Universitetet
i Sørøst-Norge

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Sustainable work after cancer

Exploring long-term journeys from a salutogenic perspective

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Department of Health, Social
and Welfare Studies

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Acknowledgments

This report was originally written as an introduction ("kappe") for my doctoral work. The PhD thesis was by the assessment committee (November 19, 2021) evaluated to be "*Worthy of defense. The dissertation or the scientific work has minor shortcomings that should be corrected before the defense*". Unfortunately, I have not been able to make the necessary corrections because of serious health issues. Due to my illness, I have realized it is not longer possible for me to finalize my doctoral defense. Despite some minor shortcomings, I hope this report, together with my already published articles (see list below), can be of interest for researchers and others engaged in making life better for people who survive cancer.

I would like to express my gratitude to The University of South-Eastern Norway (USN) and the committee of PhD Program "Person-Centred Health Care" for believing in my project and granting me the scholarship. Special gratitude goes to Professor Kirsti-Iren Skovdahl, who was the leader of the PhD program, and who always offered attention and support when I asked. I am especially grateful for her contribution while I was writing article 2 when my primary supervisor was not available.

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Birgit Brusletto

Abstract

Introduction: Research on the impact of cancer on people's work-life has shown that the majority of persons who survive cancer (PSC) are successful in their return to work (RTW). However, almost a third of employed individuals of working age fall out of work during the first six years after cancer treatment. Retaining work after cancer is dependent on cancer-related, work-related, and personal factors. Those who have had a tendency to fall out of work are those who have experienced severe cancer treatment or those who have physically demanding work. Factors such as high age, being a woman, and low education or income level, have also moderated the likeliness for RTW. Still, little has been done to investigate successful RTW after cancer and the critical resources to make that happen. Also, previous research on RTW has mainly included only the initial phases less than five years after cancer.

Aim: Our overall aim was to explore RTW experiences in a long-term perspective more than five years after cancer. The aims of the first study were a) to investigate RTW factors and the long-term perspectives involved in sustainable RTW and b) to explore experiences of PSC after they had re-established normality and returned to sustainable work. The second study's aims, derived from the results in the first study, were: a) to explore the tensions experienced by long-term cancer survivors during cancer treatment and RTW and b) to investigate the resources they utilized to resolve the tensions. The third study's aim, also derived from the first study's results, was to describe the patterns of labor-force participation, working hours, job changes, and education for nine consecutive years among women and men who had survived cancer, and to compare those patterns with matched controls.

Methods: Three studies were performed and interlinked in this thesis. The first two studies were based on qualitative data and in-depth interviews. Four men and four women aged 42–59 years, who had worked successfully at least three years or more after cancer, participated in eleven interviews, re-interviewing three participants included. The time since their last treatment was nine years on average. Interpretative Phenomenological Analysis (IPA) was utilized for the first study. For the second study, the framework of Antonovsky's Salutogenic Model of Health (SMH was used to re-analyze the interview data from the first study. An advisory team of seven members with diverse cancer experiences contributed as co-researchers for both studies.

In the third study, RTW patterns were described as they appeared in a controlled registry study and a larger population. The Norwegian Registries of Cancer provided information about 2,629 PSC who were diagnosed with cancer in 2004/2005, aged 30-50 years, who were working at the time of diagnosis, and were alive and without recurrence of cancer for a longer time than the investigated period (10 years). These PSC were monitored for nine consecutive years after the cancer diagnosis and compared to 5,258 unique controls, matched by age, education level, and working hours. The variables of employment status, working hours, job changes, and education were stratified on gender and were analyzed using descriptive statistics.

Results: Results from the interviews revealed a five-phased process model that describes the RTW processes. Individual trajectories showed a large variety of adaptations and duration of RTW processes. Critical for success was personal mastering skills. These skills included accepting the situation and changes but never giving up the aim of RTW following altered abilities and new ways of prioritizing life. Most important for achieving sustainable RTW was the participant's inner strength and decisiveness. Also significant were surrounding and supportive relationships at home and at work, opportunities to make individual work adjustments, and a financial foundation that allowed the participant to make choices. This thesis confirms that the timeframe of effects from cancer treatment on work-life goes beyond the first 5 years after the cancer diagnosis. The long-term horizon on achieving sustainable work showed the first attempt to RTW does not always last and that occupational change and re-education may be necessary. Among a larger population, about 85% of PSC managed to RTW during the first 2-4 years, but female PSC downgraded working hours or quit work more often than male PSC.

Conclusions: Crucial for achieving sustainable work is never to let go of the decision to return to work and have a combination of personal and contextual resources available to make necessary adjustments in accordance with the effects of treatment and a renewed situation. The process of achieving sustainable work after cancer may last for many years, and the first attempt to RTW does not always last. Sometimes, a total change of occupation or a new education can be essential in establishing sustainable work.

Implications: The five-phased process model described in Article 1 can be useful for increased understanding of the situation and identifying needs for support in individuals' journeys of RTW after cancer. Social welfare systems should be flexible to meet diverse individual needs during the RTW process, which can last for many years after cancer treatment. Further investigations, multivariate analysis on registry data and intervention studies for further testing and deepening of the five-phased process model may provide valuable knowledge.

List of articles

This thesis is based on the following articles:

Article 1: Brusletto, B., Torp, S., Ihlebæk, C. M., & Vinje, H. F. (2018). A five-phase process model describing the return to sustainable work of persons who survived cancer: A qualitative study. *European Journal of Oncology Nursing*, *34*, 21-27. https://doi.org/10.1016/j.ejon.2018.03.003

Can be obtained from USN Open Archive: https://hdl.handle.net/11250/2649673

Article 2: Brusletto, B., Ihlebæk, C. M., Mjøsund, N. H., & Torp, S. (2020). From shaky grounds to solid foundations: a salutogenic perspective on return to work after cancer. *Scandinavian Journal of Occupational Therapy*, *27(*7), 524-535. https://doi.org/10.1080/11038128.2019.1663922

Can be obtained from USN Open Archive: https://hdl.handle.net/11250/2649299

Article 3: Brusletto, B., Nielsen, R., Engan H., Oldervoll, L., Mjøsund, N. H., Ihlebæk, C. M., & Torp, S. (2021). Labor-force participation and working patterns among women and men who have survived cancer: A descriptive 9-year longitudinal cohort study. *Scandinavian Journal of Public Health, 49*(2),188-196 . DOI: https://doi.org/10.1177/1403494820953330

List of figures

Abbreviations and central concepts

Abbreviations

IPA: Interpretative Phenomenological Analysis

SMH: The Salutogenic Model of Health
- *GRR:* Generalized Resistance Resource
- *SRR:* Specific Resistance Resource
- *SOC*: Sense of Coherence

TTSC: Transactional Theory of Stress and Coping

GP: General Practitioner/medical doctor

Central concepts

PSC/CS: "Persons who Survive(d) Cancer"/"Cancer Survivor". The literature shows both abbreviations as commonly used, and most often, CS. To emphasize this PhD project's relatedness to person-centered health care, the abbreviation PSC is used in this thesis.

*RTW: "*Return To Work". This abbreviation is used in work-related literature as a term for describing issues of returning to work after periods of sickness absence from work as a process and as an outcome (Young et al., 2005). In the current thesis, the abbreviation is related to return to work after cancer and cancer treatment.

Sustainable work: There is a notable difference between the more frequently used phrase return-to-work (RTW) and that of sustainable work. The term RTW often refers to that of the first effort to retain the former position, which does not tell how long or how engaging or manageable the work to return to is. Sustainable work represents working conditions that support people in continuing to remain at work (Eurofond, 2016) and includes the aspect of ongoing work over a long period of time.

NAV: The local authorities and central government in Norway cooperate through the Norwegian Labour and Welfare Administration (NAV). NAV coordinates and covers sickness benefits and work assessment allowance and is also responsible for the payment of benefits. NAV also promotes a program whose aim is to include and integrate employees that are disabled for a short or long time in work-life, referred to in the current thesis as an agreement on inclusive working life: "IA Agreement" (NAV, 2020). The IA Agreement is based on cooperation and trust between employees, employers and authorities in Norway (Government.no, 2020).

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Appendices

1 Introduction

The prevalence of lifetime cancer is increasing and comprises almost 300 000 individuals in Norway (Cancer Registry of Norway, 2019). Fortunately, improvements in cancer care and earlier diagnosis have led to an increase in survival rates (Cancer Registry of Norway, 2019; Danckert et al., 2019). Moreover, the majority of persons who survive cancer (PSC) seem to manage to return to work during the first years after cancer diagnosis (Duijts et al., 2017a; Mehnert, 2011; Torp et al., 2013). A recent systematic review and meta-analysis showed that the proportion of PSC working after cancer varies from about 80% after two years to around 65% after more than six years (de Boer et al., 2020). Also, it has been reported that PSC's first attempt to work after cancer treatment may not always be lasting (Duijts et al., 2017b; Endo et al., 2016).

After cancer treatment, successful retainment of work depends on cancer-related, personal and work-related factors (Dorland et al., 2018; Paltrinieri et al., 2018). Many PSC are unable to retain work or need to reduce their working hours due to adverse or late effects from the treatment such as fatigue, cognitive dysfunction or physical complaints (Duijts et al., 2014; Gegechkori et al., 2017; Mehnert, 2011). Factors such as being female and/or of older age, as well as socioeconomic factors such as low income or education may represent a higher risk for falling out of work (Mehnert, 2011). The type of working task and collaboration with the employer can moderate successful RTW (Mehnert et al., 2013; Taskila & Lindbohm, 2007). For example, the RTW process can be smoother when offering a gradual approach for returning to work (Torp et al., 2011).

While work participation is seen as an important health-promoting factor, a substantial proportion of PSC seem to struggle with RTW (de Boer et al., 2020). To be working is, in general, regarded as healthy (Waddell & Burton, 2006). Income from work is essential for providing for ourselves and our families, and is an opportunity for fulfillment in everyday life. The workplace is also an arena that can enhance self-esteem and offer social contact. Work represents a part of our identity, as we identify ourselves with our professions and skills (Little et al., 2002). Losing both health and work may consequently represent a double personal loss (van Egmond et al., 2016). Thus, it is important to identify personal and societal resources needed to maintain work during life's challenges, for example cancer, in order to promote people’s health, workability and quality of life. To date, long-term explorations of successful RTW after cancer are still limited, and research focusing on the individual diversity of contexts and work-related goals during RTW processes is called for (Wells et al., 2013).

Health promoting aims of mastering everyday life and thriving sustainably at work are also the aims of the present thesis (WHO, 1986). Specifically, a salutogenic orientation was applied to the overall aim of exploring sustainable RTW. The thesis comprises three studies that focus on how PSC manage to return to sustainable work in the perspective of more than five years after cancer treatment. The first study’s primary aim was to explore personal RTW experiences. The second study analyzed tensions during these RTW processes and how resources were activated to resolve them. The third study described a larger population as compared to controls labor-force participation and work changes in a nine-year perspective after cancer. The workplace, health care, and social welfare services, all of which represent essential contextual components that may substantially influence RTW processes, are taken into consideration.

2 Background

This chapter focuses on how cancer may affect people and their work-life and draws upon relevant selections from the vast amount of literature on RTW. As a background, the epidemiology of cancer (Chapter 2.1), treatment and late effects (Chapter 2.2), and consequences for work after cancer (Chapter 2.3) are summarized.

2.1 The epidemiology of cancer

In 2018, approximately 18 million people worldwide were diagnosed with cancer (Mattiuzzi & Lippi, 2019), compared to 14 million in 2012 (Torre et al., 2015). In the western part of the world, including Norway, cancer incidence and prevalence have developed similarly (Engholm et al., 2010; International Agency for Research on Cancer, 2019). While, about 2 million people died of cancer in Europe in 2016 (Mattiuzzi & Lippi, 2019), during the last decades, earlier diagnosis, screening programs, and cancer care improvement have led to an increase in survival rates (Cancer Registry of Norway, 2019; Danckert et al., 2019). Still, among all diseases, cancer poses the highest burden of cause-specific Disability-Adjusted Life Years (DALYs) according to economic, clinical, and social burdens (Mattiuzzi & Lippi, 2019).

About 5.3 million people live in Norway, and it is calculated that one in three of this population will develop cancer before the age of 75 (Cancer Registry of Norway, 2019). The lifetime cancer prevalence at the end of 2019 comprised 294,855 living individuals who have experienced cancer at some point in time (Cancer Registry of Norway, 2019). Among these people and according to age distribution, a calculated rate of about 40% of cancer incidents 2015-2019 is estimated to be people of working age. From the age of about 45 for women and 50 for men, cancer incidence rates are increasing. The highest cancer incidence is among the elderly from about 60 years of age (Cancer Registry of Norway, 2019). By gender, breast cancer and prostate cancer are the most common cancer types among adults (25-60 years) in Norway (Cancer Registry of Norway, 2019). Lung cancer, malignant melanoma, testis and colorectal cancer are also among the more common cancer types. An increasing proportion of previous cancer patients are nowadays declared cancer-free (Cancer Registry of Norway, 2019). Still, the risk for cancer recurrence is high, although it varies according to cancer typology and morphology. As Black & White (2005) reported, these risks can potentially lead to anxiety and depression among PSC and influence their perceived quality of life and mental health. Clinically, cancer sites (topology), different stages and types of cancerous cells (morphology) are of high relevance for the prognosis of cancer and its treatment, but outside the scope of this thesis.

2.2 Treatment, late effects and rehabilitation

Since 2015, all citizens in Norway have been guaranteed the same cancer treatment by the standardization of 28 protocols of cancer treatment according to different diagnoses (Helsedirektoratet, 2020). The protocols give every person diagnosed with cancer the right to be examined and treated according to the protocol for the actual cancer type and within fixed deadlines. As a policy to ensure that everybody receives the same treatment when ill, the government in Norway covers practically all hospital treatment costs.

Treatment and late effects

Cancer treatment often causes more late effects than the cancer illness itself (Gegechkori et al., 2017). The typical treatment that involves surgery, chemotherapy, hormone therapy, and radiation therapy may lead to a range of short or long-term adverse effects (Corner, 2008; Gegechkori et al., 2017; Taskila & Lindbohm, 2007). Late effects according to treatment and tumor stage are the main predictors for not returning to work (Noeres et al., 2013), and the type and topography of cancer will also influence medical conditions (Gegechkori et al., 2017). Breast cancer, followed by colorectal cancer, lung cancer, and prostate cancer are among the largest groups of cancer associated with adverse and late effects (Baker et al., 2005; Bennett et al., 2018; den Bakker et al., 2018; Gegechkori et al., 2017; Noeres et al., 2013).

Chemotherapy, surgery/anesthesia, and radiation therapy are associated with fatigue and cognitive dysfunction (Asher & Myers, 2015; Gegechkori et al., 2017; Munir et al., 2011). Cognitive dysfunction can affect mental functioning, including memory loss, aphasia, decreased reaction time, and concentration problems, lasting up to 20 years after cancer treatment (Asher, 2011; Gegechkori et al., 2017; Munir et al., 2011;

Reinertsen et al., 2010). Psychosocial symptoms like coping issues, anxiety, and depression have also been shown to influence the ability to work and to have caused severe difficulties for people returning to work after cancer (Duijts et al., 2014; Sharp et al., 2016). Physical adverse effects from treatment, for example pain, neuropathy, reduced immune function, lymphedema, gastrointestinal problems, anemia, and more, may also severely affect the ability to work (Gegechkori et al., 2017; Horsboel et al., 2015; Zomkowski et al., 2018). Consequently, a diminished Quality of Life (QoL) may result from reduced physical or emotional functioning and inability to retain work (Annunziata et al., 2018). As chemotherapies, radiation therapy, and anesthesia during surgery are still widely used, many cancer survivors will suffer from late effects for many years to come (Gegechkori et al., 2017).

Lately, immune and hormone therapies have been introduced (Gegechkori et al., 2017). With new treatment methods, new late effects may arise. For instance, hormone therapy has disclosed a higher risk of bone loss and fractures (Gegechkori et al., 2017).

Rehabilitation

To increase the RTW success rates among PSC, rehabilitation programs have often included physical and/or psychosocial interventions (Thorsen et al., 2011; van Weert et al., 2005). The content in rehabilitation programs varies, but a rehabilitation process often includes a goal of function optimization, and several stakeholders are often involved in the process (Hauken et al., 2014). Physical exercise programs have been shown to help symptom management (Hunter et al., 2017) and improve PSC's working status during follow-up (Bertheussen et al., 2012). Luker et al. (2013) found that those PSC who discussed their situation with the treatment team worked significantly more hours, indicating how clinicians may be helpful during RTW processes. Psychosocial intervention programs for enhancing vocational rehabilitation have also been suggested and tested (Barnard et al., 2016; Boerger-Knowles & Ridley, 2014), but more rigorous studies are necessary to confirm if or how they affect working abilities (Fong et al., 2018). In the contexts of stressful life events, focus on meaning and meaning making have been emphasized and found to affect adjustments after stressful life events in general (Park, 2010). Some PSC may need support to re-establish a loss of meaning after cancer, and interventions to enhance meaning making have been suggested (van der Spek et al., 2013).

2.3 Consequences for work after cancer

The health consequences of being without work include extended use of health services and increased mortality rates (Mathers & Schofield, 1998). Some working conditions may also be regarded as harmful to health, but, in general, working has been shown to positively influence health outcomes (Burton, 2010), for instance, by preventing depression and psychological stress (van der Noordt et al., 2014). Thus, PSC risk experiencing a double loss when treated for cancer: first, they experience loss of health and they struggle with late effects; second, they experience employment difficulties or even falling out of work, fully or partly (van Egmond et al., 2016). The consequences for workers experiencing late effects can be that work becomes too challenging, and they sometimes lose the possibility of remaining in their job (Bijker et al., 2018; Duijts et al., 2014; Mehnert, 2011). Tamminga et al. (2019) found that for PSC 5-10 years after breast cancer, work-related factors were more challenging than clinical factors. Recent European statistics show that approximately 6 out of 10 cancer survivors return to work during the first year after cancer diagnosis (Duijts et al., 2017a), while the portions of PSC working after cancer vary at different time-points, from 80% after two years to around 65% after more than six years (de Boer et al., 2020).

2.3.1 Sickness absence, disability and early retirement

After or during cancer treatment, long periods of absence from work may be necessary (Gegechkori et al., 2017; Gudbergsson et al., 2011, Torp et al. 2012b), where an average of up to 1 or 2 years have been reported (Kiasuwa-Mbengi et al., 2018a; Mehnert, 2011; Rottenberg et al., 2017). In general, a probability of future disability pension seems to increase after a history of sickness absences (Hultin et al., 2012; Øyeflaten et al., 2014). Thus, the PSC with a history of more extended sickness absence periods, are at high risk of permanently falling out of work after cancer. PSC on sick leave have also shown an greater tendency of symptoms of depression and fatigue than PSC who are working (Horsboel et al., 2015; Paalman et al., 2016).

In Norway, local authorities and the central government cooperate through the Norwegian Labour and Welfare Administration (NAV) (NAV, 2020). NAV is responsible for the coordination and payments of sickness benefits, disability pensions and other social security benefits (NAV, 2020). Through NAV, the sickness benefit amount is based on the employee’s income and is limited upwards to the maximum of six times a so-called “National basic amount” (6G) (NAV, 2020). If the sickness absence is partial, for instance if an employee is 50% on sick leave, the sickness benefit will correspond to the degree of absence. After a sick leave period of one year, an employee in Norway has to work 100% for 26 weeks to earn the same rights to be covered financially by salary if the situation requires recurring sick leave (NAV, 2020).

As a part of the support provided to employees in their RTW process, within seven weeks after the start of the period of sickness absence, the employee and the employer must agree on a follow-up plan detailing the procedure for returning to work (NAV, 2020). Later, if the sickness absence period needs to be prolonged, a meeting is arranged where NAV and sometimes also the GP may attend, at the latest before 26 weeks of sick leave. If the employee has not fully recovered during 12 months on sick leave, the sickness benefit period stops, independent of the degree of absence. The employee can then apply for work assessment allowance (AAP), disability pension, or social benefits. AAP allows having an income while being ill or injured while still needing assistance from NAV. To receive AAP benefits, one has a “duty to act,” which means to follow activity plans and attend courses and meetings at NAV. NAV covers 66% of the income (limited to 6G) for persons receiving AAP or a disability pension. After up to three years on AAP, if the employee still does not succeed in returning to work, a disability pension or early retirement could eventually become the outcome.

Early retirement can be an option for PSC who experience long-lasting and severe health issues after cancer treatment. Among breast cancer survivors compared to controls, a higher risk has been found for retirement and for receiving disability pension up to 10 years after cancer diagnosis (Paalman et al., 2016). Overall, studies show that non-cancerous people are 2-3 times more likely to be employed than PSC (Bates et al., 2018; Noeres et al., 2013). Since the first attempt to work after cancer treatment may not always be lasting (Duijts et al., 2017b; Endo et al., 2016), finding ways to ease the RTW process to prevent people from being on sick leave longer than necessary would be of value.

2.3.2 Work adaptation

As making a living provides meaning and identity (Wells et al., 2013), and studies have demonstrated how work may be beneficial for health by offering participation in social networks and representing opportunities for development and personal growth (Waddell & Burton, 2006; Wells et al., 2013), returning to work after cancer should be an aim. In order to achieve successful RTW, an adaptation to work and the work situation might be necessary. Individual factors may also influence the capability to adapt to work. An active instead of passive coping style may contribute to protection from falling out of work after cancer and may increase the likelihood of a triumphant return to work (van Muijen et al., 2018). Adapting to a new situation at work after cancer requires job changes ranging from no or little reduction in working hours to changes of position or employer, type of work, or even new education and occupation (Mehnert, 2011; Torp et al., 2012b). Reduction of working hours or changing working tasks to adjust to a new situation may ease a person's possibility to RTW (Luker et al., 2013; Zomkowski et al., 2019).

Close planning and collaboration with health care providers and the employer have been shown to positively influence RTW results (Mehnert et al., 2013; Hauken et al., 2014). While perspectives from the worker and the workplace are interrelated, they also represent diverse views (Greidanus et al., 2018). For the employer, the employees represent valuable resources that will help fulfill the goals of the workplace. The workplace's organization and how the employer facilitates working conditions and a social context where people thrive may contribute to cultivating healthy workplaces. In Norway, cooperation between medical personnel/physicians, NAV, and the employer is the primary support available during and after cancer treatment to facilitate return to work processes and vocational rehabilitation (NAV, 2020). According to Norwegian law and the Working Environment Act (Lovdata, 2019), every employer in Norway has responsibilities for the employees' health and to facilitate healthy working conditions. They also have a particular responsibility to facilitate RTW issues when needed, in that they must have a documented plan for preventing injuries or illness at the workplace.

Employers are responsible for ensuring the financial security of their business and balancing workloads among staff. Thus, it might sometimes be challenging for them to provide the required options for PSC (de Moor et al., 2018; Greidanus et al., 2018; Tiedtke et al., 2017).

In recent years, a program has been offered to employers through NAV in Norway – the IA agreement. This program supports the employees' reintegration to work after illness (Arbeids- og velferdsetaten, 2019). The IA agreement aims to facilitate better working conditions for workers with health issues who still have working abilities. With this agreement, employees have easier access to work training programs. They have aid in testing their working abilities, and they may receive extra benefits such as financial support for further education. Although rehabilitation programs and various intervention programs may be of imminent value during a RTW process after cancer, this thesis focuses on Norwegian experiences achieving long-term, sustainable work regardless of specialized programs attended.

Adjustment opportunities and the workplace

Collaboration with employers making adjustments to the workload and provide options for job rebuilding has shown to be essential for managing to return to work (Torp et al., 2011; Zomkowski et al., 2018). Lack of adjustment possibilities can inhibit work training and make the RTW process more challenging (Stergiou-Kita et al., 2016; Taskila & Lindbohm, 2007). Alleaume et al. (2020) compared PSC who received adjustments at work to PSC who did not. Among the PSC who received adjustments, 95% returned to work after five years, compared to 77.8% in the other group. For this reason, workplaces are advised to provide close follow-up, support, and re-integration (Armaou et al., 2018; Torp et al., 2012a).

Reduction of working hours or changing working tasks to adjust may reduce cancer treatment symptoms (Luker et al., 2013; Torp et al., 2011). Both manual work requiring physical strength and work requiring cognitive skills can be more challenging after cancer than other types of work (Heinesen et al., 2018; van Muijen et al., 2013, Spelten et al. 2002, Zomkowski et al., 2018). However, an effect of picking up work early during or after cancer treatment seems to be fewer symptoms from adverse effects and overall higher scores on Quality of Life (QoL) (Alleaume et al., 2020; Duijts et al., 2017b). A consequence of these results is that it may be wise to start working part-time as soon as possible after cancer treatment rather than wait until one is ready for full-time work.

The workplace is a social arena offering development and maintenance of self-esteem and talents (Wells et al., 2013). Participating in social relationships at work may be a crucial factor for successful RTW after cancer (Armaou et al., 2018; Torp et al., 2011; Zomkowski et al., 2019). Whereas social and emotional support and positive attitudes from colleagues, friends, and family facilitated RTW, lack of support from colleagues and discrimination among employers has been found to be a barrier to RTW (Zomkowski et al., 2019).

Gender differences

Several studies utilizing Norwegian registries have shown less work participation after cancer among women than among men (Becken et al., 2015; Syse & Tønnessen, 2012; Torp et al., 2013). In general, a high portion of women work in Norway, but the proportion of about 36% women working only part time is regarded as high (Aagestad et al., 2017). Research shows female PSC reduce working hours more frequently than male PSC (Gudbergsson et al., 2008; Luker et al., 2013). Hamood et al. (2018) found that up to 70% of female breast cancer survivors downgraded to part-time work 4-14 years after cancer.

Socioeconomic and -demographic status

Socioeconomic status influences the RTW processes. Higher education and income have been associated with an increased likelihood of working after cancer (Mehnert, 2011; Torp et al., 2013; van Muijen et al., 2013), and returning to white-collar work is associated with a higher possibility of returning to work (Kiasuwa-Mbengi et al., 2018a). PSC with lower incomes have also been reported to experience less workplace support and poorer employment outcomes (Swanberg et al., 2018). Being divorced or not living with a partner has also been associated with a higher risk of not managing to return to work after cancer (Bennett et al., 2018; van Egmond et al., 2016). Job reduction, or loss of employment, can directly influence peoples' financial situation (Hamood et al., 2018; Paalman et al., 2016; Syse et al., 2008). In addition, Dean et al. (2018) found that among

PSC up to 12 years after cancer, medical conditions leading to increased costs for covering medication or necessary equipment could compromise the financial situation.

2.3.3 The complexity of RTW

Vocational and work-related interventions customized for PSC seem still to be lacking (Stapelfeldt et al., 2019; van Egmond et al., 2016). Since factors that must be considered during RTW processes after cancer are numerous and interrelated, it can be challenging to make plans for interventions to promote RTW processes for all PSC. Mehnert et al. (2013, p. 2154), presented an overview and conceptual framework where several factors and stakeholders involved showed how they influence the outcome of RTW efforts after cancer. First, the welfare policies and procedures of support are the basis for the context and can affect people's financial situation and opportunities to recover after treatment. Next, the work environment flexibility and how it facilitates RTW is another crucial factor for how fast an employee may return to work and job training. The cancer treatment and its actual consequences on the person will also influence the re-integration into the normalcy of life and will also be a factor moderating the ability to RTW. Finally, individual factors like, for instance, motivation, sociodemographic, and life-stage factors may also influence the outcome of an RTW process (Mehnert et al., 2013). This framework shows how factors are interconnected and how complex PSC and their diverse situations may be.

3 Theoretical approach

Fundamental for this PhD project is a definition of holistic health and health-promoting perspectives. A salutogenic orientation covered all studies in the present thesis as the theoretical lens. The utilization of additional perspectives grew out of a hermeneutical, spiral-like movement during analysis, the writing of articles, and the evolution of the combined studies. The movement between theoretical and empirical data also influenced the PhD project’s methodological design (see details in the methods section, Chapter 5).

3.1 A holistic and health-promoting perspective on health

A holistic view of health includes perspectives of values expressed as mastering everyday life and thriving sustainably, physically, mentally and socially, despite limitations from an illness. This thesis relies on a proposal of a renewed definition of health as the “ability to adapt and to self-manage” (Huber et al., 2011 p. 3). Huber et al. (2011) emphasize the importance of having available resources to cope in everyday life. Their definition of health also corresponds to the Ottawa Charter’s definition of health promotion that comprises individual *processes* in “enabling people to increase control over and improve their health” (WHO, 1986). The Ottawa Charter’s definition further emphasizes that health is a *resource* for coping in everyday life where subjectively perceived health also includes the aspect of well-being, which goes beyond healthy lifestyles towards a subjectively perceived emotion of perceived good health (WHO, 1986). Health promotion aims for action to create equity among people and providing them with equal resources and opportunities to make healthy choices (WHO, 1986). This overall aim includes more than re-orienting health care services: Health promotion encompasses actions that range from the individual level of developing skills to developing healthy public policies and strengthening the environments where people live and work (WHO, 1986). Overall, the WHO recommends empowering people through increased education to take charge of their own health and not merely be passive recipients of services (WHO, 2015). This recommendation goes well with the health-promoting perspective that overarches the current thesis.

Regarding healthy workplaces, the WHO stated in 2010: “A healthy workplace must include health protection and health promotion” (Burton, 2010, p. 16).The development of healthy workplaces has recently been given increased attention, for example in the WHO’s Global Model of Action (WHO, 2012), which suggests five keys that are essential in creating healthier workplaces: the focus on ethics and values regarding health in companies, leadership commitment, engagement, health resources, and cooperation on several levels. If a workplace handles these issues consciously, the likelihood of positively influencing employees’ health will increase when returning to work after absences due to sickness.

3.2 Health promotion and Salutogenesis

Health promotion is basically about aiming for social equity and people’s opportunities to influence and control matters of importance to their health (WHO, 1986). Health promotion builds historically on Public Health theories and has its intellectual roots from epidemiology, sociology, and psychology (Bunton & Macdonald, 2002). Health promotion has also been heavily influenced by Salutogenesis (Antonovsky 1979, 1986) which was developed in the 1980s when health promotion emerged as a public health approach (Mittelmark et al, 2017a; Eriksson 2007).

The word “Salutogenesis” and its fundamental theories were launched by Aaron Antonovsky (1923-1994), a professor in medical sociology, who asked: “How do we manage to stay healthy?” (Antonovsky, 1979, p. vii). He answered this question by introducing and describing the new word and theory “Salutogenesis” (from Latin: *salus* = “health” and Greek: *genesis* = “origin”). Both a health promotion approach and the salutogenic orientation focus primarily on what resources or assets create and support good health rather than exploring risk factors, causes, or curation of diseases (Antonovsky, 1996; Lindström & Eriksson; 2010, Vinje et al., 2017; WHO, 1986). The theory of Salutogenesis includes approaches and theoretical concepts linked to the overall aims of health promotion and will, according to Antonovsky, "actively promote health" (Antonovsky, 1996 p. 14).

Lindström & Eriksson (2010 p. 77) have presented a “salutogenic umbrella” including a variety of theories regarding the promotion of health. In addition to Antonovsky`s own Sense of Coherence (SOC) construct, this umbrella covers among others, the Transactional Theory of Stress and Coping (TTSC), as explained by the work from Lazarus & Folkman (1984).

In the following, Salutogenesis is presented in three categories: a) as an orientation and overarching theory (Chapter 3.2.1), b) the SOC as a singular and central construct of the Salutogenic Model of Health (SMH) (Chapter 3.2.2), and c) a summary of the entire SMH that describes the process of health development (Chapter 3.2.3). This is followed by a brief introduction to the Transactional Theory of Stress and Coping (TTSC) (Chapter 3.2.4), as this model is related to the SMH and is relevant to the topic of the current thesis. Finally, some reflections regarding the theories are presented in Chapter 3.2.5.

