

# **"The cancer treatment was only half the work!"**

A mixed-method study of rehabilitation among young adult cancer  
survivors

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Dissertation for the degree philosophiae doctor (PhD)  
at the University of Bergen

2014

Dissertation date: 06.01.2015

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Year: 2014

Title: «*The cancer treatment was only half the work!*»

A Mixed-Method Study of Rehabilitation among Young Adult Cancer Survivors

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Print: AIT OSLO AS/University of Bergen



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BACK TO EVERYDAY LIFE:

*«I'm traveling alone»*



“Discharged from hospital. The longest road is the one that comes next and you have to walk it yourself” (Participant 1)

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## ACKNOWLEDGEMENTS

Several institutions and individuals provided vital contributions during the writing of this thesis. My sincere gratitude goes to:

- The Red Cross Haugland Rehabilitation Centre (RCHRC) and its director, Inger Johanne Osland, the Department of Health Promotion and Development (Maurice Mittelmark/Elisabeth Fosse) and the Faculty of Psychology, University of Bergen. Thank you for giving me this opportunity and for providing me with a positive and stimulating work environment.

- The RCHRC, Eckbos Legat via the Red Cross Haugland Research and Development Centre, and the Norwegian Cancer Society for their generous financial support of this project.

- The participants in the study, for letting me into your lives and sharing your experiences. You have all affected me deeply!

- The interdisciplinary team at RKHR who performed the intervention by employing their excellent skills combined with human warmth and dedication to the patients. Special thanks to Kari Fismen who coordinated the project so wonderfully and with a positive attitude and an extensive work capacity. Thank you for sharing your profound experiences, for all the discussions and the fun times!

- The invaluable assistance of my supervising team, who complemented one another in a wonderful way. My efficient primary supervisor, Torill Bogsnes Larsen and her analytical way of thinking; her skills in qualitative analysis and methods, as well as health promotion has been vital contributions to this work. My co-supervisor, Ingrid Holsen, has in her gentle way provided me with vital guidance and support in the area of quantitative methods and statistics, and within the subject of theory regarding young adulthood. My other co-supervisor, Eirik Fismen, also provided important contributions based on his knowledge and extensive experience in the area of cancer rehabilitation; his ability to combine the abstract and practical aspects of rehabilitation, and his everlasting focus on human potential instead of limitations has been invaluable to me. I thank you all for your kind support, for answering my odd questions, for challenging me and making me move out of my comfort zone, for all our

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interesting and fun discussions, and all the encouragement you provided along the way. I have learned so much from all of you!

- The research groups SIPA and RKHR, as well as my research school GIGH. These groups have provided me with valuable insight regarding different aspects of the research process, as well as interesting discussion partners, which I valued highly.

- To Kari Dyregrov and my co-workers at Center for Crisis Psychology, thank you for the valuable support you gave me in finishing the synopsis. I feel so lucky working with all of you!

- To all my friends for their continuous support and providing me with enjoyable time-outs from work. Special thanks go to Astrid and Tord Hagen, Torill Skogseth and Jan Erik Endresen, who followed me through the ups-and-downs of this process, always supporting, helping and putting things into perspective. You all have a special place in my heart!

- Finally, and most of all, I want to thank my family: my most deep-felt gratitude goes to my parents, Kirsten and Erling, for their everlasting love, optimism, care and support. I dearly appreciate the love of my life, Morten, for his optimism, unwavering support and everlasting patience, love and belief in me. Thanks for all the enjoyable and valuable moments, and for sometimes making me focus on other things than work. Gratitude is also given to our two wonderful sons and daughter in law: Mathias, Marius and Helene. Thank you for help, for being there, bringing love and joy into my life and letting me be a part of your journeys, too. I feel very lucky to have you all in my life and I will love you all forever!

Bergen, August 2014

May Aasebø Hauken

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## SCIENTIFIC ENVIRONMENT

The PhD candidate has been employed at Red Cross Haugland Rehabilitation Centre, where the data were collected. Throughout the period, the candidate was associated with the Faculty of Psychology, Department of Health Promotion and Development (Hemil) at the University of Bergen.

The candidate was associated with the research group “Social Influences and Processes in Adolescent Health” (SIPA) at the Hemil. Additionally, the candidate was connected to an interdisciplinary research group at Red Cross Haugland Rehabilitation Centre.

The doctoral training was conducted at the research school “The Graduate School of Human Interaction and Growth” (GIGH) at the Faculty of Psychology, University of Bergen.

PhD Torill Bogsnes Larsen at Hemil was the main supervisor. PhD Ingrid Holsen at Hemil and MD/specialist in Physical Medicine and Rehabilitation Eirik Fismen were co-supervisors.

Haugland International Research Centre, generously supported by grants from Eckbos Legat, the Norwegian Cancer Society and Red Cross Haugland Rehabilitation Centre funded the project.

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## ABSTRACT

Young adults (18-35 years of age) are a small and understudied group of cancer survivors. Increasingly, research demonstrates that this population is at higher risk of physical and psychosocial late-effects and morbidity than younger and older cancer survivors. Nevertheless, their special needs regarding survivorship are poorly understood and there is a particular necessity to gain more knowledge of how to promote participation and health related quality of life (HRQOL) after finishing cancer treatment. Therefore, the overall purpose of this thesis was to provide an increased understanding and knowledge of rehabilitation among young adult cancer survivors (YACS) after completing cancer treatment.

Twenty YACS were enrolled in a rehabilitation program structured around three weeks of residential rehabilitation and one-week follow-up visits after three and six months. The program consisted of goal setting, physical activity, psychoeducation, individual follow-ups, peer support and a next of kin weekend. A mixed-method approach was adopted, collecting data simultaneously through questionnaires, physical testing and semi-structured interviews at four points, in addition to questionnaires at a one-year follow-up.

Using a qualitative approach, Paper I explored how YACS experienced re-entering everyday life after completing cancer treatment. "Meeting reality" was identified as a bridging theme and described that participants found re-entering everyday life much harder than they had anticipated. This was elaborated by four main themes: 1) lack of preparation for everyday life after cancer treatment, consequently experiencing a mismatch between patients' expectations and the perceived reality; 2) experiencing late-effects, especially fatigue; 3) lack of understanding from within both their own social networks and healthcare providers; 4) being neither sick nor healthy and calling for more knowledge and a more comprehensive follow-up.

Using a mixed-method approach, Paper II studied whether a goal-oriented rehabilitation program influenced participation in everyday life, as well as how participants experienced this process. The quantitative results indicated high goal-achievement and increased participation, measured as significant increases in performance and in satisfaction of performance from the start to the end of the program. The qualitative results indicated that a successful process



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seems to be dependent on experiences related to coping and control. Finding a balance between different areas of life, gaining new insight and professional follow-up were identified as important factors for enhancing coping and control.

Using a quantitative approach, Paper III studied whether participants' HRQOL and physical capacity improved after attending the rehabilitation program. The results indicated significant increases and large effect sizes within all functional dimensions of HRQOL and in overall HRQOL, as well as a decrease in fatigue at the end of the program. These results were mainly maintained at a one-year follow-up. Objective testing indicated significant changes but small effect sizes in physical fitness, lung capacity and left hand strength. No significant changes were measured in right hand strength or body mass index. The YACS' overall compliance with the rehabilitation program was high.

The results suggested major shortcomings in preparing YACS for everyday life after cancer treatment, as well as in multidisciplinary follow-up after finishing treatment. A complex rehabilitation program tailored for YACS in need appears to be helpful for initiating the rehabilitation process and for promoting participation and HRQOL. Important elements of such a rehabilitation program appears to be the setting of individual goals, individually tailored physical activity, psychoeducation based on cognitive therapy, individual follow-up and peer support. The results of this research, however, illuminates that rehabilitation is not a straightforward process, but one that requires time and professional follow-up. The knowledge gained from this study illustrates the importance of screening YACS during their treatment for HRQOL (including fatigue), and to prepare them for survivorship. The results also highlight the importance of focusing on participation in all areas of life and not only patients' professional lives. These results may be useful as a basis for the development of survivorship-care programs for YACS. Even if the results from this study cannot be generalized to YACS as a whole, the achieved results nonetheless provide important indications for crucial elements and factors within the relatively new research field of YACS rehabilitation.

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## LIST OF PAPERS

This dissertation was based on the following three papers, later referred to using Roman numerals:

- Paper I: Hauken, M. Aa., Larsen, T. M. B, Holsen, I. (2013). Meeting Reality: Young Adult Cancer Survivors' Experiences of Re-entering Everyday Life after Cancer Treatment. *Cancer Nursing* 36(5), 17-26. (Special issue in pediatric oncology) (Appendix 1)
- Paper II: Hauken, M. Aa., Holsen, I., Fismen, E., Larsen, T. M. B. (2014): Participating in Life Again: A Mixed-Method Study on a Goal-Orientated Rehabilitation Program for Young Adult Cancer Survivors. *Cancer Nursing* 37(4), 48-59. (Appendix 2)
- Paper III: Hauken, M. Aa., Holsen, I., Fismen, E., Larsen, T.M.B. (2014): Working towards a Good Life as a Cancer Survivor: A Longitudinal Study on Positive Health Outcomes of a Rehabilitation Program for Young Adult Cancer Survivors. *Cancer Nursing* 37(4). Published online ahead of print: doi: 10.1097/NCC.000000000000138. (Appendix 3)

Wolters Kluwer Health permitted reprints.

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## ABBREVIATIONS

AYA:	Adolescents and young adults
COPM:	Canadian Occupational Performance Measurement
CT:	Cognitive therapy/cognitive technics
EORTC:	European Organization for Research and Treatment of Cancer
EORTC QLQ-C30:	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30, version 3.0. Dimensions are abbreviated as follows: <ul style="list-style-type: none"><li>- PF: Physical function</li><li>- RF: Role function</li><li>- EF: Emotional function</li><li>- CF: Cognitive function</li><li>- SF: Social function</li><li>- FA: Fatigue</li></ul>
HRQOL	Health related quality of life
ICF	WHO's International Classification of Function, Disability and Health
NCS	Norwegian Cancer Society
PA	Physical activity
PEACE	Physical exercise across the cancer experience
RCHRC	Red Cross Haugland Rehabilitation Centre
STC	Systematic text condensation
YACS	Young adult cancer survivors
WHO	World Health Organization





# 1 INTRODUCTION

The Norwegian Cancer Society (NCS) and Red Cross Haugland Rehabilitation Centre (RKHRC), a private rehabilitation center at the specialist level, initiated the present study. It focuses on inpatient/residential rehabilitation of young adult cancer survivors (YACS) after finishing cancer treatment. There were several reasons for this focus:

YACS represent a small and understudied group of cancer survivors, with only recent international awareness underlining their unique survival and survivorship challenges. These specific challenges are related to their vulnerable period of life and their increased risk for morbidity and physical and psychosocial long-term effects (1-4). Recent studies have highlighted a research gap in the area of survivorship for YACS, especially as it relates to unmet needs, as well as follow-up and rehabilitation interventions that build long-term health, participation and quality of life (1, 2, 5, 6).

Until recently, there has been limited focus on cancer rehabilitation within both clinical practice and research (7, 8). In Norway, cancer rehabilitation has not been an integrated part of cancer treatment (8, 9), despite the individual's right to rehabilitation having been legally established (10). Acknowledging this gap, the new National Cancer Strategy for 2013 to 2017 (11) emphasizes rehabilitation and studies involving young adults as two of the most important objectives of the strategy.

Based on the above considerations, the overall purpose of this thesis was to provide an increased understanding and knowledge of rehabilitation among YACS after completing cancer treatment. We conducted a tailored rehabilitation program for YACS, which we evaluated by using mixed-methods and participation and HRQOL as primary outcomes. However, all aspects of such a complex theme cannot possibly be discussed within the framework of a thesis and consequently, it was necessary to make refinements in terms of focus.

Several definitions exist for the term "cancer survivor". These definitions range from the point of diagnosis to living with a cancer diagnosis after five years or longer and some even

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include family members and healthcare providers (12, 13). Since this thesis focuses on the phase of survivorship after cancer treatment, we followed the definition stating that cancer survivors are individuals with a diagnosis of cancer who have completed primary treatment (13, p.7).

In the context of cancer, there is no consistent definition of young adulthood. Instead, this age range varies from having no definition (14) to the onset of 15 to 20 years of age and to an upper age range varying from 29 to 49 years (15). Some researchers include adolescents in this group and label the population as adolescents and young adults (AYA), often using the age span 15 to 39 years of age (3, 4). Other researchers mean 'survivors of childhood cancer' (1). For this study, the age range was set from 18 to 35 years, focusing exclusively on young adults with adult-onset cancer. The rationale for choosing this onset was that the age of 18 is accompanied by legal rights and marks the transition from high school to higher education or work and leaving the parental home (15, 16). The upper age limit was chosen to be in line with other researchers (17, 18), and complied with the upper limit of the AYA-group in the NCS.

This thesis is structured around nine sections and further refinements are clarified within each section. Section 2 gives an overview of the uniqueness of cancer and cancer survivorship in young adulthood. This section; together with previous research on cancer rehabilitation (section 3) and the study's theoretical framework (section 4) provides the basis for the current study's objectives and conceptual model, presented in section 5. These sections also give the basis for the study's rehabilitation program, methods and materials, as outlined in section 6. The study's results are published in three papers, presented in section 7, where the merged results are also presented. As the results from each paper are discussed in the respective paper, the discussion in section 8 focuses on the merged findings, followed by a presentation of methodological reflections. The main conclusions, clinical implications and suggestions for further research are presented in section 9.

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## 2 THE UNIQUENESS OF CANCER AND SURVIVORSHIP IN YOUNG ADULTHOOD

Because young adulthood is seen as a vulnerable period of life where cancer adds a tremendous burden, this section provides a brief overview of the period of young adulthood and the specificity of cancer in young adults, with a special emphasis on the challenges YACS face in survivorship.

### 2.1 The period of young adulthood

Most new theories of young adulthood take a life course perspective and place young adulthood between adolescence and adulthood (16, 19-21). Since marriage and parenthood are nowadays often being delayed until the late twenties, young adulthood is largely characterized by a high degree of demographic diversity and instability, heterogeneity, frequent changes, an extended length of education, as well as identity exploration within love, work and worldviews (op.sit). Additionally, crucially important choices regarding marriage, family, work and lifestyle are often made during this period. Accepting responsibility for one's self, making independent decisions and becoming financially and socially independent are interpreted as important factors for the transition into adulthood (16, 19, 20).

Disease in this period of life can have a huge impact on the young adult and lead to marginalization, with negative effects on psychological health, quality of life and participation (20). Consequently, cancer adds a tremendous burden that is often described as life disruption related to physical health, psychological development, education, work and social attendance, and in the forming of stable relationships (1, 2, 21).

### 2.2 Cancer in young adulthood

'Cancer' is the generic term for a large group of diseases characterized by a rapid creation of abnormal cells that grow beyond their usual boundaries and has the ability to metastasize to other organs (22, 23). While the incidence of cancer rises dramatically with age, cancer is rare amongst young adults and represents only 2 to 4% of all new cases annually worldwide.

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Nevertheless, cancer denotes one of the most common causes of death in young adulthood and has become an important public health issue (3, 22, 24, 25). Contrary to improved survival rates for young children and older adults, there has been an increase in cancer incidence and no corresponding progress in the survival of young adults. Several factors may contribute to these outcomes. One is that the types of cancers in young adulthood are unique in both biology and distribution, where the most common types being lymphomas, melanomas, testis and female genital tract malignancies, sarcoma, leukemia and breast cancer (24-26). The genetic, physiological and pharmacological characteristics in young adults are also unique and as such influences their ability to tolerate cancer therapy and to effectively respond to treatment (3, 25, 27). This presents challenges related to treatment protocols and implies that young adults often present problems that neither pediatrics nor adult oncologists are fully comfortable managing (2, 24).

Young adults usually tolerate therapies that are more intensive better than both younger and older cancer patients do. Despite this, they frequently receive lower therapy dose intensities than younger patients and at less time than is provided to older patients (25). Nevertheless, the treatment of cancer in young adulthood is often aggressive, multi-modal and long lasting, with a combination of surgery, chemotherapy, radiation and other cancer therapies (3, 24). Luckily, the majority of YACS survive, although with an increased risk for severe late-effects influencing participation, HRQOL and long-term health (3, 28).

## 2.3 Challenges of cancer survivorship in young adulthood

Although YACS are an understudied population, new research shows that they are at a higher risk of developing physical and psychosocial late-effects than younger and older cancer survivors are (1, 24, 25, 28-30). The risks for developing late-effects or long-term effects in YACS are dependent on their age at initial diagnosis and their type of cancer and treatment, as well as family history, lifestyle behaviors and comorbidity (op.sit).

### 2.3.1 Physical late-effects

Some consequences are life threatening and related to the cancer itself or the applied therapy, as well as the extended period YACS spend as survivors. As such, they are at

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increased risk of cancer recurrence and for developing new and subsequent cancers such as, for example, breast, lung, thyroid, and gastrointestinal cancers (28, 30, 31). Here, mantle radiation and a combination of radiotherapy and chemotherapy seem to play a vital role in this development (op.cit). Additionally, YACS are at a higher risk of developing cardiovascular diseases, metabolic syndrome, diabetes, asthma and hypertension than healthy control and other cancer survivors (2, 28, 32, 33).

YACS also report a range of physical late-effects impairing their health and well-being. These late-effects may occur in relation to the cancer treatment or at some time after; these effects can be persistent or even lifelong (28, 34, 35). Specifically, these effects may range from pain, lymphedema, weight-loss or weight-gain, gastro-intestinal problems such as diarrhea and constipation, insomnia, neurological problems, memory loss, lack of concentration, bodily impairment and premature menopause (36-41). In particular, fertility and sexual issues are reported as primary concerns for both genders of YACS, indicating a substantial need for improved information regarding the impact of treatment on sexuality and fertility (42, 43). However, YACS frequently report fatigue as the most invasive problem, because it significantly interferes with their usual functioning and participation in their own lives (34, 44-47). Research shows that fatigue reduces activity and motivation, mediates the relationship between physical fitness and HRQOL, and is a strong and independent predictor for decreased overall patient satisfaction and HRQOL (44, 48, 49).

### **2.3.2 Psychosocial late-effects**

An increasing amount of research has revealed that YACS report higher levels of psychological late-effects compared with older cancer survivors, for example, anxiety, depression, distress and uncertainty (2, 50-53). Concerns about self-esteem, identity and body image are common issues in young adulthood, but cancer therapy and altered appearance seem to add an extra burden to these concerns for YACS (54-58). YACS also report high levels of fear of recurrence (59-61). Here, both Mehnert et al. (62) and Lebel et al. (63) found that a higher number of physical symptoms, depression and distress, as well as lower social support predicted this fear, and concluded that this was a persistent problem in cancer survivors in need of interventions.

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The importance of social support to health is well-established (64), especially as it relates to young adulthood (19, 20). Several studies have documented that social support is extremely important for YACS, but that they nonetheless still reported low levels of social functioning having an effect on close relationships, disrupting their social lives and providing a lack of social support (2, 6, 21, 38, 65, 66). Brunet et al. (67) found a lack of perceived social support to be related to stress and less physical activity in YACS. Arnett (19) states that young adults commonly express personal relationships, especially marriage, as a foundation of their future happiness. In contrast, Kirchhoff et al. (68) found that YACS were less likely to be currently married and were at an increased risk of divorce/separation than healthy controls. Becoming financially independent is another important factor for transition into adulthood (19, 20). Research has stated that YACS are at risk of an educational disadvantage and delayed preparation for higher education, career goals and financial problems, which in turn postpones their independence (1, 29, 50, 72). In line with these findings, Belizzi et al. (71) highlights the need for interventions targeting financial assistance, body image issues, relationships and helping YACS to attain their educational objectives.

Even though most research concerning YACS up to now has had a predominant focus on negative health outcomes, a small amount of research has also revealed positive outcomes and post-traumatic growth. These outcomes appear to be mostly related to experiences of well-being, coping and goal reengagement strategies (69), positive emotions and beliefs (70) and physical functioning (71), all the while stressing the importance of focusing on these factors in survivorship care.

YACS seem to be particularly vulnerable in the transition from cancer treatment to survivorship, as they report a lack of information about cancer survivorship issues, inadequate follow-ups, communication problems with healthcare providers, as well as unmet physical and psychological needs (3, 6, 15, 29, 73-76). Additionally, it appears that YACS often do not seek out appropriate follow-ups due to geographical mobility, lack of continuity in follow-ups and healthcare personnel's lack of knowledge concerning their survivorship challenges (2). Late-effects, unmet needs and physical inactivity, along with challenges related to socioeconomic status and social support, have been documented to be related to lower levels of quality of life in YACS compared to older cancer survivors (3, 6, 17, 34, 43, 48, 50, 77).

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### 3 PREVIOUS RESEARCH ON CANCER REHABILITATION

Since this study focuses on inpatient rehabilitation intervention of YACS, this section addresses cancer rehabilitation from a historical perspective and reviews previous research to illuminate effective elements of content and delivery within complex cancer rehabilitation.

#### 3.1 Historical perspective

Cancer rehabilitation emerged in the 1980's, but was not particularly a focus in clinical practice or research until the mid-1990's and is therefore still a relatively new field (7, 78, 79). At the outset, research in this area mainly focused on physical deficits and visible disabilities such as amputations and lymphedema following breast cancer, with a focus on single interventions addressing physical aspects only (7, 8, 80). During the past ten years, however, there has been a shift towards a more integrated bio-psychosocial model, acknowledging the multidimensional challenges of cancer treatment and survivorship (81-83). Consequently, there is currently a shift toward focusing research on complex or multidimensional rehabilitation, defined as rehabilitation interventions built upon a number of different components (8, 75, 80, 84).

Previous research on complex cancer rehabilitation has primarily targeted older adults. Even where YACS have been included in studies, they are seldom analyzed as a specific group (1, 78, 80, 85-87). Consequently, very few studies on rehabilitation interventions tailored for YACS exist; however, several studies acknowledge their special needs regarding such interventions (1, 14, 73, 77, 88). Research on both single and complex rehabilitation interventions has nonetheless provided crucial knowledge concerning the effective elements of cancer rehabilitation. This knowledge forms an important basis for tailoring a complex rehabilitation program for YACS.

#### 3.2 Effective elements of cancer rehabilitation

Reviewing the literature on cancer rehabilitation illuminates that effective elements are related to physical activity and different psychosocial interventions.

