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Let's work it out

- **Aspects of the occupational situation of survivors of allogeneic haematopoietic stem cell transplantation**

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Let's work it out – Aspects of the occupational situation of survivors of allogeneic haematopoietic stem cell transplantation

THESIS FOR DOCTORAL DEGREE (PH.D.)

By

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I dedicate this thesis to everyone who is now enduring, about to endure or has endured an allogeneic haematopoietic stem cell transplantation.

In loving memory of my father Leif, who opened my eyes to the struggles patients face within the world of haematology

POPULAR SCIENCE SUMMARY OF THE THESIS

In 2020, around 7 million people in Europe were living with a cancer diagnosis and over 2.3 million people are diagnosed with cancer every year. Many will suddenly be diagnosed at a relatively young age, which can cause massive disruptions in all areas of life. For people who are working, a cancer diagnosis often leads to long bouts of sick leave, resulting in feelings of concern and worry regarding the effect cancer will have on their work situation, both in the short term, but also in the future.

For people who are diagnosed with a serious life-threatening blood cancer, such as acute leukaemia, an allogeneic stem cell transplantation (allo-SCT) may be the only alternative to a cure. For this type of transplantation, stem cells from a healthy donor are transferred to a patient's body via the blood circulatory system with the hope that the new stem cells will cure the disease by replacing the cancer cells with healthy cells. Before the allo-SCT, patients are treated with high doses of chemotherapy that will weaken their immune system and lead to many side effects, such as dangerous infections, extreme tiredness and graft-versus-host disease (GvH), where cells from the donor view the healthy cells in the patient as foreign and start attacking the patient's tissue and organs. Patients undergoing allo-SCT will have all aspects of their everyday lives affected due to difficult side effects that often last several years, including their working life. For most people, work is an important aspect in life as it provides a purpose and feelings of belonging. For many patients diagnosed with cancer, returning to work after treatment is one of their main goals as it is often considered as a sign of recovery, along with providing normality and control back in their lives.

Against this background, the aim of this thesis was to explore the work situation of allo-SCT patients, including different factors' potential impact on their work situation. In Study **I** and **II**, we explored patients' sick leave status one year after allo-SCT and whether demographic aspects (gender age, education and living situation), GvH and physical activity affected their sick leave situation. In Study **III**, we investigated whether the patients had returned to work two years after allo-SCT and potential factors that either prevented or enabled them returning to work. In the last study, Study **IV**, we interviewed patients about their experiences of being on long-term sick leave and how they experienced the process of returning to work.

We found that over three quarter of patients were still on sick leave one year after allo-SCT with 39% stating that they were on sick leave full time. Patients who suffered from chronic GvH, depression, who had a low physical activity level and who experienced many distressing symptoms were more likely to be on full-time sick leave one year after allo-SCT. Two years after allo-SCT, 60% of the patients had returned to work at least 50% of a full-time position and those who had a college or university degree, along with patients who did not suffer from chronic GvH, were more likely to be working. Interestingly, when statistically analysing work-related factors, such as being able to decide when to work and/or being able to work from home if feeling unwell, there was no increase in the likelihood of being back at work two years after treatment. However, in the interviews, on an individual level, many

patients did describe that being able to work flexible hours and having the ability to work from home made it easier for them to return to work. Having the opportunity to work more flexibly meant that they could adapt to their new life and work situation, including managing their side effects better.

The findings in this thesis provide an increased understanding of both the sick leave and return-to-work situation of patients who have gone through an intense allo-SCT. This is important information for the improvement of care in this patient group and can help guide healthcare workers, patients and employers to better support these patients during their recovery. This increased knowledge and understanding will hopefully lead to improvements and/or implementation of educational and occupational rehabilitation programmes that can support allo-SCT patients in reaching their goals of returning to work.

ABSTRACT

Background: Work is an important part of life and contributes to an individual's physical and mental well-being. Being diagnosed with a life-threatening haematological disease that requires an allogeneic haematopoietic stem cell transplantation (allo-HSCT) disrupts patients' occupational situation as most end up on long-term sick leave. During recent decades, overall survival has improved and transplant-related mortality has decreased due to advances in transplantation procedures and supportive care. The treatment is nevertheless intense, and many survivors end up with long-lasting late effects that negatively affect their health, quality of life and return-to-work process. However, the scientific knowledge regarding the occupational situation of allo-HSCT survivors is limited.

Aim: The overarching aim of this thesis was to increase knowledge and gain a deeper understanding by exploring the occupational situation of allo-HSCT survivors with special focus on factors associated with sick leave and return to work.

Methods: Both quantitative and qualitative research approaches were used. Participants of working age were recruited upon admission to the allo-HSCT unit and asked to complete questionnaires at six different data collection time points up to three years after allo-HSCT. In studies **I – III**, descriptive statistics and logistic regression analyses were used to analyse self-reported questionnaire data together with data collected from the participants' medical records and potential associations with self-reported data on sick leave and return to work (Study **I**, n=189; Study **II**, n=122; Study **III**, n=104). Study **IV** had a qualitative approach where 15 participants from the larger study sample who were working full time prior to diagnosis and were still on some level of sick leave three years after allo-HSCT, participated in semi-structured interviews three to six years after allo-HSCT. The findings were analysed using qualitative content analysis.

Findings: One year after allo-HSCT, 76% of participants were still on sick leave, of whom 39% were on full-time sick leave. In univariate logistic regression analyses, factors that were found to be significantly associated with sick leave were presence of chronic graft-versus-host disease (cGvHD) one year post-transplantation, a high symptom burden and low physical activity 4 months post-treatment as well as symptoms of depression and low vocational satisfaction 7 months after allo-HSCT. All except vocational satisfaction remained significant in multivariable analyses. One year after allo-HSCT, 28% of participants had returned to work >50%, which increased to 60% two years post-treatment. In univariate analyses, factors significantly associated with return to work >50% were higher education and not being diagnosed with cGvHD with the latter being the only factor remaining significant in multivariable analysis. Work-related factors, such as being able to work from home, flexible working hours, being part of decision-making regarding work, were also analysed for potential associations but none were found. However, in the qualitative study (**IV**), different individual work-related factors were identified with flexibility in working schedules and opportunities to work from home emerging as key components. Participants also described how an affected health

due to late effects, such as fatigue, medical consequences and stress intolerance, had a negative impact on both their return-to-work process and life in general.

Conclusion:

This thesis contributes to an increased awareness and a deeper understanding of the occupational situation of allo-HSCT survivors in the first six years following transplantation along with factors influencing their occupational situation. Results indicate that allo-HSCT survivors often face long-term sick leave and that return to work is a lengthy process in which health status and psychosocial factors appear to play a greater role than work-related factors. Qualitative findings suggest that, on an individual basis, flexible working conditions, particularly in terms of time, place and assignments, were considered facilitating factors in the return-to-work process. Supporting allo-HSCT survivors through person-centred rehabilitation, including physical, mental and occupational aspects, is essential in order for both the healthcare system and employers to provide support in allo-HSCT survivors' return-to-work process.

