and quality of life in survivorship (Juvet et al., 2009; Osborn, Demoncada, & Feuerstein, 2006), but we have no knowledge of how YACS survivors experience CT in cancer rehabilitation.

#### Previous research

Cancer in young adulthood (18-35 years) is rare (Albritton, Barr, & Bleyer, 2009; Cancer Registry of Norway, 2014), where the cancer types, the genetic, biological and physiological characteristics are unique (Bleyer & Barr, 2009; Institute of Medicine, 2013). The treatment is often aggressive, multi-modal and long lasting (Albritton et al., 2009; Bleyer & Barr, 2009). For YACS, being in a vulnerable period of life (Buchmann & Kriesi, 2011), cancer adds a tremendous burden and life disruption (Albritton et al., 2006). Cancer in YACS also includes high risks of severe late-effects, where some are life threatening as cancer recurrence, subsequent cancers, and chronic diseases (Brearley et al., 2011; Woodward, Jessop, Glaser, & Stark, 2011). Other late-effects compromise health and well-being in a long term (Woodward et al., 2011). These range from physical problems such as pain, lymphedema, infertility and fatigue (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Institute of Medicine, 2013), psychosocial problems as anxiety, depression, fear of recurrence and impaired self-esteem (Albritton et al., 2006; Zebrack, 2011), impairments in social functioning (Hall et al., 2012; Zebrack, 2011), as well as risk of educational delay and financial problems (Brearley et al., 2011; Parsons et al., 2012). Despite these impairments that seriously may jeopardises YACS's ability to move into well-functioning adulthood (Sansom-Daly et al., 2012), they report inadequate follow-ups and rehabilitation interventions (Brearley et al., 2011; Hall et al., 2012; Keegan et al., 2012).

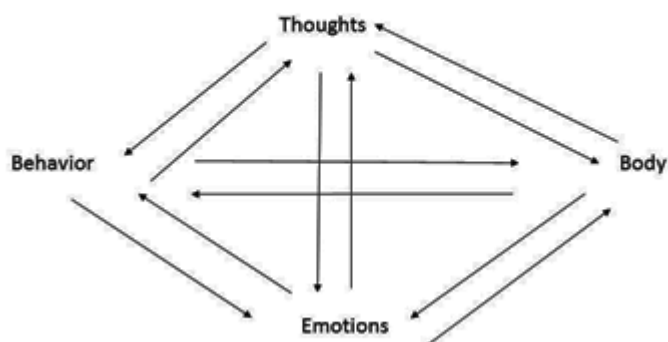
Studies of rehabilitation interventions for YACS lacks (Johansen, 2007; Juvet et al., 2009), but the two most evident effective elements in cancer rehabilitation for adults are physical activity (Speck, Courneya, Masse, Duval, & Schmitz, 2010) and different psychosocial interventions (Faller et al., 2013; Hersch, Juraskova, Price, & Mullan, 2009; Juvet et al., 2009; Osborn et al., 2006). For the latter, CT is highlighted as an important intervention, showing positive effects on coping, empowerment, self-efficacy, quality of life, depression, anxiety and fear of recurrence (Faller et al., 2013; Fors et al., 2011; Hersch et al., 2009; Juvet et al., 2009; Lebel et al., 2014; Osborn et al., 2006), as well as fatigue (Eichler et al., 2015; Gielissen, Verhagen, Witjes, & Bleijenberg, 2006). In general, the evidence-base of CT is very strong to a wide range of psychological problems (Beck, 2005; Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012), but the interventions vary greatly with respect to psychological strategies and technics, intervention content and duration. In cancer rehabilitation, CT interventions typically include education, focusing of unhelpful thoughts or behaviours as well as coping skills training (Faller et al., 2013; Hersch et al., 2009; Juvet et al., 2009; Osborn et al., 2006). The majority of these studies are quantitative, including only brief descriptions of the interventions, and it is not evident how these interventions should be designed (Fors et al., 2011). We have not found any studies elaborating how CT is experienced by cancer survivors, neither any studies of CT including YACS, indicating a research gap. In line with this, Sansom-Daly et al. (2012) state that CT is a promising, but mainly untested intervention that may equip YACS with coping skills to successfully manage their survivorship challenges.

#### Theoretical framework

Modern cognitive therapy (CT), often used synonymously with cognitive behavioral therapy (CBT), refers to a family of interventions that combine a variety of cognitive, behavioral, and emotion-focused techniques (A.Beck, 2005; Hofmann et al., 2012).

CT is based on learning- and cognitive psychology, relating on the cognitive model explaining how thoughts, emotions and bodily reactions mutually interacts (A. Beck, 2005; J. Beck, 2006). This model, also called the cognitive diamond, explains that how an individual perceives and interprets a given situation determines the feelings and behaviors associated with the event (Figure 1).