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### **3.2.1 Physical activity**

Physical activity (PA) is the single element most studied and proven to be effective in cancer rehabilitation (80, 89-91). PA has shown positive effects on physical fitness, general health, quality of life, self-esteem and return to work for most cancers and age groups (29, 49, 80, 89, 91-94). PA has also shown to have positive effects on fatigue, anxiety and depression (op.sit). A closer consideration of these interventions gives rise to several important recommendations. First, the literature recommends that knowledgeable professionals should tailor individually exercise interventions to make informed and safe choices about exercise testing and prescriptions. These should be followed-up by face-to-face counseling (84, 95-98). Secondly, the literature recommends a combination of resistance and aerobic training, finding the right balance between physical activity and rest, and including a program with a step-by-step approach (95, 99-102). Based on this research, guidelines recommend cancer survivors to be moderately physically active for at least 30 minutes during five or more days of the week (96, 103). There have been few studies on physical rehabilitation interventions tailored to YACS; however, an Internet study indicated the beneficial effects of rehabilitation, especially in instances where specific goals had been set and writing logs were included (104). Research also documents that YACS are interested in physical activity intervention, but need help to initialize this (77, 105-107).

### **3.2.2 Psychosocial interventions**

Psychosocial interventions are the second element in cancer rehabilitation that has increasingly shown evidence for being effective in reducing distress and promote coping (80, 108, 109). Such interventions can be categorized as psychoeducation, individual follow-up, goal setting and peer support.

#### **Psychoeducation**

Professionally-delivered psychosocial interventions, integrating illness-specific information and education, as well as tools for managing related circumstances are referred to as psychoeducation (110). These interventions commonly involves multiple components such as education, provision of emotional support, training in coping skills, challenging unhelpful thoughts and relaxation training (80, 108, 109, 111-114). In particular, cognitive therapy/cognitive technics (CT) and education combined with discussions have been



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highlighted as promising interventions for enhancing coping and empowerment, self-efficacy and quality of life, as well as reducing fatigue, depression, anxiety and fear of recurrence (op.sit).

### **Individual follow-up and goal setting**

As survivorship challenges are multidimensional and may vary from one person to another, research underlines the importance of addressing cancer survivors' individual needs (6, 115-117). Several researchers state that the positive effects of cancer rehabilitation are dependent on skilled multidisciplinary professionals who are able to address these multidimensional needs (118).

Individual goal setting is also highlighted as an important feature for promoting motivation, control and self-efficacy in cancer rehabilitation. Research focusing on goal setting documents improved health outcomes and restoration of physical and psychological health (69, 119-122). In line with this, Belanger et al. (106) found that strong intention and planning was significant for YACS in terms of performing physical activities. To be effective, the literature recommends that the formulating of objective and realistic goals is best applied through cooperation between the patient and healthcare providers (69, 97, 121, 122).

### **Peer support**

Research has highlighted peer support as another important element in cancer rehabilitation. Several studies show that peer support promote psychosocial function, quality of life, fosters supportive exchanges and empowerment, and is important for processes of social support and social modeling among participants in rehabilitation programs (123-127). Since the challenges of cancer survivorship are unknown in general, meeting other cancer peers can be an important factor in processing patients' experiences and gaining understanding, thus functioning as a legitimization and normalizing of their present situation (17, 86, 128). Especially for YACS, this appears to be important, as cancer at this age is rare and YACS seldom meet other young cancer peers during treatment. In line with this, Kent et al. (129) found that YACS wanted to meet peer survivors in order to talk about their cancer experiences. Rabin et al. (130) found that YACS sought out interventions that provide social

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support. Furthermore, both Barber (131) and Love et al. (132) state that social support is essential for enhancing physical activity among YACS.

### **3.2.3 Combinations are more effective than single elements**

A percentage of new studies suggest that a multimodal approach that combines physical and psychosocial elements are more effective than single approaches to address physical function, quality of life, fatigue and distress (84, 97, 99, 113, 133-135). Consequently, the holistic and complex approaches to cancer rehabilitation presently appear to have gained more approval, including elements of physical activity, psychoeducation and goal setting, peer support, as well as individual follow-ups based on survivors' expressed needs (8). In line with this, YACS ask for multidimensional programs targeting physical activity, age-specific cancer-related and other information, and having health care providers that proactively raise salient issues, emotional and peer support (5, 88).

## **3.3 Structure and delivery**

The structure and delivery of cancer rehabilitation has a wide scope, which makes it difficult to draw conclusions from. Cancer rehabilitation is carried out in various settings and ranges from primarily outpatient programs to weekly and three- to four-week inpatient programs (8). The literature is not clear whether inpatient or outpatient programs are most effective (89, 91, 133). However, inpatient programs appear to be more complex and intensive, including a higher level of multidisciplinary and peer support (99, 134). In line with this, Fismen et al. (86) found that breast cancer survivors appreciated the opportunity to have a focus on themselves for a short period, without thinking of family and everyday obligations. Scott et al.'s review (84) concludes that the most effective mode of delivery is face-to-face contact with a professional, supplemented with at least one follow-up. In general, it seems that the shortest interventions, one to two weeks, provide a limited effect on health-related outcomes. In contrast, it appears that longer programs of three weeks or more are more effective (84, 89, 91, 100, 109, 114, 133, 134). However, Scott et al.'s (84) review concludes that the positive effects of rehabilitation programs appear to plateau after approximately six months.

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Samples included in cancer rehabilitation research vary between those who are undergoing treatment and patients who have finished treatment, or even mixed samples (91). New literature recommends not mixing these groups, however, as this may influence the outcome results (136, 137). In line with this, several studies have found that, for example, physical interventions are most effectively delivered after cancer treatment (80, 89), including CT for breast cancer survivors (113). Research also stress targeting rehabilitation interventions based on the individual needs of the patient, and not all survivors (79, 89, 119, 138, 139).

Rehabilitation is an individual process (10, 140). However, rehabilitation has been delivered both as an individual and group-based intervention. This research shows that group-based interventions are more effective than individual interventions related to exercise, psychoeducation and discussions, due to social and motivational factors (49, 67, 86, 101, 133, 138, 141). Stevinson et al. (142), for example, found that cancer survivors felt more secure exercising as part of a cancer survivor group, as this facilitated social support and a feeling of solidarity, and reduced the feeling of incapacity and physical problems. Similar, Austevoll et al.'s (143) systematic review showed that group education in general provided positive effects on psychological health, coping and social support, as well as positively impacting the patient's knowledge about their illness. Scott et al.'s (84) systematic review concludes that rehabilitation programs that involve participants with a variety of cancer diagnoses show at least similar positive improvements as cancer site-specific programs.

However, research on cancer rehabilitation in general has been accused of having unclear intervention descriptions, short programs, limited long-term effects, minimal follow-up and mostly targeting breast cancer survivors as opposed to mixed populations (89, 144, 145). The current research also highlights areas that remain unresolved. Some highly debated issues are related to questions about who is in need of cancer rehabilitation, how to detect those in need, optimal timing and residential versus home rehabilitation. Other debated issues are the role of social equality, gender- and age-perspectives, follow-up and the cost-effectiveness of rehabilitation (8, 78, 80).

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## 4 THEORETICAL FRAMEWORK

The concept of rehabilitation has developed over time and spans over a wide spectrum of disciplines and theoretical perspectives (79, 81, 82, 140). However, rehabilitation is now primarily seen as a complex health intervention undertaken within a complex environment. Consequently, it is recommended to apply a theoretical framework that includes several theories and concepts, rather than a single theory (146-148). In line with this, we chose to build this framework on the Norwegian definition of rehabilitation, as this constitutes the settings for rehabilitation in Norway. The definition illuminates the complexities of rehabilitation, and highlights the fundamentals of rehabilitation to include a holistic view of health and the individual's perspective. It also stresses rehabilitation as an enabling process focusing on empowerment and coping using specific means and placing a focus on positive health outcomes, defined as participation and HRQOL (10).

### 4.1 Rehabilitation and its fundamental principles

In Norway, the right to rehabilitation has been established through regulation and thus also constitutes the framework for cancer rehabilitation (10). Here, rehabilitation is defined as:

[A] time-limited, planned processes with well-defined goals and means, in which various actors cooperate to assist users in their own efforts to achieve the greatest possible function and coping capabilities, independence and social and community participation (10 p.1).

This definition builds on the WHO's definition, which elaborates rehabilitation to be a process aimed at enabling individuals to reach and maintain optimal physical, sensory, intellectual, psychological and social functional levels, including the tools they need to attain independence and self-determination (149). Definitions of cancer rehabilitation seems to comply with these two definitions. For example, the Nordic Cancer Union defines cancer rehabilitation as a process that assists the cancer patient to obtain maximal physical, social, psychological and vocational functioning within the limits created by the disease and its resulting treatment (150). These definitions highlight two fundamental principles in rehabilitation, namely a holistic view of health and the individual's perspective.

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Rehabilitation thus addresses the “entire person” and comprises physiological, psychological and social dimensions. This encompasses a holistic view of health, often referred to as a positive or bio-psychosocial health concept (10, 82, 140, 149, 151). This health concept stands in contrast to a negative, pathogenic or bio-medical view of health, which has traditionally been applied in the Western healthcare system. In the case of the latter, health and disease are viewed as two dichotomous instances, where health is regarded as the absence of disease and disease is an objective malfunctioning or deviance from statistical normality (op.sit). In contrast, a holistic health concept includes the individual’s own experiences (illness), as well as their specific context (151, 152). The holistic health concept in rehabilitation is philosophically congruent with health promotion and views health as a resource and an interaction of physical, psychological and social factors (152, 153). In this context, rehabilitation may therefore be viewed as a health-promoting process (154, 155).

Within rehabilitation, the individual’s perspective, self-determination and involvement are fundamental principles and important values (10, 82, 140). This means that the starting point for rehabilitation is based on the individual’s needs as they relate to a reduced level of function, regardless of whether the impairment is of a physical, psychological, social or, most often, multidimensional nature (82, 151). This perspective also implies that the individual is in charge of his or her own rehabilitation process and therefore highly involved in designing and evaluating this process.

## 4.2 The enabling process of rehabilitation

Rehabilitation is defined as an enabling process with clear means that are based on the individual’s own efforts (10, 149). Consequently, empowerment and coping are conceptual cornerstones of rehabilitation (82, 140, 150, 156). The definitions also outline that goal setting, education and building capacity are seen as clear means within this process that also requires effort or work. These elements are elaborated as follows.

### 4.2.1 Empowerment

The word 'empowerment' originates from “power” and means to give (someone) the authority, power, strength and confidence to do something (157, 158). Within rehabilitation,

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empowerment refers to individual empowerment (157, 159). Here, empowerment is defined as "A process where individuals gain greater control and ability to make decisions and perform actions affecting their health" (160 p.6). Zimmerman and Warschausky's (156) conceptual framework of empowerment in rehabilitation is in line with this definition. They highlight the interconnectedness between an individual's perceived controls, how he or she thinks about and participate in the social environment to achieve goals, and having a critical awareness of the factors that hinder or enhance one's efforts to exert control within one's life. Consequently, an empowering process is meant to enhance the patient's perceived behavioral control (97). This implies that each individual is an expert on him-or-herself, thereby claiming involvement and responsibility (156, 157, 159).

However, the individual is not alone in this process and healthcare providers are seen as important assistants, for example, by providing access to information, knowledge, facilitating skills development, providing motivation and contributing to goal achievement (82, 140). This implies an equal partnership between patient and professionals to identify, cope and control issues that concern the patient, and for the latter to participate in decisions that affect their lives (156, 159). However, since individuals and their consequences of cancer and cancer treatment are essentially different, the need for assistance will vary (156, 157). Thus, rehabilitation is dependent on health professionals' skills and knowledge for enabling patients to be efficient partners in this process (82).

#### **4.2.2 Coping**

Coping is seen as a key element when individuals have to deal with stressful situations, such as cancer survivorship; consequently, it is an important element in rehabilitation (18, 82, 140, 161). Numerous theories of coping exists and most of these are based on cognitive theories of learning and stress (82, 162). However, Skinner et al. (163) highlight that coping is not specifically observed or reported behavior, but rather an organizational construct used to encompass the myriad of actions individuals use to deal with stressful experiences. Consequently, there is not a fixed number of adaptive processes, families of coping, ways of coping, or coping instances. In line with this, several theories of coping can be applied to the rehabilitation of YACS. However, the Cognitive Activation Theory of Stress (CATS) (164) focuses on the individual's coping experiences and outcome expectancies and as such, seems

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especially relevant to understanding YACS' experiences of cancer treatment and survivorship. For these reasons, this theory was therefore applied to this thesis.

In CATS, coping is defined as the acquired expectancy that most or all responses lead to a positive result (162, 164). According to CATS, a challenging situation or event (stressor) will be processed or evaluated in the brain (appraisal) in light of both previous experiences and the individual's subjective perception of the situation. This evaluation will then give a stress response, activating the individual's physical, emotional and behavioral reactions (162, 164). A stress response via coping leaves the individual with only a short-term stress response. Here, the individual experiences positive expectations for both coping possibilities and their own capabilities for coping. The individual then learns through these positive coping experiences, which involves development, well-being and positive experiences. These experiences are then stored in the brain for use in new situations. In contrast, 'non-coping' involves a prolonged stress response, where the individual has negative expectations of both coping opportunities and their own abilities. Non-coping may then result in a state of constant stress, negative experiences, helplessness and hopelessness. These negative experiences will also be stored in the brain for use in new situations and the individual may thus enter into a negative coping cycle. This stress can, however, be reduced if the individual uses psychological defense mechanisms, or through practicing and strengthening resilience. In contrast, sustained arousal may lead to illness and disease (162, 164).

#### **4.2.3 Means of facilitating empowerment and coping**

Both empowerment and coping are associated with having control over one's situation and life, a control that can be facilitated by several means within the rehabilitation process (82). Theories of empowerment and coping highlight, for example, knowledge, skills development and positive coping experiences as important facilitating means (82, 140, 156, 159). In concretizing these means, the Norwegian definition of rehabilitation highlights goal setting, education and building capacity (10).

##### **Goal setting**

The rehabilitation process does not happen by itself, but must be consciously arranged, which implies comprehensive and forward-looking goals (10, 82, 140). Goals can be defined as internal representations of desired outcomes (165). The theoretical basis is that goals

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provide control, structure and motivation that give the individual's rehabilitation process purpose or outcome expectancy (140, 156, 164, 166). To facilitate a positive and linear relationship between goals and task performance, Locke and Latham (166) outline several important factors. First, to initiate motivation and performance, the individual has to be personally committed and the goals have to be specific and attainable. Second, the individual has to have knowledge and skills for attaining the goals, or be able to develop such skills. Third, the goal-oriented process is dependent on follow-up, evaluation and reframing for building close correspondence between efforts and goal outcomes (166, 167).

### **Psychoeducation**

Development of competence, knowledge and skills are seen as crucial elements within rehabilitation, empowerment and coping in order to facilitate behavioral change and achieve goals (82, 156, 164). Psychoeducation is professionally delivered illness-specific information and tools for managing related circumstances that builds on a holistic and competence-based approach to stress health, collaboration and empowerment (110).

Psychoeducation is intended to support the individual's understanding of their own health situation, to gain access to resources, achieve an awareness of issues in order to reach their goals, develop a sense of control and coping skills and to increase participation and become independent. These factors focus on improving cognitive awareness and coping skills. However, psychoeducation is also intended to promote insights that address affective worries and concerns (110, 149, 156). Psychoeducation can be practiced one-to-one; however, group practice models set the stage for within-group discourse, social learning and the expansion of support and cooperation (110).

As a part of psychoeducation, CT is often highlighted as an important tool for enhancing coping and control (80, 112, 113). CT is based on the theoretical assumption that an individual's affect and behavior is largely determined by the way a person structures his or her world. These cognitions are based on attitudes or assumptions stored in the person's mind and developed from earlier experiences. They are activated in specific situations or states of mind that in turn influence emotions, behaviors and physiological activation. This interaction between an individual's thoughts, behaviors, emotions and body are often referred to as the cognitive diamond (168, 169). CT aims to change dysfunctional patterns of



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negative automatic thoughts or beliefs by changing ideas and thoughts, thereby relieving emotional stress and other symptoms. This is done by detecting negative thoughts, exploring misinterpretations and self-defeating behavioral and dysfunctional attitudes and assumptions. The next step is a realistic re-evaluation of these issues, followed by acting as if this re-evaluation is true (168, 169).

### **Physical capacity**

Physical capacity is also crucial for an individual's function and participation in all areas of life, reflecting the relationship between the individual's capacity and demands of everyday life (170). Function and physical capacity is defined in several ways, but includes the ability or power to produce, perform, or deploy the body in a variety of ways (op.sit). Cancer and cancer treatments are documented to have a negative impact on exercise tolerance and cardiorespiratory fitness, and thus physical capacity (28, 93, 106). Building physical capacity within the limits created by the disease and the treatment is seen as important in rehabilitation, empowerment and coping for promoting control in everyday life (93, 103, 156). Supporting this, the Physical Exercise Across the Cancer Experience (PEACE) framework states that during the period of rehabilitation and health promotion after cancer treatment, physical activity is a way of mitigating late-effects in a bid to optimize health by restoring or bringing the person back to a condition of good health, thereby expediting recovery, control, independence and capacity (171). Additionally, in terms of physical behavioral change, outcomes expectancy is also important (164).

### **Social support**

Social support is also highlighted as a key component within rehabilitation, empowerment and coping (82, 140, 156, 164). In general, social support is thought to affect mental and physical health through its influence on emotions, cognitions and behaviors (64, 127, 172). The association between social support, well-being and health is complex. Here, the social buffering theory posits that social support buffers against the adverse effects of stressors and can thus enhance well-being and coping (op.sit). Cohen (64, 173) argues that increasing the availability of social support and reducing negative interactions within one's network is essential for human health. In line with this, House and Kahn (174) indicate a conceptual distinction between different types of social support, including emotional, economic and practical help, as well as the provision of information. These types of social support in turn

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provides a theoretical basis for three types of social support within the rehabilitation of YACS: social support from skilled professionals, peer support and social support from family and friends (82, 127).

#### **4.2.4 A process in need of effort and time**

Definitions of rehabilitation emphasize the importance of the individual's own efforts and engagement in rehabilitation (10, 140). This makes rehabilitation an active process where the individual is in charge and focusing on what is perceived as most relevant (82, 140). Norman (82) calls this "personal work", understood as activity involving mental or physical effort done in order to achieve a result, in contrast to notions of work as earning an income (158). This personal work requires attention, energy and time, and is seen as vital and necessary for giving meaning to the life to be lived after a life disruption such as, for example cancer treatment (82). In contrast to the focus on re-entering occupational work, the importance and amount of this personal rehabilitation work have barely been considered in rehabilitation research (82, 175-177). Additionally, the Norwegian definition stresses that rehabilitation is a "time-limited" process, a concept highly debated within cancer rehabilitation (9). Based on the individual's needs and challenges, the rehabilitation work may take a significant amount of time and effort alongside their normal roles, expectations and obligations within everyday life (82, 140). Furthermore, a number of cancer survivors, especially YACS, will have to live with the potential for severe multidimensional late-effects all their lives and might thus be in need for repeated rehabilitation interventions (1, 9).

### **4.3 The positive health outcomes of rehabilitation**

The word 'rehabilitation' originates from the Latin "re", - meaning again, back, return to a previous state and "habil", meaning to be skilled and competent (158). Rehabilitation is therefore often interpreted as a re-establishment or restoration of something that previously existed (82). Rehabilitation is, however, accused of being based on an ideology of normality, where this ideology defines everything that does not satisfy a bodily and functional ideal as abnormal and objects in need of change (82, 128). In line with this, a fundamental assumption in cancer rehabilitation is that cancer survivors can return to "normal" life by learning to deal with the consequences of their illness. However, rehabilitation rarely means

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a return to a life one once had; more often, it implies a readjustment or an alternative developmental process (128). This highlights the importance of focusing on resources, as opposed to solely focusing on impairments or illness (82).

In line with this and as a reaction to the negative and bio-medical view of health, there has been a growing emphasis on the positive aspects of health. Positive health outcomes are defined as the presence of several positive aspects of health, not merely the absence of disease or infirmity (178, 179). A range of positive health outcomes and indicators have been identified, including outcomes for physical, mental, social, spiritual and occupational health. Thus, examples of positive health outcomes are physical fitness and activity, well-being, quality of life, participation, life satisfaction and hope (op.sit). This focus on positive health outcomes is also apparent in definitions of rehabilitation, especially those emphasizing participation and quality of life as predictors for good health (140).

### **4.3.1 Participation**

In the Norwegian definition of rehabilitation, participation is perceived as the primary outcome of the rehabilitation process (10). Additionally, within health promotion, participation is seen as an essential concept and as an outcome of the empowerment process that is crucial for quality of life and health (10, 140, 178). Participation means the action of taking part in something or the involvement of the individual in a life situation (140, 158). The literature makes it clear that participation is closely related to empowerment, control, power and decision making, which contributes to achieving optimal independence and involvement in the society (82, 180).

The literature outlines participation as a holistic concept (82, 140, 180, 181) and not one solely related to work participation (175), or the Norwegian word *brukermedvirking* (82). In contrast, participation is considered as the individual's involvement in everyday life and activities of daily living, work or education and personal relationships and sexuality within the environment and in society (82, 180, 182). The Canadian Occupational Performance Model also supports this holistic view, where participation is seen as performance and satisfaction in the areas of self-care, productivity and leisure (140, 183). 'Self-care' refers to looking after the self and includes personal care, responsibilities, functional mobility and the organization of personal space and time. Productivity incorporates occupations that make a

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social or economic contribution, or that provides economic sustenance, while leisure comprises activities for enjoyment such as socializing, creative expression, outdoor activity and games and sports.

Function and participation is also a main focus of the WHO's International Classification of Function and Disability (ICF). ICF is more often used and recommended as a research-based model or as a framework for clinical rehabilitation and research (8, 97, 140, 145, 146, 181, 184). Here, rehabilitation is defined as a coordinated process that enhances activity and participation in the environment and society (81). This definition complies with the Norwegian definition of rehabilitation and ICF is therefore applied in this study as a model for outlining different factors influencing participation (without using the specific qualifiers identifying severity). ICF is developed and based on a biopsychosocial view of health, where universal human experiences of function and participation is viewed as consequences of biological, personal and social factors (81, 181, 182). These factors are inextricably intertwined, as outlined in Figure 1.