3.2.1 The Salutogenic orientation

A salutogenic orientation is different from, yet complementary to, a medical tradition with a pathogenic focus. The focus of Salutogenesis is on reacting and adapting to life and the processes of developing and maintaining physical well-being and good health (Antonovsky, 1987). This perspective is different from the more conventional pathogenic orientation of regaining homeostasis (explained as being ill or not ill). Homeostasis and a pathogenic orientation focus on either treating people with a disease, helping them regain their health after an illness or preventing them from having disease (primarily by reducing risk factors) (Antonovsky, 1979, 1987).

Based on the theories developed by Antonovsky (1979/1987), the Salutogenic orientation is an opponent to a pathogenic orientation. The salutogenic orientation consists of six components (Antonovsky 1987):

1) Health is regarded as a continuum and not a dichotomy of being ill or not ill. When tensions are successfully managed and resolved, a movement toward ease on the health continuum will be achieved (Figure 1, p. 19). Therefore, it is possible to be diagnosed with an illness and experience being at ease. Conversely, it is also possible to be free of diagnosis but still feeling discomfort – or dis-ease.

2) A salutogenic orientation regards people’s entire stories as essential, as the individual context may vary according to a total of available resources, personal and interpersonal factors and a broader environment. In contrast, a pathogenic orientation focuses typically on fragments in order to define people’s health dichotomously as being “ill” or “not ill” according to a diagnosis.

3) In a salutogenic orientation, focusing on utilizing available resources and salutary/health-promoting factors to create health and well-being is more important than focusing on risk factors and finding cures. The essence of health-promoting research is that it primarily focuses on salutary factors rather than risk factors (Antonovsky, 1996). Subsequently, a salutary factor will, according to Antonovsky (1996, p. 14), “actively promote health”.

4) According to a pathogenic orientation, stress is usually regarded as a load. Stressors can, according to a salutogenic orientation, be defined as pathogenic, neutral or salutary. As individuals experience stressors differently, the same stressor can result in different tensions that need resolving.

5) Working with a salutogenic orientation perspective includes aiming for heterostasis (balance). Heterostasis in this context, means aiming for active adaptation to what happens instead of solely aiming for re-establishing original balance (homeostasis).

6) Research influenced by a salutogenic orientation focuses on deviation from a normal prediction, what Antonovsky called “the deviant case” (Antonovsky, 1987). In practice, this means it is essential to investigate how success is achieved when unsuccessfulness can be expected and keep in mind that experiences from successful outcomes of adaptations may shed light on the process and resources utilized when other people meet the same challenges. Implications for research are to select cases that stand out as successful despite challenges.

A pathogenic perspective has been more widely utilized as a base for research and as a general perspective on health in our modern society. Research on RTW after cancer has also been mainly based on a pathogenic orientation; it has concentrated on the illness and overcoming obstacles, treatment and late effects, and rehabilitation from cancer.

Moreover, cancer can be viewed as an event that solely creates a load or a stressor, which has to be cured. The positive results of this pathogenic focus are better screening programs and cancer treatment so that the survival rates after cancer are steadily increasing (Chapter 2.1). However, and less commonly, newer research has focused on exploring how to achieve successful outcomes from RTW processes through adaptation to a new situation. Although cancer may be defined as a pathogenic starting point, a salutogenic orientation can be applied to focus on how salutary outcomes are created.

In the current thesis, the salutogenic orientation informed all studies and influenced their inclusion criteria. The first study focused on "the deviant cases" by exploring personal trajectories and how PSC individually and successfully adapted to work-life after cancer from the salutogenic perspective that challenges and obstacles are part of life and that avoidance is not always possible (Antonovsky, 1979, 1987). This study refers to those who succeeded in returning to sustainable work, despite the challenges of undergoing severe cancer treatment.

3.2.2 Sense of Coherence (SOC)

Successful management of tensions from stressors is, according to Antonovsky (1979/1987), dependent on the influence of the individual strength of the individual's sense of coherence (SOC) (Figure 1, p. 19). The SOC construct is defined as a global orientation as if one generally regards situations to be: a) worth engaging in, b) manageable, c) understandable, and possible to overcome (Antonovsky, 1987). The level of SOC will contribute to the person's ability to utilize available resources and manage to resolve tensions (Antonovsky, 1987) and is dependent on earlier experiences:

> "*What matters is that one has had the life experiences which lead to a strong SOC; this, in turn, allows one to 'reach out,' in any given situation, and apply the resources appropriate to that stressor*". Antonovsky (1996, p. 15)

A strong SOC does not represent a reaction to tensions by psychological explanations and mastery styles as flight, fight or being paralyzed, but a person with a stronger SOC will more easily manage tensions and be more able to choose the appropriate way of handling the situation than a person with a weaker SOC (Antonovsky, 1987). SOC indicates the degree to which the person perceives himself as having the necessary resources for the actual tension management in a given situation. SOC is also regarded as the crucial factor for keeping a position at the “ease” end of the health continuum or create a movement on the continuum towards ease (Antonovsky, 1987).

SOC consists of three dimensions (Antonovsky, 1987): Comprehensibility – understanding a given situation to be clear, structured, and coherent – is the cognitive dimension of SOC; if strong, comprehensibility will help create order out of chaos from unexpected or random stimuli (Antonovsky, 1987). Manageability will comprise the confidence to have the necessary resources or instruments to handle the situation (Antonovsky, 1987). When this dimension is strong, a person will feel capable of handling the situation and not perceive himself solely as a victim. However, meaningfulness, the third dimension of the SOC, is the most critical dimension; meaningfulness also represents the motivational dimension (Antonovsky, 1987). If the situation feels meaningless, manageability, comprehensibility, or the combination of the two will not be sufficient to resolve the tensions – at least not for more than a short period of time (Antonovsky, 1987). Meaningfulness also includes the emotional aspect, where the person concerned feels that it will be worthwhile to engage in tension management processes. Antonovsky (1987) developed a questionnaire that he used to measure the strength of the SOC.

3.2.3 The Salutogenic Model of Health (SMH)

The Salutogenic Model of Health (SMH) was first presented by Antonovsky (1979, p. 184-185). SMH is a model describing staying healthy as an adaptation process toward what happens in life. In addition to describing health as a continuum and tension management as crucial for health (Chapter 3.2.1), the SMH comprises two central constructs to manage arising tensions followed by experiencing stressors: The Sense of Coherence (SOC) (Chapter 3.2.2) and available resources (Generalized Resistance Resource (GRRs) and Specific Resistance Resource (SRRs). A simplified figure of the SMH was developed during the analysis phase in the second study (Figure 1, next page).

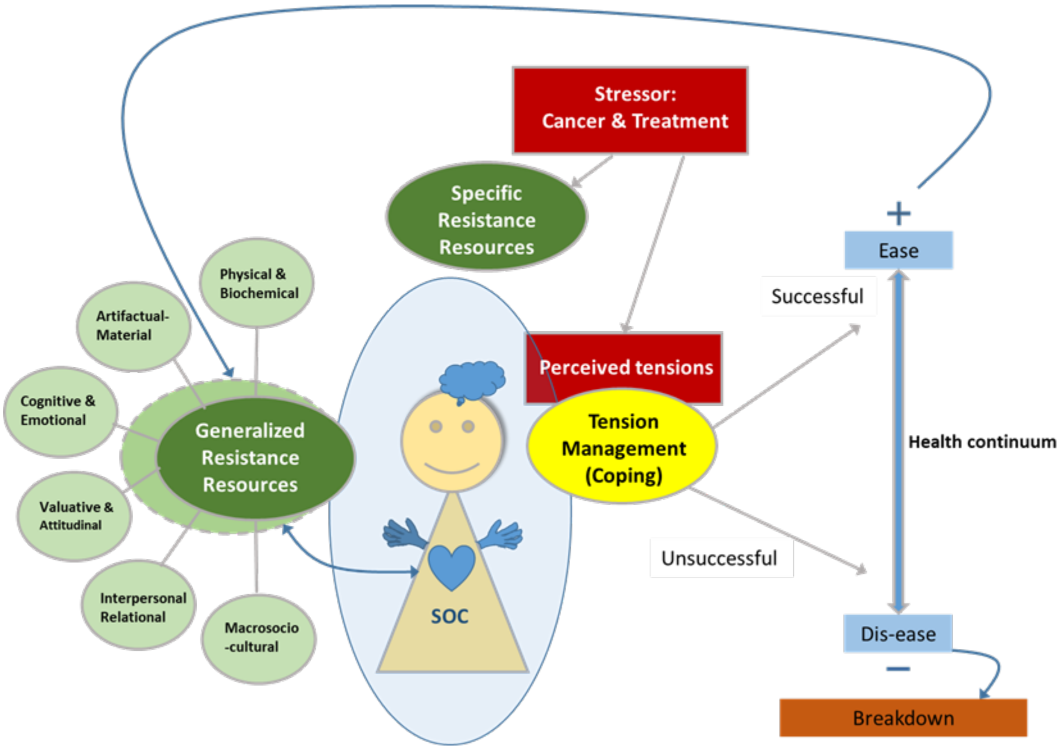

Figure 1: Simplified figure illustrating the salutogenic model of health (SMH).
The figure illustrates an adapted version of the original SMH (Antonovsky, 1979). The original model did not have an individual in the middle. Descriptions of components are explained in Chapters 3.2.1-3.2.3.

The availability of resources can be viewed as the starting point of the SMH model and represent the combined resources that may support people in seeing their lives as structured and understandable (Antonovsky, 1979). Experiences of health and physical well-being are, according to SMH, dependent on how people make sense of what happens to them in life and how they respond and cope during adaptation processes (Antonovsky, 1979, 1987). While SOC defines a personal, global orientation (Chapter 3.2.2), resources consist of two main categories: Generalized Resistance Resources (GRRs) and Specific Resistance Resources (SRRs) that are available to the individual (Figure 1, above).

According to Antonovsky, (1979), a GRR can be a characteristic of a person, a group, or the environment that contributes to the resolving of tensions. GRRs include a wide range of material, biological and psychosocial factors such as money, healthy behavior, self-esteem, culture, religion, traditions, experience, and social support (Antonovsky, 1979;

Lindström & Eriksson, 2006). Antonovsky (1979) described GRRs as consisting of eight different groups: physical & biochemical (physical strength, resistance, and immune system), artifactual-material (a financial situation, shelter, clothing), cognitive (knowledge influencing decision-making), emotional (ego, personality, identity), valuative-attitudinal (lifestyles, coping strategies), interpersonal (social support, spouse, family, relationships) and macro-sociocultural (health and service support systems, religion). These resources are relatively constant, and when substantial, they can be viewed as available tools that increase the probabilities for coping well with and handling life challenges (Antonovsky, 1979).

SRRs are resources defined as connected or related to specific situations (Antonovsky, 1979). An example of an SRR may be a rehabilitation intervention or a program or service offered to an individual in a particular situation. SRRs were later defined to be specific to the actual event, context, or situation (Antonovsky, 1987; Mittelmark et al., 2017b). However, the availability of SRRs is dependent on the GRRs to “open the way”. This dependency means that an SRR may be available, but to utilize it, one needs GRRs in the form of the ability to take advantage of it, and sometimes also a third party must grant access – for instance, to a rehabilitation program after cancer.

The GRRs and SRRs represent resources to handle stressors and the possible tensions from them (Figure 1, p. 19). A strengthening of GRRs and SOC may occur as a consequence of the process of successful tension management (Antonovsky, 1987; Idan et al., 2017). The blue arrow in Figure 1 indicates the possible strengthening of the GRRs from the experience of resolving the tensions, which also may imply strengthening the SOC. Furthermore, resolved tensions may lead to personal growth (Magrin et al., 2006). Such growth may induce growth of GRRs as well, and an increase of the SOC strength. However, the availability of GRRs and SRRs does not mean that all people will utilize them in the same way. According to Antonovsky (1987) and the SMH, the strength of SOC will influence the ability to utilize GRRs, and a person with a weaker SOC will not always be able to utilize them even if they are present (Antonovsky, 1979).

Contextual influences in the construct of resources (GRRs/SRRs)

Lindström & Eriksson (2006) based their theories on Antonovsky's and state that culture is the frame of social environment where people prioritize how they want to live their lives. The psychosocial environment is covered by Interpersonal GRRs in the SMH, whereas the broader cultural, contextual surroundings are covered by the Macro-sociocultural and Valuative-attitudinal GRRs (Antonovsky, 1979). Antonovsky (1987) emphasizes that GRRs that shape life experiences consisting of inner coherence, cohesion, and a balance between underload/overload of tensions will strengthen or build SOC. GRRs may also be regarded as protective factors. For instance, social support may contribute to buffer the impact of an illness. Antonovsky (1991) also described how the workplace offers intellectual development, cooperation and networking, and an opportunity to feel needed and valued. These factors represent *resources* (macrosocio-cultural GRRs) for improving the health of the employees at the workplace.

Moreover, in SMH, the construct of GRRs/SRRs and stressors are two sides of the same coin. Lack of or reduced GRRs may become or represent a new or additional stressor (Antonovsky, 1987). Thus, if reduced GRRs influence the actual tensions from the original stressor, the tension management can be even more challenging. For instance, will low income or poor personal economy in general limit the freedom to make choices. This situation can represent an additional burden if, for example, the ability to work suddenly cuts down. In that case, and as Antonovsky (1986) presents GRRs as continuums, the GRR of finance, if decreased, can represent an additional stressor that may result in generating additional individual tensions according to the actual context. Therefore, the mix and strength of available GRRs can all be essential for successful tension management and the individual's strength of SOC and how to tackle tensions from stressors.

GRRs and SRRs seem less investigated as constructs, compared to that of Sense of Coherence (SOC). However, both constructs will be crucial for the person's ability to resolve tensions (Antonovsky, 1979, 1987). A person who has a stronger SOC will more easily find the appropriate way to handle a situation than a person with a weaker SOC (Antonovsky, 1987). Thus, SOC can be seen as a resource in itself, improving the efficacy of utilizing existent GRRs and SRRs.

3.2.4 Transactional Theory of Stress and Coping (TTSC)

As cancer may be experienced as a stressful life event and challenge, transactional models were considered central to the present thesis. The TTSC theory is based on how the environment imposes strain that must be handled (Lazarus & Folkman, 1984). This well-known and utilized appraisal and coping theory was formed by the psychologist Richard S. Lazarus (1922-2002). Together with Susan Folkman, he defined coping as:

> *"constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."* Lazarus & Folkman, 1984 p. 141.

According to Lazarus (2012), the purpose of long-term coping is somatic health, social functioning and well-being. Therefore, Lazarus' stress terminology can be understood as how to psychologically and, in practice, manage to react or respond to what happens in life to prevent harm. He also emphasizes the environment, where stress is to be understood as a result of a continued transaction between the individual and the environment. This means the situation and the context around a person also represent resources to support an individual during a coping process, which can be crucial for the outcome.

Appraisal

Lazarus (2012) proposed that coping strategies start with an appraisal of the situation. (Note that in his last version printed in 2012, Lazarus also uses "appraising" to signify that appraisal is an ongoing process.) Appraisal is divided into primary and secondary appraising (Lazarus, 2012). The primary appraisal is concerned with emotions deriving from a situation. The individual makes a subjective judgment of relevance based on an immediate and emotional reaction, not on reflections. Examples of such emotions can be fear or anger towards something that is somehow perceived as putting a person's values, goals, or well-being at stake (Lazarus, 2012). The question that arises is basically if the perceived situation at stake is worthy of attention. If the situation is appraised as being in line with the person's personal goals and well-being, the coping process stops (Lazarus, 2012).

Next comes the secondary appraisal, which consists of finding options for dealing with the situation (Lazarus, 2012). Psychological stress reactions are divided into three categories: harm/loss, threat or challenge. The harm/loss category is basically related to the past and possible triggering factors, whereas threat and challenge are mainly directed to the future and the continuation of the coping process. According to Lazarus, an individual's personality influences whether a person is more prone to react by feeling threatened or by feeling challenged. For example, if asked to make a speech, one individual will accept the challenge and feel confident, whereas another will feel threatened. Individuals' level of confidence in having the necessary resources to handle the situation will steer their feeling of being threatened or challenged (Lazarus, 2012).

The primary and secondary appraising are distinct but not always separated. The total appraising is a complex process consisting of interaction and alternation of primary and secondary appraising (Lazarus, 2012). During coping, also reappraisals may be performed.

Coping strategies

Subsequent to the appraisals, the coping strategies come into play. These strategies are divided into emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984). Emotion-focused coping is characterized by how a person tries to reduce a negative emotional state by changing the relational meaning. One strategy may be denial, which can be dangerous. An example of denial is when a person experiences symptoms of a heart attack but denies the symptoms and makes no attempt to call emergency (Lazarus, 2012). However, denial can also be beneficial to protect oneself from anxiety loads and fear.

Problem-focused coping focuses on the perceived challenges and how to solve them by acting or changing behavior in accordance with one's self or one's personal environment (Lazarus, 1993; Lazarus and Folkman, 1984). As an example of problem-focused coping, Lazarus (2012) uses his own experience from when he was diagnosed with prostate cancer and searched for the best medical doctor for the surgery. During the trajectory of transactional processes of managing stressful reactions, reappraisals and coping strategies will be repeated and overlap (Lazarus, 2012). Lazarus (2012) also points out that threats may be reappraised as favorable since a renewed evaluation of the stressful experience may alter one's emotions and build new relational meanings.

Coping theories may help explain the psychological reactions and behaviors when facing cancer. Hoffmann et al. (2013) presented a social cognitive model of restorative well-being as a framework for coping with early-stage adult cancer. They found how acknowledging and expressing emotions were valuable coping strategies. Based on the theories of Lazarus and Folkman (1984), Barnard et al. (2016) developed a four-phased process model as a results of an intervention study for PSC who were returning to work. Their model described RTW process in psychological phases – an initial repression phase with avoidant coping with overwhelming emotions, followed by an acceptance and comprehension phase seeking understanding and facing reality, an activation/problem-focused phase of taking control and responsibility, and finally, a re-integrating phase focusing on meaning making and lifestyle changes.

3.2.5 Theoretical reflections

Health promotion and Salutogenesis (Chapter 3.2), the Transactional Theory of Stress and Coping (TTSC) (Chapter 3.2.4) were both developed during the '80s and were directly related. Antonovsky writes how his respect for Lazarus' work inspired him to develop his theories (Antonovsky, 1987). As presented by Hill Rice (2012, Chapter III), both approaches can be described as interactional and transactional models. During the recent decades, coping theories and Salutogenesis have been widely used to explain response and behavior regarding adaptation strategies and how such strategies influence health by making demands from stressors more tolerable (Hill Rice, 2012). Even today, it makes sense to compare and use these theories as lenses for explaining how to master life's loads and challenges (Braun-Lewensohn & Mayer, 2020).

A salutogenic orientation influenced the design of the current studies, and the theories described in SMH and TTSC were helpful when interpreting the results. Although the strengths of these theories are apparent, it is necessary to reflect on certain aspects of both approaches.

Mastery is the key element

SMH and TTSC overlap when it comes to responding to stressors and providing strategies for mastery of life's challenges. Both theories emphasize mastery as the key element, where learning and growing from successful experiences of adaptations is a factor that contributes to further development as human beings (Lazarus & Folkman, 1984). According to SMH, mastery from tension management will lead to ease on the health continuum (Figure 1, p. 19). If persistent, this outcome contributes to increased growth of the resources available (GRRs and SRRs) and the SOC strength (Antonovsky 1979, 1984). In practice, and due to both theories, a stressor, such as cancer and its consequences for PSC, has the potential to be mastered successfully and lead to subjective well-being and personal growth.

Tension management and the SOC construct in SMH are founded on the same starting point of a need for reaction, as explained in TTSC. Braun-Lewensohn & Mayer (2020) also compare coping strategies to that of SOC and suggest a similarity between SOC and the second appraisal of TTSC, where strategies for coping are formed. In TTSC, personal development resulting from successful coping is also central (Lazarus & Folkman, 1984). Both theories emphasize the person's cognitive ability as a key factor for creating positive outcomes on health, well-being and personal growth.

According to Antonovsky (1987), Lazarus's coping strategies focus solely on stress as a pathogenic load, whereas Antonovsky describes stressors as being pathogenic, neutral, or salutary, all of which have an influence on the individual's development of health. Also, Antonovsky deliberately differentiates between the words stressors and tensions (Antonovsky, 1987). A stressor – regardless of its nature – can generate individually perceived *tensions*. A stressor is defined as a "demand made by the internal or external environment of an organism that upsets the homeostasis" (Antonovsky, 1979, p. 72). This demand is the trigger to act, and a person having a strong SOC, will regard a situation as less threatening than a person with a weaker SOC (Antonovsky, 1987). However, Lazarus (2012) also points out that during the primary appraisal, the commitment to one's personal goals, where situations are perceived as at stake and worth fighting for, coping strategies may be applied to challenges as well as to threats. This may be understood as what is perceived as being at stake is not necessarily a load. It seems that the two theories have grown more similar on this point than Antonovsky argued in 1984. Perhaps Antonovsky's definitions of tensions can be viewed as being more similar to what Lazarus & Folkman (1984) call "stress", in that they must be handled and resolved to create a movement toward "ease" on the health continuum (Antonovsky, 1979, 1987).

Adapting to life's challenges

According to both Lazarus & Folkman (1984) and Antonovsky (1979/1987), coping strategies or tension management, respectively, consist of a response leading to an adaptation process. Antonovsky (1987), explains his theories on living life as analogous to swimming in a river. It is important to swim in the river and not resist the currents. By utilizing what is at hand (GRRs and SRRs) and the swimming skills (SOC), obstacles and upcoming challenges in the river can be handled. Sometimes, the efforts may not always result in a successful outcome, and other times heavy flows and turbulence make it hard to struggle and cope persistently. Therefore, simply floating and being adaptive to what may happen may not always be the best solution. Sometimes, deliberate action and even a complete change of direction in life may be required. Such a situation may alter the aim of adaptation to life challenges or coping strategies from being *re*active, to step into a more active state of choosing to head another way. Although Antonovsky (1987) argued that it was not possible to step out of the river of life, it should be possible to grab hold of a stone or even step up on one to get an overview or take a closer look at the map and how the river may divide further down. Still, both theories focus primarily on being "reactive" and not being "creative" which, by the way, contains precisely the same letters, but is spelled differently.

Differentiating between SMH and TTSC

Hill Rice (2012) emphasized SMH might be more comprehensive than TTSC. She stated SMH is a more abstract theory than coping strategies and a holistic extensive transactional model since it encompasses all influential factors from any context and situation. In SMH, the construct of resources (GRRs and SRRs) and SOC are thoroughly explained and categorized. Moreover, SMH covers a complexity of factors in the entire context surrounding the person(s) involved, while TTSC centers primarily around the emotional, cognitive and behavioral aspects of the individual. Nonetheless, Lazarus &

Folkman (1984) thoroughly describe and emphasize how cultural, social surroundings and relationships and the context (environment) influence and interact with the individual in their coping mechanisms.

Coping theories, represented in the current thesis by TTSC, were derived from psychology and are by nature more focused on the psychological processes and elaborate details of the individual's emotional and cognitive functions. Antonovsky's theoretical stance originated in the field of medical sociology. This may explain why SMH comprises detailed descriptions of external surrounding resources as separated constructs of GRRs/SRRs in the SMH (Antonovsky, 1979). These constructs can be understood as representing tools from the personal and surrounding environment available to resolve arising tensions (Antonovsky 1979/1986). As unsuccessful tension management can become harmful to health, the construct of resources (GRRs and SRRs) in SMH is crucial since solid GRRs and SRRs may increase the likelihood of a successful outcome (Antonovsky, 1979).

Lazarus's (2012) psychological approach sees individuals' different personalities as essential in choosing different strategies to master what is at stake and emphasizes the interactions between people and the environment. The perspectives center around the impact cultural and social structural components have on the individual level during a coping process (Lazarus & Folkman, 1984). The same event may cause fear in one culture, and be perceived as benign in another. Moreover, social structures and demographic variables like gender, age and sex also influence people's values and their appraisals and strategies. TTSC explains thoroughly how a person and the situation interact with the environment during coping phases (Lazarus, 2012), but this theory lacks constructs (like GRRs and SOC in the SMH) that operationalize and define variables in the coping strategies.

The components from TTSC and SMH are different and numerous. One can ask if they are all necessary. In their review, Skinner et al. (2013) sought to find a structure for classifying and creating a system of categorization of coping theories. They suggested that single functions (e.g. emotion-focused versus problem-focused coping) are not good action categories for operationalization because in concrete situations, coping is usually multidimensional. Coping changes in accordance with to real-time responses; people rarely act according to either their emotions or cognitive evaluation of a problem in real-time – situations are constantly evolving and require a multidimensional strategy. While Lazarus (2012) also emphasized the transactional processes as evolving where several phases interact, Skinner et al. (2013) recommended moving beyond what they called a "lower order categorization" toward a focus on adaptive processes as a higher-order where the mediation between mental and physical health and functioning is central (Skinner et al., 2013).

SOC versus emotional-cognitive GRRs

In SMH, the cognitive aspects of coping are of central value, found in the construct of SOC and the cognitive and emotional GRRs on the personal level (Antonovsky, 1979). However, it is not straightforward to understand the difference between the cognitive-emotional GRRs and SOC. These constructs may be perceived as overlapping categories. Also, according to Antonovsky (1987), SOC must not be mistaken for being similar to personality traits. However, the difference may be somewhat hard to understand. According to Antonovsky (1987), SOC is similar to a general approach to living, defined as a global orientation of comprehensibility, manageability, and meaningfulness formed by learning and experiences from childhood. SOC is a global orientation which, combined with GRRs, can be understood as personal mastery skills. Perhaps we could regard the SOC construct as an extended form of GRR that mediates between the external GRRs and the tension management.

4 Aims of the thesis

Even though knowledge on who returns to work, and factors contributing to a successful outcome is increasing, investigations on cancer survivors' success in returning to work or providing resources in employee-related issues have been lacking (Hoffmann, 2005). Still, a small number of studies on long-term cancer research have explored how people cope or manage to achieve sustainable work after cancer treatment. Of these studies, only a few that have used a salutogenic orientation to study RTW after cancer. In a long-term perspective, Norwegian or Scandinavian long-term, controlled RTW studies that include all cancer types and cover more than five years after cancer remain scarce.

Since working is essential for adults' quality of life and health, it is important to address how successful RTW processes after work absences may be achieved while ensuring that as many as possible are given the opportunities to return to work after absences. This PhD project's overall aim was to explore sustainable return to work (RTW) in a long-term perspective more than five years after cancer. The following research questions and aims guided the research presented in this thesis:

Research question 1: How do PSC describe their experiences of returning to sustainable work?

Aim 1: to investigate RTW factors and the long-term perspectives involved in sustainable RTW.

Aim 2: to explore experiences of PSC after they had re-established normality and returned to sustainable work.

The results are presented in Article 1.

Research question 2: How are resources described in the SMH activated and utilized during return to sustainable work?

Aim 1: to explore the tensions experienced by long-term cancer survivors during cancer treatment and RTW

Aim 2: to investigate the GRRs and SRRs the survivors utilized in their progress towards sustainable RTW.

The results are presented in Article 2.

Research question 3: In a larger population where all have working opportunities, are there differences between PSC compared to controls in the RTW patterns?

Aim 1: to describe the patterns of labor-force participation, working hours, job changes, and education for nine consecutive years among women and men who have survived cancer and to compare those patterns with matched controls.

The results are presented in Article 3.

5 Methodology, materials and methods

This chapter presents the materials and methods of the three studies included in this compiled thesis. Chapter 5.1 presents how the design of the studies evolved and how the studies overall became coherent through choices of methodology. Descriptions of how this methodology is used in the various parts of the study methods are further described in Chapter 5.2. Details for selecting participants are provided in Chapter 5.3, followed by collection of data in Chapter 5.4. and the data analysis in Chapter 5.5.

5.1 The evolvement of the study design

The current thesis presents a study that relied on a composition of methods in order to achieve the overall aim of exploring sustainable RTW for PSC in a long-term perspective more than five years after cancer diagnosis. The study design evolved from the outspring of being a qualitatively driven PhD project to also collecting and analyzing quantitative data. Overall, the results of the first qualitative study of 8 PSC guided the design of the two subsequent studies. Figure 2 (below) shows how the results from the first study, where experiences of sustainable work achievement were explored, led to the design of the subsequent studies. Studies two and three were not linked sequentially, but developed as parallel studies. An analysis of the tensions and resources of the PSC and how they were activated during RTW processes were explored in the second study. In the third study, RTW patterns of job changes among a larger population of persons were explored. The three studies are interlinked through the selection of participants.

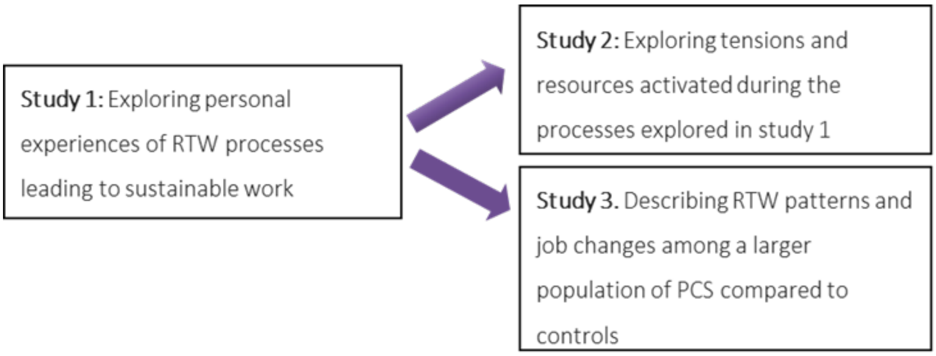

Figure 2. Studies included in this thesis.

A pluralistic view of perceptions of reality makes it possible to view situations, places, contexts, or perceptions differently (da Silva, 2002). Recognizing that different worldview perspectives could shed more light on the first study results, it was pertinent to construct the subsequent studies with different worldviews. By opening up for several ways of perceiving and taking diverse long-term RTW perspectives, it was possible to simultaneously: a) explore in-depth resources needed to achieve sustainable work and b) explore some of the results from the first study in a broader population.

Including different perspectives made it possible to epistemologically mix traditional positivism with constructivism (Shannon-Baker, 2016). As an epistemological approach, pragmatism offers the possibility of combining quantitative and qualitative methods in the same project (Doyle et al., 2016; Morgan, 2007; Shannon-Baker, 2016). Pragmatism emphasizes creating "shared meanings and joint actions" (Morgan, 2007 p. 67), which implies that results from both quantitative and qualitative results in the same project may strengthen each of their methodological advantages and reduce their disadvantages (Shannon-Baker, 2016). Further, Morgan (2007) suggests that one study's results may be used as input to the next and, developing a movement between induction and deduction on earlier observations and results can provide new insights. The first study in the thesis had an unmistakable inductive design, whereas the two next studies can be characterized as more deductive and descriptive.

This PhD project evolved from being a qualitatively driven study towards becoming a mixed-methods study, as described by Doyle et al. (2016). However, the PhD project did not aim for a mixed methods design at its onset. More details and discussions of the study design are provided in Chapter 7.4.

5.2 Choosing methodology

The first study

Initially, and based on the first research question to explore the trajectories of achieving sustainable work after cancer, we wanted to come as close to the subjectively experienced phenomena as possible (Article 1). We believed that increased and deep insight into long-term RTW trajectories after cancer was required to find ways of promoting a sustainable return to work. Thus, our goal was to ask PSC directly for their reflections upon their own experiences and how they made sense of what had contributed to a successful outcome.

To assist the reflection level necessary to cover sensitive personal topics concerning existential issues, health, and the ability to activate resources to retain work involved in RTW processes, I needed a method to describe “what” the experiences were like, and not “why”. Moreover, I wanted to be able to be part of the participants' reflections without the need to gain validity by being completely objective. I chose Interpretative Phenomenological Analysis (IPA). IPA is an inductive approach for qualitative research and comprises both a methodology and a method of analysis (Smith et al., 2009). Researchers from both health and social sciences have adopted the IPA method (Hay-Smith et al., 2013; Luo et al., 2019; Mjøsund et al., 2015; Ryan et al., 2014; Sallis & Birkin, 2014, Woodhouse & Yates, 2020), and the number of IPA studies are increasing.