Figure 1: Illustration of the connection between behavior, thoughts, body and emotions (Cognitive Diamond).



Consequently, behaviors are influenced and determined by how an individual structure his or hers world through cognitions stored in memory as schemes, developed from prior experiences (A. Beck, 2005; J. Beck, 2006). These schemes are activated in special situations or states of mind, and will affect emotions, behavior and psychological activation. Maladaptive cognitions may thus contribute to the maintenance of emotional distress and behavioral problems. In contrast, problems can be reduced, or solved, by consciously being aware of these mutual relationships (A. Beck, 2005; J. Beck, 2006; Hofmann et al., 2012).

CT typically involves a short time, structured and present-oriented training, aiming to teach individuals to identify and moderate their negative, automatically thoughts (NAT) and maladaptive behaviors, and thus reduce emotional stress (Arendt & Rosenberg, 2012; Hofmann et al., 2012). This presupposes that the individual learn to detect and be conscious of his/hers negative, automatically thoughts (NAT), to explore and questioning misinterpretations, destructive behavior and assumptions, and then find realistic and alternative reevaluations, followed by acting as this reevaluation is true.

## Aim

The aim of this study is to explore YACS' experiences of CT in a rehabilitation program after finishing cancer treatment. More specifically, we elaborated the research question: «What experiences do YACS have in using CT in a rehabilitation program? »

## Methods

### Study design

This study is a part of a larger study of rehabilitation of YACS (Hauken, 2014). Based on the present study's aim, we conducted a phenomenological - hermeneutical research design (Creswell, 2007 ).

This design aims to explore the meaning of the lived experiences of individuals about a phenomenon (phe-

nomenology), here YACS' experiences of CT in cancer rehabilitation, and the researcher's interpretations (hermeneutics) in order to gain new insight and understanding of a phenomenon (Creswell, 2007 ; Malterud, 2011).

## Participants

YACS were invited to join the study by different websites and healthcare professionals in hospitals and in primary healthcare in Norway (Hauken, 2014). The eligibility criteria were a) YACS aged 18- 35 years, b) finished cancer treatment within the last 5 years, and c) all cancer diagnoses. An oncologist or general practitioner verified the YACS's rehabilitation need and referred them to the study. The final sample included 17 informants fulfilling the 6-month rehabilitation program. Table 1 outlines the background variables, diagnoses and cancer treatments.

*Table 1: Demographic and Medical Presentation of Study Population (N=17)*

	<b>Number</b>	<b>Mean or Percent</b>	<b>Standard Devia- tion</b>
<i>Age (years)</i>	17	31,1	3,9
<i>Gender</i>			
<b>Female</b>	12	71%	
<b>Male</b>	5	29%	
<i>Education</i>			
<b>Senior High School</b>	6	35%	
<b>University/University College</b>	11	65%	
<i>Social status</i>			
<b>Married/Cohabitate</b>	8	47%	
<b>Single/Divorced</b>	9	53%	
<i>Employment</i>			
<b>Working or Study Full Tim/part timee</b>	10	59%	
<b>Full Sick Leave</b>	7	41%	
<i>Type of cancer</i>			

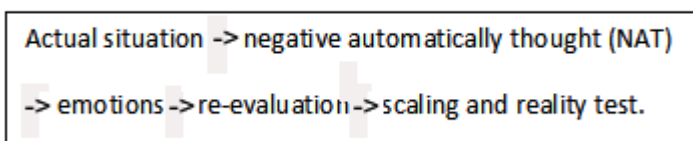
<b>Lymphoma</b>	3	18 %	
<b>Gynecological</b>	5	29 %	
<b>Breast</b>	3	18 %	
<b>Testes</b>	2	12 %	
<b>Colon</b>	2	12 %	
<b>Sarcoma</b>	1	6 %	
<b>Head &amp; neck</b>	1	6 %	
<i>Months since diagnose</i>		27,0	16,7
<i>Type of treatment</i>			
<b>Only surgery or chemo</b>	8	47%	
<b>Multimodal treatment</b>	9	53%	
<i>Months of treatment</i>		22,3	6,8
<i>Month since treatment</i>		7,3	6,3

The intervention

The rehabilitation program was structured around three weeks of residential rehabilitation with one-week follow-up after three and six months, and based on six elements: 1) individual goal-setting, 2) physical activity 3) individually follow-up, 4) peer-support, 5) psycho-education based on CT and 6) a next of kin-weekend. The intervention is described in detail elsewhere (Hauken, 2014). Here, we will only focus on the psycho-education based on CT. The psycho-education aimed to increase the participants' knowledge of survivorship-issues, and to give them tools to cope with their survivorship challenges (Faller et al., 2013; Fors et al., 2011; Luknes & McFarlane, 2004).