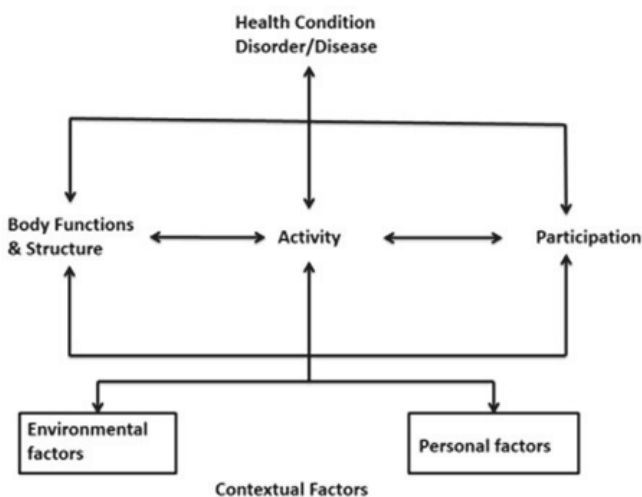


Figure 1: The ICF model.

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Explained in relation to YACS, Figure 1 indicates that a health condition like cancer and cancer treatment in young adulthood may impair YACS' body functions and structures in a negative way, for example, as physical and psychological late-effects. In this instance, body functions are related to the physiological and psychological functions of body systems, while body structures refer to anatomical parts of the body. Impairment in these functions may therefore negatively affect YACS' activity and participation. Activity is related to the execution of an action or task, e.g., exercising, while activity limitations are defined as difficulties the individual may have in executing activities (181). Participation is defined as involvement in a life situation, e.g., socializing, working and studying. This includes the performance of more complex life roles. Participation restrictions are then problems an individual may experience in their involvement in such life situations (181). Activity and participation are, however, difficult to distinguish, and are often interpreted together (181). Furthermore, the ICF also recognizes the importance of contextual factors for an individual's participation. Here, the contextual factors are divided into environmental factors and personal factors. Environmental factors make up the physical, social and attitudinal environment in which YACS live and conduct their lives, including social networks and medical and rehabilitation services. These factors operate outside or external to the person and may influence participation negatively or positively. Personal factors represent the particular background of an individual's life and the way they live, and is composed of features of the individual that are not part of a health condition or health state. Personal factors can include gender, age, coping styles, education and past and current experiences. All these influences how a health condition is experienced by the individual, and therefore impacts on participation. These factors are internal, or operate within a person (81, 140, 181). The double-sided arrows within the model (Figure 1) indicate that the domains are inextricably intertwined in several ways, reflecting the intricacy of human experiences of function and participation (81, 140). Used within rehabilitation, ICF therefore also underscores that rehabilitation interventions targeting different elements in the model may also improve participation, function and health (op.sit).

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### 4.3.2 Quality of life

Even if quality of life (QOL) is not mentioned in the Norwegian definition of rehabilitation, it is often seen as the ultimate aim of cancer rehabilitation and an important indicator of cancer rehabilitation success and perceived health (140, 185, 186).

The term QOL originated in the 1960's and the concept has been developed over time to be used within several disciplines (140, 187, 188). Within medicine and healthcare science, the concept first appeared in the 1970's to 1990's, recognizing patients' subjective feelings regarding their quality of life alongside their outlooks on survival and cure (186, 188, 189). Even if the term QOL is currently widely used, there nonetheless exists no unifying definition for it. Wahl and Hanestad (189) state that QOL may embrace different interpretations, for example, psychological well-being, satisfaction with life as a whole and degree of need-satisfaction, self-realization and happiness. To specify QOL within health science, the term "health related quality of life" (HRQOL) was introduced in order to distinguish between general QOL and aspects of QOL relevant to health. QOL is therefore perceived as a broader term than HRQOL, focusing more specifically on health aspects (186-189). HRQOL is, however, often applied as a broader concept than that of health, where health is commonly seen as biologically rooted and related to function and performance, while HRQOL is often connected to subjective concerns, values, judgments, preferences, and experiences (186, 188). Nevertheless, there is no unifying definition of HRQOL. In general, there seems to be an agreement that HRQOL is an individual, subjective and multidimensional concept that consists of physiological, psychological and social aspects of well-being. It also seems agreeable that HRQOL is determined by its dynamic nature and that it emphasizes the interaction between the individual and their environment (op.sit).

Although HRQOL is defined in several ways, the definitions for the term used within rehabilitation, health promotion and cancer survivorship appears comparable (140, 160, 187). In line with this, the WHOQOL Group defines HRQOL as:

An individual's perceptions of their position in life in the context of the culture and value system [in which] they live, and in relation to their goals, expectations, standards and concerns. It is a broad concept, incorporating in a complex way a person's physical health, psychological state, level of

independence, social relationships, personal beliefs and relationship[s] to salient features of the environment (160 p. 17).

As outlined in this definition, hope and expectations appear to play a predominant role in HRQOL. The literature supports this, stating that HRQOL may be affected by the difference between the individual's hope, their outcome expectations and their actual life (140, 164, 186, 187). In line with this, Rustøen (190) states that hope can be seen as a variable that positively contributes to the experience of quality of life and that hope can therefore be regarded as a coping strategy.

Some researchers also distinguish between HRQOL and disease-specific HRQOL, for example, related to cancer (189). The European Organization for Research and Treatment of Cancer (EORCT) define HRQOL as a multi-dimensional construct that covers several key dimensions such as disease and treatment-related symptoms, as well as physical, psychological and social functioning (191). In line with this, Ferrell et al. (192) state that HRQOL has particular relevance for cancer survivors, since physical and psychosocial late-effects can affect their day-to-day function and coping. Ferrell et al. (192) identified four domains of HRQOL for cancer survivors: physical, social, psychological and spiritual domains, as shown in Figure 2.

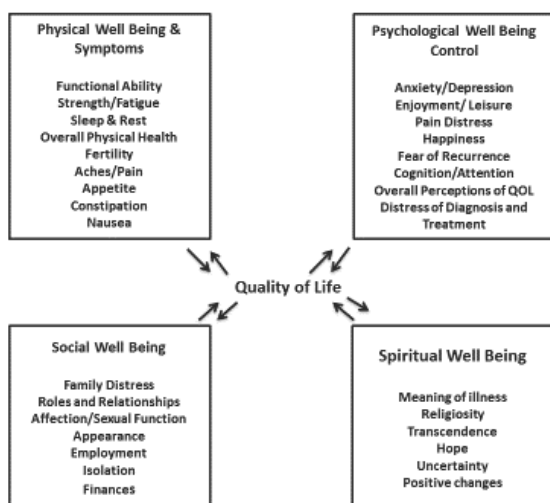


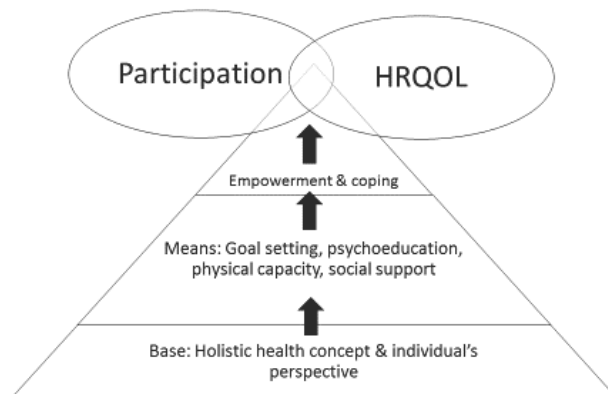
Figure 2: Ferrell et al.'s framework for HRQOL for cancer survivors.

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Ferrell et al. (192) (hereafter referred to as Ferrell's framework) include a spiritual dimension in their framework, while other researchers implement existential or spiritual factors within the psychological domain (188). Ferrell's framework outlines that cancer survivors may have a range of special concerns within each domain and that these specific concerns may influence the overall HRQOL. This framework also acknowledges a contextual dimension, as it includes a dimension of social well-being. Although strengths and challenges in specific domains can be examined and measured separately, the overall HRQOL experienced by the individual is seen as a function of the combined contributions of all domains (192). It follows from this framework that rehabilitation interventions targeting the survivor's concerns or dimensions, may therefore improve overall HRQOL and have an impact on the different dimensions of well-being (140, 186, 192).

#### 4.4 Summing up

Rehabilitation is in the present study viewed as a complex health intervention, according to the Norwegian definition of rehabilitation. However, this definition involves several theoretical concepts often interpreted in multiple ways. To clarify the connection between the different concepts in the current study's framework, these have been interpreted as shown in Figure 3:



*Figure 3: The connection between the theoretical concepts applied in this thesis.*



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The holistic health concept and the individual's perspective are seen as the basis for rehabilitation. In this context, rehabilitation implies the use of multidimensional means such as goal setting, psychoeducation, physical capacity and social support to facilitate empowerment and coping. Empowerment and coping in turn facilitates participation and HRQOL, two equally important outcomes of the rehabilitation process. Participation and HRQOL are then seen as separate terms that share a common foundation. This common foundation includes the holistic view of health and its multidimensionality, and also includes a contextual element. Participation and HRQOL also have their own unique features. Participation has a predominant focus on the individual's involvement in everyday life and activities (81), while HRQOL has a predominant focus on the individual's subjective concerns and judgments (181, 188).

The above theoretical framework is applied throughout the present study. The entire framework is used as a basis for developing the rehabilitation program (section 5.1). In Paper I, the holistic view of health and coping is the focus. In Paper II, participation is the main outcome. In Paper III, HRQOL (including physical capacity) is the main outcome. In the discussion section of this thesis, the merged results are discussed and interpreted against participation and HRQOL, and includes theories of empowerment and coping.

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## 5 THE STUDY'S OBJECTIVES

### 5.1 The study's aims and research questions

The overall purpose of this thesis was to provide an increased understanding and knowledge of the rehabilitation of YACS after completing cancer treatment. The first goal was to study YACS' experiences of re-entering everyday life after cancer treatment. The second goal was to investigate if a tailored, complex and goal-oriented rehabilitation program for YACS improved their participation in everyday life, and to explore how they experienced this process. The third goal was to examine if participating in the rehabilitation program increased positive health outcomes such as HRQOL and physical capacity.

Consequently, the study addresses the following research questions:

1. What experiences do YACS have in re-entering everyday life after cancer treatment? (Paper I)
2. Does a complex rehabilitation program increase YACS' participation in their life situation? (Paper II)
3. How do YACS experience the goal-oriented rehabilitation process? (Paper II)
4. Will participation in a rehabilitation program improve YACS' self-reported HRQOL at the end of the program and at a one-year follow-up? (Paper III)
5. Will participation in a rehabilitation program improve YACS' physical capacity at the end of the program? (Paper III)
6. How do the YACS comply with the program? (Paper III)

### 5.2 The study's conceptual model

Based on previous research involving YACS (section 2) and cancer rehabilitation (section 3), and taking into account the study's theoretical framework (section 4), a conceptual model of the study was developed and is shown in Figure 4.

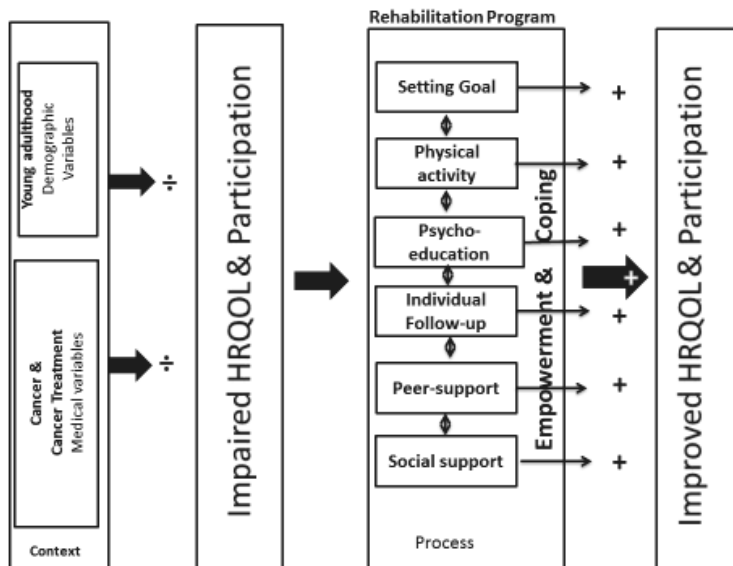


Figure 4: The study's conceptual model.

Figure 4 illustrates that cancer and cancer treatment at a vulnerable time of life may lead to impaired HRQOL and participation, influenced by medical, demographic and contextual variables. Thus, for the present study, we presumed that enrollment into a specially tailored rehabilitation program for YACS that included goal setting, physical activity, psychoeducation, individual follow-up, peer support and social support (next of kin weekend) may improve HRQOL and participation through processes of empowerment and coping. The single elements within the program were viewed as having the potential for collaborating with one another, while each single element could also have direct effects of participation and HRQOL outcomes, based on the individual's needs. However, based on the multidimensional challenges of YACS' survivorship and the predominant focus of complex and multidimensional rehabilitation, we supposed that the program as a whole would have a positive influence on YACS' participation and HRQOL.

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## 6 METHOD AND MATERIALS

Previous research on YACS and cancer rehabilitation supported by the current study's theoretical framework and guided by the same objectives and conceptual model framed the development of the rehabilitation program and the methodological choices adopted in the present study. These are presented in this section.

### 6.1 The rehabilitation program

#### 6.1.1 The content

A multidisciplinary team at RKHR, along with the author, developed the content of the rehabilitation program. The program also received external input from an advisory board, which included a YACS representative. Six elements were chosen based on evidence from previous research (section 3), support from existing theories (section 4) and the clinical experiences of healthcare professionals and YACS themselves (8, 86).

##### **Goal setting – individual**

The purpose of setting individual goals was to target YACS' individual needs and their specific priorities and to provide control, structure and motivation for defining the rehabilitation process with a specific purpose and outcome expectancies (10, 82, 140, 165). This approach was also a way to involve YACS and make them take charge of their own rehabilitation process (11, 82). The participants set a maximum of five individual goals within the three areas of self-care, productivity (work/study) and leisure (physical activity) at the start of the program (183). These goals were followed up after three weeks and after three and six months.

##### **Physical activity – individual and group**

The main goal of physical activity was to improve physical capacity and stimulate regular physical activity in line with the norm for cancer survivors, and to be able to do at least 30 minutes or more of moderate activity five or more days a week (89, 91, 97, 103, 171).

Based on the physical testing for muscle strength, lung capacity, physical fitness and BMI (see section 6.4.2), as well as preference and variation, an individually tailored program was

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agreed upon between the participant and a physiotherapist. In line with the literature, the program comprised a combination of strength and fitness elements (103, 193). The strength program was based on Cybex workout units or the Red Cord Program and was supervised and followed-up on by a physiotherapist (97, 193). The fitness elements were based on individual preferences, for example, cycling, swimming, walking, etc. The program typically contained two or three sessions every day, in which the activities varied between an individual workout program and group activities, of which at least one was outdoor walking, climbing or sea sports (49, 95, 96). The group activities generally focused on strength and physical fitness, coordination, body awareness and relaxation. Each session lasted approximately 45 minutes, started with a warm-up, and finished with stretching and relaxation. In order to learn to be familiar with their bodies again and to control their present capacity, the participants were educated and rendered experienced in using Borg's scale for perceived exertion (194) (Appendix 4). They also wrote logs to capture their physical activity (Appendix 4). For fitness training, the perceived intensity was recommended to range from 14 to 17 on Borg's scale ("hard intensity" to "very hard intensity"). The participants were advised to continue exercising between the primary- and the re-stays, and to provide activity logs to the RCHRC every fourteenth day.

### **Psychoeducation – group**

The purpose of the psychoeducation was to support individuals' understanding of their own health situation, to gain knowledge of cancer survivorship issues, to gain access to resources and gain an awareness of issues important to reaching their goals, as well as to develop a sense of control and coping skills (109, 110, 113, 156, 164). YACS were educated to use CT as a tool for coping with negative thoughts and to normalize and learn how to cope with their present situation (168, 169).

The psychoeducative program contained seven sessions during the patients' primary stay. Each session lasted 90 minutes and covered a specific topic. The topics presented a holistic perspective of challenges particularly relevant to YACS and included: 1) introduction with a focus on resources; 2) the basics of CT; 3) education and work; 4) thoughts and emotions; 5) exercise and physical activity; 6) me and my network; 7) the way forward. Each session was conducted in the same way with an introduction, training- and discussion- session, summing up and assigning homework.

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CT was used consistently throughout all sessions as a method for discovering and coping with negative thoughts and emotions (169). The 'five-columns-scheme' was used as a practical tool for detecting and revising negative thoughts (Appendix 4). For each session, YACS received homework for comparing each session's topic with their individual present situation. For each topic, they also received corresponding readings. The specific content for each session, homework and literature are outlined in Table 2 in Paper II.

An experienced physiotherapist specialized in CT and with several years of experience in conducting group sessions, led the psychoeducation. In addition, specialists in the different topics, for example, physician/nurse/social worker/physiotherapist, initiated each session with a lecture. At the follow-up visits, the respondents had one session using CT, which focused on experiences from their lives at home and the challenges ahead.

### **Individual follow-up**

The purpose of the individual follow-up was to attend to YACS' individual challenges or problems using a multidisciplinary approach (1, 2). Based on the research of YACS' challenges concerning cancer survivorship (section 2), recommendations from cancer rehabilitation research (section 3), and guidelines (97), we chose the individual follow-up to be provided by:

- A specialist in rehabilitation medicine for attending to medical issues
- A physiotherapist to test, tailor and follow-up physical exercise
- A nutritionist to screen the nutritional status and focus on YACS' present diet
- A social worker to provide information related to re-entering study- or work-environments, social rights, etc.

Each participant was scheduled to have one appointment with each of the professionals, with follow-ups based on the individual's needs.

### **Peer support – individual and group**

The purpose of peer support was to facilitate social support, social comparison and modeling, share experiences, thoughts and emotions to promote normality and to support and motivate one another during the rehabilitation process (86, 123, 124). To facilitate peer support at the residential stays, the participants exercised and took part in the psychoeducation sessions together. Furthermore, during the residential rehabilitation stays,

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participants lived together in a separate hut, ate all meals and spent most of their spare time together, thereby facilitating a high level of interaction.

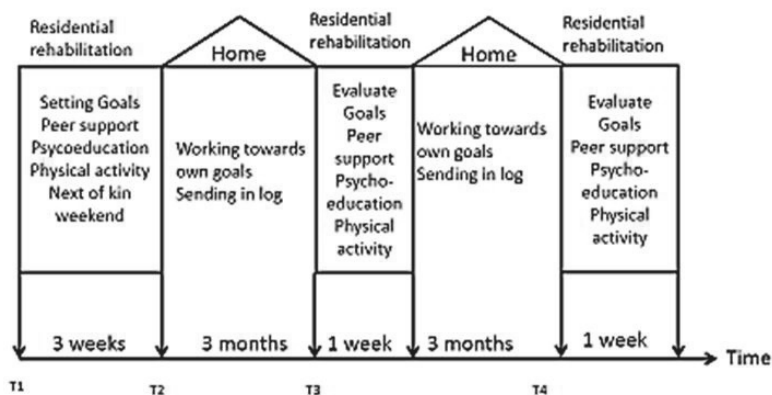
### **Next of kin-weekend – individual and group**

The purpose of this weekend was to allow next of kin to visit participants, learn about the rehabilitation process and meet other participants' next of kin who were in the same situation and thus enhance understanding and social support among relatives (10, 64, 140). This element was especially emphasized by the YACS' representative as an important input of the program. This weekend was arranged in the midst of the primary stay. Next of kin were included in two teaching sessions, one about coping and the rehabilitation process, and one about diet and nutrition.

## **6.1.2 Structure and delivery**

### **Structure**

Since the literature indicates that an effective rehabilitation intervention has to be longer than three weeks (section 3.2) and supported by clinical experiences and research from RKHRC (86), we chose to structure the program around a three-week residential stay. However, taking into account prior critiques that cancer rehabilitation lacked adequate follow-up (144, 145) and the experiences noted in Fismen et al.'s (86) study, we chose to include a one-week follow-up after three and six months. The rationale for this was that a three-week stay would give YACS a time-out period and an initiation of the rehabilitation process. Within the three months between each follow-up stay, they could continue with their rehabilitation process in their everyday environment, still knowing that they would be followed-up on through the logs and the re-stays. The follow-up week was organized in order to perform tests, reassess goals, adjust the individual's physical activity, and respond to questions that may have come up after being at home. As such, this should provide security and motivation for continuing the rehabilitation process between the primary and the follow-up stays. Figure 5 illustrates the content and structure of the program.



*Figure 5: The content and structure of the rehabilitation program.*

The total time spent on physical training, psychoeducation and individual follow-up for each participant was approximately 100 hours over the five weeks of residential rehabilitation. Psychoeducation accounted for about 15 hours, individual goal setting for about four to six hours, individual follow-up for about four to eight hours and physical training approximately 65-70 hours of the total active hours (varying individually). A detailed time schedule can be provided upon request.

### **Delivery**

The intervention took place at the RCHRC and was facilitated by their usual staff. The multidisciplinary team responsible for the intervention was highly experienced in cancer rehabilitation and had previous experience in conducting rehabilitation research. All were educated in the area of CT. To secure equal delivery of the intervention to all participants, the team received a written copy of the detailed intervention protocol and was educated to work within its structure (195). The interventions were delivered group-wise from January 2011 to May 2012, including re-stays.



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## 6.2 Research method and design

Various designs and methodological traditions have been used in previous research on cancer rehabilitation. These include randomized controlled trials (RCT), quasi-experimental designs, survey research, case studies and qualitative inquiries (7, 80, 113, 196, 197). The preferred and most used design appears to be RTC studies. However, a RCT design within cancer rehabilitation has been increasingly criticized due to heterogeneous patient populations, small samples and complex interventions, as well as difficulty in the creation of the required control over the environment (196, 198). The UK Medical Research Council guidelines for the evaluation of complex interventions (148) currently recommend alternatives to RCT for the evaluation of complex interventions. These recommend the evaluating of both processes and implementing several outcome measures for capturing an effect. Consequently, mixed-method designs are presently viewed as an important and upcoming method in rehabilitation research. This because it moves beyond simple hypothesis testing in order to provide insights into processes and mechanisms, which may yield a more complete and nuanced understanding of a topic (196, 199-202).

However, all research methods are based on a methodology that refers to a theoretical and/or philosophical basis, and the choice of research method is primarily dependent on the study's research questions and not a specific design, per se (199, 203-205). Since our research questions dealt with both an exploration of YACS' experiences, as well as the outcomes of a complex rehabilitation program, the research methodology had to reflect both a qualitative and a quantitative approach. Based on this and on the considerations outlined above, we found that a mixed method approach was most appropriate for this study (199, 200). We also believed that a mixed-method approach would strengthen the study, as we were unable to establish a control group for several reasons. First, YACS is a small population that are difficult to reach (9, 117, 206-208). Second, we found it ethically problematic to randomize YACS who had been established to have rehabilitation needs, into a control group. Third, we also found it ethically problematic to use a waiting-list control when specific needs were being established. Fourth, we found that a control group without screening for needs (e.g., members of the AYA group in NCS) would likely yield incomparable groups at the baseline.