LIST OF SCIENTIFIC PAPERS

- I.** Eriksson LV, Holmberg K, Lundh Hagelin C, Wengström Y, Bergkvist K, Winterling J. Symptom Burden and Recovery in the First Year After Allogeneic Hematopoietic Stem Cell Transplantation. *Cancer Nurs.* 2022.
- II.** Eriksson L, Wennman-Larsen A, Bergkvist K, Ljungman P, Winterling J. Important factors associated with sick leave after allogeneic haematopoietic stem cell transplantation – a 1-year prospective study. *Journal of cancer survivorship: research and practice.* 2021;15(6):933-941.
- III.** Eriksson L, Wennman-Larsen A, Bergkvist K, Ljungman P, Winterling J. Return to work after allogeneic haematopoietic stem cell transplantation – a two-year prospective study. *In manuscript.* 2022.
- IV.** Eriksson L, Bergkvist K, Wennman-Larsen A, Ljungman P, Winterling J. Experiences of the return-to-work process after allogeneic haematopoietic stem cell transplantation. *In manuscript.* 2022.

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LIST OF ABBREVIATIONS

Allo-HSCT	Allogeneic haematopoietic stem cell transplantation
cGvHD	chronic graft-versus-host disease
CI	Confidence interval
OR	Odds ratio

1 PREFACE

“Four hours of work, that is my limit. My brain starts slowing down, everything feels difficult, I get quite angry. I see things in darkness. Everything feels difficult and heavy. I get edgy towards people surrounding me, unkind. I get tired and finally, I just get like, ‘I need to get out of here’, go into a dark room and go to bed. I have had to learn that if I keep to my four hours, then I can work as I did before.”

The above quotation illustrates the struggles of a woman when returning to work after having been on long-term sick leave for three years due to an allogeneic haematopoietic stem cell transplantation (allo-HSCT). Many anecdotes from my working life as a registered nurse in various haematology settings correspond with the above quotation, as countless patients shared their worry with me about the consequences of being on sick leave and the process of returning to work. “Will I be able to go back to work?”, “Will I be able to work like I did before my diagnosis?” and “When do you think I can go back to work?” are questions I have been asked numerous times by patients undergoing intense chemotherapy regimens for haematological diseases. I have always understood their worry, as work is an important part of peoples’ lives. Work gives a sense of direction, social inclusion and often plays an essential role in both physical and mental well-being.

Allo-HSCT is a particularly intense treatment and the road to recovery is long and often accompanied by both physical and mental complications. Patients are mainly of working age and are forced to go on sick leave for long periods of time, both due to the severe treatment and the side effects, such as susceptibility to infections, as well as physical and mental limitations. Patients have often told me how much they miss working and how they view their return to work as a milestone, a sign of complete recovery and a return to “normal life”.

As a registered nurse with a degree in Psychology, psychosocial care has always interested me, and therefore I have enjoyed my many conversations with patients regarding their life and work situation whilst undergoing difficult treatments. These conversations ignited my curiosity, which led me down the path of wanting to explore how to best support these individuals in difficult times and encourage them to look ahead to a good quality of life after illness. My hope is that the findings in this thesis will do just that by supporting and helping allo-HSCT survivors to return to a good quality of life, including a successful return to work.

2 BACKGROUND

2.1 CANCER AND OCCUPATIONAL SITUATION

The number of cancer survivors is increasing due to several factors, including an aging and growing population and advances in the early detection and treatment of cancer.¹⁻³ Over half of all cancer patients are diagnosed between the ages of 15 and 64 years,⁴ an age when employment is a major part of most peoples' lives. As many countries are increasing the retirement age due to prolonged life expectancy, the number of cancer patients of working age has increased even further, as over half of all patients receive their cancer diagnosis between the ages of 15 – 69 years.⁴ As of 2020, the number of new cases diagnosed in Europe between the ages of 15 – 69 years was estimated to 2.3 million and the estimated five-year prevalence in the same age group was 7 million.⁴ Hence, there is a growing number of cancer survivors who are on sick leave and subsequently in the return-to-work process. However, surviving cancer does not always mean a return to life as it was before the cancer diagnosis, as both long-term and chronic complications can arise, which may have implications for the ability to work.

Studies into sick leave in the general population show that people who are on sick leave for longer periods of time often experience negative impacts on areas such as health, work, social relationships and financial situation,⁵⁻⁹ as well as changes in self-image, feelings of exclusion and social stigma.^{7,8,10-12} Being on sick leave is common among cancer survivors, as many struggle with their occupational situation due to their cancer diagnosis and/or cancer treatment,¹³ and research regarding cancer survivors' occupational situation has shown that they are at an increased risk of unemployment, early retirement and reduced re-employment compared to healthy controls.^{14,15}

Once the full-time sick leave period is over, the return-to-work process begins, which can be long and arduous for cancer survivors.¹⁶ However, return to work is important both for the individual and for society and being able to work is often essential for peoples' identity and studies have shown that cancer survivors are motivated to return to work.¹⁷ It can provide a sense of normality and control, as survivors feel they are on the road to recovery.¹⁸⁻²⁰ In addition, the financial burden due to sick leave, both for the individual and for society, will be reduced if and when survivors return to work.^{2,21}

There are several factors that can affect the return-to-work process for cancer survivors. Female gender, older age, lower socioeconomic status and educational level, poorer health and worse physical functioning affect return to work negatively,^{3,22,23} along with more physically demanding work tasks.²⁴ The type of treatment has also been found to affect return to work. Cancer survivors treated with chemotherapy report more difficulties in the return-to-work process and also experience a significantly longer period of sick leave.²⁵⁻²⁷ For instance, in a study on breast cancer survivors, time to return to work went from an average of seven months to just under 15 months for patients who had received chemotherapy compared to other treatments such as radiation, hormonal therapy and mastectomy.²⁶

2.2 ALLOGENEIC HAEMATOPOIETIC STEM CELL TRANSPLANTATION

Allo-HSCT is a procedure where healthy haematopoietic stem cells from a donor are infused to a recipient to replace stem cells that are defective from the underlying disease or treatment in the hope that the recipient will recover the ability to produce their own healthy haematopoietic stem cells.²⁸ Prior to allo-HSCT, patients receive chemotherapy and/or radiation therapy in order to suppress their underlying malignancy and facilitate the engraftment of the new stem cells.²⁹

The first allo-HSCT was performed in 1957 with an unsuccessful outcome, but over the last 50 years the treatment has evolved from a highly experimental technique to a standard treatment for several different diseases.^{30,31} Today, allo-HSCT is an established form of treatment for various haematological malignancies and non-malignant diseases.³¹ Overall survival has improved and transplant-related mortality has decreased significantly in recent decades due to advances in transplantation procedures and supportive care.³² The number of transplants performed yearly is increasing and in 2018, over 17,000 allo-HSCTs were performed in Europe alone.³³ With transplantation being an option for many different diseases and the improving survival rate, the number of long-term survivors is steadily increasing and now approaching half a million worldwide.³⁴ It is estimated that 80 – 90 % of patients who remain in remission for two years after the transplantation will survive for >10 years.^{35,36}

Despite advances in transplantation techniques and subsequent care, allo-HSCT is an intensive procedure associated with many risks, especially involving the immune system, which can be unpredictable and difficult to manage. Graft-versus-host disease (GvHD) is an immune reaction after allo-HSCT caused by the donated haematopoietic stem cells recognising the recipient's cells as foreign, leading to an immune response against the recipient's tissue and organs.²⁹ The first phase of this immune response, acute GvHD, causes varying degrees of direct tissue damage and generally manifests in a set of organs (i.e., skin, liver and gastrointestinal tract).²⁹ The second phase, chronic GvHD (cGvHD), tends to be more delayed in its presentation and involves a broader set of organs that can bear strong resemblances to autoimmune disorders.²⁹ cGvHD is the most common late complication in allo-HSCT affecting between 20 – 65% of survivors³⁷⁻⁴² and associated with higher transplantation related mortality rates.⁴³ However, cGvHD is not only a negative complication. It is also associated with a strong graft-versus-leukaemia effect that reduces the risk of relapse after transplantation as the donor's stem cells identify and destroy remaining malignant cells in the recipient.⁴⁴ It is therefore important to manage cGvHD appropriately, as severe cGvHD increases mortality while the lack of cGvHD can increase the risk of relapse.⁴⁵