IPA represents a thorough methodological breadth consisting of three philosophical underpinnings: Phenomenology, hermeneutics, and ideography (Smith, 2011; Smith et al., 2009). The methodology was developed and launched in the area of psychological studies and has roots in two traditions: Husserl’s phenomenology that seeks to capture the essence of the phenomenon (Zahavi, 2003), and the hermeneutic phenomenological tradition, which seeks to reveal meaning related to the phenomenon (Graneheim et al., 2017; Malterud, 2012). However, IPA focuses on Edmund Husserl’s (1859-1938) initial descriptions of phenomenology, where people's own experiences and their reflections on a given phenomenon brings the focus to personal experiences and the subjects’ own perception of their experiences (Smith et al., 2009). Thus, in the current study, we were not heading for exploring the return to sustainable work as a phenomenon in itself, but for capturing how different people perceived the experiences and how they might illuminate RTW experiences for others. The intention in IPA is to explore life experiences (Smith et al., 2009), and the phenomenological approach sets focus on the quality of dialogues in the interviews, and the requirements of detailed descriptions of a phenomenon's lived experience through the participants’ reflections and the researcher`s understanding of those.

When approaching and interviewing participants, the phenomenological underpinning required me to adopt phenomenology as a way of being. I had to make efforts to place my preunderstandings in the background (bracketing) and actively focus on the participants' personal experiences, being curious about the participants reflections without bringing in my own views or preunderstandings. Therefore, IPA provided me with a basis for coming closer to lived experiences. Through the phenomenological approach, I could focus on and plan to understand and extract meaning making based on the lived worlds of the PSC. IPA methodology provided a tool of reflexive awareness in how I related to the participants' experiences.

Hermeneutics is the second underpinning of IPA, and was also suited to my purpose since it provided analyzing meaning making and how people make sense of their experiences, phenomena, and processes (Smith et al., 2009). While Heidegger held that our perceptions from when we are “thrown” into the world are always temporal and always related to subjective perspectives and experiences, Gadamer (1990/1960) suggested how pre-understandings (that in phenomenology is dealt with as “bracketing”) and reflections upon them, could illuminate the described experience. The importance of reflections is based on a belief that knowledge cannot be accessed directly without reflections on the lived experiences.

The hermeneutical underpinning required me to understand the participants experiences as being related to their whole situation and context. “Inter-subjectivity is the concept which aims to describe this (to the world) relatedness and to account for our ability to communicate with and make sense of each other” (Smith et al., 2009, p. 17). To “make sense of each other” is an entirely different approach from that of simply “collecting” data. The production of knowledge is a “joint venture” between the participant and the researcher(s), making the methods explorative. Through the combination of phenomenological and hermeneutical approaches, I could focus on and plan to understand and extract meaning making based on the experiences of the participants.

In understanding individual experiences' particularity and their distinct voices, the ideographic philosophy as the third underpinning in IPA is helpful (Smith, 2011; Smith et al., 2009). IPA's ideographical component differentiates IPA from many other methods of analyzing qualitative data like, for instance, qualitative content analysis (Graneheim & Lundman, 2004) or systematic text condensation (Malterud, 2012), which focuses primarily on common themes for all participants. Instead, IPA opens up for the exploration of characteristic themes for all participants through the particularity of each case. Moreover, to make sense of and extract meaning from individually lived experience, as IPA ”is committed to understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people, in the particular context.” (Smith et al., 2009, p. 29). By the combined ideographic and phenomenological underpinnings in IPA, this methodology also comprises similar elements from the narratives' methods as narratives explore life stories (Creswell, 2007; Denzin et al., 2008).

The first study followed the guidelines and method for performing an IPA study (Smith et al. 2009, Smith & Osborn, 2015). The three underpinnings in IPA influenced the present study from the development of the interview schedule to the arrangement and performance of interviews and the analysis and reporting phases, as described in Chapters 5.3-5.5.

The second study

The results of the first study (Article 1) revealed personal RTW processes. We wanted to gain deeper insight into how PSC met challenges during the RTW processes, so the aim of the second study (Article 2) was designed to explore the activation and utilization of resources during return to sustainable work. The first study had provided rich data material based on the IPA analysis. In this second study, we therefore re-explored the first study's data by utilizing another method of analysis and applying the Salutogenic Model of Health (SMH) (Antonovsky, 1979) as a theoretical lens. This possibility of applying theories directly as a framework and using existing data material has been described by several authors (Bradley et al., 2007; Graneheim & Lundman, 2004; Miller & Crabtree, 1999).

Analyzing data by applying SMH, called for a method that was more suited for re-organizing data into selected groups of results according to the SMH. In other words, in this study we needed a more systematic approach to interpret data in line with the SMH theory. Inspired by qualitative content analysis (Graneheim & Lundman, 2004) and systematic text condensation (Malterud, 2012), I adapted these methods of analysis (Chapter 5.5.2).

The third study

The first study results prompted a need to get an overview of long-term changes in working patterns in a larger population that could verify results from the first study. Therefore, the third study was designed to describe RTW patterns among PSC compared to controls (Article 3). In the third study, the purpose was to explore long-term changes at work after cancer and compare PSC results to controls. We aimed to discover if changes at work, as found in the first study, were more common among a broader population of PSC. .

In line with harmonizing qualitative studies to quantitative, as described by Buetow (2011), we prioritized performing a descriptive survey. As the PhD project originated from a qualitatively driven position by involving users and performing in-depth interviews, a descriptive quantitative analysis was perceived as being closer to the qualitative realm of exploration from the first study than an analysis using more complex statistics. Thus, the research design for this whole thesis, comprised qualitative data from the first studies mixed with quantitative data provided by the third descriptive study. This third study was thus a retrospective population-based cohort study that focused on labor-force participation, working hours, changes in jobs, and education changes in a nine-year perspective (2004/2005-2013/2014) after being diagnosed with cancer.

As the third study was designed after the first study was completed, participants included in the first study and the population selected in the third study were harmonized to create as homogenous groups as possible (Chapter 5.3).

5.2.1 User involvement and the establishment of the advisory team

Research on work-related goals after cancer and increased user involvement in RTW processes have been called for (Laidsaar-Powell et al., 2019; Wells et al., 2013). In recent years, user involvement has also been given an increased focus in health care research (Boote et al., 2015). The key epistemological assumption in research where users are consulted, is that knowledge is developed through a cooperative process between researchers and experienced individuals, believing that knowledge is found in people's experiences and lives (Borg, 2012).

The level of user involvement in a research process may vary from no participation, occasional consultations, and full collaboration with the researchers through all phases of the study (Sweeney & Morgan, 2009). From their research in mental health, Sweeney et al. (2013) reported on how to extend the user's level of participation from solely being interviewed to actively being regarded as part of the researchers' team by participating with coding in the analysis process (Sweeney et al., 2013). Mjøsund et al. (2017) described how user involvement enhanced the quality of research by bringing multiple perspectives into the analysis. This involvement resulted in more insightful interpretations of the participant's accounts' nuances, complexity, richness, and ambiguity.

In the first study, we employed users' direct involvement as participants in in-depth interviews. The participants' involvement included their influence on the interview setting and content (Chapter 5.4) and their participation in evaluating preliminary results (Chapter 5.5). We regarded PSC to be our main source of knowledge and aimed to include experiences directly by performing interviews. The focus in the first study was doing research not only “for” or “to” a group, but to involve individuals and instead do research “with” them. We believed that PSC who had firsthand experience with the events represented specific know-how. Subsequently, also a deep respect for the communication and collaboration between involved parties guided the present PhD project.

User involvement also applies to ethical aspects (Ives et al., 2013). Respecting every person involved as being equal (Buber, 1958/1987) was a keystone in the present studies' ethical consideration. Collaborating with participants is distinguished from conducting research as “top-down”, where the participants are often called “informants”, indicating they should be expected to respond (to researcher’s questions), but not necessarily actively participate with their reflections. The present study was designed to consult participants and to regard them as equal co-researchers and to represent equal power dynamics, as explained by Kvale (2006).

In the current PhD project, we also took up participation and user's perspectives from a different perspective by establishing what we called an advisory team. The aim was to create access to an expert group to enhance the quality of the first study by adding the participation of persons representing several voices in the construction of knowledge about RTW after cancer. The moral obligation of hearing and understanding several voices has been emphasized in the development of health care services and research processes (McCormack et al., 2010; McCormack & McCance, 2010). Hearing several voices means that all parties embedded in a process should be involved. In the current studies, the main focus was PSC and their experiences. Other implicated parties could be next of kin, the employer and workplace, health care and social welfare personnel, and other advisors, as they could be related to the context of the first study's participants. Therefore, to include perspectives from PSC's contextual surroundings, we extended the research group by establishing the advisory team.

When recruiting members to the team, I searched for people with various experiences and backgrounds. By composing an advisory team with representatives from different groups it was possible to combine our extensive expertise and experience in a way that enhanced our collective ability to understand and interpret data and the results. The team included seven members, some of whom had experiences from being a cancer patient with RTW experiences themselves. Others were next of kin or an employer with experiences with employees returning to work after cancer. The majority of members had directly supported and advised cancer patients in RTW processes. Some also had academic skills in the realm of public health or nursing. All members volunteered to participate without any compensation.

The advisory team ensured that participants' voices were safeguarded by tightly following the first study to completion. The members collaborated with my supervisors and me in the entire research process. First, I wanted to ensure an open climate where all voices were respected and heard, and in the first meeting, we discussed and agreed upon a group contract (Appendix V). This contract included descriptions of expectations, how the members were to participate and cooperate, and the performance and content in meetings. The advisory team participated in discussions in regular meetings before the first in-depth interview took place and throughout the analysis and reporting phases of the first and second study. We met for 3-4 hours regularly during the work with the first and second studies. From autumn 2015, we met twice each semester, and our final meeting was in March 2018. From that point on, the team members were asked individually for advice upon request.

5.3 Participant recruitment

The salutogenic orientation focused on exploring successful outcomes and influenced the definition and inclusion criteria of the participants. In order to be able to explore PSC's successful outcomes in RTW, we searched for participants that either had achieved returning to sustainable work (first and second studies) or, at least, had good opportunities to be working for many years after cancer (third study).

Participants in Study 1

In the first study, the inclusion criteria for participants were defined as: a) having been diagnosed for cancer at least five years ago, and b) having undergone severe cancer treatment (surgery followed by either radiation or chemotherapy, or both) but with no reoccurrence of cancer or another diagnosis that could have severely decreased the participants' working abilities after cancer treatment, c) working before the cancer diagnosis and working for at least three consecutive years in a new or former position after their last cancer treatment, d) still working (full-time or part-time) at the time of interview, and e) approximate age of 25-55. The intention was to interview 10 participants who fulfilled the inclusion criteria and who also represented variety of gender, type of work, cancer diagnosis, and socioeconomic status.

Due to the inclusion criteria, those who would be able to fulfill them were already out of the systems for follow-ups from hospitals or other registries. Therefore, we had to search more openly and found suitable participants by contacting local cancer organizations and by advertising on Facebook and relevant internet sites at USN. I also attended local and national meetings organized by the Norwegian Cancer Society to give information about the study and the need for volunteers. Twelve individuals volunteered to take part during autumn 2015. Before making any appointments for interviews, I phoned each of the volunteers to check that they fulfilled the inclusion criteria. Three volunteers had less than three years of work experience after cancer treatment, and one lived too far away to attend the interview time and place. These were excluded. The other eight volunteers were eligible, and they varied regarding age, gender, type of work, position, and cancer type. All eight became participants. The participants' age at the time of cancer diagnosis ranged from 30–54 years, and at the time of the interview, their age ranged from 42 to 59 years. The time since the participants' last treatment was an average of nine years.

Participants in Study 2

The participants in the second study were the same as those in the first study. As the data material from the first study was regarded as rich, there was no need to recruit additional participants in order to collect additional material for the second study.

Participants in Study 3

The third study was performed to add insights to the first study's results by using statistics and quantitative data sources from Norwegian registries to describe RTW patterns and job changes among a larger population. We extracted data about persons who survived cancer (PSC) from the Cancer Registry of Norway (CRN) (Cancer Registry of Norway, 2019; Larsen et al., 2009). The CRN was used to identify people diagnosed with cancer and to extract data about their diagnoses according to the International Association of Cancer Registries (2019) classification. Through each PSC's unique identification number, we linked data about each PSC from CRN to the Statistics Norway's events database (FD-Trygd) (Statistics Norway, 2007) and the National Educational Database (Statistics Norway, 2019). From FD-Trygd, we extracted data on age, gender, work contract, working hours and employer for both PSC and controls. From the National Educational Database, we extracted data regarding the participant's educational level.

From CRN, we identified 21,819 cancer cases for all persons aged 15-68 years registered with a cancer diagnosis in the years 2004 and 2005. Overall, to ensure that the population selection in the registry study was similar to the inclusion criteria for the participants in the first two studies, a large part of the total population was excluded. Also, to cover a population with a high degree of possibility to work during the investigation period of 9 years from the date of PSC diagnosis, we included only those PSC who were alive for a longer time than the investigated period (10 years). This selection led to excluding 9,271

PSC who died during the 10 years after the cancer diagnosis, resulting in a total of 12,548 PSC.

Only working PSC in the age range 30-50 at the time of diagnosis were included. Younger people were excluded since they may still be taking an education in their twenties, or they may not have been employed over a long period of time. Thus, the lower age limit was set at 30 years. The upper age limit was set at 50 years because people at this age in 2004/2005 would be close to 60 years old in 2013/2014. It has been documented that increased age is associated with a higher risk of falling out of work (Dahl et al., 2019; Mehnert, 2011). The portion of the Norwegian population in retirement starts increasing when people reach the age of 60 (Statistics Norway, 2018), and research among PSC shows that people at this age are more likely to choose early retirement instead of returning to work after cancer (Bennett et al., 2018; Mehnert, 2011). This way, we also harmonized the registry study's age limits with the inclusion criteria from the first study. The total number of PSC aged 30-50 years when diagnosed and still alive after 10 years was 3,579. Of these, 428 PSC with more than one cancer diagnosis were excluded since a new cancer diagnosis in the follow-up time could influence the results.

As was also the case in the first studies, we wanted the participants to have some working experience before the cancer diagnosis occurred, and we included only participants who were employed when they received their cancer diagnosis. If people were on sick leave before the date of diagnosis, the working contract in the registry would still have a valid status, so this selection would also include those who were working but on sick leave before the cancer diagnosis. Therefore, 891 PSC who were not employed at the time of diagnosis or within 90 days before were excluded. Finally, 15 persons were excluded due to missing data and 44 persons because they had emigrated. Thus, a total of 2,629 PSC were included in the study.

Each selected PSC was matched with two unique controls randomly extracted from FD-Trygd, based on age, gender and education. The controls were selected based on the PSC date for cancer diagnosis. They were employed by having a work contract and as for PSC, they were found alive for 10 years after and with no occurrence of cancer diagnosis during the investigated time. All matched controls were blocked from being selected more than once.

The total dataset finally included 2,629 PSC and 5,258 controls, who were followed from 2004/2005-2013/2014; all variables were measured every 12th month from the date of diagnosis, for both PSC and controls. A total of 1,575 female PSC and 954 male PSC participated in the study. The age of female PSC was on average 42 years in 2004/2005, while among men, the average age was 41. More than 80% of the selected female and male PSC had initially completed more than the basic level of 10 years in primary school, and almost half of those had university level of education. The largest groups of cancer types among the PSC were breast cancer among female PSC and genital cancer among male PSC.

5.4 Data collection

Data material for Study 1

A total of eleven in-depth interviews were performed from November 2015 to May 2017 and provided the two first studies' qualitative data. Eight participants were interviewed once, and three of them were re-interviewed after the initial analysis (see Chapter 5.5). The interviews were videotaped and lasted between 100 and 150 minutes. Participants who have experienced cancer and its treatments could be vulnerable when they are asked to recall their RTW process, and therefore the process was carefully organized. The participants chose the time and place for the interview, which were all performed as planned. All participants were given fictitious names in alphabetical order of the first letter corresponding to the interview order.

Based on the research aims, and before the first interview, an interview schedule was developed in cooperation with the advisory team (Chapter 5.2.1). According to IPA, an interview schedule is a guide for conducting semi-structured to more open interviews where the way of performing interviews is through reflexive dialogues and following the reflections on upcoming topics and meaning making according to what participants were telling (Smith et al., 2009). Because of this, the interview schedule differs slightly from a more commonly used semi-structured interview guide, as, for instance, described by

Malterud (2001). The interview schedule comprised themes and suggestions for possible sub-questions. The interview form was aimed to be as reflexive towards the participants' stories and open as possible, making the sequence of questions asked subordinate. Also, the interview schedule focused primarily on RTW issues and not the cancer diagnosis or treatment. Working thoroughly with the interview schedule (Appendix III) heightened the level of preparation and awareness before the interviews and prevented missing essential details or perspectives. During the interviews, participants were attentive and reflected on how cancer had impacted their lives. The way of asking the questions was important – using wordings like “tell me more,” “please explain,” “why” and “how”. Preunderstandings were noted and discussed with the advisory team before the first interview took place and validated as the interviews progressed, which also changed the preunderstandings. These changes were also noted and discussed.

In trying to catch the PSC stories' essence, I wanted to come as close to the subjective experiences as possible. Due to the phenomenological philosophy of IPA, it was essential for me to develop the interviews' dialogues to reach the right level of consideration and elaborations. In practice, I focused on the importance of acting respectfully and establishing a climate for deep reflection. I made efforts to be consciously present and aware of how the participants reacted during the interviews. Profound and deep reflections came from tolerating silence. I practiced actively to wait for responses and make room for the participants to have the time to think before answering questions and to remain reflecting on a subject until the participants had no more to add.

The fifth and sixth step of analysis (see Chapter 5.5, p. 42) separated all interviews in the current study. Before moving to the next interview, I spent the time analyzing how the present case was unique. This strategy influenced my growing understanding, awareness, and consciousness toward the data and results. My understandings and knowledge increased gradually and formed more profound thoughts and reflections informed by the increasing numbers of former cases. The earlier case analyses also influenced and nuanced the next interview and made room for additional reflections and elaboration. Still, I was aware that the “next case” could be very different from the former, and I made efforts to meet all participants with an open mind.

After the eighth interview, I wondered if the emerging interpretations could benefit from more extensive illumination and elaboration from participants I had interviewed earlier. Especially from the interviews of “Britt” and “Carl”, who were interviewed quite early, I was curious if some understanding I had developed was fully comprehended. I wanted to interview them once more for further elaborations and reflections. “Grete” was also included in the re-interviewing process because I found remaining topics to reflect upon with her. Moreover, I also wanted those re-interviewed to respond and reflect on the preliminary results.

Data material for Study 2

Study 1 also provided data for Study 2. All videos and recordings from Study 1 had been stored in NVivo (QSR International, 2016) and were available for new analysis purposes. To prepare the data, and since the descriptions were sequentially stored in NVivo during the first study, I printed out all descriptions on paper this time and prepared to re-analyze the data from the desktop, separated from NVivo and the former process of analysis.

Data material for Study 3

The results from the first study guided the outcome of the quantitative data in the third study (Article 3). Of particular interest was whether PSC in a broader population changed their working situation or received more education than others. All data for outcome variables *labor-force participation, working hours,* and *job changes* were monitored every 12th month each consecutive year.

Labor-force participation was defined as having paid work by a work contract of employment for 90 days before cancer diagnosis. If we found PSC to be unemployed in a given year, they were regarded as out of work that year but were re-included if a new work contract was registered later.

Working hours were monitored as per week each consecutive year among the employed. In addition to the results emerging from the first studies, we wanted to investigate if also findings from previous research could be confirmed. Previous research had shown that PSC often downgrade from full-time to working part-time (Hamood et al., 2018; Luker et al., 2013; van Muijen et al., 2018). Data about working hours were found as a part of the working contract in Statistics Norway's events database (FD-Trygd) and as a fixed number of hours per week. In the current study, we defined three categories: a) 30 hours or more (full-time), b) 20-29.9 hours (long part-time) c) less than 20 hours (short part-time).

Job changes may include a change of position within the same company and a change of employer. Earlier cohort studies have revealed how changes in work tasks or even new education after cancer could be beneficial after cancer (Mehnert, 2011; Torp et al., 2012a). The results of our first study prompted us to monitor several changes in the working tasks of the persons investigated. However, changes in categories in the registries during the investigated period caused data about professions and positions to be inconsistent some of the years involved. The dataset provided consistent data about employer changes, which, therefore, were used as the variable for a job change. Changes of employer since the previous year were recorded every year. Data about the year before diagnosis (T_{-1}) was not available, and the first year of monitored changes was from T_0 to T_1.

Education was measured by collecting the first digit in the Norwegian Standard Classification of Education (Statistics Norway, 2019), which corresponds to the International Standard Classification of Education (ISCED). This digit clarifies which educational level the person has completed. Students were measured annually; as per October 1 of each year, who was registered as enrolled in basic/primary, secondary or university levels of education.

The variables *working hours* and *job changes* were dependent on *labor-force participation*. Since one can undergo education and work simultaneously, the variable *education* was included in the total study population every 12th month, and this variable was independent of the variable *labor-force participation*.

5.5 Data analysis and reporting

Analyzing and reporting Study 1

Each interview in the first study was analyzed following the six steps of analysis proposed by Smith et al. (2009, pp. 82-101): reading/re-reading, initial noting, developing emergent themes, searching for connectedness across emergent themes, moving to the next case, looking for patterns across the cases. Each interview in the first study was analyzed to completion before interviewing the next participant (Figure 3, below). By focusing on one person at a time, I had a better chance of understanding each participant while dwelling fully upon one at a time during the analysis phase.

Promptly after each interview, I made notes of my immediate impressions, thoughts and reflections. Then the video- and audiotapes from the interview and these notes were imported to NVivo (QSR International, 2016). Later, all comments, notes, mind maps and coding trees during the analysis phase were stored in NVivo. I linked all descriptions, quotes, and interpretations from the analysis to the actual video sequence. Both the advisory team members and my supervisors contributed to the analysis process of de- and re-contextualization of the data material in the first and second studies. However, only the current PhD supervisors in 2016-2017 were allowed to watch the videos.

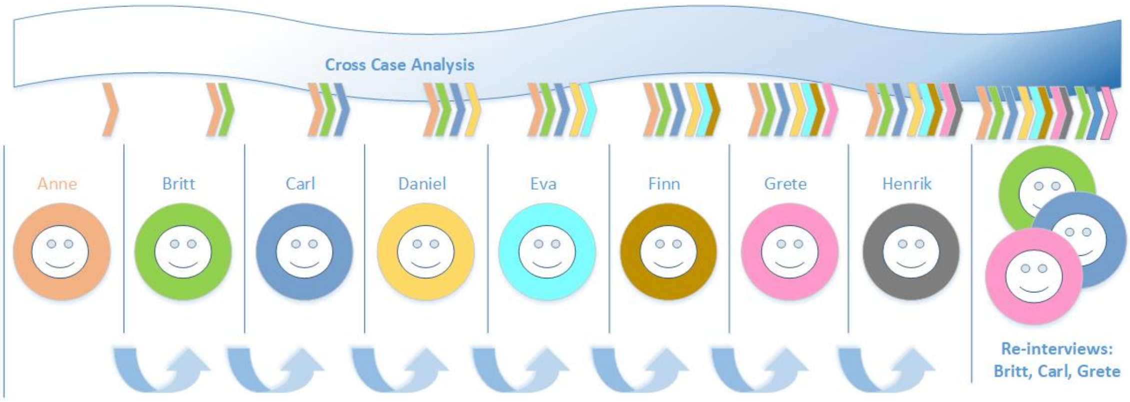

Figure 3. Ideographic, case-by-case interview and analysis process.
Every participant was interviewed and the case analyzed to completion before the next participant was interviewed (November 2015 to May 2017). The cross case analysis was initiated by notes of thoughts and reflections during the process, and the cross case analysis was finalized by making coding trees and abstractions after all cases and the re-interviewing of Anne, Britt and Carl was performed.

Reading/re-reading

I started the analysis of each case by immersing myself in original data by listening to audiotapes and watching the videotaped interviews 3-5 times. I noted every new perspective, question, or recognition that came up. This process ensured recognizing more perspectives each time, which gave valuable impressions and opened up new layers and new themes long before I delved into an analysis of the details sentence by sentence. Imported video sequences and the analysis in NVivo directly on video ensured closeness to the original data, as described by Beich et al. (2002). Experiencing this authentic way of receiving the meanings of the participants' words, incorporating both tone of voice and body language, enhanced my perceptions of their statements by allowing me to use more senses than would be possible by reading only text.

Initial noting and broadening the text

The second step consisted of systematically adding descriptive notes to all video sequences in NVivo. I divided the video into thematic sequences of 1-10 minutes of coding, depending on the actual content in the video, so that the notes were directly linked to the video sequence. I included descriptive, linguistic, and conceptual comments. This way, the text was directly linked to the video sequence. Descriptive, linguistic, and conceptual comments were added.

Developing emergent themes

The third step started during the descriptive phase by naming the sequence of videos. Later, and as the analysis and interpretation process progressed, I further elaborated the themes and organized them into levels and mind maps. Sentences from videos that illustrated the video sequence or emergent theme were transcribed verbatim and added to the textual descriptions.

Searching for connections across emergent themes

The process of the fourth step led to abstracting and organizing super-ordinate themes in coding trees and mind-maps. While I, focused on descriptions and my pre-understandings' during the IPA analysis's first phase, the next hermeneutical analysis opened up for interpretations and using understandings actively, as described by Heidegger (2006/1962). The hermeneutic circle opened up for additional and reflective thoughts and discussions, where it was essential to alternate the perspectives between looking at parts and looking at the whole. The present study was performed as de- and re-contextualization processes alone and with my supervisors and the advisory team. Double hermeneutics, as presented by Creswell (2007) and Smith et al. (2009), was utilized to make sense of the participants' sense-making of their worlds and explain the information revealed and our understanding of the participants' reflections.

The notes from the interpretation phase were then added to the same video sequence as the initial descriptions. I used different coloring of text to differentiate which phase the descriptions belonged to. In this phase, notes about the interpretation of body language were written as a being a part of the hermeneutical interpretation phase. In Appendix IV, a snapshot of the screen illustrates the first phase of analysis.

Moving to the next case

In step five, the ideographic philosophy in IPA, as explained by Smith et al. (2009), allowed me to focus on grasping the meaning in each complicated case and context and then draw the lines from each story into a common entirety. This made it possible for me to distinguish how every participant was unique in their lived experience during the RTW process. This process resulted in a new and specific mind map containing the overall themes and abstractions for the present and unique case. After the present case was thoroughly analyzed ideographically, the planning of the next interview began. The NVivo mind maps of the coding of themes from each case analysis were utilized (see example in Appendix IV).

Looking for patterns across cases

Successively, and when performing the sixth step, I made a further abstraction and mind map that gradually developed and included themes as they derived from one case to the next (Figure 3, p. 46). Interpretation and reflections from the actual case's themes were added into the notes one after the other. Common themes and the overall mind map showing superordinate themes for all cases were finalized after the eleventh interview. The next level of hermeneutical interpretation was performed through this phase, as per IPA, when co-researchers or other readers try to understand and interpret the results written by the researcher (Smith et al., 2009, p. 35). Thus, my cross-case interpretations were presented for discussions and consultations with supervisors and the advisory team.

During the analysis process, the advisory team (Chapter 5.1.1) was consulted on a regular basis to ensure both single accounts' validity and cross-case interpretations. These discussions corroborated and nuanced my interpretations. For that reason, the advisory team became an extension of the research group. The team functioned as an "independent audit," as advised by Smith et al. (2009 p. 183), where an auditor “is attempting to ensure that the account produced is a credible one”. Printed handouts, including transcripts and extracts from NVivo, were organized and presented in meetings for reflection and discussion, where we always tried to stay close to the empirical data. The advisory team did not share their knowledge solely upon request. They were actively engaged and contributed significantly to develop the results by adding their knowledge, curiosity, questions, reflections, and experiences. The advisory team gave me regular access to user experiences as well as the know-how and expertise from experienced professionals.

Together with my PhD supervisors I evaluated the results and the sample size after completing the eighth analysis. The data quality and preliminary results were regarded sufficient because 1) the aim was distinct and narrow, 2) the participants held homogeneous characters, 3) theoretical frameworks were applied, 4) the group of participants showed variety in their experiences and 5) the chosen methodology provided reflective dialogues and thorough analysis that resulted in a rich dataset. The number of eight participants was then found to be satisfactory according to information power, where the sample size was evaluated on the basis of the above five areas as described by Malterud et al. (2015).

Although the sample size of 8 could be sufficient, IPA encourages re-interviewing participants as a bolder research design (Smith et al., 2009; Wagstaff & Williams, 2014). Three participants were re-interviewed in the current study. The sum aim for this was to involve the participants directly once more to gain clarity and possible corrections or new reflections, and to discuss preliminary results. Hence, the recruitment process stopped, and three of the participants were re-interviewed (Figure 3). All three participants added new perspectives to the questions asked. They also contributed to the creation of results by their comments and reflections on the preliminary results. Finally, data from these interviews were incorporated into a final sequence of analysis, reported as participants’ journeys in Article 1.

Analyzing and reporting Study 2

In the data material from the first study, salutary factors and resources utilized by participants during their trajectories were identified. To analyze the activation of resources at a deeper level, we applied the Salutogenic Model of Health (SMH) for additional exploration of the same data material provided by IPA in the first study. Thus, Article 2 refers primarily to IPA according to the method utilized. However, qualitative content analysis was then conducted with descriptive and interpretive approaches (Graneheim & Lundman, 2004) to the existing data material. New analysis and a new process in reorganizing results from a recent study may distance a researcher from the original meaning and entire contexts (Miller & Crabtree, 1999). Therefore, I re-opened and watched the videotapes to recall impressions and understandings and to get a renewed sense of the whole. Then, the written material of 155 codes stored from the initial IPA analysis in NVivo, including all descriptions, quotes, and interpretations from the initial analysis of the data material were extracted. The codes and descriptive text were reorganized and transformed into Word documents and tables divided into new meaning fragments. Through the next process of meaning condensation, the meaning fragments were examined to find and illuminate core meanings (sub-themes). Next, the search for overall themes was performed by following threads of meaning fragments as they were found to appear repeatedly through the data and the sub-themes (Graneheim & Lundman, 2004).

The sub-themes were assigned according to the components of SMH: Stressors, Tensions, Generalized and Specific Resistance Resources (GRRs/SRRs), and Sense of Coherence (SOC) (Mittelmark et al., 2017b). GRRs were split into eight components as described by Antonovsky (1979), and SOC was divided into its three main components: Manageability, Comprehensibility, and Meaningfulness. When a sub-theme could fit into several components of the SMH, it was copied to all possible components. Making such duplicates of sub-themes is not recommended, according to Graneheim & Lundman (2004). However, and because the categories (as representing the components of SMH) were set beforehand and were not a result of categories emerging directly from the sub-themes and themes, the duplicates helped interpret how the SMH components and results from a real context could fit together. Thus, the themes were duplicated to more than one component when applicable. During the analysis process, the PhD supervisors and the advisory team members were consulted. Finally, sub-themes and relevant quotes were extracted from each component of the SMH into a coding tree of overall themes.

Research with a focus on resources seem still to be scarce, and Bauer et al. (2019) called for more focus on resources in the future. Since the analysis showed how emotional-cognitive and valuative-attitudinal GRRs overlapped the components of SOC with duplicates of sub-themes, we chose to report the results with a focus on GRRs. Thus, in Article 2, tensions and utilization of the GRRs/SRRs' constructs were prioritized and regarded as the most valuable results to report.

Analyzing and reporting Study 3

In the third study (Article 3) Stata/SE 14.2 for Windows (StataCorp, 2019) was used for all analyses. Descriptive statistics were performed using frequencies and percentages. We noticed gender differences in the data material when test-runs were performed and found it valuable to continue analyzing the differences and later report the results in this study divided according to gender. Results from earlier registry studies in Norway have shown gender differences (Becken et al., 2015; Syse & Tønnessen, 2012; Torp et al., 2013). Also, several studies from other countries have emphasized that women, overall, return to work after cancer less than men (Kiasuwa-Mbengi et al., 2018a, Marino et al., 2013; van Muijen et al., 2013). However, long-term results (more than five years) were still lacking from Nordic countries. Therefore, we compared four pairs of groups using all variables every consecutive year: female PSC versus female controls, male PSC versus male controls, female PSC versus male PSC, and female controls versus male controls. The proportions in the groups were compared each subsequent year. However, the trajectories of individual cancer cases were not followed.