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### 6.2.1 Mixed-methods

Up until recently, quantitative methods have dominated cancer rehabilitation research (7, 196). This approach, linked to the empirical-analytical tradition, is concerned with objective data, generalizability and predicting cause and effect, and has traditionally been connected to the objective biomedical paradigm (151, 196, 203). This paradigm views disability as an attribute of a person that has been directly caused by disease or a health condition.

Consequently, medical intervention is amenable in terms of correcting or compensating for the problem (151, 203). Quantitative methods are thus concerned with what can be measured (196, 199, 203). The strengths of quantitative research include testing of hypotheses and the generalization of research findings, based on replicated studies with random samples of a sufficient size. The results seem to be relatively independent of the researcher, often having high credibility and being useful for studying large numbers (195, 202, 203). Quantitative methods also have some clear weaknesses, for example, that the researcher's categories may not reflect the respondents' understanding and therefore presenting a risk of conformation bias, or producing too abstract/general knowledge that is not applicable to clinical practice (op.sit).

In contrast to quantitative methods, qualitative methods are linked to the historic-hermeneutic and emancipatory tradition, which is concerned with experiences, understanding and the values and meanings that persons ascribe to a phenomenon (204, 205, 209). Here, reality is viewed as a construct of social interactions and experiences. Qualitative methods are therefore concerned with context-sensitive and the reflective information of personal experiences, narratives or interpersonal discourses of phenomena (op.sit). As with quantitative methods, qualitative methods also have strengths and limitations. Its strengths are that the data are based on participants' own categories of meaning and their experiences of a phenomenon, which is useful for studying a limited number of participant in-depth, thereby providing rich and contextual information of complex phenomena. Furthermore, qualitative methods can illuminate dynamic processes and generate theories, and collect data in naturalistic settings in words or categories provided by participants (202-205, 209). However, when using qualitative methods, the results might not be generalizable and it is difficult to make quantitative predictions or test hypotheses and theories using this approach.

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Furthermore, qualitative data collection and analyses are often time-consuming and the researcher could easily influence the results (204, 205, 210).

Since quantitative and qualitative methods are linked to different ontological (nature of existence) and epistemological (theory of knowledge) assumptions, they have traditionally been viewed as two completely separate paradigms (196, 199, 211). However, a new paradigm debate began in the 1980's related to combining these paradigms. The rationale for such an approach was that the research world was becoming increasingly interdisciplinary, complex and dynamic, acknowledging that both perspectives are needed to facilitate communication, promote collaboration and for conducting more effective research (199, 202). Mixed-methods appear to support this complexity, as both quantitative and qualitative methodologies are used in the context of one study (196, 199, 201, 202). Therefore, mixed-methods is now more often stated as a third research paradigm that provides insight into processes and mechanisms, which may yield a more complete and nuanced understanding of a phenomenon (op.sit). Thus, mixed-methods focus on research questions closely related to real-life, as well as contextual understandings. It often implies multi-level perspectives and intentionally integrating or combining qualitative and quantitative methods to draw on the strengths and minimize the weaknesses of each strand. Furthermore, a variety of theoretical perspectives can be integrated in mixed-methods (199, 202).

The philosophical assumptions behind the mixed-methods approach are based on pragmatism (196, 199, 201, 202). Pragmatism reflects that knowledge is both socially constructed and based on the reality of the world we experience and live in. The focus is on the consequences of the research, rather than its methods. The primary importance of pragmatism concerns the questions being asked, as well as the use of multiple methods for data collection. This pragmatic approach is pluralistic and oriented towards “what works” in practice, uses different approaches, and gives priority to the importance of the research problem and questions, while valuing both objective and subjective knowledge (op.sit).

### **6.2.2 The convergent parallel design**

A considerable variety of mixed-method designs are described in the literature (196, 199, 211). Key factors for deciding what design to use are related to sequences of implementation, the priority of the methods, purposeful integration and theoretical

perspective (op.sit). Since the main aim of this study was to develop a more complete understanding of YACS' follow-up cancer treatment and rehabilitation, based on prior research and theory, a convergent parallel design was considered as the preferred design.

The purpose of this design is to obtain different but complementary data on the same topic to best understand the research problem (204). The qualitative and the quantitative strands are implemented during the same phase of the research process, and both methods are equally prioritized. The strands are kept independent during the analyses, but are combined in the overall interpretation. The intent of this design is to bring together the different and non-overlapping weaknesses and strengths of the quantitative and qualitative methods, and to view the research from both narrative and numerical perspectives (196, 204). Neither quantitative nor qualitative methods are homogeneous fields; however, both strands are connected to different strand designs. Since we were not able to establish a control group, we chose a quasi-experimental design – specifically, a design with a pretest and four multiple posttests design. Here, we also included two samples for comparison (195). In the qualitative strand, we used a phenomenological-hermeneutical approach with in-depth interviews (204). In summary, this study's place in the scientific sphere can be illustrated as shown in Figure 6 (195, 199, 203, 204).

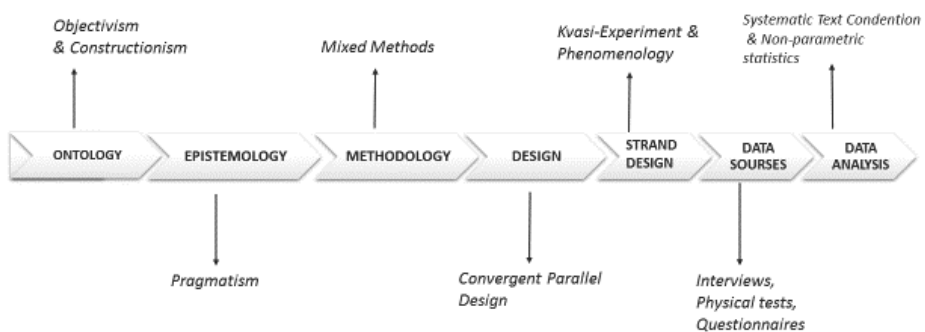


Figure 6: The study's ontological, epistemological and methodological stands.

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## 6.3 The sample

### 6.3.1 Eligibility criteria and recruitment

To be specific within the study's focus, the following eligibility criteria were elected:

- YACS 18 to 35 years of age
- Finished cancer treatment within the past five years
- All cancer diagnoses included
- Able to speak and read Norwegian fluently
- Referred to the study by an oncologist or a general practitioner due to ascertaining the need for rehabilitation

Several studies document difficulties in recruiting YACS into research, often referred to as the "AYA gap" (25, 207, 208, 212). After finishing cancer treatment, YACS in Norway are usually only provided with short follow-up appointments with an oncologist or primary physician, and are thus difficult to reach within the healthcare system (213). Consequently, we followed recommendations to recruit on a broad basis (op.sit). This strategy included letters, pamphlets and personal information to hospital- and primary-healthcare professionals nationally. We also participated in cancer-related events, advertised in newspapers, and papers for cancer survivor organizations, placed advertising on different websites, and relied on word-of-mouth referrals. The project also launched its own web site ([www.kvano.no](http://www.kvano.no)) in order to advertise the project and recruit via social networking media.

### 6.3.2 The participants

Of the 31 participants who were referred to the study, 11 did not meet the inclusion criteria. The final sample consisted of 20 participants. Most of the participants found the information about the study by themselves, via the internet/social media, brochures or word-of-mouth. The demographics and medical presentation of the study population (N=20) are outlined in Table 1 and Table 2.

*Table 1: Demographic Presentation of Study Population (N=20).*

Age mean/range	Gender	Civil status	Living status	Children	Education	Employment
31.1/24-35	15 Women 5 Men	9 Single 11 Married	7 Alone 2 With parents 11 With spouses	14 No 6 Yes	6 Senior high school 14 University college/university (undergraduate)	4 Study/work fulltime 9 Study/work part time 7 Sick leave

*Table 2: Medical Presentation of Study Population (N=20).*

Cancer Diagnosis	Months since diagnosis Mean (range/SD)	Type of treatment	Months of treatment Mean (range/SD)	Months since treatment Mean (range/SD)
5 Lymphoma 5 Gynecological 4 Breast 2 Testes 2 Colon 1 Sarcoma 1 Head and neck	24.6 (4-71/16.7)	8 Only surgery/ chemotherapy 12 Multimodal treatments	7.8 (1-30/ 6.8)	16 (1-66/15.8)

None of the participants showed evidence of cancer at the time they enrolled in the study. Seventeen of the 20 enrolled participants completed the entire rehabilitation program (T1 to T4). During the program, three participants withdrew due to relapse of cancer (one after T3), breast reconstruction (one after T2) or not being able to take time away from school (one after T2). At one year follow-up (T5), 15 of the 17 participants who had completed the program returned the questionnaires. Two participants withdrew at T5 due to relapse of cancer and sudden death in the immediate family.

## 6.4 Data collection

According to the study's design, qualitative and quantitative data were collected concurrently at the baseline (T1) at the end of the first rehabilitation stay (T2) and at the first re-stay after three (T3) and six months (T4). Quantitative data were also collected by surface mail at the one-year follow-up (T5). The data collection is outlined in Figure 7.

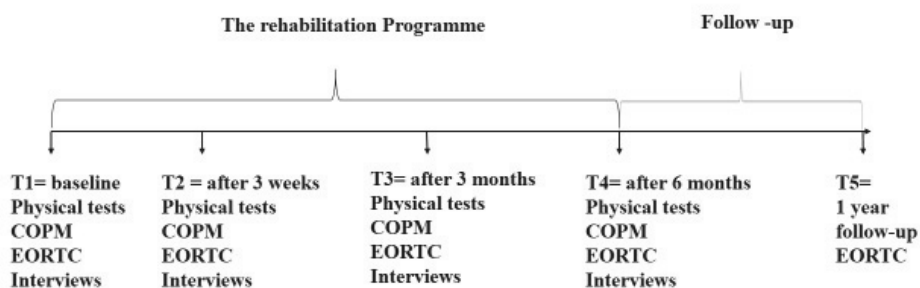


Figure 7: The data collection, timeframe and type of data.

### 6.4.1 Collection of qualitative data

The qualitative data used in this thesis was collected through in-depth interviews at T1 (Paper I) and at T4 (Paper II). The qualitative data collection was based on using a phenomenological approach, as this method is especially suited when the aim is to understand the meaning of the lived experiences of individuals involving a certain phenomenon (204, 209). The interviews were semi-structured and used interview guidelines (200, 204). The guidelines contained an outline of topics to be covered, with suggested open-ended questions to be explored during the interviews. Both guidelines contained some primary questions, followed up by other sub-questions, depending on how the individual

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interview developed. The first guideline (Paper I) focused on the participants' experiences of being young and going through cancer treatment (Table 3 in Paper I). The second guideline (Paper II) focused on how the participants had experienced the goal-oriented rehabilitation process, as well as the different elements of the rehabilitation program (Appendix 5). The first guideline (T1) was pilot tested on YACS outside the project and was found to be feasible for capturing the phenomena in focus (214).

The candidate conducted all interviews in a quiet office at the RCHRC, free from disturbance and face-to-face with each participant. This allowed for the exploration of individual experiences and perceptions in detail, and for the participant to direct the course of discussion as much as possible. Furthermore, such interviews allowed the participant to identify and describe concerns or concepts that may not have been considered by the researcher (200, 204, 210). None of the participants refused to be interviewed at any stage of measurement (204, 210).

The candidate had not met the YACS prior to the first interview, but they had read the information about the study signed by the candidate. Prior to starting the interview, the candidate presented herself briefly, including her name, experience in cancer care, her present status as a PhD student and as not being part of the intervention, thereby encouraging the participants to speak freely (210). The candidate also explained the purpose of the specific interview and that the participants could withdraw at any moment, how the candidate would ensure the YACS' anonymity and asked for permission to audiotape the interview.

During the interviews, the candidate used the interview guidelines as a framework. However, interviews are interactive, a process in which the interviewer aims to be responsive to the language and concepts used by the participant (204, 214). Therefore, in addition to the established questions, the candidate clarified and asked questions to capture participants' intended meanings, a process often described as 'member checking' (199). The candidate also observed the YACS' body language and their use of voice, which could provide important clues as to how he/she felt during the interview. If the YACS cried, became tired or lost focus during the interview, the candidate initiated a pause, reassured the participant,



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asked whether he/she would like to stop and gave them enough time to compose themselves (204, 214).

Each interview lasted between 45 and 70 minutes, and was recorded on a high quality audiotape to capture participants' authenticity and to facilitate detailed analysis. No parts of any of the interviews were obscured due to the quality of the recordings (199, 204, 210). After each interview, the candidate thanked the YACS and gave each participant an opportunity to elaborate on how they had experienced the interview situation (205, 214).

After each interview, the candidate wrote short field notes. These notes were descriptive and related to what had happened throughout the interview (e.g., crying or the general impression of how the interview went), or about the candidates' immediate reflections on special themes or nuances that had been highlighted during the interview, or important clues to be followed up on in interviews still forthcoming (204). These field notes followed the participants' transcribed interviews.

The candidate transcribed all interviews verbatim. Throughout all transcriptions, pauses, participants' stressing of words and emotional outbursts (e.g., crying) were explained and outlined in the same manner to enhance validation and transparency (199, 204). The transcripts were not returned for corrections or comments, because these were not finished prior to the YACS leaving the RCHRC; additionally, this was avoided so as not to unnecessarily burden participants (210).

#### **6.4.2 Collection of quantitative data**

The literature recommends using a range of outcome measures in complex interventions, as a single outcome may not capture the results or unintended consequences of the study (148, 185, 216). Therefore, based on the definition of rehabilitation, participation and HRQOL (included physical capacity) were chosen as the quantitative outcome measures in this study.

#### **Demographic and medical variables**

Demographic and medical data were collected from a self-reported questionnaire and included age, gender, education, social and employment status, type of cancer, months since diagnosis, type of treatment, months of treatment and time since treatment (Appendix 6).

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## **Participation**

Canadian Occupational Performance Measurement (COPM) was selected as a tool for setting individual goals and to measure multidimensional participation (140, 217, 218) (Appendix 6). COPM was preferred for several reasons: the instrument is grounded in theory of rehabilitation, i.e., the Canadian Model of Occupational Performance and ICF (op.sit). In line with the study's theoretical framework, participation was viewed as a holistic concept and in COPM is operationalized in the areas of self-care, productivity, and leisure (217). The instrument was comprehensively tested and was viewed as a valid, reliable and clinically useful measure (218). COPM has high acceptance as a responsive outcome measure, both within individual clinical practice and research and is used with a wide variety of patients, including cancer survivors and in rehabilitation (140, 217, 218). COMP was published in 1991 and has been translated into 20 languages, including Norwegian (217, 218). Two therapists at RKHRC were specially trained in using the instrument (218).

The purpose of COPM is to detect activity-problems within different areas of life, gain information about how important various activities are and to get the user's assessment of progress and satisfaction with task-execution. COPM was individually administered to each participant at T1 and reassessed at T2, T3 and T4, with support from one of two specially trained therapists. The participants identified problems within the three areas, rated the importance of each problem and scored performance and satisfaction with performance on a 10-point interval scale ranging from 1 ("not able to do it" or "not satisfied at all") to 10 ("able to do it extremely well" or "extremely satisfied" (140, 217).

## **HRQOL**

No Norwegian HRQOL measurement has been developed specifically for YACS (219) or cancer survivors. Therefore, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30, version 3.0 (EORTC QLQ-C30) (Appendix 6) was considered the most suitable HRQOL instrument for a number of reasons. This is a cancer-specific instrument appropriate for self-administration (191). It is considered to be a valid and reliable instrument, showing sensitivity to changes in clinical and psychosocial interventions among cancer survivors (191, 220). EORTC QLQ-C30 was published in 1993 and is widely used internationally, with established reference data for 50 countries, including a Norwegian norm population (191, 221-223). The instrument is recommended for the study

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of YACS and cancer rehabilitation (97, 187), and for making comparisons between cancer rehabilitation studies internationally (79, 221).

In line with the literature (187-189, 192), EORTC QLQ-C30 defines HRQOL as a subjective, multidimensional construct operationalized through nine multi-item scales (191). These include a global health and quality of life scale [global HRQOL], five functional scales (physical function [PF], role function [RF], cognitive function [CF], emotional function [EF], social function [SF]), three symptom scales [fatigue, pain and nausea and vomiting], as well as six single symptom items [dyspnea, loss of appetite, insomnia, constipation, diarrhea and perceived financial impact]. Most of the items were scored on a four-point interval scale ranging from 1 (“not at all”) to 4 (“very much”), while global HRQOL was scored on a seven-point interval scale ranging from 1 (“very bad”) to 7 (“excellent”). The EORTC headquarters provided the current study with permission to use the instrument. The study participants received the questionnaire from the nurse in charge upon their arrival at RKHRC at the baseline, at T2, T3 and T4. At the one-year follow-up, the instrument was mailed to participants, together with a pre-stamped envelope.

### **Physical capacity**

Because EORTC QLQ-C30 was initially developed for measuring HRQOL in cancer patients during treatment, the physical functioning (PH) dimension in particular, as well as some of the symptom scales are tailored to challenges related to cancer treatment that are not necessarily the same as those in survivorship (191, 221). Based on this, objective measurements of physical capacity were included in the current study. Tests of physical capacity are also normally included both in clinical practice and in research to tailor exercise programs and for measuring participants’ improvements, as well as to compare results across interventions (87, 89, 97). Such tests are also important as feedback for empowering and motivating patients during the rehabilitation process (48, 156, 166). As most definitions of physical capacity include an individual’s muscle strength, lung capacity, physical fitness and BMI (170), we operationalized physical capacity according to these concepts.

However, physical capacity can be measured in several ways and there is no standard measurements used in cancer rehabilitation (87, 89, 97). A multidisciplinary team consisting of a specialist in rehabilitation medicine, a physiotherapist specialized in cancer care and a sports educator decided that the following tests were feasibly objective measurements of

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physical capacity in this study:

- The Astrand 6-minute cycle test is a submaximal aerobic fitness test. The heart rate is measured every minute while pedaling at a constant workload for six minutes and steady state heart rate is determined (224).
- Lung capacity (FEV<sub>1</sub>) is the maximal amount of air a person can forcefully exhale in one second, measured by spirometer (225).
- As a test of general muscle strength, a handgrip test was conducted by measuring the maximum isometric strength of both hands and the forearm muscles with a dynamometer (Grippit) (226).
- Body mass index (BMI) was used as a measure for human body shape and thus measured participants' weight (kg) and height (cm). BMI was then calculated by dividing the individual's weight (kg) by the square of their height (cm<sup>2</sup>) (97)
- Physical exercise in-between residential stays was logged through self-reports noting time (minutes) and intensity (Borg Rating of Perceived Exertion) (97, 194), and sent to the RCHRC every 14 days (Appendix 4).

The above tests are recommended and widely used within both clinical practice and research, and shows adequate validity and reliability, and also has established reference values adjusted for age and gender for the three first tests (224, 225, 227). These tests were therefore assumed to be feasible for testing YACS. The RCHRC also had the required equipment and trained experienced professionals for performing the tests.

## 6.5 Data analyses

In a concurrent parallel design, the qualitative and the quantitative data are analyzed independently, using approaches best suited to the research questions, before the strands are connected (199).

### 6.5.1 Analyses of qualitative data

Qualitative data was applied in Paper I and Paper II. Data included in Paper I consisted of 20 interviews, representing 304 transcribed pages of text. Data included in Paper II consisted of 16 interviews (participants who had completed all four COPM measurements), representing

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214 transcribed pages of text. As the aim in both papers was to understand the meaning of individuals' experiences with a phenomenon, systematic text condensation (STC) was used to analyze the data (199, 204, 205, 228). STC represents a descriptive and exploratory method for thematic cross-case analysis of different types of qualitative data, such as interview studies and analysis of written texts (205, 228). Furthermore, STC represents a pragmatic approach inspired by phenomenological ideas, wherein various theoretical frameworks can be applied and is thus in line with the philosophical basis of a mixed-methods approach (205, 228).

STC is a four-step analysis that includes 1) gaining a total impression; 2) identifying units of meaning; 3) abstracting the contents of individual units of meaning; 4) summarizing their importance (205, 228). Analysis of qualitative data does not, however, involve distinct steps in a fixed linear approach, but engages the researcher in an interpretive (hermeneutic) process between the individual's expressed experience, theory and the researcher's pre-understanding (200, 203-205, 214). Furthermore, the literature also highlights that qualitative analysis already starts when planning the study, continues when creating the interview guidelines and proceeds throughout the interviews, through the writing of field notes, as well as during transcription of the interviews (op.sit). In analyzing the data, it was therefore considered a strength that the candidate both performed and transcribed all the interviews, as this is considered to enhance the validity and the transparency of the data (199, 204, 214). In line with this, the field notes were also important in these analyses, because they illuminated reflections on important themes and nuances arising during the interviews, and were taken into consideration during the analyses (204). During the analyses, both the candidate and the supervisors were aware of the researcher's pre-understandings, specifically those related to previous professional and personal experiences, as well as theoretical and professional standpoints (see section 8.3.2). Therefore, these pre-understandings were included in the discussions throughout the analyses (228).

Two of the supervisors (T.B.L. and I.H) along with the candidate coded and analyzed the data separately in Paper I, while all three supervisors and the candidate followed the same procedure for Paper II. No themes were identified prior to the analyses processes (210). All the findings were discussed throughout the analyses processes in order to reach an agreement. Consensus was reached for all interpretations, known as coding and intercoder

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agreement (204, 205). According to the steps in STC, the interviews were first read in order to obtain a general impression of the topic in focus. Secondly, the interviews were re-read and units of meaning or themes were extracted. The extracted units of meaning were coded into the NVivo 9 software package as nodes (229). Then, all interviews were re-read and every quotation associated with the single node or code was connected. Following on, an overview of all codes and their connected citations provided an overview of what the YACS had talked about, helping to validate the analyses (204, 214). Thirdly, these codes were then condensed into groups and subgroups using an analytic spiral between the identified codes. An overarching theme was extracted for both papers (Paper I: “Meeting reality” and Paper II: “Goal achievement and increased participation”). These overarching themes were further elaborated by four and three main-topics, respectively. The main-topics included several sub-themes; each theme was then examined and its essence described. The findings were summarized and direct quotations from participants were used to illustrate the findings. The quotations were translated from Norwegian to English as accurately as possible to ensure that they captured the participants’ exact meaning. The procedures for the analysis of the findings including an overview of the process (the coding tree) are outlined in Table 4 in Paper 1 and in Appendix 7 for Paper II, thereby allowing for transparency (204, 210, 228).

### **6.5.2 Analyses of quantitative data**

All quantitative data was coded, verified and statistics calculated using the Statistical Package for the Social Sciences Software (SPSS version 19.0) (230).