2.3 ALLOGENEIC HAEMATOPOIETIC STEM CELL TRANSPLANTATION AND SURVIVORSHIP

Despite the advances in allo-HSCT, many survivors report disease and treatment-related difficulties, in addition to a constant fear of relapse, during the different phases of the trans-

plantation process and subsequent rehabilitation, which negatively affect their general health and quality of life.^{22,46,47}

Allo-HSCT can lead to chronic health conditions in the aftermath of the transplantation. The cumulative incidence of chronic health conditions (e.g., cardiopulmonary compromise, musculoskeletal disorders, endocrine complications, subsequent malignancies) in allo-HSCT survivors is 64% 10 years after the transplantation and approaches 71% 15 years post-allo-HSCT.⁴⁸ Despite chronic health conditions, quality of life is not always adversely affected as studies suggest that more than 60% of allo-HSCT survivors report good to excellent quality of life,^{49,50} perhaps due to many of the chronic health conditions being relatively mild and easily controlled. The onset of a chronic health condition or GvHD after allo-HSCT can however add additional symptoms that could seriously threaten patients' health.^{48,49} Therefore, an essential part of caring for allo-HSCT patients is to identify signs of GvHD, infection and other deterioration or symptoms in the patient and subsequently manage them.

Symptoms can occur alone, but more commonly, multiple symptoms occur simultaneously and the concurrence of several symptoms is more likely to result in multiplicative experiences, rather than additive, with symptoms catalysing each other.⁵¹ Symptoms are also described as multidimensional stating that although symptoms differ from one another, they share several dimensions, including intensity, distress, timing and quality. This multidimensional, subjective symptom experience can negatively affect a person's performance in relation to functional activities, such as health status and role performance, including work.⁵¹ Accordingly, symptom burden has been defined as an overall concept that can be described as the sum of several symptoms' occurrence, intensity and distress experienced and reported by patients.⁵² Despite allo-HSCT survivors' relatively high quality of life scores,⁵³ previous research has found that patients experience physical and/or emotional distress during and after allo-HSCT with reports of a high symptom burden and a considerable drop in well-being.⁵⁴ Patients often experience different symptoms during treatment that affect several areas of their life.⁵⁵ For many allo-HSCT survivors, their impaired condition is temporary and often improve within the first year of treatment⁵⁶⁻⁵⁸ but some symptoms can persist over time, such as fatigue and emotional distress.^{53,59,60}

Due to the psychological challenges associated with allo-HSCT, patients can be at risk of experiencing anxiety and depression.⁶¹⁻⁶⁵ Among both autologous and allo-HSCT survivors, it has been reported that those who perceived the consequences of their cancer to be more serious experienced greater depression and anxiety, less well-being and were less physically active during the year following the transplant, while patients with a better understanding of their cancer reported less anxiety and depression, as well as greater well-being.⁶⁶

2.4 ALLOGENEIC HAEMATOPOIETIC STEM CELL TRANSPLANTATION AND OCCUPATIONAL SITUATION

Knowledge about long-term survivorship for patients treated with allo-HSCT is becoming more important as the number of transplantations and survival rates are increasing. Hence,

there are more survivors re-entering the labour market, especially as many patients undergoing allo-SCT are under the age of 65 years.

Due to the severity of the treatment and subsequent side effects, most allo-HSCT survivors are on sick leave both during the early neutropenic phase when in isolation at the transplantation unit as well as at later stages as an outpatient. A qualitative study on HSCT survivors indicated that patients value work as important and are motivated to return to work,⁶⁷ and research has shown that one year after allo-HSCT, 52% of survivors had returned to work (part-time or full-time unknown).⁶⁸ Moreover, three years after HSCT (autologous or allogeneic unknown), 59% of patients had returned to work full time⁶⁹ and eight years after allo-HSCT, 57% of survivors were back in full-time work or equivalent.²² Hence, the proportion of allo-HSCT survivors not returning to work remains quite large in the years following transplantation.

Return to work is often a key milestone on the long road to recovery considering that it is associated with improved general well-being and a higher quality of life^{70,71} as it represents a return to normality,^{19,69,71} a chance to feel useful and valued again,¹⁹ as well as providing an opportunity to focus the mind on things other than recovery from treatment,²⁰ all of which were shown to be important factors in other groups of cancer survivors.

Surviving allo-HSCT, however, does not always mean a return to normality as both disease and treatment-related complications can lead to negative consequences, including problems associated with return to work. Studies indicate that being off work is associated with higher ratings of fatigue and pain, as well as lower ratings of quality of life⁷⁰ and life satisfaction in allo-HSCT survivors.⁷² Patients treated with autologous HSCT who were not employed 10 years after treatment also had significantly higher levels of mental distress and fatigue, and significantly lower levels of quality of life compared to those who were employed.⁷³

Several factors can affect allo-HSCT survivors' possibilities of returning to work. Females are less likely to return to work than males,²³ while older age and worse physical functioning also make a return to work less likely.²² Moreover, patients suffering from medical complications are more likely to be on long-term sick leave^{16,23} and fatigue six months after treatment has been found to prolong sick leave.⁷⁴ cGvHD may also influence return to work as the proportion of allo-HSCT survivors returning to work was significantly lower among those with cGvHD compared to those without the condition.^{48,69} In addition, patients with a haematological malignancy who showed symptoms of anxiety were less likely to return to work.⁷⁵

Satisfaction with one's vocational and financial situation may also influence return to work after sick leave. Almost half of allo-HSCT survivors report adverse financial consequences after the transplantation⁷⁶ and earlier studies on non-haematological patients indicate that low satisfaction with one's vocational situation,⁷⁷⁻⁸¹ as well as financial situation,⁸² is associated with non-return to work.

One aspect that is important to consider regarding allo-HSCT survivors' return to work is the degree to which employees have the ability to adjust their working conditions to their present

health status. Adjustment latitude is a concept that can be used to study this dimension of return to work.⁸³ In breast cancer patients, a study has shown that work-related factors, such as physical, psychological and organisational occupational restraints limited return to work.²⁶ In addition, breast cancer survivors' return to work was delayed when they perceived a lack of moral support from work colleagues,²⁶ while a perceived facilitator of return to work among HSCT survivors was remaining in contact with the workplace during their illness and treatment.⁶⁷

The research area of allo-HSCT survivors and their occupational situation has gained more attention in recent years, but there are still relatively few studies that focus solely on allo-HSCT, especially in terms of sick leave. The existing studies on allo-HSCT survivors' occupational situation focus mainly on return to work, especially after treatment.^{16,23,67,69} There is hardly any information available regarding how allo-HSCT survivors experience the return-to-work process, i.e., what facilitators and barriers they encounter. Several studies also combine, rather than distinguish between, results from autologous and allo-HSCT patients,^{16,23,70} which is not ideal as the different types of treatment methods and medical complications can vary greatly depending on the type of transplantation. Consequently, there is a need for longitudinal and prospective studies focusing exclusively on allo-HSCT survivors and their occupational situation, both in relation to sick leave and return to work, including experienced facilitators and barriers.