The YACS participated in seven 90 minutes sessions of psycho-education during their primary stay, covering topics that were particularly relevant to them. Each session included an introduction, a teaching, training and discussion-section, followed by summing up and homework. CT was used consistently throughout all sessions as a method to discover and to cope with negative thoughts, emotions and maladaptive behaviors (Arendt & Rosenberg, 2012; J. Beck, 2006), exemplified by the YACS's own experiences. The 'five-columns-scheme' was used as a practical tool for detecting and revising negative thoughts, emotions and behaviors (Arendt & Rosenberg, 2012) (Figure 2).

Figure 2: The elements in the five-column scheme



The YACS also practiced CT by writing their own challenges in the scheme as homework between the sessions. For each topic, they received corresponding readings.

Table 2 shows the specific content for each session, and homework and literature.

Table 2: Organization and content of the psychoeducation

<i>Number</i>	<i>Title</i>	<i>Content</i>	<i>Homework</i>	<i>Literature</i>
1	Get Started	<b>Intro:</b> Purpose, structure, rules <b>Illustrate &amp; present:</b> Who am I? What am I good at?	Setting goals: short term & long-term	Introduction to Cognitive Therapy (CT), Wilhemsen: "Boss in your own life", Chapter 1-3
2	Basis of Cognitive Therapy	<b>Intro:</b> Summing up from session 1 & homework <b>Teaching &amp; discussion:</b> Intro to CT, The Cognitive Diamond & ABC tool	Use ABC on one of the main topics and identify thoughts and attitudes	Wilhemsen: "Boss in your own life", Chapter 10
3	Education and Work	<b>Intro:</b> Summing up from session 2 & homework <b>Teaching &amp; Discussion:</b> Education and Work related to cancer, rights & possibilities	Use ABC related to own situation regarded study/work	Norwegian Cancer Society: "Rights for patients and relatives"
4	Thoughts and Emotions	<b>Intro:</b> Summing up from session 3 & homework <b>Teaching &amp; discussion:</b> Coping of physical and psychosocial late effects & use of CT	Use ABC related to own situation regarded coping/negative thoughts and emotions	Wilhemsen: "Boss in your own life", Chapter 10
5	Exercise and Physical Activity	<b>Intro:</b> Summing up from session 4 & homework <b>Teaching &amp; discussion:</b> Physical activity & fatigue after cancer treatment. Benefit of physical activity, how & what to exercise (stepwise)	Use ABC related to own situation regarded to physical activity	Norwegian Cancer Society: "Physical Activity After Cancer Treatment"
6	Me and my Network	<b>Intro:</b> Summing up from session 5 & homework <b>Teaching &amp; discussion:</b> Network. Illustrate & present: «Who are in your network?» Cohabitation and sexuality related to cancer	Use ABC related to own situation regarded network/sexuality	Norwegian Cancer Society: "Cancer and Sexuality"

7	The Way Ahead	<p><b>Intro:</b> Summing up from session 6 &amp; homework</p> <p><b>Teaching &amp; discussion:</b> Summing up on theme 1 – 6. What learnt? What to bring with you? Goal achievement – short time</p>	Information on re-stay	
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The second author, an experienced physiotherapist, specialized in CT, led the psycho-education. In addition, specialists in the different topics conducted the lectures. At the follow-up visits, the participants got one 90 minutes session using CT each week, focusing on their experienced challenges at home. Altogether, the structured psycho-education and CT counted for approximately 15 hours.

### Data collection

The first author collected all data by in-depth interviews at the end of the rehabilitation program. A semi-structured interview guide with open-ended questions was developed to ensure consistency related to the YACS' experiences of CT in the rehabilitation program (Creswell, 2007 ). The main question in the guideline was: "Can you please tell me how you have experienced using CT in this rehabilitation program?" Follow-up questions were related to the different elements of the content and duration of CT, if and how the YACS had used CT, as well as their total experience. The interviews lasted for 45- 70 minutes, and were digitally recorded and transcribed by the authors.

### Analysis

Systematic Text Condensation (STC), a four-step cross-case analyses, was used to analyze the data (Malterud, 2012). However, analyses of qualitative data is not a straight forward process, but engage the researchers in processes moving in analytical (hermeneutical) circles including several facets of analyses (Creswell, 2007 ). Both authors analyzed and coded the transcribed data separately to enhance validity, and then discussed and performed the rest of the analyses together (Creswell, 2007 ; Malterud, 2012).

Following the steps in STC, we first read the interviews to obtain a general impression. The general impression revealed that the YACS emphasized different facets of using CT. Second, we re-read the interviews and extracted units of meaning. We used NVivo 9 software package to code and sort data. In this process, we extracted six codes. Third, these codes were condensed into groups and subgroups during an analytic circle between the identified codes, the transcribed interviews and discussions. We concluded with two main units of meaning or themes: "CT as a tool" and "The perceived usefulness of CT". Further analyses revealed that the two meaning units had three subgroups each. Finally, we validated the analyses by comparing the findings against the interviews to ensure that we had captured the informants' expressed and intended meanings. All interpretations reached consensus. We summarized by using direct statements. Table 3 outlines the analyses process.