My current main supervisor and a qualified expert in statistics helped me choose the tests and develop results. Due to the large numbers of participants in all groups every year and the homogeneous groups (matched on age, gender, education, and being employed), parametric tests were considered a better option than non-parametric tests (Fay & Proschan, 2010; Pallant, 2010). For these analyses, two-sampled independent t-tests were used on all outcome variables for all consecutive nine years and paired-sampled t-tests when comparing changes from T_0 to T_9 on the variables *labor-force participation* and *working hours*. The significance level was set at 5%. All tests were two-tailed to avoid predicting a specific direction of possible differences between the groups.

5.6 Ethical considerations

The studies followed the ethical principles for medical research involving human subjects, as explained in the Declaration of Helsinki (The Norwegian National Committees for Research Ethics, 2016). The Norwegian Data Protection Authority (number 16/00235) approved the registry study, and the Regional Committee for Medical and Health Research Ethics (REK) evaluated and approved the qualitative studies (number 2016/830).

All electronic data and videotapes from the interviews were stored on a secure server at USN. Another back-up of the videos was stored on an external physical hard disc and locked in a safe at USN. Hand-written notes and print-outs were kept in the same locked safe. After the interviews were completed, all email correspondence with the participants was deleted. No other person was given access to the videos, although my supervisors viewed some of the videos with me. The results from the analysis of registry data were also stored on a secure server at USN.

The participants interviewed were regarded as experts and co-researchers (Borg et al., 2012; McCormack, 2015). Treating involved parties with respect, humility, equity and openness, was followed as a principle. Respect and sensitivity toward participants and their personal stories resulted in sustained awareness in all phases of the studies, from the first contact with participants and members of the advisory team, through the interview phase, analysis, and the reporting of results and interpretations. Participants were informed several times, orally and in writing, about the opportunity to withdraw before publication and without any consequences. All participants signed informed consent before the interview took place.

Although the participants' cancer treatment was completed years ago, and the participants had recovered from cancer and returned to work, an interview might carry the possibility of re-traumatization of what they had experienced because of their cancer.

The participants were informed about this possibility and told that help could be arranged if needed. None of the participants expressed any need for such help. However, several participants explained how they were surprised at how affected they were from the recollection of their experiences and reflected upon their emotions after the interview was finished.

6 Results

This thesis comprises three studies as reported in Articles 1-3. Each article's results are briefly presented in Chapters 6.1-6.3, while the overall results of this thesis are described in Chapter 6.4.

6.1 Main results from Article 1

The first research question asked was how long-term perspectives were perceived from the onset of cancer and until sustainable work was achieved. The two aims in the first in-depth qualitative interview study were to a) investigate RTW factors and the long-term perspectives involved in sustainable RTW and b) explore experiences of PSC after they had re-established normality and returned to sustainable work. It was striking that each of the participants independently described the RTW process as a journey.

How the participants handled returning to work after cancer was very diverse in content and time, and led to different concrete developments. For example, Anne quit her former job and followed her dream and new occupational goal of becoming a shop owner by taking a new education in economics, while Carl found the social network at work being most meaningful to him to engage in – even before he was ready to start working and was still on sick leave. Britt, who initially returned to work, but later had to quit her job due to exhaustion, dedicated herself to meaningful and self-fulfilling occupational activity; as she wanted to help others, she became a volunteer instead of being employed. Britt explained how she coped with her new tasks: “I was on fire!” The experience of being of value at work engaged her so much, that she coped with her exhaustion at work. She gradually took up employment in the volunteer organization, and after more than 10 years after cancer treatment, she worked full-time there. Finn was a successful craftsman before cancer and made efforts to continue to do precisely that after cancer since he loved his job. After several years and enduring recurrent sick leave periods, he realized that he had to change his profession to cope with continuing working, took necessary action, and quit this job to continue as a handyman and janitor for another employer. Eva decided during sick leave that she had to change occupation to be able to move on. Taking the risk of choosing a completely new path or occupational shift – despite not being sure how present or future working ability will be, adds the perspective of accepting risks when moving on.

Daniel was very motivated to return to his work and own business and returned to his former work against the advice from his oncologist. Grete appreciated her employer's ability to adjust working tasks to her pace initially after cancer treatment. Henrik returned to his former workplace and working tasks, which he perceived as meaningful, but started with reduced working hours and gradually increased them. The participants' stories revealed that adaptation to former work and extensive occupational changes may be demanding to perform.

Although the participants experienced diverse trajectories in time and content, they also had a lot in common that led to the development of a five-phased process model (Figure 4, next page). During the five phases, participants adapted to their new situation after cancer by making changes according to their new situations; for some, this led to a new occupation or education, others changed jobs or employers, and some reduced their working hours.

During the two first phases (Figure 4), work was not as weighty as dealing with the shock of being diagnosed with cancer and undergoing cancer treatment. During phases 1 and 2, medical issues, health personnel, the family and close relationships were more important than work. When reaching phase 3 – which represented a transformational phase – all participants experienced that their initial exhaustion indicated they had started working too early, but being at work also helped them distance the ill-feelings from dealing with cancer and its treatment, and helped them gain hope of a renewed normality. All participants showed adaptability toward the new situations that followed cancer treatment and late effects. They decided to return to work early on, and if the former workplace did not provide what they needed or wanted, they decided to embark on a new education or change their workplace.

In phase 4, they actively prioritized what gave energy, which, for instance, resulted in cutting back on contact with former friends who gave them negativity (Figure 4). Furthermore, they prioritized activities that energized them; when work tasks were meaningful, and they gradually mastered them better, they were energized to continue. Gradually, although over different lengths of time, they all managed to return to sustainable work in a "New reality" (phase 5).

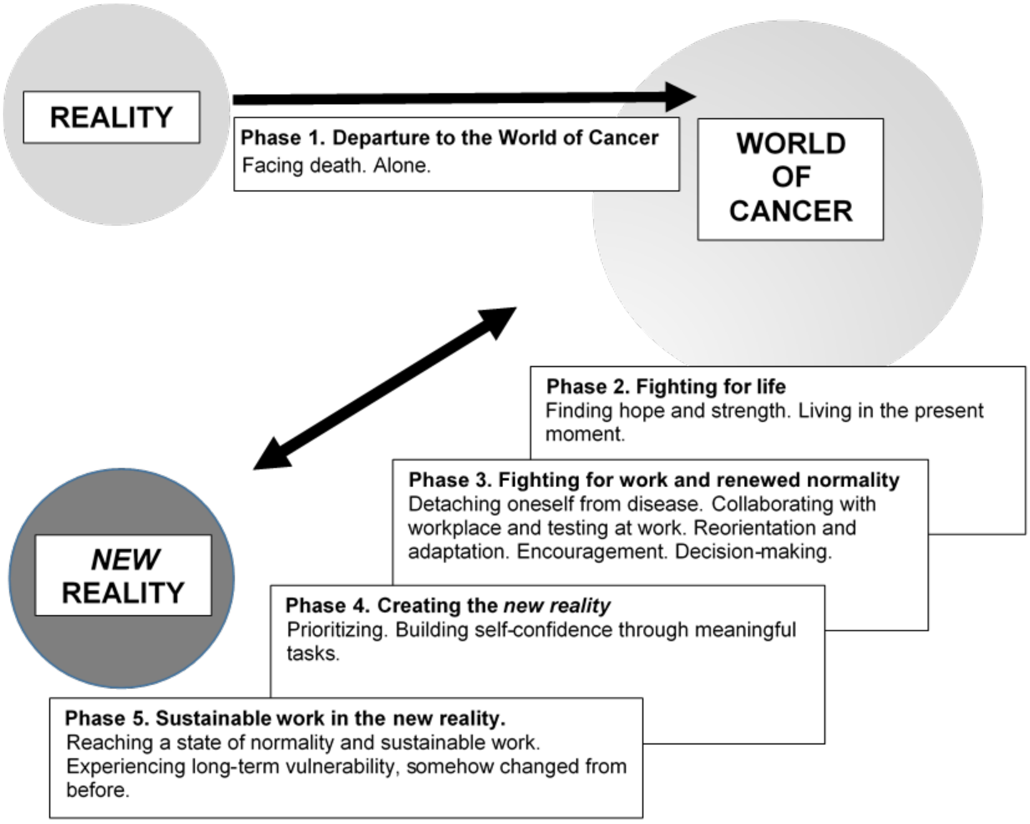

Figure 4. The five-phased process model.
It was not possible for participants to return to their former reality from World of Cancer or from their new reality. The double-headed arrow between the new reality and the World of Cancer shows that both directions are accessible.

The impact of cancer involved the participants' entire lives and not only their working lives. Their RTW trajectory led to personal growth through their handling of the situation. Facing cancer and possible death became a reality more quickly than expected and led to dealing with existential questions. After attaining sustainable work, participants perceived themselves as being different and changed as persons from before cancer occurred, as Anne expressed:

> *"You know, I will never be the same person again!* (Then, she started to move her head slowly from side to side, smiled at me and with a lower voice than before, continuing) *No, … (*pause*) I will **never** be the same person again".*

The RTW processes influenced job changes 5-14 years after cancer. During the five phases (Figure 4), some participants even changed occupations before achieving sustainable work. For that reason, the transformational phases of changes (Phases 3 and 4) may for some, be repetitive or last longer and be more divergent than expected. The results also indicate that asking relevant questions under the phase the individual is working through at the moment is essential for helping PSC return to sustainable work.

During the three re-interviews, the participants recognized the results presented as a process model. Britt summarized her impressions when discussing the model (Figure 4):

> *"No one is talking about this, because it is not understood (…) or recognized. These results are important".*

6.2 Main results from Article 2

The research question asked was how resources, according to the SMH, were activated and utilized during return to sustainable work. This article describes how PSC experienced tensions during cancer treatment and RTW; and which GRRs and SRRs they utilized to manage to return to sustainable work.

Participants described the cancer diagnosis and its treatment as a shock that violently impacted their lives, including their work-life. This level of impact corresponds to Antonovsky's description of representing a life event stressor (Antonovsky, 1987). The stressor represented both receiving the cancer diagnosis and its treatment (Figure 5, next page). Cancer (stressor) resulted in two essential tensions: a) fear of cancer reoccurrence, and b) uncertainties for present and future ability to work. The participants' medical conditions and outcomes from late effects were quite different, and led to diverse experiences. Still, they had in common their concerns that their ability to work might be permanently limited, or whether they would regain health and function as before.

Figure 5 shows relevant examples of resources utilized to resolve the tensions. The GRRs are described per the components, as suggested by Antonovsky (1979). GRRs were not utilized in the same way or during the same phase by all participants during the RTW process, and specific resources were more important to some than to others. Some SRRs available could also be classified as "macro-socio-cultural" GRR, as, for instance, health care personnel.

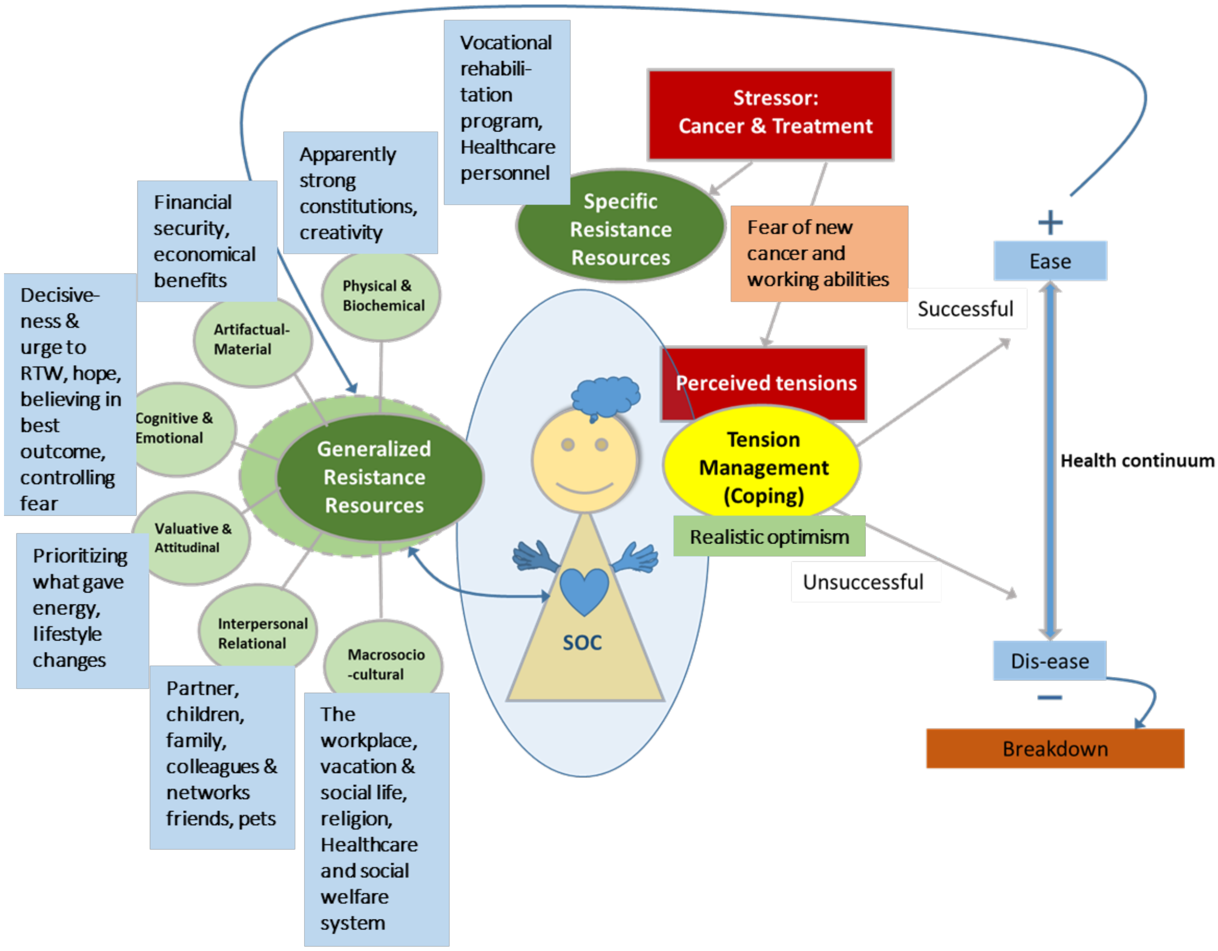

Figure 5. Main results according to an adjusted salutogenic model of health (SMH). See the description in Chapter 3.2.3. for explanations of Antonovsky's (1979) SMH. The blue squares contain examples of results derived from the analysis. All participants in the present study showed diverse but successful tension management that induced movement on the health continuum toward the "ease" pole. Some participants experienced Specific Resistance Resources (SRRs) represented by health care personnel or rehabilitation program during rehabilitation. The blue line and arrow from the "ease" pole to Generalized Resistance Resources (GRRs) indicates that GRRs may enhance if a persistent position at the "ease" pole is perceived. The blue line between GRRs and the SOC suggests that these constructs have a reciprocal effect on each other.

Physical, biochemical and artifactual-material GRRs

The participants' physical and biochemical status was unknown, but all participants worked full-time prior to being diagnosed with cancer, which demonstrated that their health was not already compromised. Moreover, they had a solid financial base by working, and by having a spouse (an interpersonal GRR) who provided a second income. An exception to this was Anne, who described her worries about having to sell her car due to her financial situation when she approached 12 months on sick leave, which also forced her to start working too soon. The threat of future income reductions (which represented a possible lack of material GRR) almost turned into another stressor for her, which temporarily added tension.

Cognitive and emotional GRRs

Participants demonstrated that withstanding exhaustion was perceived as valuable because it resulted in a return to meaningful work. They explained that the success in their RTW process, first of all, was dependent on their persistent decision never to give up trying, despite late effects from cancer treatment. Still, they did not always feel positive. They described how they handled such emotions such as fear and anxiety by recognizing them and by taking active control of them by steering their thoughts. They also made efforts to be realistic in orienting themselves about their actual situation and abilities to work. Also, they chose to believe in the best alternative if they were unsure about outcomes. This state of being a "realistic optimist" was interpreted to be one of the most critical ways of performing tension management.

Valuative-attitudinal GRRs

Participants prioritized individual activities that energized them, for instance, painting, cooking, playing an instrument, or caring for animals. Some focused on lifestyle changes, like exercise and diets, and they wanted to spend more time in nature and together with their families. Others described how they perceived different activities as "self-therapies". Grete created a blog to read for her next of kin and close friends because she wanted to avoid talking so much about her medical condition, even with her close relatives. This way, she used the blog as an instrument to process her thoughts and feelings and share some information with others without any conversations. Other participants were more outgoing than Grete in talking to others about their condition – like Carl, who actively used conversations with his colleagues as therapy, which also is explained as an interpersonal GRR to him.

Interpersonal GRRs

All participants gained energy from socializing at work or with their family. Close, social relationships like spouse, family, friends and colleagues were available resources for all of them and represented someone to fight for and hope. However, participants expressed themselves differently when they described what they needed and how they utilized their relationships as a resource. Some participants experienced challenges in their families, such as a divorce, during their RTW journeys.

Macro-sociocultural GRRs

With support from the public health care and benefits from the social welfare support system, all participants received medical support and sickness absence benefits. When they retained work, work in itself was perceived as a GRR but balanced on a fine line by being too demanding. When the work tasks could not be adjusted according to job demands and actual ability to work, the participants' tensions of worrying about not being able to work increased, and they also sometimes failed to stay working.

Employers that could offer adjustments and facilitated a gradual RTW process became a valuable asset and GRR. Participants appreciated opportunities to start working at a slower pace by adjusting their working hours or tasks. Moreover, when the employer was encouraging and cooperated with the participants in making adjustments, the participants felt both valuable and enabled to withstand challenges. Such cooperation between the participants and their employers, where they could plan a gradual introduction to returning to work, was especially valuable. During that time they had an opportunity to test their ability to work and to practice/train for the work they wanted to do.

Carl was offered and attended a vocational rehabilitation program for cancer survivors and felt that he benefitted from that. He was taught how to accept and handle panic attacks by breathing exercises and processing thoughts. As a unique program designed for cancer patients only, this represented a vital SRR to him.

6.3 Main results from Article 3

The third study's research question was to explore RTW patterns in a larger population and possible differences between PSC compared to controls. This descriptive registry study aimed to describe RTW patterns of labor-force participation, working hours, job changes and education among 1,675 women and 954 men with a mean age of 41 years who survived cancer for nine consecutive years compared with matched controls.

Labor-force participation

Both PSC and controls of both genders fell steadily out of work over the nine years showing significant differences for all groups between T_0 and T_9 (Figure 6, next page). However, in all years, fewer of the PSC were working than the controls. Labor-force participation decreased among female PSC from 100% at T_0 (similar for all groups) to 83.9% at T_9, which was more than for female controls (87.7%). Also, participation was significantly lower among female PSC than among male PSC at T_1–T_3 ($p<0.02$). Among male PSC, the labor-force participation was lower than among male controls from T_1 to T_9, but the difference was only significant at T_2 ($p=0.019$) and T_4 ($p=0.039$). Overall, male PSC dropped to 84.8% at T_9 and controls to 87.3%.

Working hours

Among those who remained working, significant reductions ($p<0.001$) in proportions of individuals working full time (> 30 hours per week) from T_0–T_9 were found for all groups (Figure 7, p. 64). Working full-time was regarded as working more than 30 hours/week. A consistent 68%–70% of female PSC worked full-time for all nine years, while the proportion for female controls increased from 69% at T_0 to 76.5% at T_9. The difference between the female groups was significant for all nine years ($p<0.001$). The proportion of male PSC who worked full-time decreased from 93.9% at T_0 to 92.5% at T_9. The pattern for male controls was quite similar, but the proportion working full-time did not decrease as much as among male PSC, and was slightly higher (93.8%–95.2%) from T_1. The difference between male groups was significant ($p<0.04$) for T_1–T_2 and for T_4–T_9. Among males (PSC and controls), the proportions of those who worked full-time were higher than among the females ($p<0.001$) for all years.

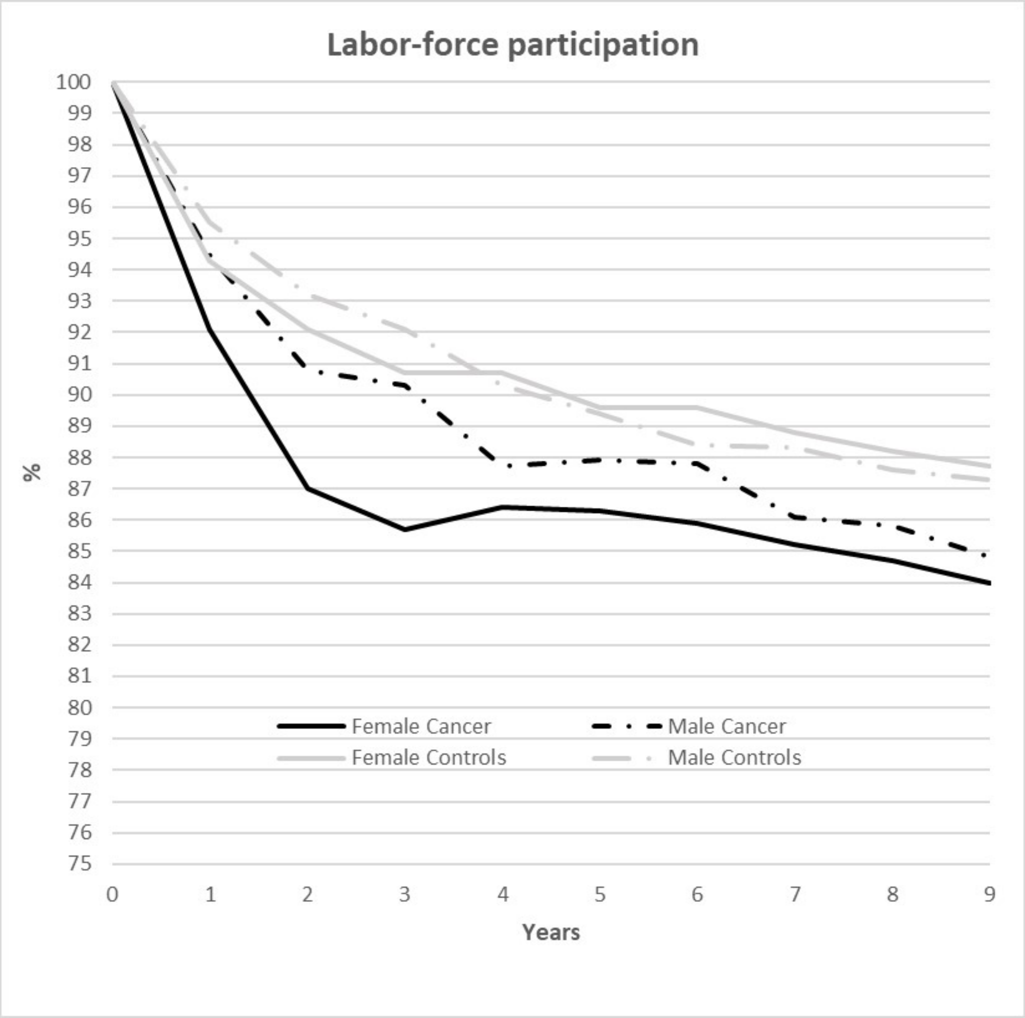

Figure 6. Annual employment rate (%) from 2004/2005 (T0) to 2013/2014 (T9) among working persons who survived cancer (n=2629) and a control group matched on gender, employment, age, and education (n=5258).

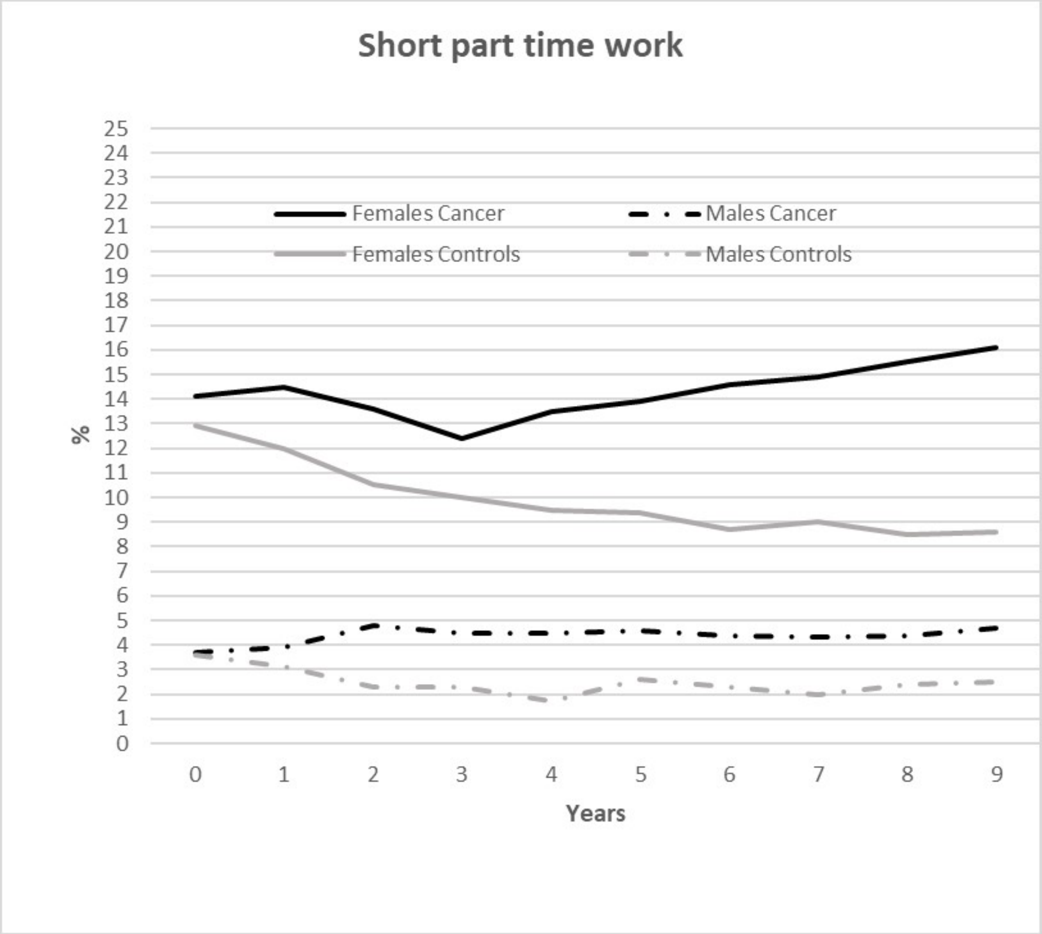

Figure 7. Annual employment rate (%) from 2004/2005 (T0) to 2013/2014 (T9) among persons who survived cancer and worked less than 20 hours a week (n=2629-2216) and a control group accordingly, matched on gender, employment, age and education (n=5258-4604).

The proportion of female PSC who worked short part-time dropped from 14.1% to 12.4% in T_3 and then increased at T_9 to 16.1% (Figure 7). The proportion decreased steadily among female controls (13.% at T_0 to 8.6% T_9). The difference between female groups was significant ($p<0.02$) every year from T_1. For male PSC, the proportion who worked short part-time increased for the first two years, from 3.7% at T_0 to 4.8% at T_3, and then stabilized. The proportion among male controls stabilized at about 2-2.5%, significantly lower than the male PSC from the year T_2 ($p<0.01$). The proportion of female PSC who worked short part-time was larger compared to male PSC all years ($p<0.001$). The difference between males (PSC and controls) versus females (PSC and controls) working short part-time work was significant ($p<0.001$) every year.

There were no differences between female and male PSC and their controls in the group that worked long part-time (20–29.9 hours/week). Among the female PSC and their controls, the proportions decreased from approximately 19% at T_0 to 14% at T_9. Among male PSC and controls, proportions were stable at 2%–3%.

Job change and education

A portion of about 10%–17% in all groups changed employers each year in periods (T_1-T_9). Among both PSC and controls, we registered a decrease in the number of job changes from T_2 to T_9, but few significant differences were found. The only exception was female PSC who showed an increase in change of employer from the years T_2 to T_4, and were significantly different from the controls at T_1, T_4, and T_8 ($p<0.01$). Except for T_1 ($p=0.012$), there were no significant differences between male PSC and controls regarding employer change. Differences between female and male PSC were almost non-existent.

The educational level was similarly distributed between the genders. About 2%–3% of female PSC and controls were registered as students over almost the entire follow-up period and approximately 1% of male PSC and controls. Compared to controls, the differences between female and male PSC were not significant, but the female PSC were in education more often than male PSC. This difference was significant every year ($p<0.05$) except T_8 ($p=0.081$).

6.4 Overall results of the thesis

The overall aim of this PhD project was to explore sustainable returns to work more than five years after cancer. The results described the RTW processes in depth, including ways in which changes were made and the resources that were needed to make those changes. The results also showed differences in RTW patterns and changes between a larger population among PSC and controls. Viewing the studies' results together revealed three main themes, as will be presented below and discussed in more detail in Chapters 7.1-7.3.

Mastering work and life

The results from the interviews revealed how the participants mastered the creation of a renewed normalcy after cancer, and that these two parts cannot be separated. A successful outcome depended on the individual`s personal determination to return to work, adaptability and mastery of a renewed normalcy after cancer.

One main theme was that cancer created a fear of not surviving that affected not only the way the participants mastered their work life, but also the way they mastered life and living. Therefore, it was difficult for the participants interviewed to limit their experiences of RTW after cancer as solely focusing on work life. The RTW processes showed how the participants mastered their challenges and included the participants' stories from the time for cancer diagnosis up to the time for the interview, and where they reflected upon that as a total life experience.

To quit working was never an option for the interviewed participants. They demonstrated inner strength and found it worthwhile to struggle and continue working towards returning to work despite initial exhaustion and other consequences from cancer treatment. Working tasks perceived as being meaningful motivated the participants to endure. This motivation, mixed with available opportunities to make work adaptations, were the key elements that ignited the process to continue moving forward.

Some of the participants experienced trials and failures when returning to work that led to their being on sick leave repeatedly. Those who did not succeed in keeping their position at their former workplace reoriented and searched for a new job identity or an education to create one. The participants showed a cognitive re-orientation phase where new and meaningful occupational work and life goals were set according to a renewed prioritization. Due to prioritizing differently from before, they also chose friends and activities that brought them new energy and excluded people and activities that did not. When they had doubts about their cancer outcome or persistency of late effects, the participants evaluated options and chose deliberately to focus on the best possible result (realistic optimism).

Participants in the current study learned from their experiences and gained mastery skills to perform major job changes and sustainable work achievement despite uncertainties about cancer reoccurrence and their future ability to work. At the time of the interview, the participants revealed that they felt that, through their RTW journeys, they had become different persons than they were before their cancer diagnosis. This perception influenced how they wanted to live their lives and prioritize in the future. Independent of the type of job or occupational changes they made, all participants faced existential questions and personal growth through managing and mastering the actions required to achieve their renewed goals at work and as individuals.

The combined results in the current thesis can give the impression that PSC in Norway generally cope quite well at work after cancer. Keeping in mind that the population of PSC as participating in the current third study had, according to the inclusion criteria, better opportunities for returning to work than a total population of PSC, we still found lower labor-force participation among PSC compared to controls (Figure 5, p. 59). These results indicate that not all PSC in the third study had the same resources available or mastery skills as the participants in the first study, where all participants finally reached sustainable work. However, and as personal factors in the third study are unknown, our current results are not sufficient to explain this result any further.

Contextual influences

A second recurrent theme centered around the influences from the interviewed participants’ situational context. The participants' RTW quests depended on resources from their surroundings to achieve sustainable work, which influenced the participants' management of uncertainties regarding future workability.