2.5 CONCEPTUAL FRAMEWORK

There are several relevant perspectives on cancer survivorship and occupational situation. A framework that conceptualises the different factors involved in the return-to-work process for cancer survivors is beneficial for both facilitating research in the area and serving as a guide for enabling healthcare workers to identify problem areas during the patients' return-to-work process.

To better understand cancer-related issues and their importance for employment, Mehnert developed a model for the investigation of work-related aspects in cancer survivorship.¹⁴ The model is based on a systematic review of 64 studies on return to work and employment in cancer survivors, where the majority of the studies focused on women with breast cancer or mixed cancer populations,¹⁴ and includes a range of factors and criteria, presented in Figure 1, that can guide research on cancer survivors' occupational situation.

Following a cancer diagnosis, the model describes disease specific and treatment-related factors as independent variables. The systematic review then identified several mediating variables related to six different categories: (1) demographic factors; (2) impairments and health related factors; (3) psychosocial factors; (4) motivational factors; (5) work related factors; and (6) work related interventions. Outcome criteria consist of different variables related to three different areas: work related outcomes, psychosocial outcomes and economic outcomes.¹⁴

Mehnert's model was developed for cancer survivors with a broad spectrum of cancer diagnoses and treatments, and allo-HSCT survivors will most likely experience many factors in the same way as other patient groups. However, as the allo-HSCT procedure differs in its intensity and potential side effects from many other types of cancer treatments, there might be other important factors relevant to allo-HSCT survivors and their occupational situation, or other directions in the relationships between the different aspects. Hence, there is a need for research that follows the same guidelines as research in the general cancer population but with a sole focus on allo-HSCT survivors.

This thesis covers several different factors and variables mentioned in Mehnert's model but mainly focuses on the following areas in the mediator variables section described in the model:

- Demographic factors, i.e., age, gender, living situation and education.
- Impairments and health related factors, i.e., exploration of symptom occurrence and symptom distress.
- Psychosocial factors, i.e., anxiety and depression.
- Motivational factors, i.e., work satisfaction and meaning of work.
- Work-related factors, i.e., work environment and employer accommodation.

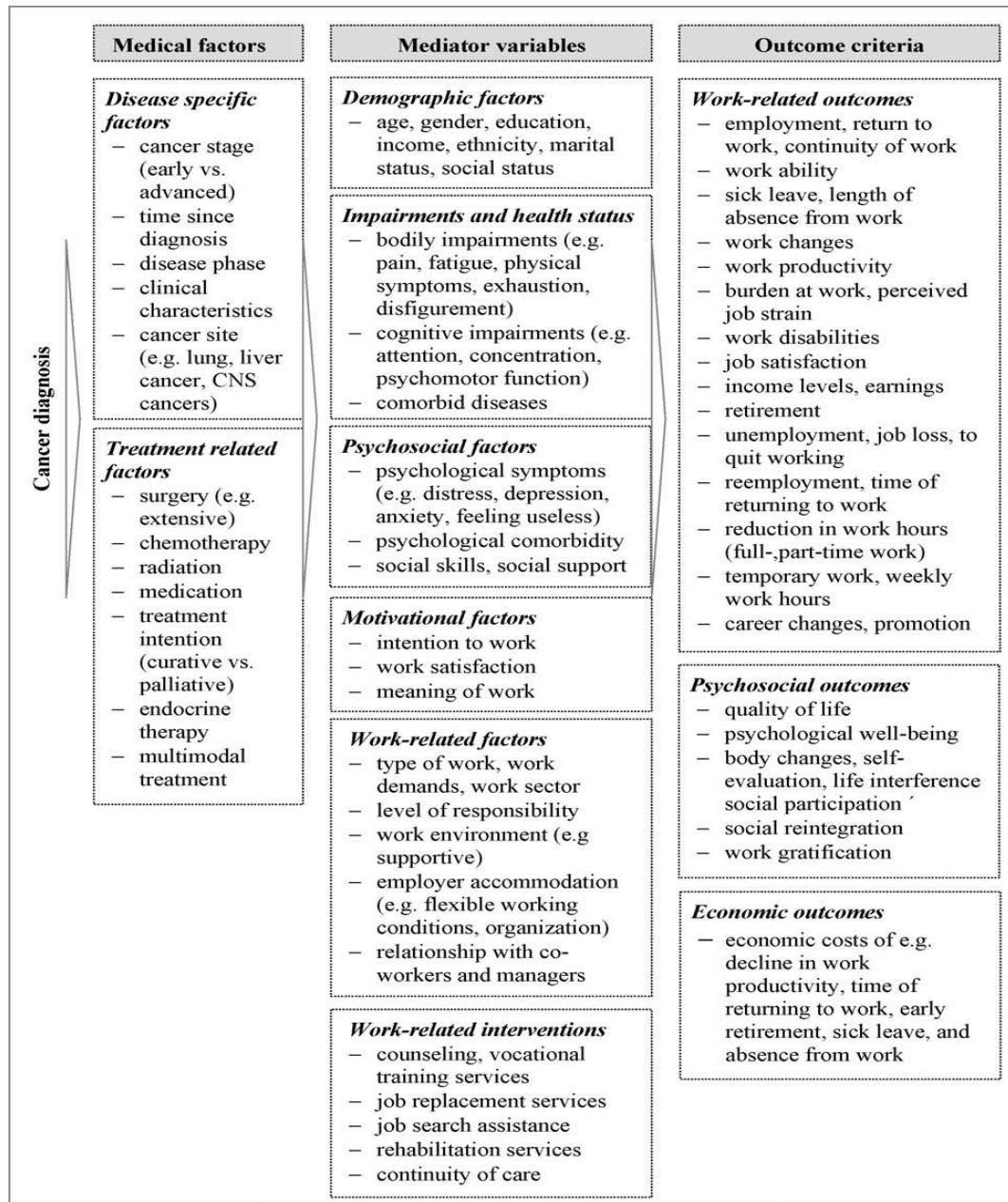
Medical factors explored in this thesis are diagnosis, conditioning treatment, total body irradiation, cGvHD and relapse.

It is important to bear in mind that the present research was conducted in a Swedish context. In Sweden, the Social Insurance Agency administers the national social insurance that provides financial security in the event of illness and disability. All individuals with an income from work, unemployment benefits, studies, or parental leave benefits are covered by social insurance and qualifies for sickness benefits if unable to work due to disease or injury that reduces their work ability by at least 25%. The levels of compensation can be full time or part time at 25, 50, and 75% of regular working hours depending on the reduction in work ability, covering approximately 80% of lost income up to a certain level. The first day of sick leave is a compensation free day and thereafter, the employer provides sick pay for the first 14 days. A medical certificate is required from a physician after day eight and if reduction in work ability remains after this period, the employee receives sickness benefits from the national social insurance system. If reduction of work ability remains after this period, the employee receives sickness benefits from the national social insurance system. If sickness benefits are still required after 364 days, individuals need to reapply, at which point the level of benefit is reassessed based on the illness and may be reduced to approximately 75% of lost income. Upon return to work, individuals are required to work a certain number of hours each day to compensate for the percentage by which their sick leave has been reduced, i.e., for someone who is on 50% sick leave, the system requires them to work four hours a day, five days a week, totalling 20 hours of a 40-hour full-time working week. If someone of working age is incapable of returning to work due to chronic illness or disability, the compensation will take the form of disability pension.⁸⁴ The differences between various countries' social security

systems might influence which factors are of importance, which should be borne in mind when investigating cancer survivors' occupational situation.