*Table 3: Overview of the STC analyzes process*

<p><b>STEP 1:</b> Getting a total impression</p>	<p><b>STEP 2:</b> Identifying meaning units</p>	<p><b>STEP 3:</b> Abstracting the contents of individual meaning units</p>	<p><b>STEP 4:</b> Summarizing of findings</p>
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<p><i>Process:</i> a) The authors read the transcribed interviews separately b) Discussed the total impression to consensus</p>	<p><i>Process:</i> a) The authors coded the data separately b) Discussed the codes to consensus within the codes</p>			<p><i>Process:</i> a) The authors analyzed the contents separately b) Several discussions to consensus</p>	<p><i>Process:</i> b) The authors discussed the findings against the transcribed interviews c) Each author found direct statements to elucidate units of meaning and discussed to consensus</p>																				
<p><b>Identified total impression:</b></p>	<p><b>Identified meaning units:</b></p>			<p><b>Abstracted contents/themes:</b></p>	<p><b>Summarizing:</b></p>																				
<p>CT used consciously and unconsciously Different elements: - education - process over time - internalization - practical use/effect</p>	<table border="1"> <thead> <tr> <th><i>Code</i> *</th> <th><i>Source</i> **</th> <th><i>References</i> ***</th> </tr> </thead> <tbody> <tr> <td>Used CT/not used CT</td> <td>17</td> <td>42</td> </tr> <tr> <td>Use of CT/applications</td> <td>17</td> <td>27</td> </tr> <tr> <td>Changed thought patterns</td> <td>14</td> <td>36</td> </tr> <tr> <td>Perceived change</td> <td>13</td> <td>69</td> </tr> <tr> <td>Education</td> <td>14</td> <td>40</td> </tr> <tr> <td>Tools</td> <td>13</td> <td>25</td> </tr> </tbody> </table>	<i>Code</i> *	<i>Source</i> **	<i>References</i> ***	Used CT/not used CT	17	42	Use of CT/applications	17	27	Changed thought patterns	14	36	Perceived change	13	69	Education	14	40	Tools	13	25		<p>1. <i>CT as a tool</i> Subthemes: -education and practicing -follow-up -internalization</p> <p>2. <i>The perceived usefulness of CT</i> Subthemes: -changed thought patterns -insight and acceptance -handling a new life condition</p>	<p>Summarized findings and presenting direct statements within the abstracted contents</p>
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\*Code: Identified meaning units

\*\* Source: Number of informants talking about the code (N = 17)

\*\*\* References: Number of quotes related to the code

## Ethics

The Western Norway Regional Committee of Research and Ethics, and The Norwegian Social Science Data



Services (NSD) approved the study. We followed their guidelines throughout the study. The YACS got written and verbatim information about the study, and all participants gave written consent.

## Findings

The aim of this study was to explore how YACS' experienced CT in a rehabilitation program. The analysis revealed two main-themes: «CT as a tool» and «The perceived usefulness of CT». Both themes had several facets, and three sub themes emerged as important elements within each theme.

Main theme 1: «CT as a tool»

Most YACS experienced that CT was a useful tool in their rehabilitation process, exemplified by these quotes: «In fact, it is a very good tool. Yes, at least it has learnt me a lot. And I will continue to use it.» (P 19), and «I think it has been a tool. I dare not think about it if I had not been here...» (P 7). Even those few who did not see CT as a useful tool for themselves, still acknowledged it as a suitably tool for others. However, the YACS highlighted that you cannot use a tool without learning how to use it. The analyses revealed that «CT as a tool» was dependent and elaborated by the three subthemes «education and practicing», «follow-up» and «internalization» which described important elements of this learning process.

### “Education and practicing”

The majority underlined that the use of CT as a tool was dependent of education and practicing to understand how it worked: «Because you get a tool...and you have to learn how to use it. This requires practicing.» (P 6).

The basic knowledge of the cognitive diamond, and how negative automatic thoughts (NAT), emotions, bodily reactions and behavior were connected, was very important: “It helped a lot... And to have the facts, how it works and to have the knowledge...I have realized that knowledge is good and can help me a lot on my way to a life...” (P 20).

Additionally, the participants underlined that using their own and others “real life” examples and write these in the «five- columns scheme» during the sessions, was an important way to acknowledge the relevance of CT into their own life situation. The scheme was experienced as a practical tool in the learning process, helping them to grasp the structure of how to use CT. However, several participants found it difficult to formulate and write their problems on their own as part of their homework: «It is most just thoughts .... I have tried to write it down, but [I] do not get it formulated so....» (P 20) and «To write it down, then I just felt a bit lame» (P 13).