The analysis of resources utilized revealed how the employer/workplace and financial safety influenced successful RTW processes. The employer's ability to adjust work tasks or working hours, along with the social support provided by colleagues, were found to be crucial. By starting to work gradually and at their own pace, the participants felt able to move towards normalcy at an earlier onset.

Some participants also expressed their achievements at work were also directly dependent on a supportive family and spouse. Moreover, friends who brought them energy, and access to nature, and leisure activities – alone or with family – were also important.

The availability of medical treatment and health care personnel were appreciated. Some participants relied on single persons among the health care personnel. As part of the macro-sociocultural resource, the social welfare system and financial issues were essential to PSC during the processes of returning to work. If the economic situation is found to be at stake, that could represent another burden and might be influential on choices of job changes.

Notably, the participants experienced that their surrounding resources supported the creation of new options for altered directions in work-life and life overall (i.e. availability for education or new job options). However, the participants interviewed did not always find support available when needed. Since the proportions of PSC in the larger population in the third study did not participate at the same level as controls for all nine years investigated after cancer, it can also be questioned if proportions of the larger population had more severe late effects from cancer. Or perhaps surrounding resources for all PSC, as found essential among the interviewed participants, were not available or utilized at the same level.

The long-time horizon on sustainable work

Our results showed that sustainable work differs from that of initial RTW. The individual RTW trajectories represented a wide diversity in the content of changes, strategies, and time needed to reach a state of sustainability at work. Some participants interviewed had to quit their job at their former workplace after initial efforts to return to their former position. Substantial changes were performed that sometimes included a total shift of job identity or new education. Thus, major job changes were considered and performed several years after initial RTW. We found that individual RTW processes and work-related changes after cancer differed in time far beyond a five-year horizon.

Among the larger population, we found that the frequency of job changes was not significantly different between the proportions of PSC and controls, although some differences were found between females and males, during a few single years. However, in the larger population, where work sustainability was unknown, higher proportions of PSC than controls fell out of work during the nine years investigated (Figure 6, p. 63), and among female PSC, the proportions working short part-time increased from about 4 years after cancer diagnosis and all subsequent years (Figure 7, p. 64).

The combined results indicate that some proportions of PSC among the larger population may have quit work without being able to create a new direction for working, as some of the interviewed participants had managed. However, we do not know if any options could have been available to them, and to conclude would need further research. Still, the combined results show job changes may occur many years after the cancer diagnosis and that a first attempt to return to work might not always last or be sustainable.

The combined results open up additional questions regarding sustainable job changes after cancer treatment. A pre-understanding in the current thesis is that to be working is the primary goal and the healthier choice after cancer compared to quit work or reducing working hours. However, for some PSC, prioritizing a different way of living might also be an active choice of coping as the outcome of an RTW trajectory. Thus, the combined results indicated that even if one is able to master a re-orientation phase and prioritize differently from before cancer, it is possible that ending or reducing a working career can become the right and a more healthy individual choice for some.

One result from the third study is that despite the differences in proportions attending work, labor-force participation patterns followed the same route of decreased active involvement in work among both controls and the PSC groups (Figure 6, p. 63). Also, the participants interviewed referred to how they, during the RTW processes, simultaneously had to deal with a divorce or had financial or other familial issues during the RTW process. Combined, these results indicate that it is important to keep in mind that events or stressors other than cancer may also affect and trigger changes in people's lives and influence how they prioritize attending work after cancer.

7 Discussion

This PhD project's overall aim was to explore a successful return to work (RTW) by persons who survived cancer (PSC) in a long-term perspective of more than five years after cancer. The research questions comprised a) how PSC described their experiences of returning to sustainable work, b) how tensions were perceived and resources according to the Salutogenic Model of Health (SMH) were activated and utilized during the processes, and c) descriptions of differences between PSC and controls according to the RTW patterns of work in a larger population where all had working opportunities.

According to the first research question on how PSC described their experiences of returning to sustainable work, Article 1 revealed how the participants adapted to and created sustainable work and a renewed normalcy after cancer. In this study we developed a five-phased process model describing the RTW processes, that for some participants, lasted several years and up to 14 years after cancer. Sometimes searching for a new job more compatible to a new situation of work ability or as a result of a personal growth process that had taken place, were required.

The second research question was to reveal how resources were activated and utilized during the RTW process. Article 2 showed how the participants from the first study dealt with uncertainties regarding long-lasting effects from cancer and their future ability to work. This article also revealed how participants activated their inner and outer resources to implement and pull through changes in their lives and work lives.

The third research question was to explore differences in work patterns during a nine-year period between PSC and controls in a larger population. Article 3 showed long-term gender differences in lower labor-force participation among PSC versus controls, up to nine years after the cancer diagnosis.

The three studies' combined results (Chapter 6.4) revealed three major findings. First, achieving sustainable work was described as dependent on the individual`s determination to return to work and their personal mastery skills. Mastering life and work-life from the perspective of personal mastery skills are discussed in Chapter 7.1. The results also showed how surrounding resources and the contextual environment and settings, like the workplace, influenced the outcome of sustainability at work. Contextual influences are discussed in Chapter 7.2. In a long-term perspective of more than five years after cancer, we found that initial efforts to retain work after cancer did not always last and that substantial work changes occurred after several years of adaptation efforts in former positions. Moreover, in the larger population, we found that higher proportions of PSC than controls dropped out of work during the nine-year follow-up period. The proportions of female PSC who quit working more often than male PSC, or who had short part-time work gradually increased from the fourth year after cancer. These results are discussed in Chapter 7.3.

The discussion of methods of this thesis is found in Chapter 7.4.

7.1 Mastering work and life after cancer

This chapter focuses on central personal mastery skills based on the interviewed participants' experiences of tension management and coping.

Facing possible death

Although the participants succeeded in achieving sustainable work as a result of their RTW processes (Figure 3, p. 46), they did not initially, and during phases 1 and 2, know whether they would survive or how cancer would affect them and their working abilities long-term. As cancer has long been regarded as a severe and deadly disease and still causes the highest burden of cause-specific Disability-Adjusted Life Years (DALYs) (Matiuzzi & Lippi, 2019), it is understandable that receiving a cancer diagnosis may still be associated with a threat to health and possible death. Research has shown how a cancer diagnosis may affect people emotionally, causing fear of death. Black & White (2005) reported the psychological impact of a cancer diagnosis as influential on mental health and quality of life. More recent research shows that emotional reactions to receiving a cancer diagnosis vary and that information about the diagnosis does not always cause emotional reactions that include fear of death (Kirby et al., 2020). Recent increased survival rate and improvements of cancer treatment (Cancer Registry of Norway, 2019) may also have influenced people's perception of cancer and that it is not always a deadly disease. However, the emotional impact of cancer in our study was found to be substantial. Interviews revealed that regardless of the type of cancer the participants had been diagnosed with, the shock of being diagnosed with cancer and the subsequent cancer treatment led the participants to perceive their situation as life-threatening and life-changing. They also reported being thrown into a new world (of cancer) where they felt distanced from their ordinary reality (Figure 3, p. 46).

According to the theory of Salutogenesis (Antonovsky, 1987), a life event stressor upsets the homeostasis. Thus, in order to keep good health, perceived as having the position in the "ease"-end of the health continuum, a life event stressor requires management to resolve the personal tensions deriving from the stressor. Being diagnosed with cancer can be categorized as a life event stressor, where this movement against "dis-ease" on the health continuum is a possible reaction (Figure 5, p. 59). Participants in the current study managed their tensions of fear by not focusing on the worst-case scenario but on the best possible outcome and by living day by day through treatments and by fighting for life. Fear of death can be understood as primary appraisal according to Lazarus' (2012) theory. Next, and by secondary appraising, the participants regarded cancer as a threat of future outcomes, but still accepted fighting for life during phases 1 and 2 of the five-phased process model (Figure 4, p. 57). This perception corresponds to how Lazarus & Folkman (1984) describe a person’s evaluation of whether the stressor is a threat or a challenge during the second appraisal.

Some of the participants in the current study found support among healthcare personnel during their treatment phase. Healthcare personnel has been advised to be aware of psychosocial needs among cancer patients due to emotional effects after receiving a cancer diagnosis (Tobin & Begley, 2008), and a focus on how communication and information about the diagnosis are given is advised (Schofield et al., 2003). Barnard et al. (2016) found that PSC, during a first phase after receiving the cancer diagnosis, were overwhelmed by emotions and repressed fear and showed avoidant coping for a while until they were ready to receive realistic information about their condition. However, in the second phase, PSC sought understanding and information, and active problem-solving became a more prominent coping strategy. This is similar to what we found, but we did not recognize a repression phase or avoidant coping among the participants in our study. That does not mean it was not present. The interviews in our study were performed many years after the incidence, and we also kept the main focus on RTW issues – not on the cancer treatment phase. Still, and following the secondary appraising, we found that the participants in the current study also transformed an initial threat and overwhelming fear of death into a challenge. However, and during phases 1 and 2, according to the five-phased process model p. 58, fighting for life was more important than considering RTW issues among the participants in the current study.

Personal mastery skills

This thesis shows how participants mastered achieving sustainable work after cancer treatment, and they described their RTW processes as analogous to a journey (Figure 4, p. 57). While participants were individually different regarding cancer types, working tasks, time and diverse adaptations, we found similarities in their personal mastery skills. In the first study they first showed cognitive skills to manage the tensions and emotions related to their cancer diagnosis and treatment. Next, they expressed that a crucial asset to their success in their RTW processes was their persistent determination and focus on returning to work that lasted from the time for diagnosis (phase 1) and throughout all phases. This result confirms findings from several other studies. Grunfeld et al. (2010), for example, found how PSC's perception and belief in their ability to work influenced the RTW process positively; other researchers have found personal expectancies of successful RTW to be an important predictive factor for RTW in general (Falkdal et al., 2006; Hansen et al., 2005; Opsahl et al., 2016).

In the second study in this thesis, realistic optimism was explained as a cognitive and emotional generalized resistance resource (GRR) that was essential for managing tensions (Figure 5, p. 59). Realistic optimism consisted of two components: first, how the participants reoriented according to an acceptance of their actual and new situation; second, they always chose to believe in the best outcome when they had doubts about future developments. This coping strategy of using cognitive skills for reorientation may have been advantageous for the successful outcome. One study showed that, among breast cancer survivors, a negative perception of one's cognitive function was directly associated with poorer work outcomes, whereas positive perceptions were related to improved ratings of work outcomes (Von Ah et al., 2017).

Realistic optimism and decisiveness may be explained as a result of the second appraisal as described by Lazarus & Folkman (1984), where options for coping strategies are outlined and chosen. Realistic optimism also comprises a form for emotion-focused coping since the belief in the best possible outcome may be regarded as a hope that represses anxiety. Using the terminology from the SMH (Antonovsky, 1979), the decisiveness to return to work and the utilization of realistic optimism can be understood as important cognitive GRRs. According to SMH (Antonovsky, 1979/1987), the strength of the construct Sense of Coherence (SOC) will also be crucial for how stressors and their possible tensions will be perceived and managed. The strength of SOC influences the ability to utilize GRRs and SRRs and, consequently, influences the outcome from tension management (Antonovsky, 1987).

To be responsive to what happens in life and to "apply necessary resources appropriate to the stressors," indicates having a strong SOC (Antonovsky, 1996, p. 15). Although they felt distressed by exhaustion after cancer treatment, some participants in the current study adapted to former work, whereas others actively searched for new opportunities when they had to give up former positions. Interventions among distressed patients designed to strengthen the meaning component by utilizing perceived manageability have been suggested (Winger et al., 2016), which might be of help if and when PSC need this support. This was also shown by Rohani et al. (2015) in a prospective and longitudinal study among PSC; the strength of SOC was a central resource for being adaptive towards life events and stressors. Similarly, Vogt et al. (2016), through a three-month study among 940 employees from a broad range of job types, found how a strong SOC predicted continued working after cancer. Thus, it might be suggested that the realistic optimism as found in the current study, and the participants ability' to make efforts to find meaningful work, indicate the participants in the current study had a somewhat strong SOC during their RTW processes.

Influences on SOC

The three components of SOC concur with the results of the present thesis. First, the comprehensibility component of SOC is reflected in the participants' cognitive reorienting skills. The participants in this study approached and accepted their new situation. They re-oriented and outlined options for developments. By actively choosing to focus on the best possible outcome, they managed to re-direct their thoughts when anxious. However, a deficiency in cognitive GRR (Figure 5, p. 59) or the comprehensibility component in SOC could inhibit some PSC' ability to utilize realistic optimism. One of the participants, Carl, received help from a rehabilitation program (described as an SRR in Chapter 6.2). This was also a confirmation that psychosocial interventions can support and strengthen the SOC components of comprehensibility and manageability. First, attending this program made him understand and accept his emotional reactions to fear and panic attacks (comprehensibility). Next, he learned how to deal with panic attacks at work (manageability). Thus, this example shows how an SRR can support strengthening components of SOC and stimulate tension management and a movement on the health continuum towards the “ease” pole.

The decision and focus to return to work from cancer onset made the participants make early efforts to return to work, which led to the demonstration of the SOC component of manageability. Manageability is the ability to act by perceiving the availability of the tools necessary to act, while making the actual actions. The results from the current study showed that despite conditions of exhaustion, the initial and early efforts to return to work allowed the participants to focus on work and distance their feelings of being ill; this distancing helped them feel they were moving closer to normalcy. Other research shows that people with a history of extended periods of sickness absence can be at a higher risk of falling out of work (Øyeflaten et al., 2014). Moreover, PSC on sick leave have shown an increased tendency for depression and symptoms of fatigue compared to those working (Horsboel et al., 2015; Paalman et al., 2016). Thus, and for several reasons, it may be fortunate to make early efforts to test returning to work. Although this may be perceived as “too early” and demanding, working became a positive experience in the current study.

The results in the second study showed how participants prioritized work, activities and relationships they felt were energizing them. These factors represented valuative-attitudinal GRRs according to SMH (Figure 5, p. 59). Moreover, if they perceived their work situation as not meaningful to them, some quit and found another direction for their future work life. These results demonstrate how meaningfulness directed the participants' plans and actions. Meaningfulness is the motivational and most critical component of SOC (Antonovsky, 1987). Our results are in line with those of other researchers who have emphasized how meaningful working tasks promote health and thus increase a person’s ability to work (Jenny et al., 2017; Magrin et al., 2006). Prioritizing meaningful activities or working tasks may be related to choosing a problem-focused coping strategy (Lazarus, 2012), whereas prioritizing activities and relationships that are perceived as energizing may be defined as a more emotion-focused strategy of coping. Thus, the participants seemed to utilize a combination of those strategies to create a meaningful coping strategy. Overall, the participants' demonstration of action and mastery skills indicated they all had a strong SOC and were able to utilize their GRRs.

Meaning making

Through their decisions, actions and conscious prioritization, the participants in our study demonstrated how meaning making was a part of their RTW experiences. This result indicates processes of meaning making can be valuable for perceiving well-being and ease in a renewed situation after cancer. In a longitudinal, cross-sectional survey, Park et al. (2008) also showed meaning making as a coping strategy after cancer. Their study revealed that through the successful creation of adaptive meanings made from the cancer experience, meaning making processes related to better adjustment. In a focus group study, van der Spek et al. (2013) concluded that cancer survivors had diverse experiences from meaning making processes; while some PSC experienced enhanced meaning after the cancer experience, others experienced loss of meaning and an unmet need for support. Winger et al. (2016) have seen similar results and suggest that meaning-centered interventions may strengthen SOC among distressed cancer patients. Our results show that meaning making is essential to participants in the current study, and indicate that interventions that provide meaning making could theoretically strengthen the meaningfulness component of SOC.

Another approach that seems to be related to the importance of meaning making and realistic optimism, is described as a self-tuning process (Vinje & Mittelmark, 2006). Although Vinje & Mittelmark’s study participants were nurses at the risk of burn-out rather than PSC, the authors found how the nurses' desire to work combined with introspection and reflection nurtured their mental health and increased their job engagement. However, this desire or “calling” could also lead to too much engagement and potential burn-out. Vinje & Mittelmark (2006) describe how finding a balance through introspection led to increased tension management and “ease” on the health continuum. Thus, increased protection from burn-out may be built through increased introspection and self-reflection. According to Lazarus’s (2012) theories, this process may be defined as making reappraisals, which can enhance a more positive perception of the situations and a more motivated way of coping. According to SMH, a self-tuning process can represent an SRR and potentially enhance the effect of tension management. A form for natural “self-tuning” is recognizable in our results; the mastery skills of reorientation and prioritization helped the participants in the current study reflect on options for the future and find a way to move on that balanced their job demands and abilities. Thus, realistic optimism (Figure 5, p. 59) and self-tuning may be complementary. The mastery of skills to focus on the best possible outcome may be required to appraise lasting and necessary adaptations or more profound transformational processes during RTW processes after cancer. Again, there are indications that interventions focusing on self-tuning or realistic optimism could be helpful to PSC not provided with the same strength of mastery skills as the present participants.

Personal growth

Overall, the participants interviewed showed personal growth during their RTW processes (Figure 4, p. 57). Similarly, and based on Lazarus & Folkman (1984), Barnard et al. (2016) explained phases of PSC adaptation as an activation/problem-focused phase, where the PSC take control and responsibility to adapt and, finally, a re-integrating phase that focuses on meaning making and re-assessing life. The five-phased process model shows how the transformational phase included reorientation and adaptation in phase 3. In phase 4, the participants prioritized and tested workability. Gradually, they become more integrated in a renewed normality in phase 5. While the four-phased model developed by Barnard et al. (2016) has a psychological perspective, the five-phased process model includes aspects of the same phases but includes more general, long-term, practical and work-oriented descriptions. This way, the long-term concrete outcomes from the RTW processes became more visible in our study. Still, the models seem complementary, and the processes described are similar; participants learn to assess a renewed normalcy through a personal, transformational journey.

All participants in the current study dealt with existential questions and felt they were reaching a state of a new reality (Figure 4. p. 57). Similarly, Pat-Horenczyk (2015) presented increased construction as being part of a growth process. Also, the participants perceived themselves as being stronger during the RTW processes. Calhoun & Tedeschi (2001) described how individuals can change their perception of self during struggling with traumas. The results in the current study are similar to Calhoun & Tedeschi's description of posttraumatic growth, where cancer can be defined as a trauma. The authors point out several changes resulting from posttraumatic growth; one change is the sense of being different from before. The feeling of being stronger than before and at the same time more vulnerable is another (Calhoun & Tedeschi, 2001).

Studies have shown that when trauma-related tensions are neutralized, positive outcomes and personal growth can follow (Hefferon et al., 2009; Magrin et al., 2006). The participants interviewed in the current study had learned to live somewhat differently from before. Their personal growth and what they learned from the process may also have impacted and enhanced their GRRs, as illustrated in Figure 4, p. 57. This way, the participants' personal growth as an outcome may have induced GRRs and perhaps their SOC, making the SMH work like a process model, spiraling GRRs and SOC growth when tension management was continuously successful. In his later work, Lazarus (2012) shows that reappraising and coping strategies may be repeated and that threats may be reappraised as favorable after a renewed evaluation of a stressful experience. Thus, the process of personal growth can also be explained as outcomes, where repeated appraisal on the same topic can alter one's emotions and build new relational meanings (Lazarus, 2012). Also, a growth of GRRs or SOC, as described by Antonovsky (1979, 1987), can explain the phenomenon of creating renewed paths in life during or after a process of successful tension management and personal growth. By their personal growth process, the participants interviewed showed how they learned how they wanted to arrange their future living. By their renewed evaluations, they may have strengthened their SOC and GRRs.

Lasting vulnerability

Although personal growth may be regarded as a positive outcome, the process may include obstacles, challenges and efforts. Some tensions for being diagnosed with cancer persisted after the participants experienced being well from cancer. Fear of cancer reoccurrence, late effects after cancer treatment and doubts about their future working abilities were still present at the time of the interviews. Although the participants did not perceive themselves as being constantly worried about these uncertainties, their consciousness was easily triggered if reminded. These uncertainties were similar to patients living with advanced cancer (stage III or IV), as Shilling et al. (2017) presented. They found that the uncertainty of unknown future trajectories challenged the patients and that this uncertainty could inhibit their ability to move forward. In the current study, the participants, with one exception, had the status of being cancer-free at the time of the interview. This may be considered a different situation from those who participated in the Shilling et al. (2017) study. Still, the participants in the current study were also concerned about future working abilities.

The lasting vulnerability from unknown future working ability reflects real threats. Studies show cancer treatments are associated with late effects that may influence workability and last up to 20 years after cancer treatment (Gegechkori et al., 2017). Cognitive and physical impairments may affect the ability to work (Duijts et al., 2014; Gegechkori et al., 2017, Sharp et al., 2016). Also, according to Noeres et al. (2013), the main predictors for not returning to work are late treatment and tumor stage effects. Consequences for workers experiencing late effects can be that it is not possible to remain in a job (Bijker et al., 2018; Duijts et al., 2014; Mehnert, 2011). Considering that other studies have shown how obstacles and challenges after cancer can inhibit RTW processes (Dorland et al., 2018; Gegechkori, Haines, & Lin, 2017; Tamminga et al., 2019), it is reasonable to assume that this was the same for some proportions of PSC groups in the third study. In the third study, we found differences in labor-force participation between PSC and controls (Figure 6. p. 63) during all nine years after a cancer diagnosis. However, although participants in the first studies had temporary setbacks, they did not give up working; they found a way to move on.

The RTW patterns in the third study also revealed that substantial proportions of PSC were finally working during the nine years investigated (Figure 6 and 7, p. 63-64). The current results sustain findings in the review by Paltrieneri et al. (2018), who found studies that showed up to 92% of PSC who were employed at the time of cancer diagnosis and who had a good prognosis, returned to work. Another and recent review and meta-analysis comprising results from recent (2000-2018) studies from many countries revealed that RTW on average was about 74% 2-14 years after cancer among persons who were working at the time of their diagnosis (de Boer et al., 2020). The relatively high proportions of PSC working during the nine years investigated in the third study can indicate they had a good prognosis from cancer (living more than 10 years after cancer diagnosis) or that they were employed before cancer. Both factors can have been protective from falling out of work long-term. Thus, they can be regarded as having better opportunities to RTW than an overall population of PSC. However, these factors are not necessarily a protection from the experience of a lasting vulnerability, as the participants interviewed expressed.

Work-related and surrounding macro-sociocultural factors will naturally also influence a perceived vulnerability of future working abilities, and will be further discussed in the next chapter.

7.2 Contextual influences

This chapter discusses the results from the present thesis regarding the primary surrounding resources (GRRs and SRRs) we found to contribute to achieving sustainable work. Although cognitive mastery skills (Chapter 7.1) were of substantial importance, achieving sustainable work was also influenced by a spouse and the family, social relationships, the workplace, the health care environment, and the social welfare system. Without the support from their surroundings, the participants' mastery skills would have been less effective. Flipping the coin, without mastery skills, existing and contextual resources may not have been fully utilized. Thus, the set of resources that influence RTW processes in the current studies must be viewed together, not as single and separate resources.

Antonovsky’s (1979) SMH shows the diversity of personal and surrounding resources of GRRs and SRRs (Figure 1, p. 19) and how a set of factors influence the Sense of Coherence (SOC), the tension management, and outcome on the health continuum. In the second study, we found how the interviewed participants utilized GRRs and SRRs and succeeded in achieving sustainable work (Figure 4, p. 57). We found interpersonal, material, valuative-attitudinal and macro-sociocultural resources (GRRs and SRRs) to be of substantial importance to be able to resolve tensions and mastering life and RTW issues. Our findings were also in keeping with, Lazarus & Folkman’s (1984) explanation of how the environment and social relationships interact and play a substantial role in people's appraisal and in their coping strategies.

The working environment (macro-sociocultural GRR)

We found the workplace as a social arena and the interaction with the employer regarding adjustments at work to be essential macro-sociocultural GRRs for the interviewed participants in the current study. As defined by WHO (2012), a healthy workplace will theoretically stimulate sustainability at work and the better health of employees. According to a report comparing working environments in Norway and EU countries, Aagestad et al. (2017) found that Norwegian employees in general seem satisfied with the balance of workload and their psychosocial environments at work. They also perceive their organization as motivating them in their job (Aagestad et al., 2017). This report indicates that Norwegian workplaces provide relatively healthy environments and may be regarded as providing good opportunities for PSC returning to work after absences.

The Norwegian working environment may give Norwegian PSC a better set of tools (explained in the current thesis as material and macro-sociocultural GRRs) to cope compared to PSC in some other countries. The working environment, including the employers’ duties to facilitate RTW for their employees according to the Working Environment Act (Lovdata, 2019), can have contributed to the current studies’ higher proportion of PSC working than other countries. Another contributing factor may be the social welfare system in Norway. The cooperation between social democratic government and active workers' unions have for decades worked to improve the working conditions in Norway (Pedersen et al., 2018). Recent reports and policies show Norway, as a social-democratic country since World War II, has developed a generous system that aims to safeguard employees' health and options of choices and benefits when on sick leave and when in need of RTW support (Aagestad et al., 2017, Pedersen et al., 2018, NAV, 2020). These services and the IA agreement (NAV, 2020) are programs established to support employers and persons on sick leave. Also, vocational interventions of supported employment have been introduced to increase work participation among people on sickness absence or disability (Sveinsdottir et al., 2020). The 75% of PCS working 2-14 years after cancer in other countries (de Boer et al., 2020) is lower than our results (about 85-86%, female and male PSC, respectively), the Norwegian working environment may explain some of those differences in proportions PSC attending work after cancer. Still, and even in a healthy working environment, it may not always be easy to achieve sustainable work.

We found less working attendance among PSC in the third study, and the participants interviewed described challenges when their former position was perceived to be too demanding after cancer treatment and when sufficient adaptations were not possible. Some participants also experienced having to find a new job when recurrent sick leave periods resulted in quitting their former job; new working opportunities or new jobs may not always be available for all PSC who strive to endure at their former position. Other studies have revealed that non-cancerous people are 2-3 times more likely to be employed than PSC (Bates et al., 2018; Noeres et al., 2013). This may indicate that employers give priority to hiring people without a former cancer diagnosis; but it may also show that PSC do not always endure working. In a recent review, de Boer et al. (2020) showed that proportions of PSC working after cancer varied at different time-points, from 80% after two years to around 65% after more than six years. The proportions working after six years were larger in our third study (about 86-88%, females and males, respectively). This difference can be explained partly by the selection of PSC in the current study (as explained in Chapter 7.1), but the Norwegian working environment may also have contributed to this result.

The interviews of participants revealed working environment GRRs in the working environment at several levels: a) the workplace as a social arena and by the support given from colleagues, b) the overall perception of being drawn toward normalcy while distancing the perceived feeling of illness from cancer by working, c) the cooperation with the employer regarding work adjustments. These factors represented resources for promoting the health of the participants in the current study. Consequently, if an employer cannot offer support when needed, the lack of adjustments or working options may turn into a stressor according to SMH (Figure 1, p. 19) and new tensions of not mastering work or not having opportunities to test working ability. Subsequently, that may also reduce the strength of the working environment as a supportive GRR, and in the worst case, become a deficient GRR, inhibiting retainment of work. However, the participants interviewed found their working environment to be supportive during their RTW journeys.

Participants interviewed in the current study emphasized a) how the workplace represented a valuable social arena and that relationships at work also offered psychosocial support (interpersonal GRR) that was influential on their RTW outcome. As an example, Carl explained how his colleagues became socially supportive and helped him to cope with life and at work after cancer. In their qualitative study, Zomkowski et al. (2019) also found how social support at work was influential on workability after cancer treatment. Attending work also made the interviewed participants b) better able to distance themselves from the disease and approach normalcy. Since sickness-related absence from work for a period of 1 to 2 years after a cancer diagnosis is common (Mehnert, 2011), being separated from the workplace without contact for a long time may increase the employee's perceived distance from the workplace and the social arena that might be supportive in their RTW process.

When participants in the current study felt valued and motivated at work, they also endured working more. The participants in the current study explained how meaningful tasks helped them to cope at work and continue working despite exhaustion. Other researchers have also underlined the importance of the employee's self-assessment and cooperation with the employer in the quest of RTW (Barnard et al., 2016; Boerger-Knowles & Ridley, 2014; Keesing et al., 2015; Mehnert et al., 2013; Stergiou-Kita et al., 2016). Thus, the current study confirms that if given work opportunities that are experienced as meaningful and manageable, PSC might withstand higher job demands.

Several studies, ours included, have concluded that c) if employers can be supportive and make arrangements to adjust work tasks, it can ease the RTW process (Greidanus et al., 2018; Luker et al., 2013; Petersen et al., 2019; Torp et al., 2011). Essential for some participants in the current study were to be offered work adjustments like changes of working tasks or working hours. Alleaume et al. (2020) compared PSC who received adjustments at work to PSC who did not. Among the PSC who received adjustments, 95% returned to work after five years, compared to 77.8% in the other group. For this reason, workplaces are advised to provide close follow-up, support, and reintegration (Armaou et al., 2018; Torp et al., 2012a). Some participants in the current study also expressed working at their own pace as beneficial and made it possible for them to start working sooner after cancer treatment. Participants in the current study gradually adapted to a renewed situation as it arose in phases 3 and 4 in the five-phase process model (Figure 4, p. 57). As suggested by Torp et al., 2011, a gradual increase of workload after cancer may be advantageous. Duijts et al. (2017b) also found that continued efforts to be working led to better functioning. An active instead of passive coping style has been shown to have given protection from falling out of work after cancer (van Muijen et al., 2018). Thus, the results in the current study support other studies that show efforts of returning to work may pay off.

Our results also showed that active participation in the RTW process in cooperation with the employer could be essential in returning to work at an early onset. Health-promoting aims comprise strengthening community action where people live and work to give all people the same opportunities to control matters of importance to their health (WHO, 1986). This aim may also include a right to be involved in planning one's own future according to working tasks and opportunities.

According to WHO’s Global Model of Action (WHO, 2012), two of the key factors for positively influencing employee’s health at work are leadership commitment and cooperation. When a workplace offers participation and opportunities for development, personal growth has been shown to be enhanced (Waddell & Burton, 2006; Wells et al., 2013). Antonovsky (1991) described how a healthy workplace would offer intellectual development, cooperation and networking, and an opportunity to feel needed and valued. Our results confirm that the working environment was crucial for the participants in the current study to be able to return sustainably to work.

Close relationships and financial issues (interpersonal and material GRRs)

All the participants interviewed emphasized close relationships (interpersonal GRRs) as essential for them to master their RTW challenges. For some, their spouse and family had a special position that was perceived as the most crucial support in their RTW quest. Moreover, their spouse was also improving their financial safety (material GRR). The results in Zomkowski et al.'s (2019) study also emphasized the value of emotional and social support from family and friends during RTW, and sustains our findings. It has also been shown that couples may be socially and economically stronger than those who live alone (Baker et al., 2005; Kent et al., 2018).

However, we also found examples among the participants interviewed that despite living as a couple, financial issues arose when the limit of 12 months for receiving sick leave benefits came closer and the reduction to 66% salary according to further benefits were approaching. The financial worries became a new stressor that the participants felt was pushing them to retain work before they felt quite ready. Since a couple usually is financially stronger together than individuals living alone, quitting work after cancer can be easier if PSC is a part of a couple. Studies have shown married women to be more likely to quit work or report cancer-related disabilities than men (Short et al., 2005). The situation of being a part of a couple may therefore not always support RTW, but sometimes also facilitate and another choice; that of not being working, which for some may also become a healthier choice.

According to SMH (Figure 1, p. 19) social support may be regarded as an interpersonal GRR, whereas a deficient financial or social situation as a result of less support from a spouse or due to less working ability may be considered to be an unsatisfactory state of a material GRR. Independent of the outcome of the RTW process, it makes sense to define a spouse as a GRR, meaning the importance of the role of the spouse according to RTW issues may be essential. As with all GRRs, if a resource is deficient, a new stressor may emerge. This means one should not take for granted that having a spouse always is an asset. If the relationship is not healthy, it may inhibit an RTW process instead of supporting it.