Using Mehnert's model as a conceptual framework has guided the decisions regarding which factors to investigate in this thesis. The model deepens the understanding of how several factors affect the occupational situation of allo-HSCT survivors and how the different factors may potentially interact with each other. As seen in the model, it is necessary to consider all areas in order to understand the underlying issues related to an individual's occupational situation and to support them in the return-to-work process. An individual may, for example, suffer from very debilitating symptoms and/or late effects from the transplantation, making it difficult to return to work despite functioning well in relation to psychosocial and motivational factors. This demonstrates the importance of taking all areas into consideration due to the interaction between them.

Figure 1. Mehnert’s model including medical factors and mediator variables along with outcome criteria related to research about work in cancer survivorship.



Note: Independent, mediating factors and outcome criteria related to research about work in cancer survivorship. Reprinted from “Employment and work-related issues in cancer survivors, by A. Mehnert, 2011, *Critical Reviews in Oncology/Hematology*, 77(2), p. 126. Copyright 2011 by Elsevier. Reprinted with permission.

By applying Mehnert’s research model for employment in cancer survivors as a conceptual framework, the goal is to achieve an increased and deepened understanding of the occupational situation of allo-HSCT survivors with the intention of improving their rehabilitation to include the support they need regarding their occupational situation.

3 RATIONALE OF THIS THESIS

The total number of adult patients undergoing allo-HSCT and becoming long-term survivors is growing. Allo-HSCT is an intensive treatment and survivors often end up with long-lasting adverse treatment effects and challenging symptoms affecting several aspects of their daily lives, and the impact of these effects and symptoms on their occupational situation is largely unknown. For those of working age who survive the treatment, return to gainful employment after full-time sick leave during the most intensive phase of the treatment is an essential factor for well-being. However, scientific knowledge about the occupational situation among survivors of allo-HSCT is limited, resulting in a lack of valuable information for healthcare professionals on how to best support allo-HSCT survivors.

Research into return to work after allo-HSCT has increased during recent years. However, many studies include different types of haematological diagnoses with few solely focusing on allo-HSCT survivors but instead combine autologous and allo-HSCT participants or individuals diagnosed with other forms of cancer. In addition, most studies that exist have a quantitative approach and there are few qualitative studies exploring the impact of allo-HSCT survivors' experiences of their occupational situation.

To achieve an increased understanding of patients' recovery in relation to their occupational situation after allo-HSCT, several aspects need to be investigated, both quantitatively and qualitatively. Identifying allo-HSCT survivors at risk of long-term sick leave and/or an unsuccessful return to work may help to improve rehabilitation and increase their quality of life, including their occupational situation.

4 RESEARCH AIMS

The overarching aim of this thesis was to increase knowledge and gain a deeper understanding by exploring the occupational situation of allo-HSCT survivors. This included a special focus on factors associated with sick leave and return to work.

The specific aims of the four studies included in this thesis were:

- I.** To examine self-reported symptom burden in the first year after allo-HSCT and whether a high symptom burden four months after allo-HSCT predicts recovery, i.e., general health and sick leave, one year after transplantation.
- II.** To examine sick leave one year after allo-HSCT and its association with demographic, medical, and psychological factors, together with vocational and financial satisfaction.
- III.** To examine return to work and investigate the associations between medical, demographic and work-related factors and return to work two years after allo-HSCT among those who were employed before diagnosis.
- IV.** To describe experiences of the return-to-work process among allo-HSCT survivors on long-term sick leave, i.e., for a period longer than three continuous years after treatment.

5 METHODS

5.1 DESIGN

Two different methodological approaches were chosen in an effort to achieve a broad understanding of allo-HSCT survivors' occupational situation. This thesis contains four studies, three of which were based on a quantitative, prospective and longitudinal research design approach (studies **I-III**) and one with a descriptive qualitative research design (Study **IV**). Participants were assessed at baseline (on admission to the allo-HSCT unit), at four, seven, 13 months and at two and three years post-allo-HSCT as well as being interviewed between three and six years after treatment. An overview of the studies is presented in Table 1.

Table 1. Overview of studies included in the thesis

	Study I	Study II	Study III	Study IV
Study aim	To examine self-reported symptom burden in the first year after allo-HSCT & whether a high symptom burden four months after allo-HSCT predicts recovery, i.e., general health & sick leave one year after transplantation.	To examine sick leave one year after allo-HSCT & its associations with demographic, medical, and psychological factors, together with vocational & financial satisfaction.	To examine return to work & investigate the associations between medical, demographic and work-related factors & return to work two years after allo-HSCT among those who were employed before diagnosis.	To describe experiences of the return-to-work process among allo-HSCT survivors on long-term sick leave, i.e., for a period longer than three continuous years after treatment.
Study design	Quantitative, prospective, longitudinal survey.	Quantitative, prospective, longitudinal survey.	Quantitative, prospective, longitudinal survey.	Descriptive, qualitative interview study.
Sample	189	122	104	15
Data collection	At baseline, 4 mths, 7 mths & 1 yr after allo-HSCT. Questionnaire data incl. SFID-SCT, SF36. Medical records.	At baseline, 7 mths & 1 yr after allo-HSCT. Questionnaire data incl. HADS, Li-Sat11. Medical records.	At baseline, 7 mths, 1 yr & 2 yrs after allo-HSCT. Questionnaire data incl. SF36, ALS, National Working Life Cohort. Medical records.	Between 3 – 6 yrs after allo-HSCT. Semi-structured interviews.
Data analyses	Descriptive statistics. Logistic regression.	Descriptive statistics. Logistic regression.	Descriptive statistics. Logistic regression.	Qualitative content analysis.
Predictor variables	Gender, age, education, physical activity at 4 mths, symptom burden at 4 mths & cGvHD at 1 yr.	Gender, age, education, living situation, diagnosis, conditioning, TBI, relapse, anxiety & depression at baseline & 7 mths, vocational & financial satisfaction at baseline & 7 mths & cGvHD at 1 yr.	Gender, age, education, general health at 1 yr, cGvHD at 1 yr & work-related factors at 1 yr.	
Outcome measures	General health & full-time sick leave 1 year after allo-HSCT.	Full-time sick leave 1 year after allo-HSCT.	Return to work >50% 2 years after allo-HSCT.	

Abbreviations: allo-HSCT, allogeneic haematopoietic stem cell transplantation; mths, months; yr, year; cGvHD, chronic graft-versus-host disease; TBI, total body irradiation; SFID-SCT, Symptom Frequency, Intensity and Distress Questionnaire for Stem Cell Transplantation; SF-36, Short Form 36; HADS, Hospital Anxiety and Depression Scale; LiSat-11, Life Satisfaction Checklist-11; ALS, Adjustment Latitude Scale.

5.2 SETTING

All participants were treated at an allo-HSCT unit at Karolinska University Hospital, Stockholm, Sweden. The unit is the largest of six allo-HSCT units in Sweden with approximately 100 allo-HSCTs performed yearly on both children and adults. The majority of the patients are from the local catchment area, but transplantations are also performed on patients both from other areas within Sweden and abroad.