As a part of the learning process, the participants also got readings related to the actual topic as homework, but the YACS experienced these differently. Some expressed that the readings filled out the education and practical training in the sessions in a good manner, while others had trouble in concentrating and called for less and more specified literature related to their situation: «Related to the book, then... I think a lot of us read it, but reading page up and page down...I think it do not give the right understanding. ....Shorter and easier perhaps...» (P 6).

Summing up, learning to use CT seem to be dependent of an introduction of the basic elements in CT, how the cognitive diamond work, as well as an introduction of the “five-column scheme”.

Furthermore, practicing CT by using the YACS' own challenges, as examples seem to be important. The initial practicing by writing their own challenges at home as well as comprehensive readings seemed to be more challenging.

### «Follow-up»

The majority experienced that learning to use CT was a process in need of time and follow-up. The YACS stated that the knowledge had to be internalized, where training and focus over time was essential: «...It has to

be followed-up over time if you shall learn to use CT. You have to have some time to let it sink in» (P 4). In contrast, a few participants did not like this focus over time because they found it difficult to “open up” and be confronted with their own challenges: «I did not want to ...dwell a lot with it... and puh...go through those [difficult thoughts]» (P 8). Still, these participants acknowledged that this was necessary to be able to cope with their present challenges: «I found it very useful to be forced to..., yes, to deal with it myself. To address issues and work constructively. » (P 8)

The YACS had only one session of CT on each of their two re-stays, focusing on their experiences at home. These challenges were guided on by using the “five-column scheme”: «I used my problem as an example in CT, so then I got to think of it in a different way» (P 13). However, several informants called for more CT sessions at the re-stays: «You need some time, even if it is very simple. It is not as if you need many hours to understand what it is. You just need practice and maybe more time on the re- stays...I would like to have even more focus on this way of thinking. Not just focus, but more follow- up» (P 13).

Some participants found it difficult to share their problems openly in the group, especially related to sexuality and fertility problems, and thus needed more individual follow-up.

Summing up, learning to use CT as a tool seem to be a process over time in need of continuously repetition and professional follow-up.

#### **«Internalization»**

«Internalization» emerged as the third subtheme in using CT as a tool, describing how the participants eventually internalized CT in different ways. The majority worked with CT in line with the program by first writing down actual examples, before they eventually freed themselves from the scheme. At the end of the program, most of the informants expressed that they had internalized CT and used it more or less automatically: «Now I do not write, I wrote in the beginning, but now I think. To say it in a simple way, I try to think alternatively» (P 2) and «I use it, have internalized it. I have practiced on myself, inner training I guess» (P 4).

Some participants expressed that they had CT back in their minds, but did not use it consciously. In contrast, some YACS used CT consciously and still wrote down their challenges: «Mmmmm, I write too ....on the scheme, because at a certain point I discovered that I really thought negatively about myself, that I did not COPE...» (P 17).

Summing up, the majority of the participants had learned to use CT, and still used it, at the end of the rehabilitation program, even if they had internalized it at different levels. However, the degree of internalization of CT seemed to be connected to which, and the degree of, survivorship challenges they experienced.

#### **Main theme 2: «The perceived usefulness of CT»**

The «The perceived usefulness of CT» emerged as the second main theme. In general, all the YACS expressed that CT was useful in their rehabilitation process. They described several aspects of this usefulness, elaborated in the three subthemes: «changed thought patterns», «insight and acceptance» and «handling a new life condition».

#### **«Changed thought patterns»**

The majority of the participants expressed that CT had changed their way of thinking, by being able to discover and be aware of their own NAT: «At least, now I take myself in thinking wrong....Yes, automatic thoughts that comes, and then I take myself ...» (P 13). The most frequent mentioned NAT were related to fatigue, sexuality and fertility issues, follow-up, and cancer recurrence. The YACS underlined that CT not necessarily was an easy way to solve their challenges, because some problems were very realistic as for example physical alterations, fertility problems and risks for cancer recurrence. But identifying NAT still seemed to be a prerequisite to be able to change their thought pattern and handle the situation in a more appropriate way: «I think that I

have learned [to use] CT and that has lifted me up from....I was quite down when I came in January dealing with my grief [being infertile]. I feel that I have got a lot of help from it...at least up to certain level». (P 3), and «Now, I can recognize them [NAT], but I have to work a lot more with them.....» (P17). This work was especially related to reevaluation of NAT, and finding alternative interpretations. Through this process, several participants told that their levels of anxiety, concern and even physical symptoms were eased: «I used it when I was going to the follow-up... The difference is that you in a way can try to.... You can in a way turn your thoughts.... That you... Why are you so nervous and....to think a little bit more....That I try to not worry about things I cannot do anything with» (P9).