The total score of COPM was calculated according to the manual by adding together the respective points for performance and satisfaction of all problems, divided by the number of problems at T1 and T4 (183). The difference between the scores was calculated by subtracting performance and satisfaction scores at T1 from the respective scores at T4. These final scores provided a value for participation and satisfaction with participation. To enhance the validity of the data, we chose to include only those participants who attended all four measurements in the analyses of COPM, outsourcing missing data as a problem in Paper II. Spearman’s rho ( $\rho$ ) showed a strong correlation between performance and satisfaction both at T1 ( $\rho = 0.62 P > .001$ ) and T4 ( $\rho = 0.89 P > .001$ ). An increase in score of two points or

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more indicated a clinically significant change and thus represented increased participation (217).

According to the manual, the EORTC QLQ-C30 items were calculated following a linear transformation procedure to the scales ranging from 0-100 (231). A higher score represented a higher quality of life at the global and functional scales, as well as a higher level of fatigue. The instrument appeared to be easy to complete and there were few missing values.

According to the manual, missing items for EORTC QLQ-C30 ( $n=3$ ) were calculated through the mean, because at least half of the items from the scale had been answered (231). Missing forms due to dropouts were operationalized as “missing” in the dataset. A Kruskal-Wallis test showed no significant differences between the dropouts and the completers at T1, and T2; this was interpreted as missing data not having had a serious effect on this study (203, 232). Reliability, using Cronbach’s alpha ( $\alpha$ ), indicated strong internal consistence ( $\alpha = 0.7-0.9$ ) for PF, RF, EF, SF and fatigue, and acceptable internal consistence for CF and global HRQOL ( $\alpha$  between 0.5-0.6). Analyses of concurrent validity with Spearman’s rho ( $\rho$ ) showed a strong correlation ( $\rho > 0.6$ ) between the different dimensions and global HRQOL, except for EF ( $\rho = 0.4$ ) and CF ( $\rho = 0.3$ ). These correlations were comparable to a sample of cancer patients at stages I-II (221). According to the scoring manual, clinical significance may be interpreted as changes or differences in scores, where: 5-10 = little change; 10-20 = moderate change;  $>20$  = large change (231).

The results of the physical tests (physical fitness, lung capacity and muscle strength) were converted to a percentage of the predicted normal score considering gender and age, and was adjusted for the dominant hand for muscle strength tests (224, 225, 227).

Normality for all HRQOL data was assessed through examinations of skewedness and kurtosis. Most data had standard scores of less than 2.52 (1% level), which indicate normal distributions (203, 232). The exceptions were question 3 in PF (difficulties with a short walk), as well as some of the symptom scales (appetite, vomiting). We therefore chose to report only on the global HRQOL, the five functional scales (PF, RF, CF, EF, SF) and one symptom scale (fatigue), because these scales are interpreted as most relevant for participants who have completed primary treatment for cancer (233). These dimensions are also seen as more robust than single symptom questions (221, 231).

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Despite the fact that most of the data were distributed normally, non-parametric statistics were considered most appropriate, due to the small sample size of the study and to reduce the likelihood of type-2 errors. All statistical tests were two-tailed with statistical significance defined as  $P < .05$  (203, 232, 234).

Descriptive statistics included means or percentages, standard deviations [SD] and different ranges were used to describe the socio-demographic and medical variables in all three papers, as well as baseline results for COPM, EORTC, physical tests and self-reported physical activity (203).

The Wilcoxon matched-pairs signed-ranks test was used to calculate changes in performance and satisfaction from T1 to T4 (Paper II) (203, 232). This test was also used to examine the changes in the different dimensions of the EORTC QLQ-C30, as well as changes in physical capacity from the baseline (T1) to each of the four post-tests (T2, T3, T4 and T5) (Paper III).

Spearman's rank correlation ( $\rho$ ) was used to test the relationship between satisfaction and performance between T1 and T4 (Paper II) (203, 232). This was also used to test the relationship between the EORTC QLQ-C30 scales at all measurements, between the single items and the dimensions, between the different dimensions and global HRQOL, between the EORTC scales and socio-demographic and medical variables, as well as physical parameters (Paper III).

Mann-Whitney U tests were used to compare categorical data between groups (Paper III) (203, 232).

Cronbach's alpha coefficient ( $\alpha$ ) was used to determine the internal consistency reliability for EORTC QLQ-C30 (Paper III) (203, 232).

Effect size ( $d$ ) was calculated to examine the power of change within the different dimensions of the EORTC QLQ-C30 and physical capacity from the baseline (T1) to each of the four post-tests (T2, T3, T4 and T5) (Paper III) (203). The effect size represents a standardized measure of change over time, calculated by dividing the difference between pre-test and post-test scores by the SD of the pre-test score (186, 203). Calculating effect size is highly recommended for use in rehabilitation research when comparing results



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between studies (op.sit). The effect size was interpreted against Cohen's criteria, where  $d > .20$  indicated a small effect,  $d > .50$  a moderate effect and  $d > .80$  a large effect (186).

As we were not able to establish a control group, using references or norm data made it possible to compare the present study's HRQOL scores (221). Since norm populations are often accused of consisting of older people that also have other health complaints, we decided to use two different samples and thereby compare our results with one healthy norm population and one cancer population within the same age-frame (223). The first sample was extracted from the Norwegian norm population (N=1965) and comprised 631 individuals (353 males and 278 females, mean age 39 (aged between 19 and 86) years and reported no health problems (223). The second sample was an international cancer sample retrieved from EORTC. This sample included 5237 individuals (2603 female, 2347 male, 287 unknown gender). This sample included individuals below 50 years of age, but the mean age was unknown; however, it was indicated that 35% were below 40 years of age and had different cancer diagnoses in different stages (221). In comparing the present study's results with these populations, we applied the Jacobsen and Truax principle, which states that a patient should be in the normal range of function following clinical intervention (186). This means that the patient's score after clinical intervention should be closer to the mean of the functional population (the Norwegian norm population) than to the mean of the dysfunctional population (the cancer population). Thus, the dysfunctional and functional populations served as anchors for determining recovery status (186).

### **6.5.3 Merging quantitative and qualitative data**

Paper II included a concurrent parallel design with the quantitative data from COPM at the baseline and at the end of the program (T4), and the qualitative data from in-depth interviews from T4. The first two steps for analyzing a concurrent design are analyzing the quantitative and the qualitative data separately, as previously described. The third step in this analysis was to identify content areas that were represented in both data sets and compare, find contrast and or/synthesize the results (199). During this process, the amount and content of the goals that were present in both the quantitative and qualitative data sets were examined and structured. Then, the qualitative data set was re-read to determine which participants mentioned goals, thereby enabling us to discover the total amount of goals, as well as the

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prioritizing of goals. Furthermore, these goals were analyzed and related to the three areas (participation, self-care and leisure) of participation defined according to COPM (217). Through this analysis, the prioritized areas for participation could be identified (199). The results of this analysis process are outlined in Table 3 in Paper II. In the fourth step, the analyses were based on the changes of COPM from T1 to T4, and the qualitative data was analyzed in relation to these changes. Here, data-convergences and divergences were searched for to produce a more complete understanding of the data (199). The results of these analyses are presented in the discussion section of Paper II.

The same procedure was used in the overall analyses of the three papers. The results of the analysis process is presented in Chapter 7.4 and discussed in section 8.

## 6.6 Ethical considerations

Research on human beings is governed by strict regulations and legal acts (203, 235, 236). The research protocols for the current study were approved by the University of Bergen and by the management of the RCHRC. The study was recommended by the Regional Committee of Research and Ethics, but fell outside the Act on Health Research and could be conducted without their consent (Appendix 8). Due to a misunderstanding, the application to the Norwegian Social Science Data Services (NSD) was delayed, but NSD nonetheless approved the study (Appendix 8).

Ethical issues are an integral part of all phases of the research process (203, 214). The current study was conducted in compliance with the Declaration of Helsinki (235) and the requirements for data processing outlined in the NSD (236). However, quantitative and qualitative methods may imply different ethical issues, for example, issues regarding confidentiality, potential stress and closeness (199, 204, 214). These issues were addressed throughout the entire study: All professionals involved the study had extensive experience as researchers or clinicians in the field of cancer, young adults and rehabilitation, as well as the competence for securing ethical and safe conditions for all YACS. We assumed that the project would not harm the participants (237). As this was an inpatient rehabilitation program, skilled professionals could immediately attend to any problems that arose.

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All participants were given oral and written information about the study; participation was voluntary and the data was kept anonymous (Appendix 9). Everyone provided their written, informed consent when they were enrolled in the study (Appendix 9). Confidentiality was ensured in several ways: the candidate was not involved in the intervention and only met the participants during the interviews. Confidentiality was also ensured through a coding system, where numbers replaced the names of participants. The list connecting names and numbers was kept in a locked cabinet in a different place than the encoded data.

The numbered questionnaires were delivered to the participants by the project coordinator, who was not involved in the analyses of the data and was returned to the front desk at RCKRC. The participants filled out the COPM together with one of two trained therapists and the results were given to the candidate as encoded files. The physical tests were also performed by a sports-educator who was not involved in the intervention and the results were given to the candidate as encoded files. To hide the identity of participants within the interviews, only numbers and no names or background data were recorded. When the interviews were transcribed, all names and geographical locations were omitted. All the completed questionnaires were stored in locked cabinets at the RCHRC. All encoded data, as well as the anonymously recorded and transcribed interviews were digitally stored on a password-protected computer only available to the candidate (203, 235).

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## 7 FINDINGS

Here, the findings from the three papers are first presented, followed by the merged data, in which the findings are connected.

### 7.1 Paper I: “Meeting reality”

The objective of this study was to explore how YACS experienced re-entering everyday life after cancer treatment. Using a qualitative, phenomenological approach, 20 YACS were interviewed at the baseline of the rehabilitation program. “Meeting reality” was identified as a bridging theme. The participants experienced re-entering everyday life after cancer treatment as much harder and more demanding than they had expected and experienced a considerable mismatch between their own expectations and the perceived reality. This mismatch was explained through four main themes: lack of preparation, late-effects pervading throughout their entire life, lack of understanding and being neither sick nor healthy.

The participants felt that the healthcare providers had not prepared them adequately for everyday life after cancer treatment. They missed a summing up dialogue with their oncologist, information about what they could expect after finishing the cancer treatment in relation to late-effects, how to rehabilitate themselves and how they ought to re-enter work or studies again. Consequently, the participants were unprepared for the range of physical and psychological late-effects they experienced after cancer treatment; prevalent among these late-effects was fatigue. The participants experienced that the late-effects pervaded their entire life and had widespread consequences on their physical, psychological and social capacities. The participants also perceived a major lack of understanding from their surrounding environments, including families and friends, work and study networks and even healthcare providers. They explained this as a lack of knowledge about late-effects and survivorship challenges. The participants understood this lack of knowledge within their own networks, but were very disappointed in the healthcare providers, whom they expected to be experts in the subject. They were also skeptical about several different physicians performing regular follow-ups, resulting in experiencing a lack of continuity and feeling that their late-effects were not being taken seriously.

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The participants expressed feeling that they were neither in a state of being healthy or sick. Even when they no longer perceived themselves as cancer patients, they expressed a feeling of being in an "unknown" world and having been transformed into a person they did not know.

## 7.2 Paper II: "Participating in life again"

The purpose of this study was to examine whether a goal-oriented rehabilitation program increased participation in the different areas of the lives of YACS, and to explore how they described and experienced this process. We used a mixed-method approach with a convergent parallel design, in which sixteen YACS were included. It was hypothesized that the rehabilitation program would increase YACS' participation in their life situations and that the qualitative data would elaborate this process.

At the baseline, each participant was identified between two to five prioritized goals. The results indicated high goal achievement with significant ( $P<.001$ ) improvement in performance and satisfaction from the baseline to the end of the program. The mean change was 2.3 points for performance and 3.5 points for satisfaction, interpreted as clinical increased participation related to productivity (e.g., work/school), self-care and leisure activities (e.g., physical activity).

The main theme from the qualitative analyses was identified as "goal achievement and increased participation". The participants found that having goals motivated them and helped them to structure, commit to and take responsibility for their own rehabilitation process. They expressed an overall high level of goal achievement, resulting in increased participation in all areas of life by the end of the program. Three sub-themes emerged as important elements for this goal achievement and increased participation: building capacity and finding the balance between the different areas of their lives, gaining new insight and the follow-up process.

Tailored physical activity was experienced as an important factor for increasing coping and gaining control, as well as building both physical and psychological capacity. However, the participants struggled to find a balance and in distributing their energy between the different

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areas of self-care, productivity and leisure. They met this challenge by using different coping strategies such as structuring everyday life, acknowledging the importance of each area, redefining areas and prioritizing supportive friends.

The participants expressed gaining new insight as an important factor for increasing coping and control, and consequently for increased participation. This new insight was related to acknowledgement of their own responsibility for the rehabilitation process, the new knowledge they retrieved through psychoeducation, learning to use CT as a tool for discovering and coping with negative thoughts, as well as accepting their present health situation.

The follow-up process also appeared to be important for increasing participation.

Highlighted elements here were professional assistance over time, the step-by-step approach both within physical activity and CT, writing logs, the re-tests, as well as meeting other YACS.

### 7.3 Paper III: “Working toward a good life as a cancer survivor”

The aims of this study were to investigate whether a complex rehabilitation program increased YACS' HRQOL, including physical capacity and how YACS complied with the program. Here, we hypothesized that participation in the rehabilitation program would improve YACS' self-reported HRQOL at the end of the program and after a one-year follow-up, and physical capacity at the end of the program. Twenty YACS were included in this longitudinal prospective study with a pre-test and four follow-up tests over one year. A Norwegian norm population with no health complaints and an EORTC cancer population were used as comparison groups.

The results of the EORTC QLQ-C30 revealed that the participants scored substantially lower on global HRQOL, on all functional scales and higher on fatigue at the baseline than both the Norwegian norm population and the cancer population. Fatigue was significant and negatively correlated with all dimensions of EORTC QLQ-C30, with the exception of CF. There were no differences in the HRQOL dimensions based on medical or demographic data at the baseline.

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The results showed significant increases in overall HRQOL ( $P<.005-.001$ ), all functional dimensions ( $P<.001-.05$ ) and a decrease in fatigue ( $P<.000-.05$ ) and effect sizes ( $d$ ) between 0.72-1.30. The results were also clinically significant and was demonstrated as large changes ( $>20$  points) within RF, EF, CF and SF and fatigue, and a moderate change (10 to 20 points) for global HRQOL and PF within the program. At the end of the program, the participants scored better than the cancer population on all dimensions, except for CF and fatigue, and closer to the normal population. The values of EORTC QLQ-C30 were stable after a one-year follow-up. At this point, participants scored closer to the normal population and higher than the cancer population on all dimensions, except for CT and fatigue.

At the baseline, the participants scored lower than the norm on physical fitness, following adjustments for age and gender. They also scored within the lower norm on lung capacity, muscle strength and somewhat over the norm on BMI. Significant changes occurred in physical fitness ( $P<.005$ ), lung capacity ( $P<.05$ ) and left-hand strength ( $P<.001$ ), but not in right-hand strength or BMI within the program. The logs between the re-stays indicated that the participants continued with physical activity at home in excess of the guidelines provided for cancer survivors. Nevertheless, the effect sizes indicated small effects for physical fitness ( $d=0.42$ ) and strength in both right ( $d=0.32$ ) and left ( $d=0.47$ ) hands, and no effect ( $d=-0.03$ ) on BMI.

The participants showed high compliance with the different elements in the program, except for the next of kin weekend, where only nine participants received visits. Thus, both the content and the structure of the program seemed feasible for the participant program, as 17 participants completed the program; withdrawals were not related to the program.

## 7.4 Merging the results from the three papers

Merging the results of research is an essential aspect of the mixed-methods approach (199). The merging of the results of the present study provided a more comprehensive picture of the participants' situation at the baseline (T1) (Paper I, II and III), from the rehabilitation process (T1-T4) (Paper I, II and III) and from the outcomes (T4 and T5) (Paper II and III). Creswell and Clark (159) recommend developing a joint display of the qualitative and quantitative data in mixed-method, as shown in Table 3.

Table 3: The merged findings from the three papers.

Data	T1 Mean/SD	T2 Mean/SD	Home 1	T3 Mean/SD	Home 2	T4 Mean/SD	T5 Mean /SD
	<b>BASELINE</b>	<b>PROCESS</b>			<b>OUTCOMES</b>		
<b>Interviews</b>	Lack of preparation & understanding Late-effects Neither sick, nor healthy	Coping and control: - Finding the balance - Insight - Multi-dimensional follow-up			Achieving goals and increased participation		
<b>Performance</b>	4.7/1.5	6.6/1.0*****		6.8/1.2*****		6.9/1.6****	
<b>Satisfaction</b>	3.3/1.6	6.0/1.4*****		6.6/1.7*****		6.9/1.8*****	
<b>Overall HRQOL</b>	53.8/17.8	69.7/13.7***		69.7/15.5**		72.1/16.4***	74.4/17.7**
<b>PF</b>	75.7/16.9	85.6/12.4*		87.0/8.2***		86.7/12.5*	92.0/9.2**
<b>RF</b>	46.7/29.9	71.9/24.9***		67.5/29.6***		72.5/25.6***	73.3/33.8*
<b>EF</b>	60.4/23.9	77.2/16.9****		75.9/19.8*		82.4/18.1**	79.8/17.5**
<b>CF</b>	54.2/28.0	72.8/14.9**		73.7/19.5**		76.5/24.3***	71.4/25.7
<b>SF</b>	37.5/28.0	69.3/29.5****		67.5/28.0****		74.5/28.1***	75.0/26.8**
<b>FA</b>	62.8/26.0	47.9/27.3*		36.8/23.1*****		37.3/19.6***	34.1/24.1**
<b>Fitness</b>	78.9/19.4	86.3/17.3***		88.8/18.4		86.8/20.0	
<b>Lung capacity</b>	83.7/11.2	85.2/8.5		86.7/8.0*		85.5/10.0	
<b>Muscle strength (r)</b>	103.1/17.6	105.2/16.6		108.4/18.0		106.6/17.5	
<b>Muscle strength (l)</b>	101.9/18.5	105.4/18.4		112.4/22.0*		109.3/15.4**	
<b>BMI</b>	26.2/4.3	26.1/4.2		26.2/4.5		25.7/3.9	
<b>Exercise</b>							
<b>Minutes per week</b>			276.2/116		231.4/104.1		
<b>Intensity</b>			13.7/1.1		13.8/1.8		

Significance level from the baseline and to the actual point (T2, T3, T3, T5): \*  $P < .05$ ; \*\*  $P < .01$ ;

\*\*\*  $P < .005$ ; \*\*\*\*  $P < .001$ ; \*\*\*\*\*  $P < .000$ .

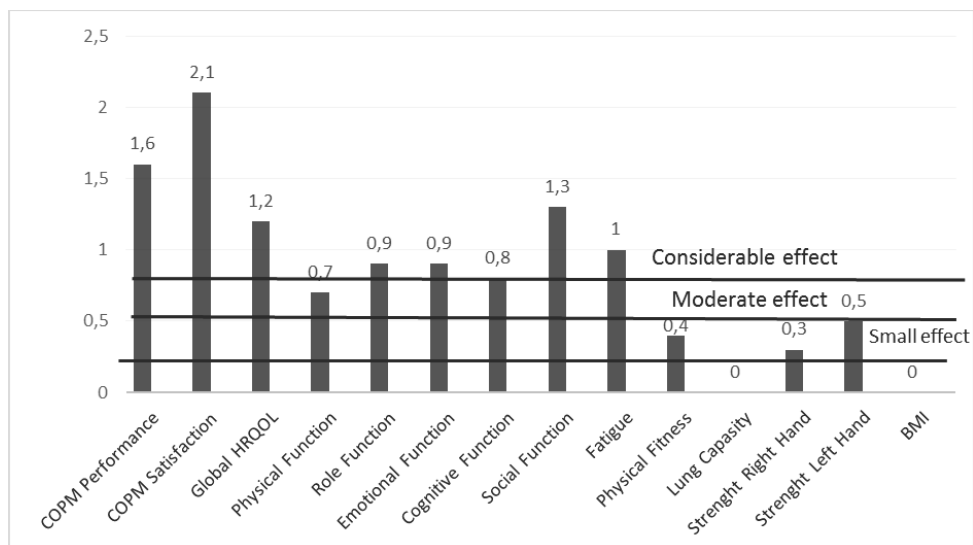


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Table 3 shows that the results from the baseline indicate that the participants were not prepared for re-entering life after cancer treatment and experienced late-effects and a lack of understanding of their present situation. The quantitative results supported these findings, since the participants scored considerably lower on all HRQOL scores than both comparison populations, and correspondingly higher on fatigue at the baseline. Furthermore, the participants scored below the norm or within the lower norm on the objective physical tests. The participants also scored low on role function (RF), which corresponds with the low level of performance and satisfaction concerning performance at the baseline, interpreted as impaired participation within their life situation.

Furthermore, Table 3 shows that the merged results from the rehabilitation process (T1-T4) indicate that the largest significant changes for global HRQOL, all functional scales, fatigue, physical fitness, performance and satisfaction with performance occurred during the first rehabilitation stay (T1-T2). The participants appeared to have continued with physical activity in excess of the guidelines for cancer survivors at home between the first stay and the first re-stay. At the first re-stay, participants' scores on all the physical parameters, performance and satisfaction with performance, PF and CF were slightly increased and fatigue had decreased. Overall, HRQOL and BMI were stable, while RF, EF and SF showed a slight decrease while participants were at home. The participants described this as a process of developing coping and control mechanisms, where finding the balance between different areas of life, gaining new insight and follow-up visits were important elements. Additionally, the participants seemed to continue with physical activity at a level in excess of the physical guidelines provided for cancer survivors between the first and second re-stay. The scores showed a slight increase from the first re-stay for performance and satisfaction with performance, overall HRQOL, RF, EF, CF, SF and fatigue, but a slight decrease in all the physical parameters, as well as in PF.

Within the program (T1-T4), the results showed a significant increase for all outcomes, except for right arm strength and BMI. The effect sizes for performance and satisfaction with performance, global HRQOL, RF, EF, CF, SF and fatigue were large and moderate for PF and left hand strength. The effect sizes for physical fitness were small, while there were no effects on lung capacity, right hand strength or BMI. These results are illustrated in Figure 8.



*Figure 8: Effect sizes of COPM, EORTC and physical capacity within the rehabilitation program (T1-T4).*

At the end of the program, the participants came on level with, or close to, the Norwegian normal population on both the physical parameters and the different dimensions of HRQOL, except from fatigue and CF. Participants reported a high level of goal achievement and experienced increased participation in all areas of life. The HRQOL results were also relatively stable or even nearer to the norm at the one-year follow-up.