5.3 PARTICIPANTS

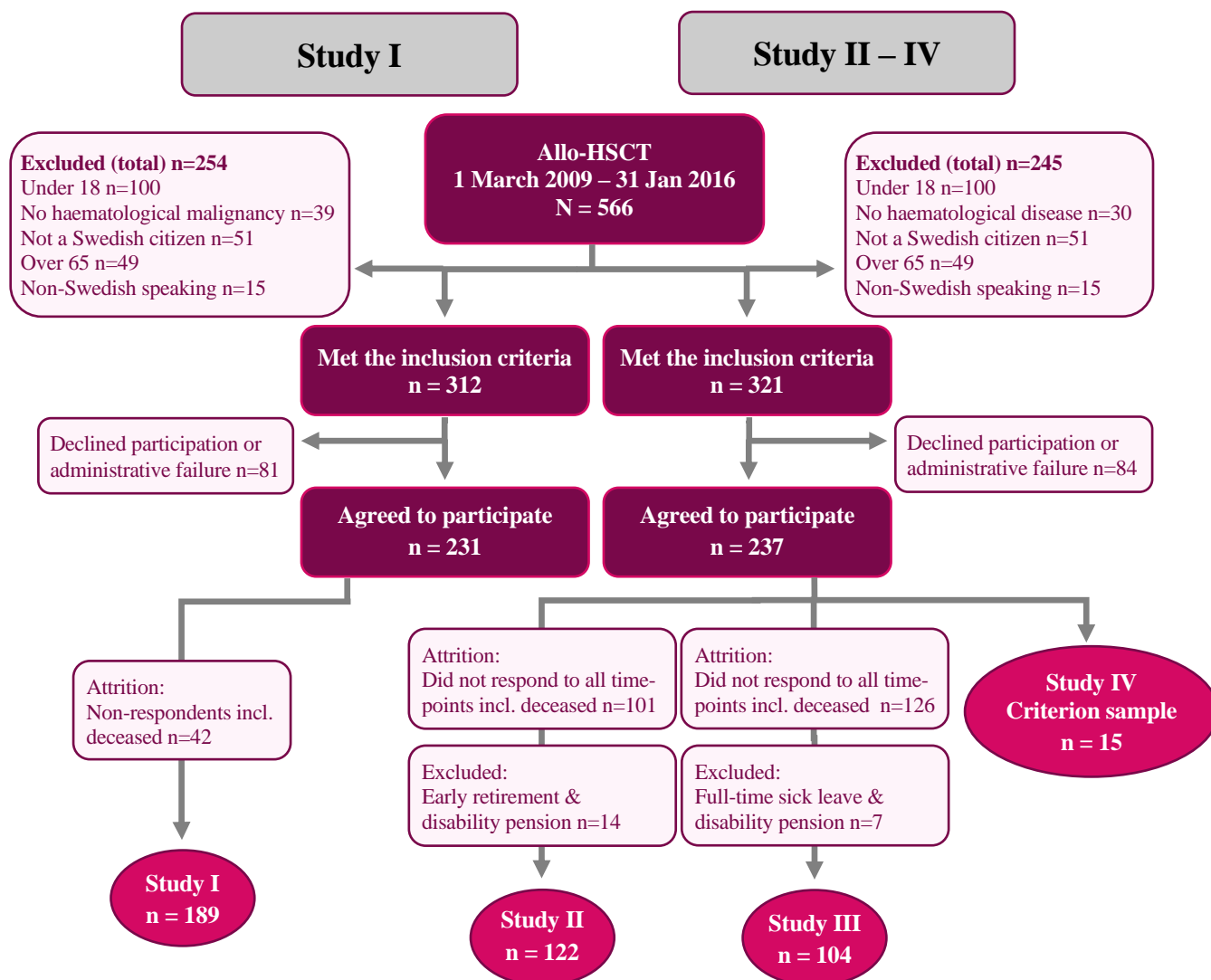
Participants were recruited at the allo-HSCT unit during a five-year period between March 2009 and January 2016. The criteria for participant inclusion were undergoing allo-HSCT due to a haematological disease, age 18 – 65 years, able to understand Swedish and living in Sweden. In total, 566 allo-HSCT were performed at the unit during the study period. All consecutive adult patients admitted during the inclusion period who fulfilled the inclusion criteria were eligible for participation (N=321). An exception was Study **I** where only patients with a haematological malignancy were included as treatments prior to the allo-HSCT procedure were considered more relevant to the aim (N=312). Non-participation was due to either patients declining or not being invited to participate (Study **I** n=81; Study **II** – **IV** n=84), resulting in a total sample of 231 for Study **I** and 237 for Studies **II** – **IV**. The reasons for the latter were not recorded but were probably due to the staff being too busy or the patient too sick to participate. The number of participants who died during the study period was 55 during year one, 18 during year two and six during year three. The enrolment of participants can be seen in Figure 2.

Differences between respondents and non-respondents at baseline regarding age, diagnosis and gender were analysed. No significant differences were found in relation to age or diagnosis in any of the quantitative studies (**I** – **III**). However, in Study **I**, a statistically significant difference was found between respondents (n=189) and non-respondents (n=42) regarding gender with females participating to a higher degree ($\chi^2(1, N = 231) = 6.9, p = 0.008$). Analyses performed in Studies **II** and **III** between respondents (n=194) and non-respondents (n=42) also revealed a higher degree of female participation ($\chi^2(1, N = 237) = 4.6, p = 0.03$).

5.3.1 Study I

In total, 231 participants agreed to participate in Study **I** with 187 responding at baseline (81% response rate). Due to the inclusion criterion of being diagnosed with a haematological malignancy, the sample of eligible participants who agreed to participate in Study **I** was marginally smaller (n=231) compared to Study **II** – **IV** (n=237), where patients with a haematological disease were eligible for participation. In the final study sample, only participants who responded to the questionnaire at one or more of the four measured data collection time points were included (n=189, 82% response rate). A majority of the participants were male (57%), and a slight majority were classified as younger as they were at or under the median age of 52 years (53%).

Figure 2. Enrolment of the study participants included in the thesis



5.3.2 Study II

In total, 237 patients agreed to participate in Study II with 194 participants responding to the baseline questionnaire (82% response rate). In the final study sample, only those who responded to the questionnaire at all three measured data collection time points (n=136) and did not report early retirement or disability pension (n=14) at any time point were included (n=122). Men participated to a higher degree than women (60%) and 52% were ≤52 years of age (median age).

5.3.3 Study III

The sample for Study III was the same as that of Study II with 237 patients agreeing to participate and 194 participants responding at baseline (82% response rate). Only those who responded to the baseline and two-year follow-up questionnaires (n=111) and did not report

full-time sick leave (n=2) or disability pension (n=5) at baseline were included in the final study sample (n=104). As in Studies **I – II**, just over half of the participants were men (60%) and younger than the median age of 52 (54%).

5.3.4 Study IV

From the 237 eligible participants in Studies **II – III**, a criterion sample of 16 patients who remained on some level of sick leave at the three-year time point was formed and the 16 patients were invited to participate. One patient declined due to not wanting to be interviewed online. The interviews were performed three to six years after allo-HSCT. The decision to only include participants who remained on some level of sick leave was made to ensure that the data collected included personal experiences of both barriers and facilitators in the return-to-work process. In total, 15 patients participated in Study **IV**: eight women and seven men between the ages of 36 and 60 years old. All participants were on full-time sick leave at the time of allo-HSCT and twelve were working to varying degrees at the time of the interview, while three participants were either on full-time sick leave or full-time disability pension.

Characteristics of all participants included in the four different studies on which this thesis is based on are listed in Table 2.