Health care services (macro-sociocultural GRRs)

The participants interviewed generally appreciated the health care services and were quite satisfied with the medical treatment they received. In Norway, the cancer treatment protocols are standardized to every diagnosis (Helsedirektoratet, 2020) and should ensure the same medical treatment for all. Healthcare services were recognized as GRRs (Figure 5, p. 59) that were of value for the PSC during their RTW processes. Although the protocols are customized to cancer type, age, and functional level, the personal relationships that might arise during cancer treatment are not a part of that protocol. Medical personnel have also been recognized to have a crucial role in providing PSC with information when they reorient toward sustainable work (Keesing et al., 2018). Luker et al. (2013) found that those PSC who discussed their situation with their treatment team worked significantly more hours, indicating how healthcare professionals also may be helpful during RTW processes. The focus in hospitals should primarily be on people’s cancer and treatment, but health care personnel may also be involved in questions and advice regarding RTW issues since they have knowledge about how late effects may affect possibilities for recovery. However, they may not always feel confident about advising according to RTW and work-life issues (Lamort-Bouché et al., 2019).

Participants in the current study mentioned a specific doctor, or somebody they felt connected to and relied upon as resources for support. These interpersonal relationships were defined as SRRs that helped the participants reflect upon their situational options and to choose and rely upon the best possible outcome (Figure 5, p. 59). This result may also be explained as stimulating a second appraisal (realizing opportunities) according to Lazarus (2012) and also as contributing factors in both an emotion-oriented coping (contribute to reducing anxiety and fear) and a problem-focused coping (giving advice and support on how to move on).

Other services offered in Norway may also be regarded as SRRs. The Norwegian Cancer Society (NCS) offers support to people diagnosed with cancer and their next of kin.

Together with some municipalities and hospitals in Norway, they offer consultations with a “cancer coordinator”, who often is a specialized cancer nurse. The purpose is to create a link between the medical support from the GPs/hospitals and the work-related issues (NAV and the employer). These cancer coordinators may provide valuable support, for instance, in discussing with PSC how to reorient towards reality regarding their clinical situations and to find meaningful activities. This service is randomly distributed and not available for all PSC (making it an SRR for some PSC).

Various Norwegian hospitals provide courses and intervention programs, but these programs are not offered to all PSC in Norway and must also be regarded as an SRR offered to some PSC only. In the current study, one participant interviewed attended a rehabilitation program, and benefited from that. Thus, our results indicate that all PSC do not require interventions to cope, but some may benefit from them.

Collaboration between health care personnel, the social welfare systems, and employers have been reported to be effective and required to achieve successful reintegration to work (Kiasuwa Mbengi et al., 2018b). In Norway, the GP is sometimes invited to the employee's and employers' regular meetings with NAV (NAV, 2020). However, it can be questioned if the employee, among all the professionals and authorities feels empowered or feels forced to agree upon suggested work plans. In a systematic review, Jørgensen et al. (2017) found that few articles have explored how cancer patients are empowered during follow-up and found a lack of attention to the patients' perception of their position according to empowerment. NAV, the GP and the employer must be regarded as separate GRRs and vital resources for PSC. Also, a collaboration between them could be another resource to be regarded as an SRR. Therefore, the question should be raised about whether the Norwegian system of follow-up meetings covers the need for collaboration to empower PSC on their RTW journeys, or if other interventions might be better designed to enhance the resources from the social welfare system to strengthen people's SOC and available GRRs. As we also found needs for support and resources available to vary in time and type among the interviewed participants, a more flexible and individually tailored system of support long-term could be considered.

7.3 The long-time horizon on sustainable work

This chapter discusses how initial RTW is different from long-term and sustainable work. The achievement of sustainable work sometimes entailed that the first attempt to return to work failed or was reconsidered after initial efforts. The shift from adaptations to a complete change of work is discussed in the first part. The discussion continues on gender differences where proportions of female PSC who worked short part-time increased in a long-term perspective. Finally, a summary of the complexity involved in long-term RTW issues ends this chapter.

Transformational changes years after initial adaptations

In the present study, participants interviewed in a long-term perspective of RTW retained work at different time points. Some also made major changes of occupation after some time in their former position. Thus, phases 3-4 in the five-phased process model (p. 58) were repeated several years after initial work retainment. Few researchers have explicitly focused on initial versus sustainable work. Duijts et al. 2017b investigated the sustainability of employment and health-related Quality of Life up to four years after a diagnosis. They found that PSC who had been working continuously had higher Quality of Life scores and fewer symptoms from late effects. However, this study did not report job changes. Barnard et al.'s four-phased process model focused primarily on the psychological phases based on TTSC. Since Barnard et al. (2016) did not distinguish between initial RTW and that of sustainable work as our current model does, concrete redirections the participants made, as detected in our study and shown in the five-phased process model did not become quite that visible in Barnard's model.

The results of the current long-term study showed a difference of adaptations (to former work and position) versus transformational changes (job identity). Independent of the content or level of work changes, both outcomes can be defined as coping. However, to make more extensive transformational changes can be viewed as going beyond being adaptive. The word adaptation indicates a reactional mode, which semantically differs from words like creation, construction, or transformation. We found the RTW processes in a long-term perspective to be an ongoing and life span process that included crucial turning points. The first attempt to work after cancer did not always lead to a sustainable working situation, and a complete job change prevented some participants from falling out of work after cancer.

Still, it is important not to glorify a complete job identity change as an aim of an RTW process to sustainable work. That is not what the results in the current study show. However, to be aware of the difference between adapting to former work and creating a new job identity can make it easier to detect that it may be required to make a larger transformational shift for some PSC, perhaps also at an earlier point. In turn, that may alter their ability to return sustainably to work.

Gender differences

The proportions of female PSC who worked short part-time gradually increased compared to both controls and men in the years $T_3 – T_9$ (Figure 7, p. 64). In the long-term perspective of nine consecutive years after cancer in our study, an increasing proportion of female PSC compared to male PSC and controls, either reduced from full-time work or long part-time work. Also in the current third study, the proportions of female PSC participating in labor-force were significantly lower than male PSC for all of the years (Figure 6, p. 63), showing a persistent difference between genders. Consistent with our findings, other researchers have also shown that women reduce working hours more frequently than men (Gudbergsson et al., 2008; Luker et al., 2013; Mehnert, 2011). Hamood et al. (2018) found that up to 70% of breast cancer survivors, which primarily consists of women, downgraded to part-time work 4-14 years after cancer. However, reductions in working hours have also been reported to be temporary, and if related to late effects from cancer, it might sometimes pass (Lee et al., 2008; Mehnert, 2011). As we did not follow single PSC over the years in the current study, we can only confirm that a larger proportion of women gradually worked short part-time up to nine years after cancer. Thus, the increasing proportions found in our study do not confirm that working part-time seems to be temporary among female PSC.

Culture may influence how PSC choose to move on if returning to the former work is too complicated or, for several reasons, may not be possible. Details in cultural factors influencing the ability to achieve sustainable work after cancer is outside the scope of this thesis the present thesis focus and study aims. However, some of the gender differences we found, can be due to cultural factors influencing how people prioritize and balance their life and work-life. In our modern society, and according to western culture, women should be regarded as equal to men and offered the same opportunities to attend work and build a job identity. In Norway, a large proportion of women work compared to many other countries (Aagestad et al., 2017). Moreover, more women in Norway than in other countries work part-time (36%). As women seem to have a longer tradition in mixing family and work by working part-time, reducing working hours may be easier for women to choose than for men – since it is more common for men to work full-time in Norway. If so, the culture is offering an increased macro-sociocultural GRR for women by enhancing flexibility to choose from more options during a transformational route of RTW processes. Also, the increased proportion of female PSC working short part-time in the present study can be due to extended perceived freedom to prioritize and make optional choices. This freedom can also be related to having the financial ability to reduce or quit work. If so, flexibility and financial freedom to reduce working hours may be regarded as an available resource (GRR). However, it might also be more complicated.

The gender differences found in the current study can also reflect other differences in perceived values and prioritizing between men and women. A "double burden effect" for women has been presented as a theory describing how women may have a responsibility and distress towards balancing their time and energy between family and work (Emslie & Hunt, 2009; Nilsen et al., 2017). If so, and as a consequence, female PSC may consider and decide to reduce their working participation more easily than men, but not necessarily because they want to. It may be a sign that gender equality may not yet be fully covered in our cultural values. Supporting this hypothesis, Marino et al. (2013) found that married men seemed to return faster to work after cancer than married women. Studies of both short- and long-term RTW have shown that the risk for not returning to work after cancer has been higher among female PSC than male PSC (Marino et al., 2013; Torp et al., 2013; van Muijen et al., 2013). Kiasuwa-Mbengi et al. (2018a) also found that male PSC returned sooner to work than female PSC during their 7-year follow-up. These differences among genders can be due to the men's role as the family's main provider due to the cultural remnant of the men's role. Gender differences in finding a balance between family and work were supported by testing mid-career men and women, were found to be increasingly important among women and less important among men (Mainiero & Gibson, 2018). Thus, prioritizing family before work among women (Nilsen et al. 2017, Mainiero & Gibson, 2018) is likely to contribute to explaining why more female PSC in the current study seemed to choose not to work or reduce their working hours than did the controls and males.

An increased risk of being disabled among middle-aged women when compared to men has also been documented (Haukenes et al., 2012). The researchers explained that the primary reason could be lower educational levels among women. Gragnano et al. (2018) found that having low education was a barrier for returning to work after severe illness. If the socio-economic positions among women in general are lower than among men, that can explain a decrease in the proportions of women who work after cancer. The average salaries in Norway are still lower among women than men (Statistics Norway, 2021), and the educational level among women is also generally lower (Statistics Norway, 2020). In the current study, however, the educational level was quite similarly distributed between the genders. Still, women tended to downgrade working hours or quit work more often than men, indicating other factors than education were the cause. For instance, deliberately choosing to quit working due to other goals in life being perceived as more valuable and optional could, for some, be more meaningful than being employed. We found no significant differences in the variable education in the current study. However, larger but non-significant portions of females (PSC and controls) were educated compared to men. These results may be further investigated to elaborate if the gender differences are substantial, and in that case, why.

The complexity of individual context and different need of RTW support

The current thesis shows the different contents, complexity and long-term duration involved in individual RTW processes. According to PSC's diverse contexts as described in the five-phased process model (Figure 4, p. 57), and the different GRRs utilized (Figure 5, p. 59), a set of factors influential to the RTW process were revealed. For example, the participants’ supportive key persons came from diverse settings (family, workplace and health care environments) and were essential at different times during the individual RTW processes.

In general, and as work is regarded as healthy (Burton, 2010), and is associated with identity and being of value (Little et al., 2002), adults should be provided with the necessary resources to self-manage their lives to keep good health and, if they so desire, to continue working. Such aim would be in accordance with health promotion and the definitions of health as defined in this thesis (p. 13). According to the WHO (1986) aim of enabling people to make healthy choices, existing policies and procedures might not always be flexible to meet what different PSC may need of support and advice for future planning of their life and work-life.

Several researchers have emphasized the importance of understanding the individual complexity during adaptation to work after cancer and when focusing on work-oriented goals (Barnard et al., 2016; Little et al., 2002; Wells et al., 2013). Mehnert et al.'s (2013) conceptual framework depicts how complicated the individual RTW processes can be, as they are dependent on policies and financial factors, workplace environment/employer, supportive interventions, personal and medical factors. Thus, when planning supportive systems, it can be a puzzle facilitating required resources to support all PSC who need support to cope at all times and for years following cancer. A literature review by Kiasuwa Mbengi et al. (2018b) showed few studies discussing how social welfare support systems and the labor market influence RTW's process after cancer. They call for more research to achieve inclusion equity when workers with chronic diseases and PSC integrate or return to the workforce. Their call is sustained based on the current thesis results showing the high complexity and long-term trajectories of RTW processes.

Our results showed the vast differences of individual trajectories and the composition of personal mastery skills and surrounding GRRs. Based on this thesis' results, and to achieve effective outcomes, the focus on PSC and their uniqueness as individuals when planning supportive interventions, programs or systems aimed to support PSC, is required.

7.4 Discussion of methods

The reflections of this thesis' methods will start by positioning the combined studies according to a mixed methods study design (Chapter 7.4.1). The acquisition of qualitative and quantitative data is discussed separately (Chapter 7.4.2-7.4.3).

7.4.1 Reflections on study design and the compilation of studies

The need for a change of world views during a research project, as in the current PhD project, may give reason to define the design of the study as evolving into a mixed methods study design. Recently, and when it comes to designing research, mixed methods studies have developed from being merely studies providing quantitative and qualitative data to become more thoroughly defined methodologies and research approaches of integrated studies (Creamer, 2018b). Different authors have presented mixed methods with various definitions and levels of integration of interlinked studies, where terminology and definitions for what is or is not a mixed methods design are also explained (Creamer, 2018a; Creswell & Plano Clark, 2018; Hesse-Biber et al., 2015).

Purists from the qualitative as well as the quantitative traditions have claimed that diverse methods and data may be incompatible in the same thesis and that such different studies should not be combined (Denzin, 2010; Howe, 1988). However, other researchers have argued that the different methods ought to focus more on how qualitative and quantitative research represent a continuum in opposition to a dichotomy of being either “exploratory” or “confirmatory” (Onwuegbuzie & Leech, 2005).

According to Creswell (2015), the studies in a mixed methods design must be connected to each other in such a manner that the validity is not threatened. A thoroughly mixed methods design requires the involvement of a mix of qualitative and quantitative techniques within one or several stages of the research, according to Leech & Onwuegbuzie (2009). In the current PhD project, different methods were conducted sequentially, and each separate study was entirely completed before the next was executed. The salutogenic orientation influenced the selection of participants and methods of the studies, but all three studies were not designed as a fully mixed methods study from the start. Thus, the methods for the studies were not fully integrated, but evolved towards a mixed methods design.

According to Creamer (2018a), there can be numerous reasons for studies to evolve into a mixed methods design; this PhD project is an example of such. In the project, new research questions were raised, based upon the initial results from the first study. Due to the PhD project’s commitment to a qualitative approach of methodological and epistemological focus at the baseline and first study, it is also possible to define this PhD project as a Qualitatively Driven approach, as presented by Hesse-Biber et al. (2015). The quantitative method in the third study takes a secondary role in the methodological design of the thesis as a whole. However, the results are equally valuable in all studies. According to Creswell & Plano Clark’s (2018) typology of mixed methods studies, calling the present PhD project a mixed methods study could be criticized for not being defined as a mixed methods study from the beginning. The aims and methods should in that case have been more closely interlinked. Nevertheless, and since there seems to be no worldwide agreement on common standards for what is required or when to name a study mixed methods, I chose not to focus on mixed methods as the design, but rather a compilation of studies containing qualitative and quantitative data. However, the studies in the current thesis are interlinked, and the combined results hopefully illuminate the field of RTW after cancer.

The studies provided the possibility to study the phenomenon of RTW after cancer from different angles. As the current first study was interpreted first separately, and then guided the next two studies design, the chosen design brought nuances to the combined results that single, separated studies could not do. Moreover, there were no important contradictory results to be found in the studies using different methodologies, but they rather informed each other. The results and perspectives from the various studies brought valuable insights to the same phenomenon investigated. This is a strength of the current study design.

A general limitation in the current thesis is its retrospective design. The development of cancer treatment changes over time and can lead to other or new late effects (Gegechkori et al., 2017). In that respect, results from the period 2004-2015 could already be regarded as “history”. Nonetheless, there are a large number of people of working age that currently suffer from long-lasting and well-known late effects. New treatment protocols may lead to new late effects to deal with (Gegechkori et al., 2017), but cancer will still represent a severe condition that can make a considerable impact on individual lives and on returning to work in the future.

The participants selected in the present studies present a somewhat skewed population of PSC. The participants interviewed were selected due to their achievement of sustainable work. We could expect to find management of tensions and broad utilization of resources. Also, the larger population of PSC in the third study consisted of persons who had the best opportunities to make necessary changes by being employed from before cancer. Also, none of them died during the investigated period. This meant we could expect the differences between PSC and controls to be less than had been shown in previous studies. This is important to emphasize when interpreting the results.

Also, PSC and controls' age ranged from 40-60 during follow-up in the third study, and the factor of age may have influenced labor-force participation. Norwegian statistics show that, in general, labor-force participation in Norway peaks at about 40-50 years for both genders (Statistics Norway, 2012, 2018). The overall employment rate then starts to decrease, and sickness absences and disability pensions are increasing in general (Statistics Norway, 2012; The Norwegian Labour and Welfare Administration (NAV), 2019). The highest cancer incidence is also found among the elderly from about 60 years of age (Cancer Registry of Norway, 2019). Paalman et al. (2016) found PSC, compared to controls, had a higher risk for retirement and receiving disability pension up to 10 years after their diagnosis. According to age distribution, a calculated rate of about 40% of cancer incidents 2015-2019 is estimated to be people of working age. As shown in the current study, some of the drop-out from labor-force participation (Figure 6, p. 63) may partly be explained by an overall tendency of more people being disabled or being on sick leave from about 50 years of age. However, this tendency is expected to be quite similar for all groups investigated in the current study, and may explain that all groups also showed the same pattern of development (Figure 6).

The influence of person-centered research perspectives

The present PhD project was qualitatively driven from the start, and person-centered research perspectives as outlined by Buetow (2011) and McCormack et al. (2010) influenced the design and performance of the present research. According to Buetow (2011), a study that fills the criteria of being “case-oriented, co-constructed, caring, contextualized, and complete,” is person-centered. The main principles for being a person-centered researcher are, according to Jacobs et al. (2017), to give attentiveness to, and to create meaningful dialogues and critical reflexivity together with the participants in the study. These principles were followed. During the two first studies, the IPA methodology facilitated analyzing dialogues. This method of performing reflexive dialogues, where hearing and trying to understand the different voices are in line with the influence of a person-centered health care research approach. Further, the ideographic philosophy of exploring the uniqueness in each case, as well as to analyze across cases (Smith et al., 2009) led to a thorough analysis.

The advisory team helped me build knowledge and expertise during the first studies and added their expertise in interpreting results and data. This team represented several voices representing experiences as PSC and diverse stakeholders. Further, these voices illuminated the interview and analysis phases by adding different perspectives, thoughts, and nuances to the data material. Although planned meetings with the entire team stopped after conducting the qualitative phase of the project, single members of the advisory were also consulted for discussions during the last phase and the third study.

7.4.2 Qualitative data

The discussion that follows comprises the first and second studies since the interviews provided data from utilizing the IPA methodology in both studies. The process of analysis were different in the two studies, as will be addressed below (Chapters 7.4.2.1-7.4.2.2).

Overall limitations and strengths

In qualitative studies, 10 or more interviews are often performed (Mason, 2010). Some would argue that eight participants, as in the current studies, might be too few. However, the number of participants which is sufficient in a given study will depend on several factors such as the methodology, aims, the participants, the interview guide, performance of the interviews and the quality of provided data (Creswell, 2007; Malterud et al., 2015; Mason, 2010; Smith et al., 2009). In the current study, we preferred depth of interviews and analysis before breadth. The methodology chosen (IPA) provided a thorough analysis method that was managed according to the method described (Smith et al., 2009). IPA studies have shown to commonly comprise 5-15 interviews (Hay-Smith et al., 2013; Mjøsund et al., 2015; Ryan et al., 2014; Sallis & Birkin, 2014). Smith et al. (2009) argue that a low number of interviews or participants can be sufficient if the research aims are well defined, and the performance of the interviews and the analysis process are thoroughly managed. The current supervisors actively contributed in the evaluation of the interviews by watching videotapes and by evaluating the quality of data. Also, the advisory team was engaged in the discussion of themes and results during the analysis process, similar to what Smith et al. (2009, p. 183) call an “independent audit”. The advisory team and the supervisors contributed to ensuring the credibility of the results. Rather than exploring new participants’ stories, re-interviewing of three participants was prioritized to deepen some remaining questions and to validate and discuss preliminary results. The number of interviews was thus finally 11.

The “deviant“ cases in the current study

Taking the position of salutogenic orientation (Chapter 3.2.1), we explored “deviant cases” of successful experiences among the interviewed participants in the first studies. The participants demonstrated how they mastered the life event of cancer and the following RTW challenges, contributing to inform how those who are less resourceful can be supported. PSC in the third study were selected by an assumed working experience due to age (> 30 years at the time of diagnosis) and being employed when diagnosed with cancer. Also, they had survived for more than ten years without any reoccurrence of cancer during follow-up. Therefore, we could expect beforehand the differences between PSC and controls in the third study to be less than other studies had shown earlier, and the current study's PSC can be regarded as having a better chance to return to work after cancer than an average population of PSC of working age.

7.4.2.1 Validation of data from the interviews

In the first study, IPA was fully utilized, and the data provided from this study was also used in the second study. As IPA is a relatively new methodology and analysis method, the method has been the object of criticism (Giorgi, 2010; Giorgi, 2011), followed by some public discussion (Smith, 2018; van Manen, 2018; Zahavi, 2018). The criticism has concentrated around IPA's three philosophical underpinnings and that, primarily, the phenomenological keystone may be too shallow. Another objection has been that IPA may be too demanding for novice researchers to practice due to all three methodologies being separately extensive and requiring diverse skills and understanding. In my experience, the bold design of the IPA methodology was challenging and a source for deep learning and developing new skills.

Smith et al. (2009) suggest evaluating IPA studies by Lucy Yardley's guide (Yardley, 2000). Below, the qualitative data and results from the first study will be discussed according to her four main characteristics of high validity: 1) Sensitivity to context, 2) Commitment and rigor, 3) Transparency and coherence, and 4) Impact and importance.

Sensitivity to context

Sensitivity to context is related to the expertise, literature, theories and the research team's approach and handling of sampling, interviews, and the data material (Smith et al., 2009; Yardley, 2000). The research team was skilled in the field of RTW after cancer and also experienced researchers in qualitative and quantitative data. Gradually, I gained expertise and sensitivity on RTW after cancer by reading vast amounts of literature in this field, attending seminars in Norway and abroad, and taking part in discussions with supervisors and the advisory team members. The advisory team provided correctives and nuances through all phases of the two first studies in their contribution of direct experiences from either being or observing cancer patients and years of practice. During the interviews, the initial interview schedule focused primarily on RTW questions. As the participants' stories revealed the connections between work-life and their entire life, we chose to include parts of the participants' whole individual stories as they were regarded important for understanding the RTW context.

The analysis process using video sequences directly instead of written text made it easy to stay close to the data. The analysis included interpretation of body language, and the number of verbatim extracts from several participants were high on each theme. The primary supervisor contributed to evaluating the data from the videos, and contributed in the analysis process of iterations and de- and re-contextualization of themes.

Creswell (2015) claims that the quality of data requires that the researcher has personal skills, like, for instance the ability to observe and communicate well with people involved in a study. Subsequently, the interviewer’s attitudes, experiences and personal skills may also influence the results. I performed all interviews and felt confident in the interview situation because of my long experience in practicing dialogues from about 30 years of diverse professions ranging from sales and management in different sectors to health consultancy. Even though efforts were made to limit unequal power dynamics to evolve during the interviews, my preunderstandings and previous experiences may have influenced the topics discussed and the interpretation of data. Pre-understandings were consciously bridled, and efforts were made to be observant of the participant in the dialogue.

Commitment and rigor

Commitment concerns the researcher's attentiveness toward the participants and the performance of the interview (Smith et al., 2009), and the depth and breadth of the data analysis (Yardley, 2000). A bold design of conducting almost open interviews, as explained by Smith et al. (2009), was chosen in the present study. The almost open interviews led to deepening reflections concerning participants’ personal endeavors, which later led to the interpretation and understandings of their meaning making. For the participants, the incidence of cancer treatment and RTW work periods were some years back. The passing of time may have altered their memories and perceived experiences and stories to a certain extent. As Lazarus (2012) points out, threats may be reappraised as favorable after new and renewed evaluation of the relational meanings, and such processes may have happened before the interviews took place. Consequently, the participants might also, due to the long-term perspective and successful outcome of still being working, be able to reflect upon their experiences on an elevated level.

The recurrent recollection of participants' reflections by watching video sequences facilitated being close to the experiences. The process of data gathering and analysis was a prolonged engagement that lasted for about two years. All involved parties were at all times dedicated, engaged, and eager to participate and share their experiences. The nuances received from the advisory team and the re-interviewing of participants led to an increased richness of the reflections during the analysis process.

The rigor of a study comprises the number of participants included (Yardley, 2000). The eight participants and eleven interviews in the two first studies were evaluated in accordance with Malterud et al.'s (2015) definition of information power (Chapter 5.5). The re-interviewing of three participants was prioritized over recruiting new participants. The results from the reinterviewing strengthened the belief of correctness in interpretations and themes in the results, and we decided to stop interviewing.

If, however, a comparison group of PSC who had not succeeded in returning to sustainable work had been included, we might have created an even better overall understanding of RTW processes among PSC. The existing literature widely covers the issue of not being able to return to sustainable work, so we relied on the literature to tell about barriers and obstacles. Furthermore, the aim of this study was primarily to explore and understand the phenomenon of long-term and sustainable return to work.

Transparency and coherence

Transparency and coherence comprise clarity and cogency in the presentation and reporting of results (Yardley, 2000). IPA has been carefully described, and COREQ, a checklist containing 32 items/questions (Tong et al., 2007), was added and used when reporting the second study. The analysis was systematically conducted, as described in Smith et al. (2009), utilizing the philosophies of phenomenology, hermeneutics and ideography.

The case-by-case study design safeguarded the ideographic underpinning. By returning to the videos several times during the analysis and report phases, sensibility to the participants and their original stories was actively performed. Themes from the single case analysis and the final cross-case analysis were organized using mind maps. Later, these mind maps were used to discuss the content of themes with the PhD supervisors and the advisory team for consistency and logical connection in the results. Some multiple understandings in themes were found and discussed through the ideographic cross-case analysis. For instance: Grete, chose to communicate with her friends and next of kin by writing a blog, while Carl actively used his colleagues for telling his story, which felt like therapy to him. This result showed that both participants needed to express and tell their close relationships what they went through, but they chose different strategies due to their different personalities.

Impact and importance

Impact and importance are about the current studies' influence and how the results contribute to research (Yardley, 2000). The comprehensive way of performing the thorough IPA methodology from the interview phase and through the analysis phase was performed as intended. The studies contribute to the field of research by their long-term perspective and the focus on resources needed to manage to return to sustainable work. The data material and preliminary results were discussed with several stakeholders, as in the advisory team, with supervisors and the participants, who all recognized the results.

7.4.2.2 The second study

In the second study of this thesis (Article 2), we applied theories directly as a framework on existing data material and previous IPA analysis (Chapter 7.4.1). This method has been described as a possibility (Bradley et al., 2007; Graneheim & Lundman, 2004; Miller & Crabtree, 1999), but is, to my knowledge, not widely utilized. In this study, qualitative content analysis (Graneheim & Lundman, 2004) was used upon video material and the descriptions from the first study. Furthermore, SMH was applied as a theoretical lens upon the results as a step 2 (see descriptions in Chapters 5.4 and 5.5.).

First, it may be argued the application of theory could bias the results because previous results and data were deductively categorized according to the constructs in the theory model (SMH). However, before the results were applied to the SMH categories, the data were analyzed and re-organized according to the methods of content analysis. During analysis, we found when categorizing themes into SMH components that the results overlapped according to GRRs and SOC constructs. This represented another finding that helped us raise questions about the SMH theory model. The first thought was the analysis perhaps was not deep enough and that the results overlapped due to a too high abstraction level of the data material. By efforts to go deeper, the overlap was still not possible to avoid. Another reason for overlap could be that the constructs of SOC and GRRs as described by Antonovsky (1979/1987), to some extent, actually do overlap.

In order to exploring activation of resources in general during RTW processes, the GRR results were reported in Article 2 at the expense of the results from the construct of SOC. However, interpretations of SOC components based on the results from the first study are provided in this discussion chapter.

7.4.3 Quantitative data

The third study (Article 3) was reported in accordance with standards for quantitative research in psychology (Appelbaum et al., 2018). Below, a discussion of validity is presented based on Brewer and Crano (2014) and Laake (2007). Validity refers to the results' relatedness to the purpose of the study, systematic errors, and how the statements are drawn from the research (Brewer & Crano, 2014).

7.4.3.1 Internal validity

Internal validity refers to a relative truth in the relationship between variables (Brewer & Crano, 2014). Since the current study is descriptive and the groups investigated are homogeneous, confounding factors are presumed to be limited. However, possible systematic errors in the data material can lead to errors in the results (Laake, 2007). In the current study, data were extracted from the Cancer Registry of Norway (CRN) (Cancer Registry of Norway, 2019), which has earlier been evaluated and found to be reliable (Larsen et al., 2009). Both Cancer Registry of Norway and FD-Trygd are official registries and are frequently used in Norwegian population-based studies (Dahl et al., 2016; Lindbohm et al., 2011; Torp et al., 2011; Torp et al., 2013). This is a strength of the current study.

Data in the registry study were systematically cataloged and statistically measured and treated in the same way for all groups investigated. To minimize the risk for systematic errors, only trained personnel handled the data, and the consistency of data was controlled by performing preliminary tests and inspections. Through this process, it was found that information about work in FD-Trygd for some PSC in the year 2015 was lacking. Therefore, the follow-up period was reduced from 10 to 9 years by omitting this year entirely in the study.

Statistical validity is achieved if the analysis and measurements chosen produce reliable results (Laake, 2007). If the tests utilized are not suitable for the data material and aim of the study, informational quality can be compromised. Non-parametric tests, like chi-square or odds ratio tests, have been suggested to be preferred before parametric tests if there are doubts about the normal distribution of the populations investigated (Fay & Proschan, 2010). During the analysis phase, odds ratios were randomly tested for comparisons reason on the t-tests, and confirmed the results. When the population is numerous, as is in the current study, and proportions of groups are compared and not individuals, a parametric test may be more reliable than a non-parametric test, despite the question of normal distribution (Fagerland, 2012). The variance showed to be narrow when t-tests were run in the present study, which indicates that the distribution was similar for the groups compared.

We monitored the variable *working hours* dependent on those who were still participating in the labor-force each year. Since smaller proportions of PSC than controls were participating in the labor-force from $T_1 – T_9$, there was a slight difference between the numbers in the PSC versus the control groups from year to year when monitoring *working hours*. However, the differences did not significantly influence the results. Some studies may not distinguish between variables of working participation and the number of working hours (van Muijen et al., 2013), which can lead to ambiguous conclusions since the number of working hours may be reduced without influencing the number of employees working. The current study split these variables.

Selection biases may occur if the studied population deviates too much from the total study population in a way that influences the conclusions (Laake, 2007). In the current study, the total population according to our inclusion criteria was selected, which is a strength of this study. The inclusion criteria were strictly implemented for all groups selected: All PSC and controls worked and lived for more than ten years after the first year of follow-up, neither PSC nor controls received any (additional) cancer diagnosis during the follow-up, they were also similar according to age and educational level. This selection, where the PSC who died and those with an additional cancer diagnosis during the follow-up time were excluded, may have led to a selection of the PSC population that was somewhat healthier than the total population of PSC; the included PSC may have been somewhat less exposed to severe late effects. Late effects from cancer treatment may be assumed as the leading cause for the limited working abilities (Gegechkori et al., 2017; Marino et al., 2013), and less invasive cancer has been associated with a better prognosis for RTW (Gegechkori et al., 2017; Steiner et al., 2008; van Egmond et al., 2017). Therefore, the selected study population may have led to a too positive interpretation of the portions of PSC returning to work after cancer in the current study compared to other studies that include all working PSC.

Whereas women tend to be younger when diagnosed with cancer, men are often diagnosed when 50 years of age or more (Becken et al., 2015; Cancer Registry of Norway, 2019; Kiasuwa-Mbengi et al., 2018a). Also, the incidence rates of cancer in Norway show a higher number of men diagnosed with cancer than women (Cancer Registry of Norway, 2019). For the years 2014-2018, the proportions of five-year relative survival after cancer are approximately the same among females and males, at 73.5% and 74.1%, respectively (Cancer Registry of Norway, 2019). The fact of differences in ages at the time of diagnosis compared to the inclusion criteria in the current study (being 30-50 years of age at the time of diagnosis) may explain why women represent 64% of the studied population.