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## 8 DISCUSSION

The contributions from the three papers represent a new research field in Norway focusing on YACS, making the current study, to our knowledge, one of the first studies internationally to focus on an in-rehabilitation program tailored for YACS. In addition, the discussion concerning the merged data from the three papers may add strength to the study. Since the main outcomes of this study were the evaluation of HRQOL and participation, the merged baseline and outcome results are discussed based on these concepts. This section ends with reflections on the study's methodological strengths and limitations.

### 8.1 What do the merged results reveal about the participants' situation at the baseline?

#### 8.1.1 Physical and psychological factors influencing HRQOL and participation

In line with previous research (1-3, 25, 40), the participants reported a range of physical and psychological late-effects after cancer treatment (Paper I and III) and as such, experienced re-entering everyday life after cancer treatment as much harder than they had expected. The participants described their late-effects from a holistic perspective (151), where fatigue was expressed as the main problem outlined both in the qualitative (Paper I) and quantitative results (Paper III). This was because the fatigue was diffuse and difficult to describe and understand, but mostly because it pervaded their entire lives. In line with these findings, previous research has shown that YACS seem to be especially exposed to fatigue (6, 44, 46, 47). Research indicates that high levels of fatigue and other late-effects are connected to the distinctive types of cancers in YACS and the multimodal and long-lasting treatments the participants had experienced (1, 3, 25, 28). These results comply with ICF, illustrating that a health condition, for example, cancer and cancer treatment may influence YACS' body functions and structures in a negative way, appearing as physical and psychological late-effects (81). Interpreted within Ferrell's framework, these results indicate impairment in YACS' physical and psychological well-being (192).

Following both ICF and Ferrell's framework, impairment in one dimension may negatively influence other dimensions, either directly or indirectly (81, 192). According to ICF,

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impairment in body functions and structures may lead to activity and participation restrictions. These connections appears to have been confirmed by the merged baseline results, which showed low scores in RF, SF and physical capacity, low scores in participation, that most participants had been on sick leave or were working/studying only part time, and on their elaboration of reduced capacity within self-care and their professional and social lives. This is supported by international research on YACS that document the severe challenges of daily living (36), low levels of physical activity (93, 238), education and work interruptions (1, 29, 50, 72), as well as impaired social functioning (6, 50, 65). These results also appeared to confirm Ferrell's framework, stating that impairment in physical and psychological well-being may impair overall HRQOL, which in our study was documented as a low level of overall HRQOL (Paper III). According to Ferrell, impairment in overall HRQOL may in turn impair social and spiritual well-being, in our study documented as low scores on SF, RF, low work/study attendance (Paper III) and feelings of isolation and uncertainty (Paper I).

These merged baseline results indicated that it was very difficult for the participants to re-establish the regular roles and obligations they had fulfilled within their everyday lives prior to their cancer treatment (20). These results call for increased attention to YACS' physical and psychological late-effects and their consequences for both HRQOL and participation after cancer treatment. They also pinpoint the importance of having a holistic view of health in survivorship care.

### **8.1.2 Environmental/social factors influencing HRQOL and participation**

Both ICF and Ferrell's framework acknowledge that contextual factors may influence HRQOL and participation, even if these contextual factors are outlined differently (81, 192). ICF divides contextual factors into environmental and internal personal factors, where the environmental factors are related to the external or social environment. Consequently, influence from environmental factors may also be a factor in explaining and understanding an individual's participation (81). In Ferrell's framework, the influence of contextual factors are outlined as social well-being, where impaired social well-being may negatively influence overall HRQOL (192). Consequently, the lack of both preparation for survivorship and

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follow-up supported by low scores in SF and RF likely influenced YACS' HRQOL and participation at the baseline.

Even when participants mainly related their present situation to the late-effects of cancer treatment, they raised a clear voice against the healthcare professionals who did not provide them with advice and the necessary tools for managing everyday life after cancer treatment (Paper I). Previous research has documented that the transition from cancer treatment to survivorship is crucial for long-term health (39, 85). Being in a risk population, YACS are particularly vulnerable during this transition (2, 39, 85, 239, 240). The participants called for a summative dialog with their oncologist, information about late-effects and rehabilitation, and especially clear advice on how to re-enter work or studies, and take part in physical activity. They mainly related their lack of preparation to healthcare professionals' incomplete knowledge of survivorship issues and a salient biomedical focus on cancer as a disease. International research shows the same results where cancer survivors ask for information and rehabilitation interventions, while healthcare professionals display limited knowledge of survivorship issues, and do not screen for rehabilitation needs or refer participants to rehabilitation programs (8, 15, 73, 78, 117, 241, 242). These results highlight the need for following up the international approach to implementing cancer survivorship plans in Norway. Such plans include a treatment summary, information about potentially late-effects, a plan for individual and holistic follow-up care, and health promoting practices (85, 213, 243). Implementing survivorship plans for a more structured follow-up seems especially important for YACS, based on their vulnerable period of life being characterized by instability, heterogeneity and frequent changes (19, 20). Such a plan may therefore help YACS to gain a realistic understanding of their present situation, help them to structure re-entering everyday life and prioritize what to focus on. A survivorship plan may also empower YACS to be feel more in control and better able to cope with their new life situation, as well as securing individual follow-ups, and reducing marginalization (82, 128, 167, 244).

Another environmental or social factor with potential for negative influence of the YACS' participation and HRQOL relates to the finding "lack of understanding". This lack was mainly experienced as a discrepancy between the informants' own perceived late-effects and the external expectations that they were cured and healthy. Close relationships and social

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support were documented as crucial factors for coping and adjustment to survivorship for YACS (57, 245, 246), as well as for health and HRQOL (64). In contrast, YACS experienced a lack of understanding from their close networks, which had also been found in previous research, especially for those reporting a high symptoms burden (65, 68, 123, 129, 247). In line with the participants' interpretations, this may reflect limited knowledge of cancer survivorship issues and stressing the need for raising this knowledge within the general population (1, 248).

However, a bigger concern was the participants' experiences of being let down by healthcare professionals who performed followed-ups on them (Paper I). Factors like trivializing symptoms, demonstrating limited knowledge of late-effects and a lack of continuity in follow-ups appeared to have negatively affected participants' experiences. These results were in line with previous research (1, 76, 85, 248) and consequently, in the present research, an underestimation of the impact of late-effects on HRQOL and participation was evident (44, 242). These findings are unsettling, because these factors may reduce YACS' possibilities for coping, improving HRQOL and participation in their various life situations (36, 65, 240, 249).

In Norway, the variation in follow-ups of cancer survivors is substantial, but in general, it includes short appointments with a physician/oncologist focusing on surveillance for recurrence (213). In line with our results (Paper I), research indicates that the present follow-up of YACS is disease-oriented and limited, and that follow-up visits in contrast requires multi-disciplinary services and a holistic focus (15, 74, 250). This seems especially important in the case of YACS, being in a risk population and at a vulnerable time of life. A unilateral focus on the surveillance of recurrence in follow-ups may lead to a communication gap and risks for missing out information important for YACS' participation and HRQOL (1, 2, 81). These results also actualizes the ongoing discussion of how to follow-up on the increasing number of cancer survivors (14, 85, 250). Even if several models are discussed, interesting new research indicate that nurse-led follow-ups appear to provide a more holistic focus that is in line with cancer survivors' needs without presenting an increased risk for recurrence (251, 252).

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### 8.1.3 Personal factors influencing HRQOL and participation

According to ICF, personal factors like age, education and current experiences may also influence a person's participation in their life-situation (81). In Ferrell's framework, these personal factors are not as clearly indicated; but included as factors within psychological, social and spiritual well-being. All these factors have the potential to influence HRQOL (192). In line with these frameworks, it is therefore likely that participants' specific period of life, their coping styles and their experiences of cancer treatment may have negatively influenced their HRQOL and participation.

The participants had lived through experiences of cancer and cancer treatment, which has been documented as being especially distressing and life changing for YACS (36, 38, 46, 51, 53, 247). They expressed discomfort concerning experiences throughout their cancer journey about their appearance (e.g., losing a breast), as well as concerns for the future related to study and work, fertility and fear of recurrence. Consequently, they felt that the cancer experiences had transformed them into a person they no longer recognized. The same findings are elaborated by Hølge-Hazelton (247) and described as "the new me". These findings may have led to marginalization (20), as YACS would have had to deal with other issues than their friends, leaving them feeling different and isolated from them. Such an experience of marginalization may therefore affect HRQOL and participation negatively (20).

Coping style and degree of control are, according to both ICF and Ferrell's framework, regarded as important factors for how an individual experienced and handled health impairment (82, 140, 181). Research has shown that YACS use a range of coping styles to manage their life situation after cancer treatment, where striving for normality seems to be a common approach (18, 21, 58, 161). Research has also shown that a high degree of uncertainty and a lack of knowledge, follow-up and social support can negatively affect coping (53, 65, 253). Consequently, the experienced lack of preparation and follow-up may have left YACS without sufficient knowledge and skills to handle their "new normality" after cancer treatment, rendering them unempowered and with fewer possibilities for coping with their present situation (156). According to CATS, coping with challenging situations is dependent on earlier experiences and a minimal gap between expected and perceived reality

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(164). The results of the current study revealed that YACS experienced a considerable mismatch in several areas, for example, related to late-effects, social support, follow-up and re-entering work or school – all factors that may have affected their coping abilities in a negative way (123, 164). This is in line with both Davis (140) and Rustøen (190), who state that a mismatch between expectancy/hope and reality may lead to decreased HRQOL. According to CATS (164), repeated negative experiences can lead to a negative coping loop. One could therefore suspect that some of the participants experienced a negative coping loop as an explanation for their low scores in HRQOL and participation.

In summary, the merged results from the baseline appear to support the first two steps in the study's conceptual model (Figure 4), indicating that cancer and cancer treatment in young adulthood may impair HRQOL and participation. The merged qualitative and quantitative results appear to support one another and provide a more comprehensive picture of the participants' situation at the baseline, more so than a single strand would. The merged results show that YACS experienced multidimensional challenges that were likely to have been impacted on by medical, demographical and contextual factors. In line with ICF and Ferrell's framework, these factors seem to have influenced YACS' participation and HRQOL in a negative way, and when taken together, is able to explain why participants experienced "meeting reality" as challenging as they did. Results also indicated that this process was experienced as hard "personal work" alongside fulfilling their normal roles, expectations and obligations in everyday life (82). Not being properly prepared for this work may thus be extra challenging for YACS, because of their limited life-experience, unstable social and educational/work situations, as well as their limited contact with healthcare professionals guiding them through this situation (1, 2, 19, 20). These results also appear to verify that the participants were in need of rehabilitation at the baseline, as recommended within the literature (79, 171).



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## 8.2 What do the merged results reveal about the participants' situation after rehabilitation?

The rehabilitation program was complex and developed to target the multidimensionality within HRQOL outlined in both Ferrell et al.'s (192) framework and participation, as described in ICF (81, 181). It is therefore logical to discuss the outcome results in line with this multidimensionality and to try to illuminate which element in the rehabilitation program seem to have the potential for influencing its different dimensions, and discuss whether the improvements were related to the interventions or the influence of time.

### 8.2.1 Improvements in physical and psychological factors influencing HRQOL and participation

It follows from both ICF and Ferrell's framework that interventions related to strengthening bodily functions and structures, interpreted as physical and psychological well-being, have the potential to improve HRQOL and participation (81, 192). The outcomes of the program seem to support these connections, documented as significant increase in PF, EF, CF and a corresponding decrease in fatigue, as well as an increase in physical capacity (Paper III and II). The effect sizes of these outcomes were large for fatigue, EF and CF, moderate for PF, physical fitness and left hand strength and small for right hand strength; no effects were shown on lung capacity and BMI.

These results appear to be in line with the mechanisms of both ICF and Ferrell's framework, where improvement in one dimension may have a positive effect on other dimensions. It follows on from ICF that improvements in bodily and structural dimensions facilitate improvements in activity and participation (81). In this study, this was demonstrated by the logs showing increased physical activity between the re-stays at a higher level than the norm set for cancer survivors (103). Supporting this, the qualitative data revealed that building physical capacity was an important task in the rehabilitation process. The increased participation was also documented as significant increases in RF and SF, as well as an increase in participation. The effect sizes were large for SF, RF and participation, and 14 of the 17 participants worked or studied full-time at the end of the program, also supporting an increased level of activity and participation.

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In line with Ferrell's framework, the improvements in physical capacity seem to have enhanced the participants' physical well-being by effecting improvements in function, ability and strength, and a reduction in fatigue (192). Furthermore, the improvements in CF and EF function, as well as overall HRQOL, indicated improvement in the participants' psychological well-being and control. Increased control was also a clear finding in Paper II. The improvements in SF and RF and the increased participation and work status also indicated improvements in the participants' social well-being. These positive changes, in addition to increased insight may according to Ferrell's framework, may also have increased participants' spiritual well-being (192).

In light of empowerment theory, the results of the present study indicated that participants gained greater control and ability to make decisions and perform actions affecting their health in a positive way (140, 156). This was confirmed by the qualitative and the quantitative results regarding participation (Paper II). According to Zimmerman and Warschausky (156), increased participation will be an outcome of an empowering process. In line with our results, they state that empowered people feel a sense of control, understand their environment and current health situation, and become active in efforts to exert control and participate in life situations (op.sit). Within empowerment and coping theories, several different interventions may facilitate empowerment and coping (82, 140, 156). With reference to the level of bodily functions and structures enhancing participation in ICF, or physical and physiological well-being in Ferrell's framework, it seems that physical activity, goal setting and individual follow-up were important elements for enhancing these improvements (140, 165, 166).

Within cancer rehabilitation, physical activity has been documented to have positive effects on both physical and psychological factors such as physical fitness, strength and lung capacity, as well as a reduction in fatigue, anxiety and depression (45, 80, 89, 94, 97). The results from the present study appeared to confirm this. First, improvements in physical capacity cannot be achieved without physical exercise (89); supporting the notion, that physical activity was an important element in the intervention. Secondly, participants showed high compliance to physical activity (Paper III), indicating that the physical intervention was feasible and targeted to their needs. The tests for finding participants' present level of physical activity, the individually tailored exercise program, as well as

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performing both group and individual sessions appeared to be significant factors, as supported by previous research (105, 254-256). These findings also pinpoint the importance of professional follow-up, as outlined in both theories of rehabilitation (10, 82) and empowerment (156, 159).

In line with both ICF and Ferrell's framework, preceding research has demonstrated that physical interventions also have positive impacts on participation such as return to work and social functioning (132, 254). The improved results shown within physical parameters and participation support these connections. Here, the decrease in fatigue seems to play an important role, because this is associated with improvements in physical parameters (45, 92). Supporting this, the participants expressed that building physical capacity was an important factor for reducing fatigue and facilitating participation (Paper II). However, a crucial finding here was "finding a balance". The participants expressed that they struggled with establishing a balance between participation in the different areas of life such as exercising, working/studying and being with family and friends. Thus, reduced fatigue and increased participation appeared to be guided by finding this balance, which is also supported by previous research (111, 255). These results set the focus on the rehabilitation process as personal work that required YACS' attention, effort, engagement and energy. Previous research has revealed that cancer treatment is seen as fulltime "work" (257), a factor that has, however, barely been discussed within rehabilitation (82). Instead, cancer rehabilitation up until now appears to have had a predominantly one-dimensional focus of the return to work (258). Such an approach may negatively influence participation in other areas, such as building physical capacity or social participation and thus provide a fragmented picture of holistic participation (180-182). In line with this, Norman (82) states that the personal work done in rehabilitation is vital and necessary for giving meaning to the life to be lived following a disruption to said life. Given that rehabilitation is work that requires energy, this calls for more attention to be focused on enabling cancer survivors to find such a balance.

Concurrent with physical activity, the merged results indicated that setting goals were important for increased physical and physiological function and therefore for HRQOL and participation (Paper II and III). These results are in line with theories of rehabilitation, health promotion and empowerment, where setting realistic goals is seen as a main intervention for achieving independence and participation (10, 81, 140, 156, 166). The participants set

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specific goals related to self-care, leisure time and productivity. These goals were comparable to goals set by other YACS after cancer treatment; however, in contrast to our study, this research did not elaborate on whether the YACS achieved their goals (77, 120, 122). However, the YACS in our study found it difficult to set specific goals, because they were unfamiliar with their present situation and experienced multidimensional challenges, making it difficult to choose specific priorities. With assistance, most of the participants prioritized building capacity and physical goals first, again underlining the importance of physical activity. However, the totality of 58 goals across the participants stressed the YACS' individual challenges and addressed the importance of targeting what was important for each individual (1, 2, 166). The significant changes and high effect sizes within participation, together with the qualitative results of "achieving goals and increased participation" supported that the participants experienced high goal achievement at the end of the program. The YACS expressed that setting goals helped them to structure their rehabilitation process and provided motivation, continuity and responsibility for their own rehabilitation process. In terms of physical activity, the guidance and help received from rehabilitation providers in prioritizing and setting realistic goals appeared to have been important. Likewise, research has found that healthcare professionals are crucial to assisting cancer survivors in adjusting and finding new and meaningful goals for enhancing their well-being (119, 121). This is also comparable to theory of rehabilitation, which outlines it as being a goal-oriented process in cooperation with healthcare providers (10, 140). Locke and Latham (166) emphasize the importance of feedback, stating the vital role of individual follow-up and for focusing on what is most relevant to the individual. Clear goals are supposed to provide direction in the rehabilitation process (10, 140), but these may also limit the ability for being open to new and other solutions or for changing approach or focus when appropriate. Repeated goal reassessment may therefore be seen as a strength of the current study that promoted openness and provided the opportunity for changing direction if needed.

The outlined results may also be interpreted in light of CATS (164), where positive coping experiences, for example, within physical activity and experiences of goal achievement, may have led to positive outcome expectancies and enhanced coping. Furthermore, professional guidance and knowledge of how to exercise and balance activity can also be seen as factors that strengthened the YACS' coping abilities (164).

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## 8.2.2 Improvements in environmental/social factors influencing HRQOL and participation

Based on ICF and Ferrell's framework, interventions related to environmental or social well-being also have the potential to increase HRQOL and participation (81, 192). This study's intervention targeted environmental or social well-being through peer support, individual follow-up and a next-of kin weekend. The participants reported a significant increase and a large size effect in SF at the end of the program. The qualitative data highlighted the importance of the follow-up process including the re-stays, collaboration with the rehabilitation providers and peer support. Research documents that peer support has a positive effect on psychosocial function, quality of life, as well as fostering supportive exchanges and empowerment (38, 124, 125). Our results supported this, as the participants reported that meeting other YACS was very important, because it gave them the opportunity to share experiences, motivate, and empower each other during the rehabilitation process. This element may be especially important for YACS, as cancer at this age is rare and they seldom have the opportunity to meet other YACS during treatment (25). In line with this, Rabin et al. (130) found that YACS asked for interventions that provided social support, especially from other YACS, in order to meet the multiple competing demands of young adulthood.

Close relationships and social support have been documented as crucial factors for survivorship coping (56, 65, 246). However, participation in the next of kin weekend was very low, indicating that this element in the intervention had a limited influence in strengthening YACS' HRQOL and participation. The participants explained the low rate of next of kin in several ways: some participants had small children and lived a long distance from the RCHRC, and thus found it difficult to attend. Others would not involve their parents in the rehabilitation process, as they wanted to be viewed as independent adults (20). Some had newly formed close relationships and found it too early to involve their new partners in the rehabilitation process, while others simply found it inconvenient. These explanations explored the variety in demographic variables characterizing young adulthood and illustrated YACS' vulnerability in relation to their social environment (20). However, the next of kin who did come to visit valued getting more information and knowledge about YACS' rehabilitation process and meeting other next of kin.

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Although the rehabilitation team cooperated with both the participants' local physicians, social services, cancer nurses, employers and schools, in addition to the low attendance at the next of kin weekend, the intervention appeared to primarily target the participants and not their environment. This may therefore be a weakness in the intervention and in residential rehabilitation. Alternatively, the split between the residential and home-stays may have weighed against this disadvantage. The intervention may therefore have empowered the YACS at the first stay, after which they "practiced" at home, received feedback and further empowerment at the re-stays (156).

While the intervention did not seem to target the participants' home environments directly, the positive outcomes related to this area may still be explained using the stress-buffering theory (64). According to this theory, peer support and the follow-up from the healthcare providers at the RCHRC may have been important facilitators for social support and thus may have enhanced coping and empowerment (156, 164).

According to both ICF (81) and Ferrell's framework (192), contributions from other dimensions may also have had a positive impact on environmental or social factors. It is, for example, likely that increased knowledge and coping may have helped YACS to learn how to include or manage their networks during their rehabilitation process. This is supported by the qualitative results in Paper II, where the YACS used different strategies for balancing their participation, such as making special appointments with their friends or distancing themselves from unsupportive friends. Furthermore, their increased physical capacity may also have enabled them to participate within their networks in a more normal and regular manner after rehabilitation (64).

### **8.2.3 Improvements in personal factors influencing HRQOL and participation**

The current study's merged results showed that the participants reported improvement in participation, while the qualitative results also expressed increased control and coping at the end of the program (Paper II). In light of theories of empowerment and coping, psychoeducation appeared to be a key intervention or promoting control and coping, and for becoming independent (156, 164). Research suggests that completion of cancer treatment is a "teachable moment", where survivors may be more receptive to messages about health behaviors (239). The psychoeducation in this study primarily targeted coping styles and

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strategies, increasing knowledge, as well as highlighting how participants thought about and experienced their past, present and future (Paper II) (109, 259). According to empowerment theory, the development of knowledge and skills is vital for supporting individuals' understanding of their own health situation, and to develop a sense of control for increasing participation and becoming independent (156, 178). Research shows that psychoeducation involving CT enhances coping and empowerment, reduces fear of recurrence and improves fatigue, depression and anxiety (45, 80, 109, 111, 112, 239). Congruent with the psychoeducation in this study, research has revealed that a combination of knowledge, tools for coping, opportunities for asking professionals questions, as well as discussions with peer-survivors are essential factors for increasing coping (108, 256). The qualitative results indicated that the participants' educational needs were met, as one of the subthemes in this context was "getting insight" (Paper II). The participants elaborated this aspect as gaining new insight into their present health condition and knowledge related to physical activity, fatigue, social-rights, etc. The participants also underpinned the importance of learning CT as a tool for coping. CT aims to change dysfunctional patterns of negative automatic thoughts or beliefs, thus relieving emotional stress and other symptoms (169, 259). This also seemed to have been the case for the study participants, because the outcomes showed an increase in EF, control and coping. Including CT in all themes, and not only in the theme "thoughts and feelings" appeared to be important, as CT was then rendered "harmless", and participants could practice and learn how to use it over time in terms of how it related to several issues. The participants expressed that CT was especially useful related to fear of recurrence and facing follow-ups at the hospital.