5.4 DATA COLLECTION

In Studies **I – III**, data were collected using a comprehensive Swedish questionnaire originally developed for patients diagnosed with breast cancer⁸⁵ but adapted to fit patients treated with allo-HSCT.^{22,86,87} The questionnaire took approximately 30 minutes to complete and consisted of a range of different scales or parts of scales, with most having been tested for validity and reliability. Medical data were retrieved from participants' medical records and included age, diagnosis, conditioning treatment, total body irradiation, clinical status at allo-HSCT, stem cell source, type of donor, re-transplantation and relapse, as well as presence and severity of cGvHD.

5.4.1 Study I

From the larger questionnaire, data were collected on sociodemographics, symptom occurrence and symptom distress, physical activity, general health and sick leave. Medical data reported in Study **I** were diagnosis, conditioning treatment, total body irradiation, clinical status at allo-HSCT, stem cell source, type of donor, re-transplantation, presence and severity of cGvHD and relapse. Data were collected at four time points; at baseline (on admission to the allo-HSCT unit), at four and seven months and at one year after allo-HSCT.

Table 2. Characteristics of the participants included in the research project

		Study I n = 189	Study II n = 122	Study III n = 104	Study IV n = 15
Demographic data		n (%)	n (%)	n (%)	n (%)
Gender	Women	82 (43)	49 (40)	42 (40)	8 (53)
	Men	107 (57)	73 (60)	62 (60)	7 (47)
Age in years	Younger (≤ 52) ¹	100 (53)	58 (48)	56 (54)	36 – 60
	Older (>52)	89 (47)	64 (52)	48 (46)	Median 48
Marital status	Married	114 (60)	77 (63)	36 (35)	13 (87)
	Not married	68 (36)	40 (33)	65 (63)	2 (13)
Living situation at allo-HSCT	Living with someone	153 (81)	17 (13)	16 (15)	14 (93)
	Living alone	29 (15)	102 (87)	88 (85)	1 (7)
Children	Yes	145 (77)	93 (76)	-	13 (87)
	No	39 (21)	26 (21)	-	2 (13)
Education	Lower (Elementary/ Secondary school)	77 (41)	45 (38)	39 (38)	6 (40)
	Higher (College/University)	101 (53)	74 (62)	64 (62)	9 (60)
Medical data		n (%)	n (%)	n (%)	n (%)
Diagnosis	Acute leukaemia	82 (43)	51 (42)	39 (38)	6 (40)
	Chronic leukaemia	28 (15)	24 (20)	19 (18)	1 (7)
	Lymphoma	18 (9)	10 (8)	6 (6)	3 (20)
	Plasma cell disorders	15 (18)	10 (8)	9 (9)	2 (13)
	Myelodysplastic syndrome	37 (20)	16 (13)	17 (16)	1 (7)
	Myeloproliferative neoplasia	9 (5)	7 (6)	10 (9)	2 (13)
	Other ²	-	4 (3)	4 (4)	-
Conditioning	Myeloablative	58 (31)	38 (31)	30 (29)	-
	Reduced intensity	131 (69)	84 (69)	74 (71)	-
Total body irradiation	No	134 (71)	86 (70)	76 (73)	-
	Yes	55 (29)	36 (30)	28 (27)	-
Stem cell source	Bone marrow	13 (7)	14 (12)	11 (11)	1 (7)
	Peripheral blood	175 (92)	108 (88)	93 (89)	14 (93)
	Cord blood	1 (1)	-	-	-
Type of donor	Related ³	58 (31)	47 (36)	35 (34)	9 (60)
	Unrelated ⁴	131 (64)	78 (64)	69 (66)	6 (40)
Retransplantation		<u>At 1 yr</u>	<u>At 1 yr</u>	<u>At 2 yrs</u>	<u>At 3 yrs</u>
	No	180 (95)	116 (95)	99 (95)	15 (100)
cGvHD	Yes	9 (5)	6 (5)	5 (5)	0 (0)
		<u>At 1 yr</u>	<u>At 1 yr</u>	<u>At 2 yrs</u>	<u>At interview</u>
Clinical status at baseline	No	112 (73)	90 (74)	68 (65)	8 (53)
	Yes	41 (27)	32 (26)	36 (35)	7 (47)
	Complete remission	119 (63)	74 (61)	59 (57)	9 (65)
	Partial remission	42 (22)	24 (20)	23 (22)	3 (21)
	Chronic phase	14 (7)	9 (7)	8 (7)	-
	No response	2 (1)	2 (2)	2 (2)	-
	Stable disease	9 (5)	6 (5)	5 (5)	1 (7)
Relapse	Untreated	3 (2)	3 (2)	3 (3)	-
	Not applicable	-	4 (3)	4 (4)	1 (7)
Relapse		<u>At 1 yr</u>	<u>At 1 yr</u>	<u>At 2 yrs</u>	<u>At 3 yrs</u>
	No	146 (77)	108 (88)	92 (88)	14 (93)
Relapse	Yes	43 (23)	14 (12)	12 (12)	1 (7)

Abbreviations: allo-HSCT, allogeneic haematopoietic stem cell transplantation; cGvHD, chronic graft-versus-host disease.

¹Divided by the median; ²Immunodeficiency, severe aplastic anaemia; ³Identical sibling, syngeneic, mismatched relative; ⁴Matched unrelated, mismatched unrelated, unrelated.

Symptom occurrence and symptom distress were measured using the Symptom Frequency, Intensity, and Distress Questionnaire for Stem Cell Transplantation (SFID-SCT) included in the larger questionnaire,⁵⁴ which includes 36 items on symptom occurrence and distress common among allo-HSCT patients. The participants were asked to state how they felt the previous week. Symptom occurrence was measured by asking if the participants had experienced the symptom with the response alternatives “not at all,” “yes, a little,” “yes, quite a lot,” and “yes, a lot.” If they reported the “yes” alternatives, they were asked to grade the level of distress of the symptom using the same response alternatives. Symptom occurrence was then dichotomised into “no” (“not at all”) and “yes” (“yes, a little,” “yes, quite a lot,” and “yes, a lot”). Symptom distress was dichotomised into “lower distress” (“not at all,” “yes, a little”) and “higher distress” (“yes, quite a lot” and “a lot”).

The SFID-SCT questionnaire does not include an overall symptom burden score, but instead, the participants reply to each item asking whether they are experiencing a symptom and, if so, how often and how distressing they find it. Thus, a symptom burden score was derived by totalling each participant’s “higher distress” symptoms (range, 0-36), which was dichotomised by the median into “low symptom burden” (0-3) and “high symptom burden” (4-36).

Physical activity was measured by a question asking about the current frequency of weekly physical activities for a minimum duration of at least 30 minutes; “How often do you spend time doing any type of physical activity for at least 30 minutes?” with response categories dichotomised into “more” (“4 times or more/week” and “2-3 times/week”) and “less” (“about once/month,” “once/week,” and “never”).

General health was measured using one item from the Short-Form 36,⁸⁸ “How would you rate your general health?”. The item had five response categories: “excellent,” “very good,” “good,” “fair,” and “poor,” dichotomised into “good health” (excellent, very good, and good) and “poor health” (fair and poor).

Sick leave was measured at the 1-year follow-up by the question: “Are you on sick leave now?” with the response alternatives “no” and “yes.” Participants also responded to questions about “full-time sick leave” or “part-time sick leave” with space to write the percentage of sick leave. For the few participants who did not reply to this question, equivalent data were gathered from their medical records.