When the number of controls is higher than the number of cases, validity may increase (Grimes & Schulz, 2005). Grimes & Schulz (2005) suggest that when the number of cases in case-control studies is small, the number of controls may be raised up to four times the cases to improve the study's power and validity. In the current study, the total population of 2 629 PSC can be regarded as high, and one control per case could be regarded as sufficient. Still, and despite the high number of cases, two controls were used per case in the current study.

The results in the current study also showed a reduction in proportions of the controls in labor-force participation. Since Norwegian statistics show that, in general, labor-force participation in Norway peaks at about 40-50 years for both genders (Statistics Norway, 2012, 2018), this is also similar to the ages represented in the studied population. This fact may explain a general drop in working participation and a reduction in working hours in all studied groups. Also, we had no data about the health of the controls or information on PSC's health other than the cancer diagnosis. Lack of this knowledge and its influence on the ability to work, limited the interpretations of the comparisons between PSC and controls in that all groups may have experienced other illnesses or other significant impacts in their lives that are not registered.

7.4.3.2 External validity

External validity is the extent to which results and conclusions may “go beyond the results themselves” (Brewer & Crano, 2014, p. 19), and how results and conclusions can be generalized to the entire population (Laake, 2007). In general, the current study’s number of selected participants represents the total population in Norway for the actual years investigated. However, by the narrowing inclusion criteria, we excluded a substantial amount of the total population of PSC in Norway. Consequently, it is important not to generalize the results to all PSC, but only PSC, as defined by the inclusion criteria of this study.

Construct validity concerns how outcomes are interpreted from variables based on theoretical abstracts or concepts (Brewer & Crano, 2014). In the current study, the lack of completeness of valid data about positions and professions can explain why the results showed few significant differences between the groups in the variable *job changes*. Unfortunately, only data about employer shifts in FD-Trygd were reliable for all years. Therefore, shifts of jobs related to working tasks in the same company were not covered by the variable *job changes*. Although it has been shown that PSC may change working tasks after cancer (Mehnert, 2011; Torp et al., 2012a), they do not necessarily have to shift employers to change profession or position. Likewise, a change of employer is not the same as altering the working tasks, which might be of importance when investigating working patterns of PSC. For future research, data about different changes in working tasks are recommended to be included in a job change variable.

In the registry study, averages for all four groups were compared yearly. Therefore, all changes regarding job changes or education that may have occurred for every individual in the respective groups were not monitored or measured. The one-time-per-year monitoring of data may have concealed changes, for instance, in employer changes or education during the elapsed time. However, the differences from one year to another will also reflect overall and significant RTW patterns of labor-force participation and working hours. Further studies segmenting education, income, work type, and testing predictors for changes in a long-term perspective are recommended.

8 Conclusions and implications

This chapter summarizes this thesis conclusions, its implications and suggestions for further research. Due to an ongoing discussion concerning a Norwegian project of changes in sickness absence benefits, some additional discussions related to this topic and the results from the current studies are presented in Chapter 8.2.1.

8.1 Conclusions

The interviewed participants in the current study were found to master life event stressors and adapted to a new situation and a renewed reality after cancer treatment. The exploration of the individual RTW trajectories showed a wide variety of unique courses across years of duration and diverse ways of adapting to reach sustainable work. Resources required to cope were found in their personal resources and their surroundings. The results also showed that initial RTW may not always last. RTW journeys may include years of trials in adapting to the new situation. Cancer and its treatment can profoundly impact and persistently change people’s lives in general, and work lives in particular.

PSC may utilize personal and surrounding resources differently, but crucial for achieving sustainable RTW can be mastery skills that consist of a determination to never give up working and an orientation towards moving on in creating a renewed reality based upon a new situation after cancer. Prioritizing what or who brings energy may be helpful. A sound financial basis and supportive social relationships can also be crucial resources for being able to move on. Personal growth is likely to be achieved as an outcome of the process, but the efforts and initial exhaustion to make it can represent substantial obstacles.

The workplace represented distancing the illness, and cooperation to start working as soon as possible may be beneficial for successful RTW. Vital in reorienting was to find meaningful working tasks and setting goals realistically according to workability. However, this thesis also confirms that cancer and its treatment can lead to decreased active work participation. The timeframe of lower participation goes beyond the first 5 years after the cancer diagnosis. Although most PSC seem to manage to RTW in Norway, female PSC downgraded working hours or quit work more often than men.

This thesis also confirms that the long-term horizon showed how the first attempt to return to work after cancer may not always be sustainable. After initial efforts of returning to their former position, some participants chose to create a completely new job identity, including taking further education. These results showed that, if, for some reason, adaptations or adjustments at work cannot be made or are not sufficient, evaluating other options could open up for reaching sustainable work.

8.2 Implications

The results of this thesis indicate that the social welfare system around PSC should be flexible to meet the individual needs during the different phases of the RTW journeys. Notably, people may need support to create future work-life several years after cancer treatment, independent of initial RTW. A re-organization of the social welfare system in Norway to offer more individualized tailor-made support and flexibility of benefits that last longer than one year may further increase the number of PSC returning to sustainable work after cancer.

To support more people to return to sustainable work can require individual support at different times during many years after cancer treatment. The support could be based on the PSC`s individual set of resources available and detection of which of them may be deficient at the actual time. The five-phased process model and the simplified SMH model can be used as tools when planning and offering support to PSC. In finding and reflecting on the current phase for the person concerned, the resources available may be evaluated, and the type of support needed to support their motivation and finding meaningfulness at the actual time may be easier to find. In addition, identifying and discussing which individual resources are available or limited can be another instrument to find a way to find helpful support and to facilitate a movement towards sustainable work.

8.2.1 Improvement of The Norwegian social welfare system

Due to the relatively generous public welfare benefits in Norway, the participants in the current thesis were likely to manage to maintain an adequate income during their initial RTW process. However, the sickness absence benefit in the Norwegian system is reduced from 100% to 66% of salary after 12 months – regardless of whether the person is 100% on sick leave or works part-time when on sick leave (NAV, 2020). Earlier reports in Norway have emphasized that PSC need a more flexible system of sickness absence and benefits to cope during RTW processes that can be of variable lengths (Becken et al., 2015; Fløtten et al., 2008).

The Norwegian Government, represented by the Department for Work and Social Welfare, initiated a study group to investigate how to facilitate increased employment in Norway (Sysselsettingsutvalget, 2018). Re-designing the social welfare system according to benefits when on sick leave in Norway is one factor they evaluated (Sysselsettingsutvalget, 2018). Their work has led to suggestions for changing today's rules and entitlements. For example, to ensure more flexibility and promote earlier RTW after illnesses in general, they suggested extending the sick leave period to 18 months, but, after six months, to cut the benefits to 80% of the salary (Sysselsettingsutvalget, 2018). The current thesis shows how cancer treatment may lead to years of adaptation and changes toward achieving sustainable work. The average time of RTW processes has been shown to be about 1.6 years among PSC in general (Kiasuwa-Mbengi et al., 2018a). Based on this result, it would probably be helpful for some PSC to extend the maximum period of sickness absence from 12 to 18 months, as suggested by Sysselsettingsutvalget (2018). However, how the reduced benefits from 100% to 80% after six months will impact people's ability to manage is perhaps not fully known or investigated. The results from the second study (Chapter 6.2) showed that the financial situation could be a critical GRR and that the time needed to adjust and adapt to work varied greatly. A reduction in salary during rehabilitation periods will probably not stimulate a healthy increase in PSC's working efforts. A financial stressor that forces people to return to work earlier than they have the energy to cope may risk that some increase their work efforts too much initially, and then may fall out of work instead. During that period, a need for sickness absences partly or entirely is to be expected. Also, persons on sick leave have to work for a prolonged time after sick leaves to regain the same benefits as when on initial sick leave in Norway. This may lead to a risk of losing these beneficial rights and a poorer financial outcome, which can become a new stressor and potential additional tensions, according to SMH (Chapter 7.3).

Their last report was distributed 11. February 2021 (Holden et al., 2021). In this report, the project group maintains that the portions of people on long-term sick leaves in Norway are higher than in other countries. They claim a slight rearrangement of the system is needed to stimulate more people to work instead of becoming disabled. A part of a program with this aim is to stimulate the employer to take more responsibility for adjustments by reducing their days of payment of salary at initial sick leave to 12 days (from 16). After that, NAV coordinates and covers the sickness benefits as before (NAV, 2020). The employer covers 100% of the salary on short sick leaves up to a maximum of 12 days per year. The report also suggests that the employer be responsible for paying 10% of the employees' salary if the employee is on sick leave for more than 3 months (Holden et al., 2021). Our results show that 3 months on sick leave is not a long time for being treated for cancer. If an employer becomes preoccupied with avoiding paying the 10% of salary rather than actually helping the employee to find a way to return to work, this suggestion for stimulation of returning to work may have the effect that PSC are forced back to work before they are ready for it. The reports and suggestions – including implications from the results of this study – will be discussed publicly and in relevant organizations.

Based on the current study’s results, an alternative could be to build up a financial system for sickness absence benefits during RTW as a time account. The same amount of time and financial coverage limit can then be kept as before, but the system will then be more flexible. Based on a budget for 12 months on 100% sick leave, the time can be extended to, for instance, 24 months on 50% sick leave or 36 months on 30%. An account like this would give PSC more freedom to not give up too early in their RTW process. Such a time account may stimulate to RTW gradually, but as soon as possible, so that people who want to and can work part-time, can start working at their own pace while testing their ability to work without worrying about their initial salary.

According to the IA-Agreement (NAV, 2020), scheduled meetings with the employee should be performed after a maximum of eight weeks on sick leave, and then after about 26 weeks. NAV requires a planned RTW process with the employer and their suggestions and opportunities for adjustments. However, the timing may be too early for some since PSC's challenges show that the RTW process may last for years. If PSC start to work too early, an extended period of trials of renewed sickness absence periods can be required later due to initial over-exhaustion.

Due to the diversities of situations and RTW progress in time and content, perhaps some prioritizing or detection system for evaluating who needs what and when may be more effective and better for all parties than offering the same program to all PSC. A more flexible approach would be not to operate with fixed time points for these meetings arranged by NAV, but adjust the time for them to fit the individual PSC and their medical situation. According to the five-phased process model, it would probably be valuable to arrange for such meetings when approaching the transformational phase 3 (Figure 4, p. 57). According to our results, reaching this phase can be at different time points, which even may be recurrent during several years after cancer.

Researchers have emphasized the need for designing more individualized support systems for PSC (Dorland et al., 2016; Ekenga et al., 2018; McEwen et al., 2013; Munir et al., 2009). These suggestions are in line with calls for person-centered treatment goals and techniques to support individual processes (Boerger-Knowles & Ridley, 2014). The combined results show a need for focusing on the set of PSC resources: mastery skills (Chapter 7.1) and surrounding resources (Chapter 7.2), to achieve sustainable work. Consequently, using SMH (Figure 5, p. 59) and the five-phased process model (Figure 4. p. 57) as tools in dialogues with PSC, may contribute to an increased understanding of the total situation and possibly uncover deficits of GRRs or the SOC that may need support. Such dialogues could enhance the possibility of achieving sustainable work after cancer by detecting the potential support required to move on at the actual time.

8.2.2 Further research

More research is required to explore the SMH in depth according to life event stressors like cancer, and the connections between SOC, GRRs, SRRs and other theories.

Furthermore, research is still needed to explore GRRs in more detail, and investigate cultural influences and the differences between women and men and other sub-groups – for instance, those living without partners or close family members. More research on how contextual and cultural factors influence RTW after cancer will be valuable to fully understand how RTW's complexity after cancer can be handled and supported to achieve a goal of more people returning to sustainable work in the future.

Since the five-phased process model (Figure 5, p. 59) might increase the understanding of PSC actual situation and detect needs for possible support according to the actual phase, the process model needs further development and can be included in future intervention studies.

Prospective intervention studies covering a more in-depth exploration along the timeline of RTW processes could be valuable to discover essential turning points and support requirements that might help more PSC return to sustainable work in the future. Moreover, a prospective study design could open up for exploring SOC as both a dependent and independent variable: a) following how SOC may be influenced during RTW processes, and b) how SOC strength might influence an outcome of sustainable work after cancer. PSC with a weaker SOC may need more support than those with a stronger SOC and more research is required to investigate if PSC who drop out of work may have somewhat weaker SOC than those who achieve sustainable work after cancer.

Independent of the strength of SOC at an initial point, strengthening GRRs and SOC may take place due to the process of successful tension management (Antonovsky, 1987; Idan et al., 2017). As Antonovsky (1979) defined the category “Specific Resistance Resources" (SRRs), a professional psychosocial nursing practice with the focus on strengthening a situational SOC (SSOC) as outlined by England & Artinian (1996), may be an example of a practice that could be further investigated to test its influence on RTW outcomes. Prospective intervention studies on PSC based on SSOC could be designed to evaluate and explore further how SOC may be changed during RTW processes.

More multivariate analysis using registry data are also required to explain the RTW patterns among PSC in more detail. Future research should include more details regarding job identity shifts and new educations. Moreover, variables such as sick leave periods and disability are still needed in a long-term perspective of more than five years. The analyses could also be stratified on socio-economic factors and marital status.

More research can reveal how the relationship between partners influences the RTW process. In future research, it could be relevant to stratify on marital status in addition to gender; this could contribute to understanding if women rely more on men as the primary provider when living together. It would also be valuable to perform cross-disease investigations that might shed more light on RTW patterns after illnesses in general.

Since we focused on proportions and not individuals in the third study, we cannot tell how PSC or controls in the registry study coped or how they detected possible needs for changes. Consequently, how these PSC mastered changes compared to the participants interviewed in Articles 1 and 2 cannot be known, and more studies are required to conclude.

9 References

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Appendices

Appendix I. Approvals

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Hege Holde Andersson	22845514	23.09.2015	2015/1232 REK sør-øst B
			Deres dato:	**Deres referanse:**
			16.06.2015	

Vår referanse må oppgis ved alle henvendelser

Birgit Brusletto
Høgskolen i Vestfold og Buskerud

2015/1232 Arbeidsliv og kreftbehandling i et langtidsperspektiv - en kvalitativ studie med personer som har gjennomgått omfattende kreftbehandling

Forskningsansvarlig: Høgskolen i Vestfold og Buskerud
Prosjektleder: Birgit Brusletto

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 19.08.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektleders prosjektbeskrivelse
"Studiens formål er å utforske og beskrive personenes opplevelser knyttet til gjennomlevd kreftbehandling, og å fortolke erfaringene for økt forståelse for faktorer som har betydning for å igangsette og styrke helsefremmende prosesser på veien tilbake til et aktivt arbeidsliv og virksomhet. Det er hittil lite forskning som er gjort blant personer som er friske fra sykdommen 5 -10 år etter behandling. Hensikten er å utdype den helsefremmende kunnskapen, slik at både helsevesenets og arbeidslivets aktører kan få bedre mulighet til å støtte tidligere kreftpasienter tilbake til et robust arbeidsliv. Studiens design er kvalitativ, og datainnsamling vil foregå gjennom dybdeintervjuer med personer som har erfart omfattende kreftbehandling fr ca. 7-10 år siden i alderen 25-55 år. Fokusgruppeintervju med deltakere fra fagmiljøer (fastleger, bedriftshelsetjeneste/ledelse, Kreftforeningen og andre med erfaring) vil i oppstarten bidra med basiskunnskap."

Komiteens vurdering
Komiteen har ingen forskningsetiske innvendinger til at prosjektet gjennomføres.

Vedtak
Komiteen godkjenner prosjektet i henhold til helseforskningsloven § 9 og § 33

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden.

Tillatelsen gjelder til 30.03.2018. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 30.03.2023. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder ”*Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*”

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Komiteens avgjørelse var enstemmig.

Med vennlig hilsen

Grete Dyb
førsteamanuensis dr. med.
leder REK sør-øst B

Hege Holde Andersson
komitésekretær

Kopi til:
- *Høgskolen i Buskerud og Vestfold ved øverste administrative ledelse*
- *Dekan Heidi Kapstad, Høgskolen i Buskerud og Vestfold*

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst B	Marianne Bjørnerem	22845531	09.03.2020	12016
			Deres referanse:	

Birgit Brusletto

12016 Arbeidsliv og kreftbehandling i et langtidsperspektiv - en kvalitativ studie med personer som har gjennomgått omfattende kreftbehandling

Forskningsansvarlig: Universitetet i Sørøst-Norge

Søker: Birgit Brusletto

REKs vurdering

Vi viser til endringsmelding for ovennevnte forskningsprosjekt mottatt 27.02.20. Søknaden er behandlet av sekretariatet på delegert fullmakt fra REK sør-øst B, med hjemmel i helseforskningsloven § 11.

Tidligere referansenummer: 2015/1232.

Endringene innebærer

1. Ny estimert sluttdato: 01.01.2023.

2. Nye prosjektmedarbeidere: Camilla M. Ihlebæk (Norges miljø- og biovitenskapelige universitet) og Nina Helen Mjøsund (Vestre Viken HF).

Vurdering

Sekretariatet i REK har vurdert de omsøkte endringene, og har ingen forskningsetiske innvendinger til endringene slik de er beskrevet i skjema for prosjektendring.

Vedtak

Godkjent

REK har vurdert endringssøknaden og godkjenner prosjektet slik det nå foreligger, jf. helseforskningsloven § 11.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad, endringssøknad, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

Med vennlig hilsen

Jacob C. Hølen
Sekretariatsleder REK sør-øst

Marianne Bjørnerem
Rådgiver
REK sør-øst B

Kopi sendt til: Forskningsansvarlig institusjon.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

Datatilsynet

LHL Helse
Røros Rehabilitering
Dato 9/12 -16
Saksnummer 0119
Saksbehandler MAB

LHL-klinikkene Røros
Øverhagaen 15
7374 RØROS

Deres referanse	Vår referanse	Dato
	16/00235-4/RCA	02.12.2016

Gitt konsesjon til å behandle personopplysninger i forskningsprosjektet - Arbeidsdeltagelse ved kreftsykdom ved LHL-klinikkene Røros

Datatilsynet viser til søknad av 28.01.2016 om konsesjon til å behandle personopplysninger i forskningsprosjektet «Arbeidsdeltakelse ved kreftsykdom». Søknaden til Datatilsynet er sendt via personvernombudet ved Landsforeningen for hjerte- og lungesyke (LHL). Vi viser også til senere innsendt tilleggsinformasjon av 09.03.2016, og besvarelser av Datatilsynets forespørsler om ytterligere informasjon om prosjektet fra forsker av 08.06 og sist 20.09.2016. Vi beklager at saksbehandlingstiden er blitt lang på grunn av stor saksmengde.

1. Sakens faktiske forhold

Prosjektet er forankret i Landsforeningen for Hjerte-lungesyke ved Rørosklinikkene og i samarbeid med NTNU, Høgskolen i Vestfold og FAFO. Undersøkelsen skal legge grunnlag for videreutvikling av rehabiliteringstilbudene og gi ny kunnskap om effekt av rehabilitering for kreftpasienter. Prosjektet har en varighet på 10 år.

Prosjektsøknaden er vurdert av Regionaletisk forskningskomité (REK) som har konkludert med at prosjektet faller utenfor helseforskningslovens område for medisinsk og helsefaglig forskning. REK har innvilget dispensasjon fra taushetsplikt for relevante opplysninger til studien samt nærmere vilkår for dispensasjonen.

Formål med forskningsprosjektet
Formål A: På nasjonalt nivå å dokumentere arbeidsforløp før, under og etter kreftsykdom og effektene av rehabilitering i spesialisthelsetjenesten for pasientenes arbeidsdeltakelse.

Formål B: Å sammenligne effekt for alle kreftpasienter som har mottatt rehabilitering ved LHL-klinikkene Røros og Nærland med kreftpasienter som har gjennomførtdagbasert rehabilitering og kreftpasienter som ikke har gjennomført rehabilitering.

Utvalget av pasienter som omfattes av forskningsprosjektet:
For det første formålet består utvalget av alle kreftpasienter i arbeidsfør alder som på diagnostiseringstidspunktet er mellom 15-68 år innenfor tidsrommet 2004-2015.

For det andre formålet består utvalget av kreftpasienter som har mottatt rehabilitering ved LHL-klinikkene Røros og Nærland samt kreftpasienter som har mottatt dagbasert rehabilitering og kreftpasienter som ikke har mottatt rehabilitering.

Kontrollgruppe:
Formål A: Norges befolkning i arbeidsfør alder med unntak av kreftpasienter.

Formål B: En kreftfri gruppe i befolkningen, matchet på kjønn, alder, diagnose samt sosioøkonomisk og sosiodemografisk bakgrunn.

Opplysninger fra lov- og forskriftsregulerte registre som skal benyttes i prosjektet:
Norsk pasientregister (NPR): følgende opplysninger fra 2008-2015: diagnose, komorbiditet, behandlingssted, henviser, bostedsfylke, rehabiliteringstilbud, rehabiliteringsinstitusjon, kjønn og alder.

Kreftregisteret: Opplysninger om spesifikk kreftdiagnose, spesifikk tumor behandling, spesifikke tumoropplysninger, tidligere kreftbehandling, komorbiditet.

FD-Trygd: Sysselsettingsstatus, utdanning, sosioøkonomiske og sosiodemografiske opplysninger.

Reseptregisteret: Opplysninger om legemiddelbruk (mengde og styrke), profesjon og spesialitet for forskriver, dato for forskrivning.

1. Rettslig grunnlag

Behandling av sensitive personopplysninger krever konsesjon fra Datatilsynet jf. helseregisterloven § 7, og personopplysningsloven §§ 9 og 33-35. Utlevering fra- og sammenstilling av opplysninger med Reseptregisteret som går utover reseptregisterforskriften § 5-3, 1 ledd skal alltid søke om konsesjon fra Datatilsynet jf. forskriften § 5-3, 2 ledd. Denne studien omfattes av konsesjonsplikt etter § 5-3, 2 ledd, ved at det er søkt om sammenstilling mellom reseptregisteret og andre registre enn de som er nevnt i 5-3, 1 ledd.

Konsesjonsvurdering etter personopplysningsloven § 34 innebærer at Datatilsynet skal avklare om det foreligger lovlig adgang til å behandle personopplysninger og om den konkrete behandlingen kan volde ulemper for den enkelte som ikke avhjelpes gjennom bestemmelsene i personopplysningsloven kapittel II til V og vilkår etter § 35.

Det må foretas en helhetlig vurdering av behandlingen, hvilke personopplysninger som er omfattet og hvilke tiltak som skal iverksettes for å begrense aktuelle personvernulemper.

Reseptregisterforskriftens krav til pseudonym identitetsforvaltning er et viktig tiltak som begrenser personvernulemper for de registrerte. Dette kravet må oppfylles også når Datatilsynet gir konsesjon. Dette betyr at samtlige personopplysninger som inngår i sammenstillingen med helseopplysninger fra Reseptregisteret må pseudonymiseres, og resultatet av sammenstillingen skal også være pseudonymt.

Reseptregisterets tiltrodde pseudonymforvalter er Statistisk sentralbyrå, jf. reseptregisterforskriften § 3-1. Sammenstillingen må utføres av Reseptregisteret.

Reseptregisterforskriften § 5-2 stiller vilkår for utlevering av helseopplysninger fra Reseptregisteret. Disse vilkårene må oppfylles også når Datatilsynet gir konsesjon. Vilkårene innebærer blant annet at opplysningene i registeret kun kan behandles i samsvar med registerets formål jf. reseptregisterforskriften § 1-3. Videre skal det ikke utleveres flere opplysninger enn det som er nødvendig for å ivareta søkerens berettigede formål med behandlingen av opplysningene. I tillegg skal opplysningene slettes straks prosjektet er avsluttet og enkeltpersoner skal ikke kunne gjenkjennes ved offentliggjøring av resultatet av behandlingen.

Vilkåret om at det ikke skal utleveres flere opplysninger enn det som er nødvendig for å oppnå formålet er et viktig tiltak for å redusere mulighetene for å gjenkjenne enkeltpersoner til et minimum. Årsaken til dette er at omfanget av personopplysninger kan bidra til å bakveisidentifisere enkeltpersoner.

2. Datatilsynets praksis

Datatilsynet har gjennom langvarig praksis slått fast at det ikke kan utleveres opplysninger som er særlig egnet til å identifisere enkeltpersoner og at det i slike tilfeller kan være nødvendig å endre prosjektdesignet for å hindre bakveisidentifisering. Vi anbefaler derfor forskere å kontakte de som forvalter de ulike registrene. Hver av registerforvalterne/ databehandlingsansvarlige har kunnskap om hvilke opplysninger som er særlig egnet til å identifisere enkeltindivider.

Dagens teknologi medfører at det kan være vanskelig å fjerne enhver mulighet for å gjenkjenne et enkeltindivid i et sammenstilt datasett. Slik identifikasjon kan for eksempel følge av at personell som skal arbeide med studien kjenner pasientene. Det stilles derfor krav til overholdelse av sikker lagring og bruk som forhindrer ulovlig bruk av og tilgang til opplysningene, jf. personopplysningsloven § 13 og personopplysningsforskriften kapittel 2 om informasjonssikkerhet.

Videre er Datatilsynets praksis at utlevering av opplysninger fra Reseptregisteret når mottaker har tilgang til direkte identifiserbare opplysninger om de registrerte, kun er tillatt når de registrerte har samtykket til deltakelse i prosjektet.

3. Datatilsynets vurdering

Konsesjonsvurdering etter personopplysningsloven § 34 forutsetter en avklaring av om det foreligger lovlig adgang til å behandle personopplysninger. Hovedtemaet i § 34 er om behandlingen av personopplysninger kan volde ulemper for den enkelte, og om disse kan avhjelpes gjennom bestemmelsene i personopplysningsloven kapittel II til V. Hvis dette ikke er tilstrekkelig for å redusere personvernulempene, kan Datatilsynet stille særlige vilkår etter personopplysningsloven § 35.

Denne registerstudien er basert på helseopplysninger fra Norsk pasientregister og Kreftsregisteret som begge er opprettet ved lov, jf. helseregisterloven § 11, og nærmere regulert i pasientregisterforskriften og kreftregisterforskriften. Reseptregisteret er opprettet ved forskrift og har særskilte krav til hvordan de registrertes identitet skal behandles, jf. tidligere omtale av rettslig grunnlag.

Dette prosjektets behandling av helseopplysninger fra de 3 nevnte registrene ligger innenfor de formål registrene er opprettet for å betjene. REK har også innvilget dispensasjon fra taushetsplikt. Prosjektet har dermed lovlig adgang til å innhente nødvendige og relevante opplysninger. Lovlig innhenting av personopplysninger fra FD-trygd krever dispensasjon fra Statistisk sentralbyrå som forvalter dette registeret. Under forutsetning av at sistnevnte tillatelse innvilges vil sammenstillingen av opplysninger fra samtlige registre kreve konsesjon fra Datatilsynet.

Konsesjon til å behandle sensitive personopplysninger kan gis hvis behandlingen er nødvendig for historiske, statistiske eller vitenskapelige formål og samfunnets interesse i at behandlingen finner sted klart overstige ulempene det kan medføre for den enkelte, jf. personopplysningsloven § 9 h.

Hovedregelen for en lovlig behandling av helseopplysninger er at de registrerte samtykker til at deres opplysninger kan benyttes til et konkret formål. Utlevering av helseopplysninger uten de registrertes samtykke vil derfor alltid representere et vesentlig inngrep i den enkeltes rettigheter og krav på beskyttelse av sine sensitive, personlige opplysninger. Dette anses som en klar personvernulempe for de registrerte. Det avgjørende blir derfor resultatet av en avveining mellom prosjektets samfunnsnytte og personvernulempene for de registrerte. Ettersom vi har konkludert med at det foreligger personvernulemper vurderer vi om ulempene kan avhjelpes eller om disse er av en så inngripende karakter at konsesjon ikke kan gis.

I dette prosjektet er det gitt gode begrunnelser for prosjektets nytte og verdi både for samfunnet og for fremtidige pasienter. Ettersom samfunnsnytten oppfattes å være godt dokumentert blir spørsmålet om denne interessen klart overstiger personvernulempene for de registrerte, eller om det kan etableres tiltak som begrenser aktuelle personvernulemper i tilstrekkelig grad.

Prosjektet skal ikke registrere pasientenes eller helsepersonellets identitet. På grunn av sammenstilling med reseptregisteret blir samtlige personopplysninger utelukkende gjort tilgjengelig for forskere i pseudonym form. Videre har forsker vektlagt å begrense antall opplysninger fra registrene til et nødvendig minimum. For å begrense personvernulempene ettersom de registrerte ikke skal samtykke og heller ikke motta individuell informasjon om prosjektet, skal både LHL-klinikkene og Reseptregisteret gi informasjon om prosjektet på sine respektive hjemmesider.

Som et ytterligere tiltak for å begrense personvernulemper må databehandlingsansvarlig foreta en grundig vurdering av om opplysningene om LHL-klinikkenes pasienter og forskrivere tilfredsstiller kravene til pseudonym identitetsforvaltning. Dersom dette kravet ikke innfris må det innhentes samtykke fra hele eller deler av pasientgruppen og forskrivere som omfattes av formål B.

Datatilsynet er kommet til at personvernulempene er tilstrekkelig avhjulpet dersom overnevnte vurderinger tas til følge.

4. Vedtak

Datatilsynet har vurdert søknaden og gir med hjemmel i helseregisterloven § 7, jf. personopplysningsloven § 33, jf. § 34 og reseptregisterforskriften §§ 5-2 og 5-3 konsesjon til å behandle helseopplysninger til følgende formål: «Arbeidsdeltakelse ved kreftsykdom».

Databehandlingsansvarlig er øverste ledelse ved LHL- klinikkene Røros. Gjennomføringen av det daglige ansvaret kan delegeres.

Konsesjonen er gitt under forutsetning av at behandlingen foretas i henhold til søknaden med senere tilleggsopplysninger og REKs vilkår for innvilget dispensasjon fra taushetsplikt. Det forutsettes videre at prosjektet gjennomføres under de forutsetninger som er lagt til grunn i dette brevet. Prosjektet gjennomføres i samsvar med helseregisterloven med forskrifter og de bestemmelser som følger av personopplysningsloven med forskrifter.

Vi minner om at det i samsvar med helseregisterloven §§ 23 og 24 skal informeres om prosjektet på LHL-klinikkenes og Reseptregisterets hjemmesider slik at registrerte og andre interesserte kan finne informasjon om bruk av helseopplysninger.

Det presiseres at konsesjonen, i samsvar med søknaden, er tidsbegrenset til **31.12.2026.** Etter dette tidspunktet må opplysningene slettes i samsvar med Reseptregisterforskriften § 5-2 sjette ledd.

Dersom det skjer endringer i behandlingen i forhold til de opplysninger som er gitt i søknaden, må dette fremmes i ny konsesjonssøknad.

Klageadgang

Dette vedtaket kan påklages til Personvernnemnda i medhold av forvaltningslovens kapittel VI. Eventuell klage må sendes til Datatilsynet senest tre uker etter at dette brevet er mottatt.

Med vennlig hilsen

Camilla Nervik
Camilla Nervik
seniorrådgiver

Ragnhild Castberg
Ragnhild Castberg
seniorrådgiver

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Hilde Eikemo	73597508	13.06.2016	2016/830/REK midt
			Deres dato:	**Deres referanse:**
			03.05.2016	

Vår referanse må oppgis ved alle henvendelser

Harald Engan
LHL-klinikkene Røros

2016/830 Arbeidsdeltagelse ved kreftsykdom

Forskningsansvarlig institusjon: LHL-klinikkene Røros
Prosjektleder: Harald Engan

Vi viser til søknad om dispensasjon fra taushetsplikt i ovennevnte prosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 27.05.2016. Vurderingen er gjort med hjemmel i helsepersonelloven § 29 første ledd og forvaltningsloven § 13 d første ledd.