The reported insights were also related to participants' acknowledgment of being responsible and in charge of their own rehabilitation process, and that they had the power to effect changes themselves. These factors are crucial within rehabilitation and indicated that the rehabilitation process seems to have empowered YACS (10, 140, 156). Yet another element was related to the insight they received from fellow YACS. This insight was mainly related to sharing experiences and acknowledging the "normality" of their own thoughts and experiences, and of not being alone. These findings are in line with theory of psychoeducation, where the rationale is that the more knowledgeable individuals have about their own situation, the more positive the health-related outcomes will be (110). Following

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this, Korstjens et al. (256) found an increase in cancer survivors' HRQOL following a group-based multi-modal cancer rehabilitation program, including psychoeducation. Rabin et al. (88) also found that YACS expressed interest in programs targeting physical activity, relaxation, emotional support and the provision of cancer-related and other information.

Another important finding that seems to have enhanced coping and empowerment was the subtheme “multidimensional follow-up” (Paper II). This theme included both the structure of the program, the residential rehabilitation combined with periods of being home and “practicing in real life”, as well as the re-stays. The individual follow-up involved physical testing, individual appointments with specialists, logs and re-stays, all of which were highlighted by the participants as important. According to ICF and Ferrell’s framework, it is likely that individual follow-up and goal setting influenced personal factors and therefore also coping and empowerment (81, 156, 192). Most participants set goals related to coping and expressed high goal-achievement within this area (Paper II), thereby reinforcing this interpretation. The reported insights may also have resulted in more realistic goal setting, as discussed earlier (144, 167). Additionally, research has shown that sharing experiences and telling the “cancer narrative” is important for coping with cancer survivorship (253, 260). The participants spent a significant amount of time together with one another and with the rehabilitation staff; as such, their cancer narratives were the focus on several occasions, which could have influenced their perceived coping.

#### **8.2.4 Improvements due to single elements or combinations?**

As the intervention in this study was multidimensional, the results cannot solely be credited to a single or separate element of the intervention. As discussed in section 8.2.3, it appears that the different elements of the intervention targeted different dimensions within a holistic health perspective. This is in line with the study’s theoretical framework and the intention of both participation and HRQOL (81, 192).

In line with ICF and Ferrell’s framework, coping theories stress that each individual copes in their own specific way, and that coping is dependent on a range of factors; including age, gender, prior experiences, culture and how stressors are processed and judged (162-164). Consequently, the elements of the intervention that enhanced the participants’ HRQOL and participation were likely to have been specific to the individual. Thus, the merged results of



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this study seem to support prior research suggesting that a multimodal approach that combines physical and psychosocial elements is more effective than using a single aspect approach (50, 84, 97, 113). The participants showed high compliance with all the elements of the rehabilitation program, except for the next of kin weekend, indicating that the elements of the program and the structure were feasible and convenient for them. Supporting this interpretation, one participant summed it up thus:

It's the totality; exercising, the knowledge and the discussions.... and cognitive therapy .... It has helped me. The good thing is that I feel that I have received a personal follow-up, although we've been in a group.... and meet people who understands you ....Then it's the time at home, it makes you think and you can practice. .. Every time I've been here I have made a bit more progress... I had the long and short-term goals, and I have reached my key objectives. I'm more secure in myself ... got more confidence ...But you have to work at it, .... it takes time....”  
(Participant 7).

The merged outcomes seems to support the final two steps in the study's conceptual model (Figure 4), indicating that a complex rehabilitation program consisting of goal setting, physical activity, psychoeducation, individual support and peer support may enhance HRQOL and participation through a process of empowerment and coping. However, as indicated in the model, these elements may have different significance for each individual and may also interact with each other. Even if the next of kin element was not successful in this study, it is still supposed that social support is important in the rehabilitation of YACS (64). The merged results therefore indicate that the conceptual model in this study might be useful for understanding YACS' situation after cancer treatment and rehabilitation.

### **8.2.5 Improvement due to time or the intervention?**

The outcomes of the study showed significant improvement in all the measurements, except for muscle strength in the right hand and BMI. Not having a randomized control group make it difficult to establish whether the outcomes were caused by the intervention or by the amount of time that had passed (203). However, the merged results and the multiple points of measurement provide valuable and complementary information about the rehabilitation process over the course of six months, suggesting a real influence on the part of the intervention on HRQOL and participation. Several arguments support this suggestion.

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First, to observe the effect of cancer rehabilitation interventions, there is a clear recommendation for including participants based on their need for rehabilitation, as established by a physician's referral (89, 137, 138). Following these recommendations, the baseline results and the discussion in section 8.1 indicate that the participants in this study had an established need for rehabilitation.

Second, there is an upcoming need for specifying the phase of survivorship, guided by the "Cancer Control Continuum" (12) and the "PEACE framework" (171), allowing for more specific results. Courneya and Friedenrich (171) state that the period of rehabilitation and health promotion starts three- to six months post-treatment, when the acute effects of medical treatments have dissipated and the individual is attempting to resume normal activity. The YACS in this study were all in approximately the same period of survivorship, in mean, 16 months after completing treatment. Research has revealed that improvement in the first year after cancer treatment is especially important for avoiding a prolonged experience of poor HRQOL (34, 35, 233). The participants' low baseline of HRQOL and participation in the present study may therefore indicate that their natural recovery had been unsuccessful, and that their need for rehabilitation had not been acknowledged early enough to prevent severe impact on HRQOL and participation.

Third, following Cohens' criteria (203), the effect size ( $d$ ) within the program (T1-T4) was large for performance and satisfaction with performance (participation), global HRQOL, RF, EF, CF, SF and fatigue. The effect sizes were moderate for PF and left hand strength, small for physical fitness and left hand strength, and showed no effect on BMI and lung capacity. The HRQOL results were considerably higher than reported in other studies concerning cancer rehabilitation (134-137, 233). Effect size estimate is independent from the normal distribution and sample size, and is therefore seen as a strong predictor for changes in small samples (186). Though these results have to be interpreted with caution, it does not seem likely that these results had been caused only by the passing of time. However, according to Crosby et al. (186), these differences have to be seen as being linked to the baseline values, because improvements are normally greater for individuals who have lower scores at the baseline. Similarly, Swenson et al. (102) found greater improvements in participants who scored lowest at the baseline. Since the participants' physical results were nearer to the norm

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than the HRQOL results at the baseline, this may explain why the effect-sizes within physical capacity were lower than for HRQOL dimensions.

Fourth, the major changes in participation within all dimensions of HRQOL and in physical fitness occurred within the first residential stay (T1-T2). It is therefore unlikely that these significant changes, which occurred over three weeks, were due to maturation or time only (203). Based on the low baseline results and a mean of 16 months after ending cancer treatment, it is also not likely that these improvements were related to spontaneous recovery (171). These results therefore suggest that a residential stay may be important for initiating the rehabilitation process. In line with this, theories of empowerment and coping highlight that empowering and developing coping skills are dependent on being in a setting that facilitate interacting, authentic coping experiences, social modeling, social support, as well as knowledge (156, 164, 259). The results also show that the participants continued with physical activity while they were at home, achieving the goal of improved physical capacity and engaging in recommended regular physical activity in line with guidelines (96, 103). Furthermore, all outcomes gradually improved from T2 to T4. The scores of HRQOL were also relatively stable or showed a small increase from T4 to the one-year follow-up. Here, only small effect sizes appeared, supporting the notion that the outcomes were related to the intervention and not the passage of time.

The interpretation of the results with respect to the effectiveness of the program should be made with caution, because we did not include a control group. However, fifth, for the physical tests we were able to compare our sample to an age-adjusted norm. The results showed that the participants' physical capacity were within the norm at the end of the program and can be seen as a direct result of physical activity (89). Likewise, for the HRQOL results, we were able to compare these to an age-adjusted Norwegian norm sample and a cancer sample. The participants' HRQOL had normalized and they scored closer to the Norwegian normal population than the cancer population at the end of the program (T4) on global HRQOL, PF and RF. According to the Jacobsen and Truax's anchor principle (186), this supported an effect on behalf of the intervention and not only due to the passage of time. However, the participants scored closer to the cancer population on SF, CF and fatigue, indicating that they still experienced challenges at the end of the program. This was supported by the qualitative data, in which most of the participants expressed that they were

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not finished with their rehabilitation process and the end of the program (expressed as not being “fully rehabilitated”). However, they expressed that they coped and had enough control to move on alone or with support from the primary healthcare system. Consequently, these results highlights the discussion that rehabilitation rarely means a return to a life one once had, but more often implies a readjustment or an alternative developmental process (128). The qualitative finding “gaining new insight” appears to indicate that the participants did not have unrealistic expectations about returning to their previous state before the cancer treatment. In contrast, and in line with research (18, 261), it seems rather that they strived to find a new normality and had hope and expectations for improving their health. These results also highlights rehabilitation as a process that takes time and therefore questions the concept of “time-limited” as used within the definition of rehabilitation (10). The time aspect has not been emphasized enough within cancer rehabilitation; however, in line with our results, new research shows that cancer rehabilitation takes time and is an area that requires further elaboration (114). The HRQOL scores on the 12-month follow-up still showed an increase in global HRQOL, PF, RF and SF, and a decrease in fatigue further documents this point. This indicates that participants managed to take care of their own rehabilitation process after the intervention, as they had stated. However, at this point, they still scored closer to the cancer population on fatigue, SF and CF. The fatigue dimension in EORTC QLQ-C-30 only captures physical fatigue. However, the CF seemed to have captured a cognitive part often associated with fatigue, as it measured loss of concentration and memory (44, 221, 231). This indicates that fatigue remained a primary problem at follow-up. In line with previous research, this supports that an amount of cancer survivors, especially YACS, will have to live with multidimensional late-effects over time (1, 9).

Six, the changes found in this study were not only statistically significant, but also appeared to be clinically relevant. For participation, Table 4 in Paper II indicates a 4.7-point (mean) increase in performance and a 3.3-point increase in satisfaction with performance within the program. According to Law et al. (217), an increase in a score of two points or more indicates clinically significant change and thus represents clinical increase in participation. The changes within all the HRQOL dimensions were also clinically significant, documented as a large change (>20 points) within RF, EF, CF, SF and fatigue, and a moderate change (10

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to 20 points) for global HRQOL and PF within the program (231). These results indicate improvement related to intervention, not time.

Seven, finding significant changes in small samples and using non-parametric statistics also reduce the likelihood of type-2 errors and therefore adds trustworthiness to the study's results (203). Furthermore, the mixed-method design and multiple points of measurement also adds trustworthiness to the results, because the qualitative and quantitative results illuminate one another and therefore provides a more comprehensive picture of both the baseline results, the rehabilitation process and the outcomes. Together, these merged results supports the interpretation that the results are likely connected to the intervention and not only the passing of time.

### **8.3 Reflections on the study's methodological contributions and limitations**

Reflections on a study's methodological contributions and limitations generally include discussions concerning the study's validity and reliability. Validity is defined as the degree to which data are accurate and credible, while reliability is defined as the degree to which an instrument applied will produce similar results at a different period (203). However, methodological discussions about trustworthiness in mixed-methods are relatively new and there is no consensus on how to perform such legitimation (199, 211). Mixed-methods research involves both qualitative and quantitative approaches and these methods differ in terms of how they verify the quality of the data and results. The candidate followed Creswell and Clark's (199) recommendation to address the specific types of verification checks that would traditionally be conducted for each strand, and then for the merged data. Before these are presented, this section begins with reflections on the intervention. This section must also be seen in connection with the description of the intervention (section 6.1), data collection (section 6.4) and data analyses (section 6.5), and the discussion of the merged results (section 8.1 and 8.2), as verification of a study's results is a function of the entire research process (203).

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### 8.3.1 Reflections over the intervention

The intervention in this study was complex and several advantages and disadvantages thereof can be discussed:

**Fundament and content.** The evidence base and the multidimensionality, alongside a careful description of the program, is viewed as a strength of this study, fulfilling new recommendations for cancer rehabilitation research (8, 75, 80, 262). On the other hand, the complexity of the program also represents a challenge, making it difficult to evaluate outcomes and to control for biases. Here, the mixed-method design is seen as a counterforce, as the different methods elucidate both the process and outcomes and thereby provide a more comprehensive picture of the influence of the rehabilitation program (199).

**Delivery.** The intervention was delivered through five groups, raising questions regarding whether all groups received the same intervention (203). The same experienced team at RKHRC delivered the intervention, all of whom were familiar with the content of the program from their regular clinical practice. They were educated in the intervention and the importance of facilitating equal intervention for each group. The candidate met the team after each group had finished for screening compliance with the intervention protocols. This appeared to have been very high, because the only discrepancies found were related to the next of kin weekend, where only nine YACS (45%) received visits. Even if the team had been familiar with the elements in the intervention in advance, it is possible that the team matured during their delivery from the first to the final groups (203). However, this maturing had likely been compensated for within each group through the re-stays.

**Compliance.** The YACS' compliance, both to the program and research, was generally high. No adverse events were reported and dropouts were not related to the program. This indicated that the program was feasible and that the intervention had been delivered at an appropriate level for the participants, and was therefore viewed as a strength in this study. However, the difficulties experienced in recruiting participants can possibly be linked to the content of the intervention, for example for being too complex, or some participants being skeptical about CT. Since more women than men participated, it is also possible that the content targeted women better than it did men (58, 257).

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**The candidate's role.** The candidate was not involved in the delivery of the intervention and only met the participants through the in-depth interviews. Since the candidate did not live nearby the RCHR and only came to the site during the interviews, the candidate did not influence the participants in any other way. However, a major question is whether the in-depth interviews in some way influenced the participants and therefore must be viewed as a part of the intervention. Research shows that telling narratives can help to acquire understanding, establish meaning and decrease emotional distress (246, 253, 260). Thus, participants telling their cancer and rehabilitation narratives in the interviews may then have influenced the outcomes of the study. On the other hand, YACS also told their narratives in several other settings within the intervention, e.g., when setting goals, in designing their exercise program, in discussions during psychoeducation, in the individual follow-ups and, perhaps most importantly, through sharing thoughts, experiences and feelings with other YACS. It is therefore not likely that the in-depth interviews alone had a single influence on the study outcomes. However, this highlights that making room for YACS' narratives may be important in a rehabilitation program.

**Practicality/economy.** The program was delivered free of charge to participants. Stays and travel expenses were covered by ordinary rates for rehabilitation at the specialist's level. The project covered the participants' deductible (123 NOK pr. day) expenses, as well as that of next of kin travel and stays. Even if the research had found that residential rehabilitation provided a personal timeout for participants (86), personal barriers such as travel distance, family responsibilities and practical barriers related to work or studies, or long referral procedures may have impacted the study's recruitment (249). The program did not demand any professionals or employees besides the regular staff at the RCHR. On the other hand, when prioritizing for scarce resources, a five week residential program may be viewed as rather resource demanding. However, this program targeted YACS in need of rehabilitation and the resources used did not vary considerably from other residential cancer rehabilitation programs in Norway (8, 86). In fact, rehabilitation appears to be cost-effective and having the potential for reducing both direct and indirect healthcare costs (135, 139, 216). However, it is possible that some of the follow-ups could have been conducted in cooperation with skilled primary healthcare professionals, for example, cancer nurses, cancer coordinators or

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primary physicians, or even online, an element that can be further elaborated and tested in future research.

### **8.3.2 Reflections on the qualitative results**

Different strategies for perspectives exist in the validation of qualitative research (203-205, 209). In this instance, the candidate followed Creswell's (204) recommendation to reflect on reflexivity/researchers bias, prolonged engagement, member checking, thick and rich descriptions, peer review and external audits. The candidate has also followed Tong's (210) consolidated criteria for reporting qualitative research. Qualitative data were applied in Papers I and II; common reflections based on these strategies follow below, after a reflection on the sample.

**The sample.** The qualitative studies typically examine small samples in depth, providing rich information on the individuals who have experienced the phenomena (202-205). In Paper I, we included all 20 participants and in Paper II, we included all 16 participants who fulfilled all COPM requirements. These samples were therefore interpreted as sufficient qualitative samples (204, 215). More so than sample size, data saturation is emphasized as important in qualitative research (199, 205, 215). Data saturation was achieved for both papers after 13 to 15 interviews, meaning that no new issues occurred, but nonetheless conducting all interviews. This was seen as a significant strength, i.e., that both samples included a diverse population of informants across the country, with varying sociodemographic and medical variables (Table 1 and 2). Such variability increases the likelihood that the findings will reflect different perspectives, which is an ideal in qualitative research (204). However, this sample had under-representation of men and the youngest age group (18 to 23), meaning that possible gender and young age specific differences were not detected.

**Reflexivity.** The candidate's motivation for this study was based on the possibility for doing "in depth" research and learning more about YACS, rehabilitation and research. Since the researcher is "the instrument" in qualitative research, it is important to elucidate the researcher's qualifications, experiences and reflexivity throughout the research process, to understand the researcher's position and any biases or assumptions that may influence the inquiry (204, 205, 209).



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*Previous experiences and potential biases.* The candidate has in her nearly 30-year-career as a nurse always worked within cancer care in different settings and at different levels, mostly related to the palliative care of older patients. These experiences may therefore count both as an advantage and as a source of potential bias in the research process. First, being familiar with working with severely ill individuals can potentially lead the candidate to both downsize YACS' described challenges or focusing predominantly on symptoms and challenges as opposed to resources. Second, the candidate's limited experience working with YACS could also have led to less attention being paid to their specific challenges and overlooking certain nuances and ambiguities in the data. On the other hand, this could also be an advantage, in terms of meeting the YACS with a more open-minded perspective (209). By extensively reading literature of the period on young adulthood and researching YACS, the candidate tried to be aware of both these issues. Third, the candidate's extensive experience in communicating with cancer patients about personal and serious matters, and being used to coping with tears and emotional outbursts, as well as having knowledge of different cancer treatment protocols, were seen as advantages during the interview process (214). Fourth, the candidate also reflected on private experiences and life events having the potential to influence the inquiry, for example, having her own children in the same age group and her own experiences with sickness. These issues were kept in mind during the research process.

*Prejudices and orientations.* Based on the outlined pre-understandings, and to be aware of her own interpretations and decisions made during the research process, the candidate wrote short, irregular notes in blog form. Examples of these blog-notes include reflections on choices of method and design and realizations regarding the transcription of audiotapes to text transcripts, how to capture participants' intended meaning, etc. Revisiting this blog, as well as the short notes made after each interview, helped the candidate to be aware of and maintain a researcher's perspective throughout the study (204, 214). The discussions and critical questions from the three supervisors representing different professional and methodological standpoints were also important for enhancing the candidate's consciousness and reflexivity regarding issues in both designing the study and in collecting and analyzing data. Furthermore, questions from peer PhD candidates, presentations and discussions in the research groups SIPA and at RCHR, also provided important contributions to this

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reflexivity. Concerning the theoretical basis, the candidate's professional training and experiences as a nurse, her own previous research within HRQOL and Hemil's focus on health promotion clearly influenced the study's holistic and individual focus and theoretical framework. This holistic perspective and mixed-method design was seen as important for capturing the YACS' own voices, and an important way for overcoming potential biases in the candidate's pre-understanding. These factors may therefore all be seen as comprising the candidate's perspective when analyzing the data (204, 209). Likewise, attending the research school and different PhD courses added to this theoretical basis, and forced the candidate to clarify her own perspective, as for example illustrated in Figure 5, section 6.2.2.

**Prolonged engagement and persistent observation** is seen as an important validation strategy in qualitative research (204). Each participant was interviewed four times, using one to two hours per interview. It is arguable whether this amount of time can be labeled 'prolonged engagement', but here, we had to consider the mixed-method design and balancing the researcher's involvement in the study (199). On the other hand, this can be considered enough time to gain an in-depth understanding, to build trust, to test for misinformation and distortions and to achieve saturation of key categories (204). To build trust, it was important to prepare and create good settings for the interviews, and giving the YACS the same information about the content, timeframe and the voluntary and confidentiality aspects of the interviews (see section 6.4.1). Since the candidate was not involved in the intervention, it was assumed that the participants were able to talk freely about their experiences during the rehabilitation program. After each interview, the candidate asked the participants how they had experienced this interview situation. No negative experiences were revealed, even if this may have been the case. As discussed earlier, it is also difficult to judge how these interviews may have influenced the participants' experiences during the rehabilitation program (204, 214).

**Member checking** is another validation strategy used in qualitative research and had been performed in several ways in this study (204, 205). First, the interview guide in Paper I was pilot-tested to target its usefulness. The candidate found this process educating, because it was an opportunity to test both the information, practical arrangement and the interview guide in a real-life setting. This process helped the candidate to feel more confident when starting the interviews, to ask open and fewer questions and to focus more on the YACS'

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narratives (214). Based on the clear aim of the study and the fact that the candidate had already performed nearly 60 interviews prior to T4, the candidate and the supervisors did not find it necessary to pilot test the interview guide for Paper II. Member checking was also done during the interviews by asking follow-up questions and clarifying meanings and statements. During the analyses, this was done by constantly going back to the transcribed interviews to check the YACS' intended meaning against the interpretations. The results from Paper I were presented to 11 of the participants, all of whom supported and recognizing themselves in the results. These results were furthermore presented in several settings for cancer survivors, where the feedback indicated high validity (204).

**Thick and rich descriptions (transparency)** is a qualitative validation strategy that means letting the voices, feelings, actions and meanings of the participants be heard (204, 214, 228). Based on this, the candidate tried to provide detailed and transparent descriptions of the participants, data collection and analyses, and rich quotations in presenting the results of the study. The two tables that illustrate the analyses processes in Paper I and Paper II also add to the transparency of the study (Table 3 in Paper I and appendix 6 for Paper II). To enhance the trustworthiness of the quotations, each quotation was identified using the participant's number as opposed to fictive names and gender (210). In the papers, the candidate also strived to let alternative and multiple voices be heard within the text (204). The candidate's closeness to the participants in the study through conducting, transcribing and analyzing the interviews also adds to the accuracy of the research (204).

**Peer review and external audits.** The three papers in this study, including the qualitative results in Paper I and II were published in *Cancer Nursing*, an international peer-reviewed journal at level two. Paper I and III had three reviewers, while Paper II had two reviewers, adding to an external check for the research process and enhancing its validity (199, 204). It is likely that different reviewers reviewed the papers, because they all represent different methodological approaches, indicating that publishing the papers in the same journal does not represent any bias.