#### **«Insight and acceptance»**

Most YACS expressed an increased insight and acceptance of their own situation through the CT and psychoeducation. This was important in order to process what they had gone through during the treatment: «Yes, it must have helped while instead of trying to repress the whole situation; I have rather tried to accept it and just...let it be» (P 11). By being more consciousness of their own thought patterns, some YACS discovered that they had “placed a lid over” their present situation, and that CT and the increased insight made room for «open the lid» - even if this was difficult: «Yes, I do not think the lid is as closed anymore. However, it is difficult, because I cry a lot more than I did before.” (P 17).

The YACS expressed that they were «normalized» through the psychoeducation, using CT and sharing their own experiences and challenges with others. This «normalization» also contributed to an increased insight and acceptance of their present situation: «To be able to process these thoughts and feelings while being here....That’s when you have had the time thinking properly. The thoughts still are there afterwards, but to be reassured that you are not alone thinking like that...» (I 19). Through this process, several participants expressed that they had regained some of their former security and self-esteem, even if this had been a long and demanding process for some: «I now manage to have the right focus and to avoid negative thoughts... And gradually, yes, you just work steadily with the stuff and reminding that you shall reach the goal, and then you manage.....Yes, it is simply the self-esteem. Because, the negative and the bad stuff in your head then in a way becomes weaker and weaker» (P 5).

#### **«Handling a new life situation»**

By using CT, and being able to detect NAT and the increased insight and acceptance, «handling a new life situation» emerged as the third subtheme of how the YACS used CT. For most participants, the cancer treatment had caused extensive changes in their present life-situation. Especially, fatigue led to an extensive decrease in their capacity to participate in different areas of life. To cope with and accept this situation, handling the fatigue was crucial, where CT seemed to be an important tool: «CT has helped me to realize that my fatigue is not that un-normal» (P8). By understanding that it was not realistic to have the same levels of activity as before, several participants expressed that CT was a useful technic to correct their own requirements and to discover their own coping capabilities. «I have learned that I have to listen to my body... and (sighs)... and not set too high standards for myself, but it takes time...and THAT is something I have learned during this rehabilitation....[ I have] LEARNED a lot of myself.....and got more self-secure while I can SEE that I can cope....» (P 19).

For all the YACS, it was very important to be able to participate in work/studies after a long sick leave. Several used CT to be realistic and adjust their plans in accordance to their new life situation. Here, follow-up and guidance seemed to be essential as well: «Yes, that someone.... pointed out my direction, and that I in fact ought to scale down my work and have a greater focus on myself and not that conscience... That was the most important part» (P 12).

Handling everyday life also included restarting «normal» activities as for example their social life, but several participants experienced anxiety and NAT in this process. Here, CT seemed to help them to reduce their anxiety.

ety level and to handle different everyday situations: «I have not as much anxiety. Mmmm...I strived a lot with negative thoughts...or I didn't know how to handle situations» (P 18).

Summing up, the YACS found CT useful in several ways, where detecting NAT and changes in thought patterns were especially important. Together with the psychoeducation, and the discussions with the other YACS, it seems that CT helped them to get insight and acceptance of their present situation, and thus handle their new life-situation in a more constructive way than before.

## Discussion

The purpose of this study was to explore YACS' experiences of CT in cancer rehabilitation. The findings show that the participants experienced CT as a useful tool, dependent of education, practicing and follow-up before it could be internalized. Additionally, the YACS perceived that CT was useful in their rehabilitation process, as it changed their thought patterns, helped them to get insight and acceptance of their present situation, and thus handle their new life-situation. This is one of the first studies of a CT intervention targeting YACS, and in our knowledge, the first study to explore the learning process of CT and the perceived usefulness for YACS.

### Using CT needs education, practicing and professional follow-up

The first important message is that the YACS experienced and acknowledged CT as an important tool in their rehabilitation process. This is in line with Sansom-Daly et al's (2012) assumption that CT may equip YACS with coping skills to handle their survivorship issues, as well as studies of older cancer survivors where CT has shown positive effects of several survivorship challenges (Faller et al., 2013; Gielissen et al., 2006; Osborn et al., 2006). This is also in line with the theory of CT to promote self- help and being a tool that individuals can use in challenging situations (A. Beck, 2005; J Beck, 2006).

We have found no other studies on how cancer survivors learn to use CT, and our findings give important knowledge into this process. The YACS expressed that the education and practice along with repetitions and follow-up were crucial elements in internalizing and using CT. Especially, the knowledge to understand the cognitive diamond and the connections between thoughts, feelings, behavior and body was crucial. Supporting this, J. Beck (2006) states that it is by understanding these connections, that the individual is able to solve or reduce their problems. Likewise, Luknes and McFarlane (2004) state that knowledge is essential to cope with one's own situation.