Prosjektomtale

Dette er en registerbasert studie organisert av forskere ved LHL-klinikkene Røros, NTNU, FAFO og Høgskolen i Sør Øst Norge og Aix Marseille Universitet. Hovedformålet med studien er å undersøke kreftpasienters arbeidsdeltagelse over en 10 års periode ved bruk av informasjon fra offentlige registre i Norge. Et annet formål er å undersøke betydningen av spesialisert rehabilitering på arbeidsdeltagelse for kreftpasienter. Studien vil også identifisere sykdomsrelaterte, økonomiske og demografiske forhold som kan påvirke arbeidsdeltagelse for pasientgruppen. For å kunne undersøke disse forholdene er det nødvendig å koble informasjon fra fire offentlige registre: norsk pasientregister, statistisk sentralbyrå (FD-trygd), kreftregisteret og reseptregisteret. Andre opplysninger enn fra registrene innhentes ikke. Forskningsprosjektet vil bidra til å dokumentere arbeidsforløp før, under og etter kreftsykdom samt effektene av rehabilitering i spesialisthelsetjenesten på tilbakeføring til arbeid

Vurdering

Komiteens prosjektsammendrag

Studien er en registerbasert undersøkelse organisert av forskere ved LHL-klinikkene Røros, NTNU, FAFO og Høgskolen i Vestfold. Hovedformålet er å undersøke kreftpasienters arbeidsdeltagelse over en 10-årsperiode. Her vil utvalget være alle kreftpasienter i Norge av begge kjønn mellom 15-68 år med diagnosetidspunkt fra 2004 til 2015. Kontrollgruppen vil være alle nordmenn uten kreftsykdom av begge kjønn i aldersgruppen 15-68 år. Man skal også undersøke betydningen av spesialisert rehabilitering på arbeidsdeltagelse for kreftpasienter, og identifisere sykdomsrelaterte, økonomiske og demografiske forhold som kan påvirke arbeidsdeltagelse for pasientgruppen. Her vil utvalget være alle kreftpasienter som har gjennomgått rehabilitering ved LHL-klinikkene Røros og Nærland. Kontrollgruppen vil bestå av kreftpasienter som ikke har gjennomført rehabilitering og som har gjennomført dagbasert rehabilitering. I tillegg vil det være en kreftfri kontrollgruppe matchet på kjønn, alder, diagnose, sosioøkonomisk og sosiodemografisk bakgrunn. Data skal hentes fra norsk pasientregister, statistisk sentralbyrå (FD-trygd), kreftregisteret og reseptregisteret. Forskningsprosjektet vil bidra til å dokumentere arbeidsforløp før, under og etter kreftsykdom samt effektene av rehabilitering i spesialisthelsetjenesten på tilbakeføring til arbeid.

Tidligere vurderinger

Prosjektet har tidligere vært søkt REK som et helsefaglig forskningsprosjekt, men REK sør-øst C avviste søknaden som utenfor mandat, jf. vedtak datert 9.10.2015, ref.nr. 2015/1605. I prosjektet skal man imidlertid benytte taushetsbelagte helseopplysninger uten å innhente samtykke fra deltakerne, og prosjektleder trenger derfor en dispensasjon fra taushetsplikten for annen type forskning (enn helsefaglig forskning).

Dispensasjon innvilges
Komiteen har ingen innvendinger til studiens formål eller plan for gjennomføring. Variablene som skal hentes fra de ulike datakildene vurderes som relevante for formålet. Antall deltakere er så høyt at det blir praktisk vanskelig å innhente samtykke. Videre finner komiteen at forskningsprosjektet er av vesentlig interesse for samfunnet, og hensynet til deltakernes velferd og integritet er tilstrekkelig ivaretatt.

På bakgrunn av dette viser komiteen til helsepersonelloven §§ 29 og 21 jf. forvaltningsloven § 13d og delegasjonsvedtak etter forvaltningslovforskriften § 8 bokstav c og innvilger dispensasjon fra taushetsplikten slik at opplysninger kan gis fra registre uten hinder av taushetsplikt, til bruk i det beskrevne prosjektet. Komiteen godkjenner også at prosjektleder behandler personopplysninger uten samtykke fra den enkelte deltaker. Prosjektleder kan delegere nødvendig tilgang til de andre personene som er nevnt i søknadens liste over medarbeidere.

Komiteen viser også til den generelle opplysningsplikten som databehandlingsansvarlig har etter personopplysningsloven § 20 og helseregisterloven § 24. Komiteen vurderte informasjonsplikten for prosjektet og fant at det ikke skulle stilles vilkår om informasjon i dette tilfellet av samme grunn som over.

Vilkår for innvilget dispensasjon

1. Dispensasjonen fra taushetsplikt gjelder kun for de opplysningene som er relevant for studien.
2. Enhver publikasjon basert på studien må skje i en slik form at enkeltpersoner ikke kan gjenkjennes.
3. Registerkoblingene i prosjektet kan ikke deles med andre forskergrupper for andre forskningsformål enn det som er beskrevet i dette vedtaksbrevet.
4. Dispensasjonen fra taushetsplikt gjelder i studieperioden for de prosjektmedarbeidere som prosjektleder har delegert nødvendig tilgang til. Av mulige kontrollhensyn innvilges prosjektleder også dispensasjon i fem år etter sluttmelding er sendt REK.

Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge innvilger dispensasjon fra taushetsplikten.

Komiteens beslutning var enstemmig.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Siri Forsmo
Dr.med. MPH
Professor

Hilde Eikemo
Sekretariatsleder

Kopi til: Harald.Engan@lhl-klinikkene.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK midt	Hilde Eikemo	73597508	07.02.2017	2016/830/REK midt
			Deres dato:	**Deres referanse:**
			26.01.2017	

Vår referanse må oppgis ved alle henvendelser

Harald Engan
LHL-klinikkene

PROSJEKTENDRING GODKJENNES

Det vises til søknad om prosjektendring datert 25.01.2017. Søknaden er vurdert av sekretariatsleder for REK midt på fullmakt, med hjemmel i helsepersonelloven §§ 29 og 21 jf. forvaltningsloven § 13d og delegasjonsvedtak etter forvaltningslovforskriften § 8 bokstav c.

Ønsket prosjektendring
Det søkes her om å få utvide dispensasjonen til også å gjelde opplysninger om primærdiagnose for trygdeytelse. Opplysningene ønskes for alle kreftpasientene som inngår i prosjektet. NAV har opplysningene, men disse skal gis forsker via SSB. Opplysningene ønskes for alle kreftpasientene som inngår i prosjektet.
I tillegg er listen over prosjektmedarbeidere oppdatert.

Vurdering
Prosjektendringen er vitenskapelig begrunnet, og endrer ikke premissene for den opprinnelige dispensasjonen fra taushetsplikten. Opplysningene utleveres til forsker i avidentifisert form, og risikoen for integritetskrenkelse for den enkelte deltaker anses som liten. Komiteen har følgelig ingen innvendinger mot prosjektendringen.

Vedtak:
Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner søknad om prosjektendring.

Med vennlig hilsen

Hilde Eikemo
Sekretariatsleder, PhD
REK midt

LHL-klinikkene
Øvrehagaen 15

7374 RØROS

Att: Prosjektleder Harald Engan

Deres ref:	Vår ref: (må oppgis ved kontakt):	Saksbehandler:	Vår dato:
	17/341	**Knut Brenne**	**14.03.2017**

Dispensasjon fra taushetsplikten i forbindelse med forskningsprosjektet «Arbeidsdeltagelse ved kreftsykdom»

Arbeids- og velferdsdirektoratet viser til søknad mottatt 9.1.2017.

Sakens opplysninger
Prosjektet er en registerbasert studie organisert av forskere ved LHL-klinikkene Røros, NTNU, FAFO og Høgskolen i Sør Øst Norge og Aix Marseille Universitet. Hovedformålet med studien er å undersøke kreftpasienters arbeidsdeltagelse over en 10 års periode ved bruk av informasjon fra offentlige registre i Norge. Et annet formål er å undersøke betydningen av spesialisert rehabilitering på arbeidsdeltagelse for kreftpasienter. Studien vil også identifisere sykdomsrelaterte, økonomiske og demografiske forhold som kan påvirke arbeidsdeltagelse for pasientgruppen. For å kunne undersøke disse forholdene er det nødvendig å koble informasjon fra fire offentlige registre: norsk pasientregister, statistisk sentralbyrå (FD-trygd), kreftregisteret og reseptregisteret. Andre opplysninger enn fra registrene innhentes ikke.

Forskningsprosjektet vil bidra til å dokumentere arbeidsforløp før, under og etter kreftsykdom samt effektene av rehabilitering i spesialisthelsetjenesten på tilbakeføring til arbeid

Utvalget av pasienter som omfattes av forskningsprosjektet:
For det første formålet består utvalget av alle kreftpasienter i arbeidsfør alder som på diagnostiseringstidspunktet er mellom 15-68 år innenfor tidsrommet 2004-2015. Til dette formålet er det en kontrollgruppe bestående av hele Norges befolkning i arbeidsfør alder med unntak av kreftpasienter.

For det andre formålet består utvalget av kreftpasienter som har mottatt rehabilitering ved LHL-klinikkene Røros og Nærland samt kreftpasienter som har mottatt dagbasert rehabilitering og kreftpasienter som ikke har mottatt rehabilitering. Kontrollgruppen er her en kreftfri gruppe i befolkningen, matchet på kjønn, alder, diagnose samt sosioøkonomisk og sosiodemografisk bakgrunn.

Søknaden gjelder tilgang til diagnosedata fra NAV i forbindelse med forskningsprosjektet. I søknadens punkt 8.1.6 er angitt at det søkes om primærdiagnose for trygdeytelse der dette finnes. I e-post av 14.2.2017 angis at prosjektet i tillegg til primærdiagnose ønsker sekundærdiagnose der dette finnes.

SSB skal motta diagnosedataene fra NAV. Prosjektet får utlevert avidentifiserte data (anonym på forskers hånd). Videre kobling mellom registrene skjer som beskrevet i søknaden/prosjektbeskrivelsen og i tråd med konsesjon fra Datatilsynet av 2.12.2016. Koblingsnøkkel oppbevares av SSB som tiltrodd pseudonymforvalter. Datatilsynet har i melding av 31.1.2017 til prosjektet godkjent at primærdiagnose for trygdeytelse kan benyttes i prosjektet. REK midt har i vedtak av 13.6.2016 gitt dispensasjon fra taushetsplikten i relasjon til krav i helsepersonelloven.

Prosjektslutt er oppgitt til 31.12.2023.

Rettslig utgangspunkt
Det rettslige utgangspunktet for taushetsplikten er forvaltningsloven § 13, jf arbeids- og velferdsforvaltningsloven § 7 og lov om sosiale tjenester i NAV § 44.

Taushetsplikten er ikke til hinder for at opplysninger brukes når behovet for beskyttelse må anses ivaretatt ved at de gis i statistisk form eller at individualiserende kjennetegn utelates på annen måte, jf forvaltningsloven § 13a nr. 2.

For at det skal kunne gjøres unntak fra taushetsplikten i forbindelse med et forskningsprosjekt, må det foreligge et gyldig rettsgrunnlag. Dette innebærer enten gyldig samtykke fra de personene som er omfattet, jf forvaltningsloven § 13a nr 1, eller dispensasjon fra taushetsplikt til forskning, jf forvaltningsloven § 13d. Arbeids- og velferdsdirektoratet er delegert avgjørelsesmyndighet etter forvaltningsloven § 13d første ledd til å kunne dispensere fra taushetsplikten til forskningsformål for så vidt gjelder opplysninger i saker på vårt ansvarsområde.

Vurdering
Arbeids- og velferdsdirektoratet legger til grunn at opplysningene som skal innhentes dekker et stort antall personer, og at det ville være uforholdsmessig vanskelig å innhente samtykke fra disse. De omsøkte opplysningene skal avleveres avidentifisert til prosjektet, men på grunn av muligheter for identifiserbare forekomster er opplysningene underlagt taushetsplikt. Vi legger til grunn at prosjektet ikke kan gjennomføres som forutsatt dersom opplysningene gis i anonymisert form.

Opplysningene skal utleveres avidentifisert og i en størrelsesorden som tilsier at det er liten risiko for at enkeltpersoner kan identifiseres.

De opplysningene det søkes tilgang til, er relevante og nødvendige for å besvare prosjektets problemstillinger. Prosjektets resultater anses å ville ha samfunnsmessig betydning.

Arbeids- og velferdsdirektoratet er etter en helhetsvurdering kommet frem til at det er rimelig å gi slik dispensasjon som det er søkt om. Vi viser i den forbindelse til de tiltakene som er beskrevet i Datatilsynets konsesjon. Utleveringen av diagnosedata fra NAV anses ikke å ville utgjøre en uforholdsmessig ulempe for de personer som undersøkelsen er ment å omfatte, jf forvaltningsloven § 13d første ledd. Personvernhensyn antas derfor å være tilstrekkelig ivaretatt.

Vi gir derfor dispensasjon fra taushetsplikten under forutsetning av at følgende vilkår overholdes, jf forvaltningsloven § 13d annet ledd:

- Prosjektet gjennomføres i samsvar med prosjektbeskrivelsen og det gis kun dispensasjon for bruk i dette prosjektet av de diagnoseopplysninger innen NAVs område som det søkes om, med disse begrensningene:
    - Det gis bare tilgang til primærdiagnoser for trygdeytelser (med dato og år). Sekundærdiagnoser kan bare gis dersom Datatilsynet godkjenner det som innen rammen av konsesjonen.
    - For kontrollgruppen «hele Norges befolkning uten kreftdiagnose» skal prosjektet ikke ha noen diagnoseopplysninger fra NAV.
- Rapport eller annen publisering av undersøkelsen må ikke inneholde personidentifiserbare opplysninger. Vi legger til grunn at personantall under fem medfører fare for personidentifisering.
- Vilkårene i godkjenninger fra Datatilsynet og REK må overholdes.
- Det forutsettes at Statistisk sentralbyrå foretar en avidentifisering av opplysningene før de utleveres til forskningsprosjektet. SSB skal oppbevare koblingsnøkkelen og forskningsprosjektet skal ikke ha tilgang til denne.
- Det er en viss mulighet for at de avpersonifiserte opplysningene som utleveres kan identifisere enkeltpersoner, og søker og prosjektmedarbeidere i prosjektet er derfor pålagt taushetsplikt for opplysninger som er underlagt taushetsplikt etter arbeids- og velferdsforvaltningsloven § 7 og lov om sosiale tjenester i NAV § 44, jf forvaltningsloven § 13e.
- Søker må påse at opplysningene oppbevares slik at de ikke kommer uvedkommende i hende og alt materiale som ikke er anonymisert og der identifikasjon kan være mulig, må oppbevares innelåst eller tilsvarende elektronisk sikret.
- Personidentifiserbare data og koblingsnøkkelen slettes straks det ikke er lenger behov for dem og senest ved prosjektets avslutning.
- Utlevering av opplysninger og kostnader knyttet til utlevering og videre kobling bæres av prosjektet.

Dette vedtaket kan påklages innen 3 uker fra mottakelsen av brevet, jf forvaltningsloven § 29. Klagen fremsettes for Arbeids- og velferdsdirektoratet som forbereder klagesaken til Arbeids- og sosialdepartementet.

Med hilsen
Arbeids- og velferdsdirektoratet
Økonomi- og styringsavdelingen
Sikkerhetsseksjonen

Terje André Olsen
Seksjonssjef

Knut Brenne

Knut Brenne
Seniorrådgiver

Kopi: Statistikkseksjonen, Arbeids- og velferdsdirektoratet

Folkehelseinstituttet

LHL-klinikkene
Pb. 8766 Youngstorget
0184 OSLO

v/ Harald Engan

Deres ref.:	Vår ref.:	Dato:
	17/10132-63	12.12.2018

FØLGEBREV VED TILGJENGELIGGJØRING AV DATA TIL PROSJEKT "ARBEIDSDELTAGELSE VED KREFT" (PDB1970)

Folkehelseinstituttet viser til forespørsel datert 29.11.2018 om datafil med reelle datoer fra Kreftregisteret i prosjekt «Arbeidsdeltagelse ved kreft» (PDB 1970), samt følgebrev datert 3.7.2018 om tilgjengeliggjøring av data og tilhørende vilkår for dette prosjektet. Ved denne utleveringen utleveres datafil fra Kreftregisteret.

Datamateriale fra Kreftregisteret

- PDB1970_utlevert_des18_201812

Filen inneholder alle rader Reseptregisteret mottok fra Kreftregisteret. Hvert løpenummer er erstattet med et prosjektspesifikt løpenummer fra Reseptregisteret, kolonnen PasientLopeNr_PDB1970.

Prosjektets behandlingsgrunnlag

LHL-klinikkene har dokumentert lovlig grunnlag for behandling av særlige kategorier av personopplysninger i prosjektet, dokumentert ved Harald Engan i e-post datert 3.12.2018, i samsvar med personvernforordningen artikkel 6 og 9 og reglene om taushetsplikt:

- Personvernforordningen (GDPR) artikkel 6 nr.1 e
- Personvernforordningen (GDPR) artikkel 9 nr.2 j
- Nasjonalt supplerende rettsgrunnlag, jf. artikkel 6 nr.1 e og artikkel 9 nr. 2 j: Dispensasjon fra taushetsplikten fra REK, datert 13.6.2016 (ref.nr: 2016/830/REK midt).

LHL-klinikkene har dispensasjon fra taushetsplikten fra REK midt, (ref.nr2016/830/REK midt), vedtak datert 13.6.2016 for behandling av taushetsbelagte personopplysninger fra Norsk Pasientregister, Statistisk Sentralbyrå (FD-trygd), Kreftregisteret og Reseptregisteret i prosjektet.

Ansvarsbegrensning

Folkehelseinstituttet er ikke ansvarlig for tolkninger eller analyser av dataene som blir gjort av andre.

Fakturering

I henhold til forskrift om Reseptregisteret §5-5 kan Folkehelseinstituttet kreve dekket faktiske utgifter som påløper i forbindelse med behandling og tilrettelegging av opplysninger knyttet til konkrete oppdrag. Ved denne utleveringen leveres data kostnadsfritt.

Kontaktinformasjon

Reseptregisteret kan kontaktes per e-post reseptregister.data@fhi.no, telefon (21 07 70 00, FHIs sentralbord) eller brevpost (Folkehelseinstituttet, Reseptregisteret, Pb 222 Skøyen, 0213 OSLO).

Vennlig hilsen

Sissel Torheim

for Maj-Lis Baldersheim
Avdelingsdirektør

Sissel Marie Torheim
Seniorrådgiver

Appendix II. Participants interviewed

A short description of each participant follows.

“Anne” was the first to be interviewed. She was in her mid-forties, was married and had two daughters that were approaching their teens when she received her breast cancer diagnosis. Anne received chemotherapy and radiation therapies after surgery. She started to work before the treatment was finished and after being on sick leave for 12 months. Anne loved to work in her garden and to be with animals, where she gained energy. Before cancer, Anne worked as a senior advisor in a public office. Shortly after cancer, she decided to study and later she bought a store and became self-employed.

“Britt” was at the beginning of her thirties and establishing a family with her husband and a baby when she received the diagnosis with giant cell cancer. Britt received severe cancer treatment. She found energy by singing, painting, and participating in activities as a volunteer, which also later inspired her to study. Before cancer, Britt worked as a customer advisor in a retail shop but had to give up her previous position. During the 10 years that followed, she transformed her life and career toward marketing and management and had worked full time for many years when the interview took place.

“Carl” had reached his forties at the time of his kidney cancer diagnosis, and a few years after, he was also diagnosed with lymphatic cancer. His wife was pregnant at the time of the first diagnosis, and they were establishing a family. Carl’s family, friends, and colleagues became most vital for him during cancer treatment. Carl had a position as an executive in a large company. During treatment, he found it very helpful to participate in a vocational rehabilitation program. After his first diagnosis, Carl returned to work shortly after surgery, but the second time he was diagnosed he was on sick leave for some months after radiation therapy before he returned to full-time work. Carl still worked full time at the time of the interview.

“Daniel” was in his fifties when his brain tumor was diagnosed. Daniel had adult children and was very grateful toward his wife and his sister, who had been crucial for him in coping during and after cancer. He loved to cook meals for friends and family. At work, Daniel was the owner and manager of a company that had several employees. He explained how his company after cancer “fell like a rock” (financially) because nobody was able to step in and do the management job while he was on sick leave. Daniel managed to rebuild his company, even though his employees had to quit while he was away, and he was left alone as a consultant for the future business. Daniel had been working for several years at the time of the interview.

“Eva” was in the middle of her thirties and lived with her two daughters and husband when she was diagnosed with breast cancer. Eva was consciously utilizing cognitive coping strategies during treatment and had practice in dealing with fears from before. She was working as a teacher when diagnosed but wanted to move on and quit her previous job during cancer treatment. Eva started full-time in a new teaching position in another school while still recovering from chemotherapy treatment. Later, Eva continued moving on, and after some years had passed, she became a general manager in a larger company, which was Eva’s position at the time for the interview.

“Finn” was about 40 years of age, and lived with his wife and family when he was diagnosed with testicle cancer. Later, the diagnosis also showed that lymph nodes were involved. Finn struggled during treatment with severe late effects and called his experience a “terribly long journey”. It was so difficult that he found it hard to explain to his family. Nevertheless, he was determined to never give up returning to work and tried for many years to cope in his work as a craftsman, but finally had to change occupation because the work was too demanding. He experienced several periods on sick leave before he had to quit. He felt lucky when he could continue working as a janitor, was cancer-free, and had worked for several years in this position when he was interviewed.

“Grete” was about 40 years of age and was in the middle of a new education and a new job when diagnosed with breast cancer. She lived together with her spouse and their four-year-old daughter at that time. Grete was determined to return to work from the day of diagnosis, and consciously turned away from what brought negative energy. She worked in a private company as a receptionist, and during cancer treatment, her employer made it possible for her to perform tasks she could manage at her own pace and as a part-time job. Later, Grete increased her working hours gradually to full-time work and was promoted in the same company after finishing her new education.

“Henrik” had reached his thirties when he was diagnosed with leukemia. He was married and had two sons who were under 10 years of age. Some weeks before the cancer diagnosis, Henrik felt very ill and was on sick leave. At the time of diagnosis, he was shocked that it was cancer, but during treatment, he experienced a steady recovery. His interest in music and his closest family were crucial during recovery and the RTW process. Henrik experienced the RTW process as hard and started by working part-time. He increased his working hours gradually towards working full-time. At the time of the interview, Henrik was not cancer-free, but was well on medication and had worked full-time for several years.

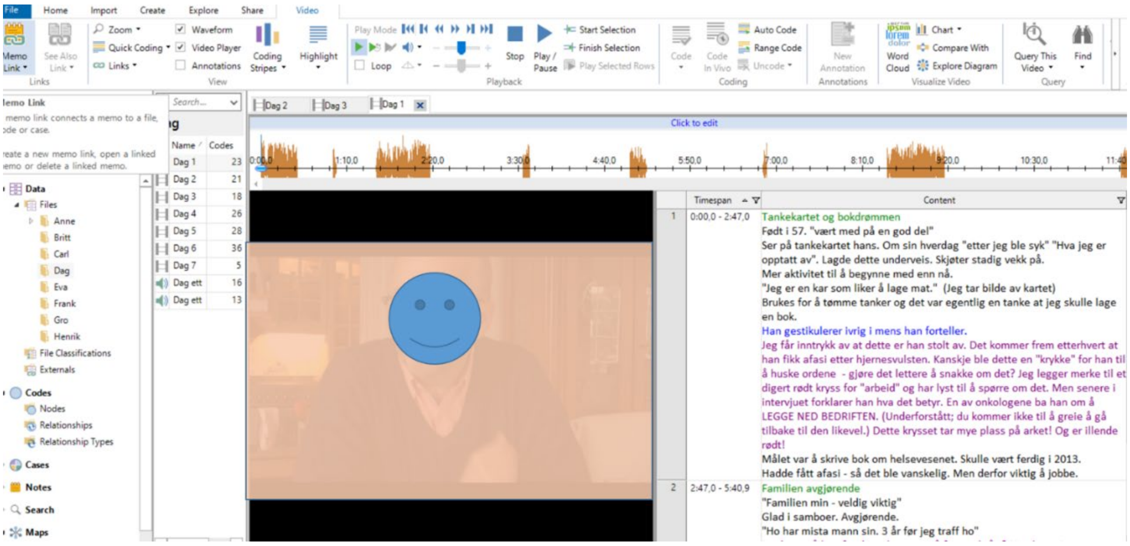
Appendix III. Interview schedule

Topics covered during the interview

Topic no.	**Headline of topic**	**Open questions (Bullet points: Topics covered. Detailed suggestions for questions are not listed here.)**
1	First question:	Would you please give me an overview of your working and medical situation and what happened during the time from the cancer diagnosis and until now?
2	Looking back, creating the timeline	• Family situation • Work at the time for diagnosis • Treatments and duration • Follow-up (medical) • What happened with the working situation
3	Deepening the treatment and return to work period	• Working situation • Contact employer, cooperation, adjustments • Influences work-health\health-work • Life quality and well-being • Turning points • Support (NAV, social-, health-, family, other) • Own characteristics in use (inner resources) • Protective factors • Environmental surroundings, descriptions
4	The present time	How are you now? • Working situation • Perceived health • Changes from before
5	The future	• Outlooks • Long-term influence after cancer • Expectations
6	2-5 minute break	(Introducing the final question (below). Time to think it over (in silence). The interviewer reads the topic guide to see if all is covered before the final question is answered.)
7	Final question:	Is there something more you would like to add, explain, pin-point, or tell others before we end this interview?

Appendix IV. Video-analysis

Due to large files containing video recordings, the interviews were split into parts, in this case, 7. Only pseudonyms were used in naming the participants, and the picture from the video shows the participant in the background. The pictures are blurred to keep anonymity. The video parts were divided into sequences according to upcoming themes. Most often, the heading was transformed into a theme, but sometimes the content in the sequence was coded into more than one theme. Every theme was stored as a "node" in NVivo, which later was used to build mind maps and coding trees. The video sequences were directly attached to all text, and each sequence could be run separately.

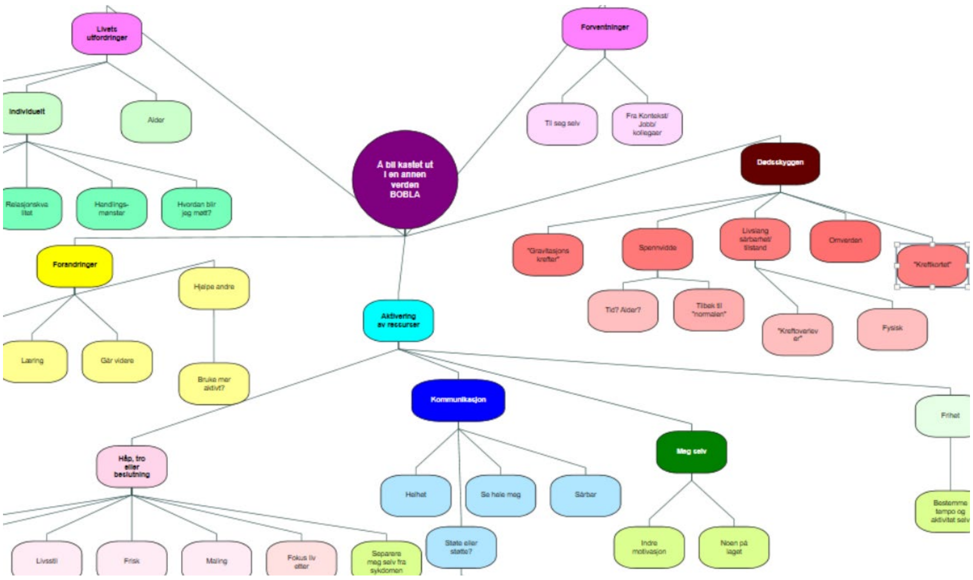


Name	Codes
Dag 1	23
Dag 2	21
Dag 3	18
Dag 4	26
Dag 5	28
Dag 6	36
Dag 7	5
Dag ett	16
Dag ett	13

	Timespan	Content
1	0:00,0 - 2:47,0	Tankekartet og bokdrømmen Født i 57. "vært med på en god del" Ser på tankekartet hans. Om sin hverdag "etter jeg ble syk" "Hva jeg er opptatt av". Lagde dette underveis. Skjøter stadig vekk på. Mer aktivitet til å begynne med enn nå. "Jeg er en kar som liker å lage mat." (Jeg tar bilde av kartet) Brukes for å tømme tanker og det var egentlig en tanke at jeg skulle lage en bok. Han gestikulerer ivrig i mens han forteller. Jeg får inntrykk av at dette er han stolt av. Det kommer frem etterhvert at han fikk afasi etter hjernesvulsten. Kanskje ble dette en "krykke" for han til å huske ordene - gjøre det lettere å snakke om det? Jeg legger merke til et digert rødt kryss for "arbeid" og har lyst til å spørre om det. Men senere i intervjuet forklarer han hva det betyr. En av onkologene ba han om å LEGGE NED BEDRIFTEN. (Underforstått; du kommer ikke til å greie å gå tilbake til den likevel.) Dette krysset tar mye plass på arket! Og er illende rødt! Målet var å skrive bok om helsevesenet. Skulle vært ferdig i 2013. Hadde fått afasi - så det ble vanskelig. Men derfor viktig å jobbe.
2	2:47,0 - 5:40,9	Familien avgjørende "Familien min - veldig viktig" Glad i samboer. Avgjørende. "Ho har mista mann sin. 3 år før jeg traff ho"

Colors in the text outlined the type of text. Green was used for headings/themes, and black was used for descriptions and for quotes. Blue was used to describe body language or intonation/cadences of voice. Lilac was used for the researcher's reflections and/or interpretations. The bar on the left in the picture shows the numbers of codes created for each part of the interview. The text in the sequence was after each interview coded into individual themes (named "nodes" in NVivo) for each participant. Similar themes were collapsed into super-ordinate themes for each participant, and a mind map was made as a result of the ideographic analysis. Carl's mind map is shown below. His story was called: "The journey to the world of death".

After all the cases were analyzed separately, a cross-case pattern was visualized using mind maps. The patterns were discussed with co-researchers as well as the advisory team. The abstracted and overall super-ordinate theme was never changed: “Being thrown into the world of cancer”.



Appendix V. The group contract

GRUPPE-KONTRAKT

RÅDGIVNINGSGRUPPE ARBEIDSLIV OG KREFTBEHANDLING I ET LANGTIDSPERSPEKTIV

2015 - 2018

1. Det overordnede målet med dette gruppearbeidet er å sikre kvalitet og fremskaffe ny viten gjennom prosjektet - som kan komme mange til nytte senere.

2. Vi ønsker å arbeide sammen for dette målet med høy etisk standard - der respekt, verdighet, åpenhet, trygghet, nysgjerrighet, ærlighet og vennlighet gjennomsyrer vår måte å være på overfor hverandre.

3. Vi ønsker å være positivt nysgjerrige på hverandres erfaringer og kunnskap slik at alle deltakere i gruppen får mulighet til å komme til med sine tanker og meninger.

4. Informasjon som blir delt og som har personlig karakter, skal eventuelt refereres anonymt i prosjektmaterialet og anses konfidensielt innenfor gruppen. Dersom noe blir delt i felleskap og som ikke ønskes referert på noen som helst måte – ei heller anonymt - er det helt i orden å reservere seg mot det ved å gi beskjed der og da.

5. Gruppemøter eller deler av disse, kan på anmodning tas opp med lyd. Dette for å gi prosjektleder mulighet til å gå tilbake å høre detaljer i samtalene på nytt. Opptakene overføres sikret område på HBV-server og slettes ved prosjektavslutning.

6. Dersom vi opplever noe som problematisk, utfordrende eller dårlig håndtert i gruppen underveis, skal det være rom og takhøyde for å snakke om dette for å finne en felles og god løsning.

7. Deltakelse i oppsatte møter er ønskelig – men frivillig. Alle har et ansvar for å dele sin kunnskap og erfaring i henhold til agenda, enten det skjer ved oppmøte eller på annen måte.

8. Vi starter og avslutter med noen minutter refleksjon i alle møter.

9. Denne gruppe-kontrakten kan til enhver tid endres ved konsensus ut fra nye innspill

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Sustainable work after cancer
Exploring long-term journeys from
a salutogenic perspective
Birgit Brusletto

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