**Making use of multiple sources,** methods and theories, providing collaborative evidence to shed light on a theme (as within this study) is also considered a validation strategy (204).

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**Reliability** in qualitative research can be addressed in several ways, where the quality of collecting data, transcriptions and intercoder agreement are especially emphasized (203, 204). The candidate found that the careful and transparent description of the qualitative data collection and analysis, including intercoder agreement, supported the reliability of the results. To prevent bias related to pre-understanding, the candidate found it especially helpful to use NVivo for making sure that the YACS' perspectives came through. To avoid influencing interpretations of the qualitative data, the candidate did not explore the quantitative data prior to the analyses of the qualitative data.

Results from qualitative studies cannot be generalized; however, these results are more concerned with their transferability, where the degree to which the data are context bound is of most interest (203, 204). The participants in this study represented a diverse sample from across the country with a variety of backgrounds and medical variables. Therefore, it is less likely that the results from Paper I are context bound. In contrast, the qualitative results in Paper II may be more context bound, because these represent results from a specific rehabilitation program within a specific context. On the other hand, this program also involved long periods of homestays and therefore, different contexts. Furthermore, the common themes in both papers were consistent, suggesting that we captured a valid sample of the experiences of YACS after cancer treatment and rehabilitation. Based on this and the strategies of validity and reliability, it is likely that the qualitative results are trustworthy.

### **8.3.3 Reflections on the quantitative results**

Quantitative data were used in Paper II and III. Issues concerning the sample, reliability and validity are vital for deciding the quality of a quantitative study (195, 203).

**The sample.** A principal limitation of the quantitative part of this study was its low sample size (203). We used an extended and intensive recruitment procedure in order to reach YACS nationally. The unsuccessful recruitment process may be related to the low YACS population in Norway (22) and that YACS in general are known to be difficult to recruit into research (8, 9, 117, 206-208, 241). This may also be related to health professionals underestimating the incidence, severity and distress of symptoms experienced by cancer survivors (242). Other factors may also be the lack of knowledge about survivorship and the lack in screening for rehabilitation needs and referrals to rehabilitation services within the

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healthcare system (8, 95, 241). These interpretations are supported by YACS elaborating about physicians who would not refer them to the study because he/she thought that they did not need it, and YACS experienced problems concerning approval from the coordinating unit for rehabilitation and habilitation in their region. We also experienced a neglect of referrals based on research competition from several units at the specialist healthcare level.

The final sample had an overrepresentation of women, indicating that the results were biased towards the female population of YACS, potentially compromising internal validity (195, 203). This has been documented as a common issue in cancer rehabilitation research (80, 134). This study did not reach the youngest part of the population. This may have been because they are more apt to try to perform “normally” and not wanting to be institutionalized (21). The sample may also be accused of representing especially resourceful YACS. However, the demographic data outlined that the participants’ level of education was not especially high in relation to the Norwegian population norm within the same age group (263). Most of the participants found out about the study themselves, indicating that they were motivated to do something about their own situation and as such, were resourceful. The demographic diversity and medical variables in the sample supports the diversity typical for cancer during this period of life (20, 24). However, the inclusion of different types of cancer in the sample might also have been a limitation, because the sources for physical and psychosocial distress and how to treat them could vary considerably. Due to the small sample of the study, we could not conduct analyses on a sufficiently large group of different cancers. On the other hand, rehabilitation programs for mixed cancers are recommended (144, 145) and for YACS, the period of life is likely more important than diagnosis (1, 28, 250). Scott et al.’s (84) review supports this, as they found that interventions with mixed cancer populations showed at least similar positive improvements as cancer-specific interventions. Furthermore, the individual follow-up in the program probably made up for this limitation. However, retrospectively viewed, it could have been an advantage to extend the age frame up to 39 in order to increase the sample size in this study.

**Control group.** To examine the effects of an intervention, randomized controlled trials are often applied as a standard study design (195, 203). Thus, not being able to randomize or include a control group was another limitation of the quantitative results in this study. However, a pre- and post-test design with external group comparisons is considered a

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suitable option for testing the feasibility of new methods and interventions (195). Although the latter is not optimal for examining the effect, it nonetheless provides an indication of the possible effects of the intervention. In Paper III, we used two external comparison groups and several points of assessment for adding trustworthiness to the HRQOL results (195, 203, 221). One limitation of external comparisons is that groups are likely to differ in many other relevant variables besides HRQOL. Another limitation is that cross-sectional differences in HRQOL may not equate to longitudinal changes within the same group (203, 221).

However, using both a Norwegian norm population in the same age group with no health complaints and an international EORTC sample of cancer patients below 50 years of age were suggested for countering these limitations (221). Likewise, having several points of measurement, using non-parametric statistics and applying Jacobsen and Truax's principle in the comparison, as well as calculating effect sizes, added to the trustworthiness of the HRQOL results (186, 203). Another strength of Paper III was the inclusion of objective tests and being able to compare them to a gender- and age-adjusted population norm.

In Paper II, we used a mixed-method approach, which also added trustworthiness to the qualitative results (see next section).

**Instruments.** In Paper II, COPM was used to collect data. In Paper III, EORTC QLQ-C30 and physical tests and logs were used. Both COPM and EORTC QLQ-C30 are used nationally and internationally, with high-established responsiveness; validity and reliability (see section 6.4.2).

The same two trained professionals, adding validity and reliability to these assessments, conducted COPM four times. However, setting goals using COPM was a process between the participants and the therapist (183). It was therefore possible that the two therapists may have influenced the participants' goals, or that they conducted these assessments differently. However, after each group had finished, the two professionals met and discussed their assessments in order to be as compliant as possible. The three re-assessments and following-up on the participants in this process was also seen as an advantage to adding trustworthiness to these results.

Since EORTC QLQ-C30 had initially been designed for cancer patients and not survivors, it is possible that this instrument did not capture all aspects of HRQOL among the participants.

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This was especially seen in the questions related to physical function and the skewed results in the single symptoms that we chose not to report on in Paper III. Viewed in retrospect, we still should have included the single symptoms to provide an overview of all the HRQOL results. Another disadvantage with EORTC QLQ-C30 and this study may have been the lack of measuring a spiritual dimension as outlined in Ferrell et al.'s (192) framework. However, some of the factors described within this spiritual dimension became visible in the qualitative results, for example, hope and uncertainty. The HRQOL instrument also did not have questions related to sexuality and fertility, which are documented to be important issues for YACS and are also addressed in the HRQOL framework. This highlights the need for specific HRQOL instruments capturing YACS' needs and challenges in survivorship.

The physical tests all had established validity and reliability. Performed by the same experienced sports educator, with the same equipment and at the same time of day, this added trustworthiness to the results. However, it is possible that the Astrand 6-minute test was too short to capture the participants' fatigue, and that a different fitness test should be considered in future studies.

The participants completed self-reported logs between the rehabilitation stays. It was seen as an advantage that the participants learned and experienced how to log physical activity by using Borg's scale during the first rehabilitation stay. However, it may be suspected that the participants over-reported their activity between the rehabilitation stays. This is, however, not very likely, since the logs were filled out in a very detailed and specific way. They also knew that they would be tested during the re-stays and that "cheating" in the logs would most likely have been discovered.

**The researcher's role.** In contrast to qualitative research, the researcher's role in quantitative research should be more objective, distanced and not influence the results (195, 203). The candidate was not involved in collecting any of the quantitative results. The collection of COPM and the physical tests have previously been discussed. The EORTC QLQ-C30 was delivered to participants by the research coordinator at all points of measurement and they were delivered back to the front desk at the RCHRC. Consequently, the participants completed the questionnaire under the same conditions every time and always prior to the in-depth interviews. At the follow-up (T5), the questionnaires were

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mailed to the participants in a pre-stamped envelope, addressed to the RCHR and not the candidate. The candidate did not begin analyzing the quantitative data before all the qualitative data had been collected. Based on these considerations, it is not likely that the candidate influenced the quantitative results.

Even if several measurements were performed to enhance validity and reliability to the quantitative data, the small sample size and not having a control group compromised the external validity of the research (195). Thus, the quantitative results of this study cannot be generalized and especially Paper III may be considered as a pilot study. However, these results may be useful if planning a study with a more comprehensive study design, in terms of content and length of the intervention, selection of study population and choice of assessment methods.

#### **8.3.4 Reflections on the merged results**

Strategies for enhancing the validity and reliability for this study had been conducted for both strands and we also enhanced validation strategies for merging the data according to Creswell and Clark (159 p. 240). Potential validity threats in mixed-method research are related to data collection, analyses and the interpretations of the merged strands.

**The sample.** To enhance validity for a mixed-method approach, it is recommended that the same sample be used in both the qualitative and the quantitative strand to render the data comparable. Therefore, to avoid unequal sample sizes, the same number of cases was selected in both strands. Thus, the sample in this study fulfilled the requirements of mixed-methods by using a small quantitative sample and a relatively large qualitative sample (199).

**Data collection.** Using different data collection procedures by collecting quantitative data through in-depth interviews and quantitative data through a self-administered questionnaire and logs, as well as a professionally-led questionnaire and objective tests decreased the risk for potential bias from one data collection to the other (199). An advantage of using a convergent parallel design is that both types of data were collected at the same time. This represents a comprehensive picture of the same phases within the study and addresses the same themes. However, this design requires equal weight for both strands and therefore, expertise related to both strands (199). This challenge was met by having three supervisors



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with complementary expertise in qualitative research, quantitative research and cancer rehabilitation. The candidate had prior experience in both strands, as well as long clinical experience within cancer care. Furthermore, the recommended strategies for enhancing validity and reliability for each strand were used, as discussed above, and were thus viewed as strengths of the research.

**Data analysis.** To enhance the trustworthiness of the merged data, a joint display with qualitative and quantitative data was made and quotes that matched the statistical results were outlined (Paper II, Table 3). Furthermore, several other known measurements for enhancing validity and reliability in a mixed-method approach were performed: the transformation was kept straightforward, the distribution of scores was examined and non-parametric statistics were used; each research question was addressed and both sets of results were presented (Paper I-III). Moreover, having been collected and analyzed separately, techniques that are traditionally associated with each data type could be used to increase the strengths of each methodology (199).

**Interpreting the data.** Merging the results from the two strands are challenging, as one of the strands may have unintentionally been given more weight than the other (199, 200). The candidate was aware of this issue and tried to prevent a skewed distribution of the data through several measurements: each research question was addressed and the candidate tried to present both sets as equally as possible. Moreover, the data in all three papers were reanalyzed during the peer review processes, when publishing the papers, securing and checking the findings and interpretations. No major disagreements or unresolved divergent findings were encountered during the data analyses between the qualitative and quantitative data, which made the merging of the data easier and added trustworthiness. Furthermore, throughout the study, the supervisors and the candidate discussed and negotiated the overall project objectives and negotiated philosophical and methodological differences. The different phases of this study were related to a theoretical framework, which also enhanced the study's trustworthiness. Gray (203) states that trying to synthesize the findings and interpretations of two different approaches may add more complexity, rather than validation and congruence. This was a possible limitation of this study. However, given the complexity of the multidimensional challenges of YACS and of cancer rehabilitation intervention, a

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mixed-method approach is viewed as an appropriate choice for providing a comprehensive picture of the important factors involved.

The use of ICF and Ferrell's frameworks are also seen as important and helpful models for interpreting and providing an overview and structure of the complex research results. It may be argued that the study's framework is too comprehensive, but the candidate found that the framework explained and met the stated complexity in a suitable manner. One may also question the use of both participation and HRQOL as outcomes of the study. Both concepts are, however, seen as vital outcomes of cancer rehabilitation (10, 140) and the use of several outcomes are recommended in this research for establishing the complexity of rehabilitation (148, 185). However, these concepts may also be accused of overlapping without clear boundaries. It may even be argued whether Ferrell's framework and ICF represent two sides of the same case. In this study, the candidate viewed HRQOL as the individual's internal evaluation of their life situation as it related to several dimensions and overall HRQOL (192). ICF was used to understand the multidimensional factors influencing an individual's participation in their life situation, interpreted as having a more external focus (81). Based on this, the candidate found that HRQOL and participation complied with one another and thus added to the comprehensive picture of the results, which were in line with the mixed-method design. However, neither concepts are fixed and are constantly evolving, thereby illuminating that the boundaries between them may be an important focus of future research.

**The researcher's role.** The researcher's role in a mixed-method study is challenging, and relates to having knowledge of both strands as well as the time involved (199). However, most challenging is balancing the researcher's involvement between being objective and not being involved as required in quantitative research, while serving as an "instrument" in qualitative research. The candidate was conscious of these challenges and tried to solve these issues in the manner previously described for each strand.

This study represents one of the first using mixed-methods in research involving YACS. Mixed-methods are supposed to move beyond simple hypotheses testing to provide insights that are more comprehensive and thus a more complete and nuanced understanding of the study's results (199). In line with this, the merged results from this study indicate that a mixed-methods perspective focusing on positive health outcomes provides valuable

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knowledge, and illuminate the baseline results, the rehabilitation process, as well as the outcomes. The main strength of a mixed-method approach is that the inherent bias of one measure can be counterbalanced by the strengths of the other (199). The merged results from this study are in this context viewed as more than the sum of the individual qualitative and quantitative parts, and by corroborating one another, strengthen the validity of the results described above (203).

The knowledge from this study may be transferable to other individuals or other settings, understood as guiding what might occur in a different situation (199, 203, 204). However, the findings cannot be generalized to the YACS population as a whole, because the findings may be unique to the relatively few YACS included in this study (195, 203). Both the content of the rehabilitation program and concurrent parallel mixed-design approach of this study is complex, and may count as a limitation. However, this was a real-life rehabilitation intervention designed to empower YACS in order to move on with their lives. Based on the complex challenges of YACS in cancer rehabilitation and given the difficulty and ethical limitations in creating control groups, the mixed-methods approach may be superior to a RCT study (196, 199). Previous research on YACS has focused on single elements, especially late-effects; to our knowledge, however, no study of YACS has collected mixed-method data and interpreted this in the light of participation and HRQOL. Using this approach therefore provided a more comprehensive and meaningful overall picture of the complexity of the rehabilitation of YACS. The merged results illuminated that focusing on the overall picture instead of the separate parts is important in order to increase knowledge regarding YACS. Other advantages in this study were the long follow-up time, the nationwide recruitment basis and a program offered free of charge to YACS.

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## 9 CONCLUSIONS

### 9.1 Main conclusions

The purpose of this thesis was to provide an increased understanding and knowledge of the rehabilitation of YACS after completing cancer treatment. The study also explored the effect of a complex, goal-oriented rehabilitation program on positive health outcomes such as participation and HRQOL, and how YACS experienced the rehabilitation process. The main findings of these investigations can be summarized as follows.

The participants experienced re-entering everyday life after cancer treatment as much harder and more demanding than they had expected, experiencing a considerable mismatch between their own expectations and reality. This mismatch was explained through four main themes: lack of preparation, late-effects that pervaded their entire life, lack of understanding and being neither sick nor healthy. The quantitative results from the baseline indicated that the participants scored considerably lower on HRQOL than both a Norwegian population norm and a cancer population on overall HRQOL functional dimensions (FP, RF, EF, CT) and considerably higher on fatigue. Furthermore, the YACS scored lower or within the low range of the population norm on physical fitness, lung capacity and strength, and somewhat higher on BMI. The results also revealed a low level of participation in their own life situation, measured as low performance and satisfaction with performance. The participants' period of life and their experiences during the cancer trajectory appeared to have influenced their coping abilities. Environmental factors such as lack of understanding, knowledge and social support from their networks, and especially from the healthcare system also seemed to have influenced their coping abilities, and thereby their participation and HRQOL. The baseline results indicated that the participants were in need of complex rehabilitation.

The outcomes indicated a high goal achievement with significant improvement and large effect size on participation within productivity (e.g., work/school), self-care and leisure activities (e.g., physical activity). The qualitative data displayed an overall high level of goal achievement and increased participation explained by three elements: building capacity and finding balance, gaining new insight and the follow-up process. The results documented significant improvements in all dimensions of HRQOL and on most of the physical tests.

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The effect sizes within the program were large on seven of the eight dimensions of HRQOL, with a small or no effect on physical capacity. The main differences occurred within the first rehabilitation stay, with a more gradual improvement thereafter. Interpreted through ICF and Ferrell's HRQOL framework, the outcome results displayed improvements within both dimensions related to internal factors and dimensions related to contextual factors, interpreted as improvements in HRQOL and participation. The values of the HRQOL dimensions were stable after the one-year follow-up. Both at the end of the program and at the one-year follow-up, the participants scored closer to the normal population and higher than the cancer population, except for CF and fatigue, indicating that fatigue continued to be a problem for the YACS.

The participants showed an overall high compliance with the program, indicating that both the structure and content of the program were feasible. The merged results, interpreted through a multidimensional perspective outlined within participation (ICF) and HRQOL (Ferrell et al.'s framework) indicated that setting goals, individual follow-up, psychoeducation, peer support and physical activity were all important elements of the program. In contrast, the next of kin weekend appeared to not have been feasible for YACS.

The study included a small sample and could not establish a control group; therefore, the results cannot be generalized to the entire population of YACS. However, the strength of using a mixed-method design, a sample based on complex rehabilitation needs, a clear evidence-based intervention lasting six months, five points of measurement and significant improvements and effect sizes within HRQOL and participation indicate that the findings are trustworthy. This study then represents a promising start for tailored rehabilitation interventions for YACS. The merged results also indicate that building rehabilitation interventions for YACS around a theoretical framework grounded in the basic concepts of rehabilitation, such as a holistic view of health, empowerment and coping, and focusing on positive health outcomes such as HRQOL and participation may be advisable. The merged results also indicate that the study's conceptual model may be useful for better understanding the rehabilitation of YACS.

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## 9.2 Implications for clinical practice

The results from this study suggest a major shortcoming in both preparation for survivorship and multidisciplinary follow-up, factors that will enable cancer survivors to cope better in their everyday lives. The results support a call for increased knowledge of cancer survivorship, especially as it relates to the needs of YACS, both within the healthcare system and in the general population.

The low baseline levels, especially on HRQOL and fatigue, indicate important areas for prevention action. Healthcare providers should be especially aware of the symptom burden and HRQOL of YACS, implementing a holistic perspective of YACS throughout the entire treatment phase. Using the framework of ICF and HRQOL may be valuable tools for healthcare providers to facilitate a more comprehensive picture of YACS' present situation and to promote HRQOL and participation. Monitoring YACS' own perceptions of their HRQOL, symptom burden and participation may also help patients to communicate concerns to healthcare providers that might not otherwise be discussed. Screening for HRQOL and participation may be a valuable basis for detecting resources and areas of good functioning, ascertaining requirements for medical attention and holistic survivorship care, as well as for detecting those in need of complex rehabilitation. Moreover, it seems paramount to prepare YACS for survivorship by making them aware of the expected late-effects, the importance of healthy life-style interventions, how to gradually re-enter work or school, and to provide them with information about rehabilitation services. Another important issue seems to be encouragement and facilitating peer support between YACS throughout the cancer journey.

After ending cancer treatment, the follow-up of YACS should be facilitated by the same experienced and knowledgeable healthcare providers. Thus, the results of this study add to the discussion of survivorship follow-up in Norway, where new models, for example, by cancer nurses, might be advisable. Again, screening for participation and HRQOL, especially fatigue, ought to be standard procedures alongside ordinary physical screenings to detect those in danger of health impairments and those in need of complex rehabilitation interventions. Furthermore, the results of the study indicate the importance of including multidimensional interventions for improving participation and HRQOL into survivorship care.

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The study's results also highlight that healthcare professionals play an important role in cancer survivorship care through their collaboration with YACS, setting goals to build upon the individual's own involvement, needs and priorities, and following-up on the rehabilitation process. The findings indicate that YACS may be in need of – and will profit from – complex rehabilitation that is especially tailored to their unique needs. The results also indicate that COPM may be used in clinical practice to help YACS set and follow-up on individual goals.

Participant 4 summarized the clinical implications as follows:

The healthcare system should provide patients with an understanding of what comes next. *Everyone* should have been back somewhere in the beginning to be caught up ... taken some tests... A reality check, not “everything's going to be ok”. To determine if you need rehabilitation... Perhaps after three months, you are out of the “illness shock” and everyone thinks that you are healthy... I think many [cancer survivors simply] continue to live in the “healthy world” and don't know what's wrong.

### 9.3 Suggestions for future research

This study represents a starting point for cancer rehabilitation research especially tailored to YACS and future research is therefore highly warranted.

To improve cancer survivorship care, research on implementing and evaluating cancer survivorship plans for YACS appear to be of special interest. Research regarding healthcare professionals' current knowledge of cancer survivorship issues and late-effects, as well as interventions for increasing this knowledge also seems crucial. Further research should focus on illuminating the use of regular screening for HRQOL and participation, as well as physical capacity, in order to identify YACS in need of complex rehabilitation based on cut-off values. Complex rehabilitation research should target YACS in need and within the same phase of survivorship. It is suggested that the rehabilitation phase starts three to six months post-treatment.

Research on cancer rehabilitation for YACS should address both the content and the structure of the rehabilitation program. The content of the program in this study, except for the next of kin weekend, seemed feasible and ought to be tested more comprehensively. In

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line with this, future research should determine whether the considerable effect sizes of HRQOL and participation within this study can be confirmed by larger representative samples and randomized trials. However, developing an HRQOL instrument that target YACS' special needs seems preferable, for example, by supplementing a YACS-specific questionnaire module within the EORTC QLQ-C-30. Likewise, other physical tests should be trialed to see if these capture YACS' fatigue better than the method used in this study. To understand the process of rehabilitation for YACS better, explorative and qualitative studies within this field are highly warranted.

It seems important to explore the concepts of time and follow-up within cancer rehabilitation, and to compare residential rehabilitation with home-based programs for YACS. Acknowledging YACS' availability and their use of internet, online rehabilitation programs should be compared with face-to-face programs as they relate to effectiveness and costs. The findings from this study indicate that the complexity of the participation process needs further investigation. Important questions concerning how much "work" cancer rehabilitation imply and how this work is experienced and performed should be highlighted. Focusing on all areas of life seems to support the use of multidisciplinary approaches, particularly in the case of YACS. Our results indicate that creating empowerment and coping through a goal-oriented process are the main factors in the rehabilitation of YACS, and therefore, more research concerning these issues are warranted.

A mixed-method perspective in cancer rehabilitation research appears to meet the complex challenges of cancer survivorship, as well as complex intervention, and research within this perspective ought to be further illuminated. Both the use of HRQOL and ICF seemed to provide a suitable framework for developing rehabilitation interventions, and for interpreting baseline and outcome results. The use of HRQOL and ICF as tools in the rehabilitation of YACS may therefore be advantageously further elaborated.



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