The results revealed that education in itself was not sufficient to learn to use CT. The YACS highlighted that practicing and using their own examples were essential in the learning process, as this helped them to acknowledge the relevance of CT into their situation. Accordingly, Osborn et al (2006) and Sansom-Daley et al (2012) found that targeting specific problems in such interventions more likely bring positive outcomes. Using their own examples, the YACS also expressed that the five- column scheme was a practical tool and important to understand how CT worked. A clear goal in using the five column-scheme is to detect negative thoughts and feelings and to clarify the connection between these (Arendt & Rosenberg, 2012; J. Beck, 2006).

According to literature (Arendt & Rosenberg, 2012), the YACS got homework between the sessions to stimulate the learning process. However, several participants found both the writings and readings difficult. This may be due to overload, based on their fatigue and subsequent difficulties in concentrating as described in other studies (Campos, Hassan, Riechelmann, & Del Giglio, 2011; Smith et al., 2013). The readings also seemed to be too comprehensive and not enough tailored to their needs. These results indicate that it is not easy to learn CT by yourself, and that homework should be initiated gradually, not be too comprehensive, and more directly tailored to the YACS' situation.

The participants also highlighted that learning CT was a process over time in need of professional follow-up.

This is in line with other studies indicating that CT interventions have to involve more than 6 sessions and last for more than 3 months to achieve positive outcomes (Faller et al., 2013; Juvet et al., 2009; Osborn et al., 2006; Sansom-Daly et al., 2012). However, the participants need for follow-up seemed to vary. Some found that the follow-up in the program were sufficient, while others called for more follow-up, - especially at the re-stays. The YACS need for follow-up seemed to be connected to the degree and privacy of their challenges. Some participants felt not comfortable sharing their challenges within the group, but preferred to discuss them with a therapist in privacy. In line with this, the literature underlines the importance of addressing cancer survivors' individual needs as these are multidimensional and may vary greatly (Brearley et al., 2011; Hall et al., 2012; Institute of Medicine, 2013). However, the literature also illuminate that group based interventions are important in providing positive effects on psychological health and coping, as it promotes social support and positive impact of cancer survivors knowledge about their illness (Austvoll-Dahlgren, Nøstberg, Stensbekk, & Vist, 2011). These results highlights that the program perhaps should have included a few more structured CT sessions on the re-stays, but that the combination of the group sessions and offers of individual follow-up seems to be important.

Even if the results from the subthemes "training" and "follow-up" indicate some areas for improvements, the results show that the majority "internalized" CT as tool. However, the degree of internalization varied from using it "by the book", to internalized it in their ordinary way of thinking, while other just bared CT in their minds. This indicates that the majority got enough knowledge and practice to use CT as a tool in their rehabilitation process. In line with these results, previous research has shown that education and training in using coping tools are important and useful elements in rehabilitation (Luknes & McFarlane, 2004). These results are also in line with theory of CT, stated to be a tool to increase the individuals' understanding and handling their own situation (Arendt & Rosenberg, 2012; A.Beck, 2005; J. Beck, 2006).

### The perceived usefulness of CT

The second important message from this study is that the YACS experienced that CT had been useful in several ways in their rehabilitation process.

First, the participants expressed that learning to use CT had changed their thought patterns. Here, they expressed that the most important element was to be aware of and to recognize their own negative thoughts (NAT). This result is consistent with theory of CT, pointing out that to discover and be conscious of negative thoughts as a vital element in changing thought patterns and thereby cope with challenging situations (A. Beck, 2005; J. Beck, 2006). This may be special important for YACS in order to cope with survivorship, as they have limited life-experiences and are fronting an unsecure future with potential health risks (Buchmann & Kriesi, 2011; Institute of Medicine, 2013). By discovering their own NAT, the participants expressed CT was a way to rethink and change NAT, and thereby be better able to handle their present challenges. This result support theory of CT, stating that maladaptive cognitions may contribute to maintenance of emotional distress and behavioral problems, while problems can be reduced or solved by consciously being aware of these mutual relationships (Arendt & Rosenberg, 2012; A. Beck, 2005). The YACS especially experienced that CT was useful related to fatigue, fertility problems, anxiety, follow-ups and fear of recurrence. These are common problems reported by YACS, all with potential seriously to jeopardize their health and wellbeing (Hall et al., 2012; Institute of Medicine, 2013; Woodward et al., 2011). In line with our results for YACS, previous research of older cancer survivors have demonstrated to be efficient for similar problems (Eichler et al., 2015; Faller et al., 2013; Gielissen et al., 2006). Other researchers support this, for example Lebel et. al. (2014) who found that group-based CT decreased cancer survivors' fear of recurrence. However, the YACS stated that CT did not change their "real life" challenges as for example infertility or fear of recurrence, but helped them to cope and come to turn with these in a better way. In line with this, CT is about realistic and appropriate thinking, and not a way of "positive thinking", as unrealistic thinking may reduce the individual's ability to cope with the actual problem (Arendt & Rosenberg, 2012; J. Beck, 2006). In contrast, CT aims to seek alternative thoughts and

solutions on perceived and actual challenges (Arendt & Rosenberg, 2012).

Second, the YACS experienced that the psychoeducation equipped them with an insight and acceptance of their present situation. As for most CT intervention for cancer survivors (Faller et al., 2013; Hersch et al., 2009; Juvet et al., 2009), this study included education in both theory of CT and issues specially relevant for YACS, focusing of unhelpful thoughts or behaviours as well as coping skills training (Faller et al., 2013; Hersch et al., 2009; Juvet et al., 2009; Osborn et al., 2006). The YACS expressed that using CT in this process, “forced” them to reflect over different issues. By being concious about the connections in the cognitive model, made room for an insight and acceptance of their present situation. The individual’s experiences of being able to affect and change their own NAT and thereby cope with their own challenges, is a basic goal in CT (A. Beck, 2005; J. Beck, 2006). In particular, a normalization of their present situation, feelings and thoughts, seemed to be important.

Since the challenges of cancer survivorship in general are unknown, other studies highlights that discussions with other survivor-peers are important in processing experiences and gaining understanding, as well as legitimization and normalizing of their situation (Hansen & Tiernhoj- Thomsen, 2007; Mattson, Demshar, & Daly, 2013). However, as the YACS’ challanges could be very sensitive, severe as well as quite realistic, this demonstrate the importance of experienced and knowledgable professionals to facilitate the session. In line with this, several researchers state that positive effects of CT are dependent on skilled professionals who are able to address cancer survivors multidimensional needs (Faller et al., 2013; Hofmann et al., 2012; Osborn et al., 2006).

Third, the results indicate that the YACS experienced that CT changed their thought pattern that provided an increased insight and acceptance of their present situation, and was thus an important tool in handling their new life situation. Previous research has shown that cancer often represent a serious life disruption, and that YACS are not well prepared to survivorship, lacking information, follow-up and rehabilitation interventions (Albritton et al., 2006; Hauken, Larsen, & Holsen, 2013; Institute of Medicine, 2013). YACS ask for tools to handle their life situation (Albritton et al., 2006; Institute of Medicine, 2013), and in line with research of older cancer survivors (Hofmann et al., 2012; Juvet et al., 2009; Osborn et al., 2006), it seems that the YACS experienced that CT represented such a tool. In particular, CT seemed to help them to normalize their life, for example related to anxiety and self-esteem, but also in making realistic judgements in how to return to work and studies, based on their reduced capacity. Here, several YACS experienced CT especially useful in their reality orientation, and being able to cope with the discomfort they experienced by having to adjust and change their own demands and goals. CT builds upon that individuals structure their world through cognitions based on previous conceptions and experiences stored in their mind, explaining why new challenges can be difficult to handle. By using CT, the goal is to understand and see these connections in order to reduce the stress.(J. Beck, 2006).

Even if the results gives new and important knowledge of the learning process of CT and how the YACS used CT in multiple ways, this study has some limitations. Because of its qualitative design, it includes a relatively small sample from which findings cannot be generalized to the broader population of young adult cancer survivors (Creswell, 2007 ). Enrollment in this study was biased toward self-selection into the rehabilitation program, and with an underrepresentation of men and the youngest age group (18-23 years). A significant strength is, however, the enrollment of a diverse population of informants across the country, with varying backgrounds, life circumstances, and cancer diagnoses, age at diagnosis, cancer treatment, and duration of survivorship. Despite these limitations, the common themes were consistent, suggesting that we captured a valid sample of the experiences of using CT in a rehabilitation program directed to YACS that may help direct both future research and clinical practice.

## Implications clinical practice and recommendations for further research

The results indicate that CT can be an important tool for YACS to handle unmet needs and survivorship challenges. However, being able to use CT seems to be dependent of education by professionals, where understanding of the cognitive diamond, use of the five-column scheme, relate CT to the YACS' own examples, as well as follow-up over time seem to be important factors in the learning process. Group-based education, discussions and follow-up may provide normalization, but based on the degree and sensitivity of the problems, individually sessions may also be necessary.

Further research is necessary, both related to larger RCT studies examining the effects of using CT in rehabilitation of YACS, as well as exploring the content of CT to optimize and develop CT intervention for YACS further.

## Conclusion

This study reveals important information about the unique experiences of how YACS experience CT in a rehabilitation program, an issue that has not been explored before. Most importantly, the findings indicate that the YACS experienced CT as a useful tool in their rehabilitation process. This was, however, dependent of adequate training where a combination of education, practicing, connecting CT to YACS's own challenges, as well as professional follow-up where important factors before CT could be internalized. Additionally, the YACS found CT useful in their rehabilitation process, as it changed their thought patterns and helped them to get insight and acceptance of their present life situation, as well as handling their new life-situation. Even if these results cannot be generalized, they suggest that CT could be an important tool for YACS to handle important survivorship challenges, and further research is highly warranted.

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