5.4.2 Study II

Data on demographics, psychological factors, life satisfaction and sick leave were gathered from the larger questionnaire described above. Medical data reported in Study II were diagnosis, conditioning treatment, total body irradiation, clinical status at allo-HSCT, stem cell source, type of donor, re-transplantation, presence and severity of cGvHD and relapse. Data were collected at three time points; at baseline (on admission to the allo-HSCT unit), at seven months and at one-year post-transplantation.

Sick leave was reported and measured using the same question posed in Study I.

Anxiety and depression were measured using the validated self-assessment Hospital Anxiety and Depression Scale (HADS).⁸⁹ The scale consists of 14 questions divided into two seven-item subscales (anxiety and depression) with each item scored from 0 to 3. Total scores for each subscale range from 0 – 21. A lower score suggests clinical stability, while a higher score indicates greater levels of anxiety and/or depression, where the cut off value for symptoms of either anxiety and/or depression is ≥ 8 .⁹⁰

Life satisfaction was measured using the validated Life Satisfaction Checklist-11 (LiSat-11)⁹¹ previously used in comprehensive studies of life satisfaction including cancer⁹² and its test-retest reliability, specificity and sensitive have been found acceptable.^{91,93,94} Two items were used: satisfaction with vocational situation and satisfaction with financial situation. The participants rated each item on a six-point scale from “very dissatisfied” to “very satisfied”. The responses were dichotomised into “low satisfaction” (“very dissatisfied” to “rather satisfied”) and “high satisfaction” (“satisfied” to “very satisfied”).

5.4.3 Study III

Demographical data, occupational status and data on work-related factors were gathered from the larger questionnaire described in section 5.4. Medical data reported in Study **III** were diagnosis, conditioning treatment, total body irradiation, clinical status at allo-HSCT, stem cell source, type of donor, re-transplantation, presence of cGvHD and relapse. Data collection occurred at four different time points; at baseline (on admission to the allo-HSCT unit), at seven months, at one and at two years post-allo-HSCT.

Occupational status was reported by the question “What is your occupational status at the moment?” with response alternatives “Gainfully employed”, “On parental leave”, “On sick leave”, “Unemployed”, “Student”, “Homeworker”, “On disability pension” or “Old age pension”. Each alternative included a space for the participant to report the percentage of a full-time position that they were working.

General health one year after allo-HSCT was reported and measured by the question already described in Study **I**.

5.4.3.1 Work-related factors

Work-related factors were measured by questions pertaining to the participants’ perceived work adjustment one year after allo-HSCT and measured by four items from the Adjustment Latitude Scale questionnaire^{95,96} and three items from the National Working Life Cohort questionnaire,⁹⁷ which has previously been used on breast cancer patients.⁹⁸

Possible adjustment to physically demanding work was measured by the question “When the work you do becomes too physically strenuous, is it possible for you to slow the pace or perform your duties in some other way?” from the Adjustment Latitude Scale. The response alternatives were “Always” (3), “Sometimes” (2), “Seldom/Never” (1) and “Not applicable” (0).

Possible adjustment to mentally demanding work was also measured by a question from the Adjustment Latitude Scale; “When the work you do becomes to psychologically strenuous, is it possible for you to influence your situation?” with the response alternatives “Always” (3), “Sometimes” (2), “Seldom/Never” (1) and “Not applicable” (0).

Possibility to influence work conditions was measured by the three questions from the National Working Life Cohort; “Can you set your own work pace?”, “Can you to some extent decide when various tasks are to be done?” and “Are you sometimes/partly allowed to participate in the planning/organisation of your work?” with response alternatives “Always” (3), “Usually” (2), “Seldom” (1) and “Never” (0). The last two response alternatives (seldom and never) were collapsed into seldom/never to correspond with the response alternatives of the Adjustment Latitude Scale. A mean index of the three questions was calculated, with lower scores indicating less work adjustment (Cronbach’s $\alpha = 0.62$ and inter-item correlation 0.25 – 0.49), creating the variable possibility to influence work conditions.

Possible work adjustment when not feeling well was measured by the questions “If you are not feeling well, can you go home and do your work at a later time?” and “If you are not feeling well, can you work from home?” from the Adjustment Latitude Scale with the response alternatives “Always” (3), “Sometimes” (2), “Seldom/Never” (1) and “Not applicable” (0). The variable was created by calculating the mean index of the with lower scores signifying less perceived work adjustment when not feeling well (Cronbach’s $\alpha = 0.83$ and inter-item correlation 0.71). The index varied between 1 and 3 and the distribution was dichotomised by the median into high (≥ 2) versus low (< 2).

5.4.4 Study IV

The interviews were performed by the first author, who has considerable experience of haematology nursing care but has not been involved in the care of the participants. The interviews followed the consolidated criteria for reporting qualitative research (COREQ),⁹⁹ lasted on average 76 minutes (range 25-113 min; 10-28 single spaced transcribed pages) and explored a range of topics related to the interviewees’ occupational situation. A semi-structured interview guide was used, which started with an open question “What does a normal working day look like after your allo-HSCT?”. Other topics included were occupational situation prior to allo-HSCT, duration of sick leave, thoughts and feelings regarding their occupational situation, adverse late effects, financial impact of allo-HSCT and practicalities of return to work. A pilot interview was performed, which was included in the total sample as the interview guide did not change. The interviews proceeded at the pace and direction of the participants, and they were asked to describe and reflect on their experiences, including probing, clarification and summarising by the interviewer as needed. Analysis of the data began after 12 completed interviews to gain a sense of the content. Interviews were ceased after completion of 15 interviews as the research team felt that no new data emerged. Field notes were made after each interview and all interviews were audio-recorded with the participant’s consent and transcribed verbatim. Medical information regarding diagnosis, conditioning,

stem cell source, donor type, relapse, retransplantation as well as sick leave status three years after allo-HSCT were obtained from the patients' medical records.

5.4.5 Study I – IV

The aim of this thesis was to explore occupational situation of allo-HSCT survivors with a special focus on factors associated with sick leave and return to work. Mehnert's model contains several factors related to research about work in cancer survivorship¹⁴ (p. 9) and has guided the decisions regarding which factors to examine in this thesis. All factors included in the studies on which this thesis is based on are compiled in Table 3 and how they relate to the medical factors, mediator variables and outcome variables in Mehnert's research model.

5.5 DATA ANALYSES

In the quantitative Studies **I - III**, potential statistical differences between baseline respondents and non-respondents were analysed using either independent t-tests or two-sided χ^2 -tests depending on the data level. Relevant variables were presented as descriptive statistics with frequencies (n) and percentages (%). Odds ratios (OR) with 95% confidence intervals (CI) were calculated using univariate logistic regression analyses between each factor and sick leave or return to work after allo-HSCT. The significance level was set to $p < 0.05$. To establish independent associations, all significant factors in the univariate logistic regression analyses were inserted and analysed in a multivariable logistic regression analysis. All statistical calculations were conducted using SPSS versions 24.0 – 26.0 (IBM, Chicago, IL, USA).

5.5.1 Study I

Univariate and multivariable logistic regression were performed between the factors gender, age, education, cGvHD one-year after allo-HSCT, physical activity level and symptom burden at four months post-allo-HSCT and the likelihood of experiencing poor general health or being on full-time sick leave one year after allo-HSCT. The logistic regression analysis regarding general health included participants who returned the questionnaires at the four-month and one-year follow-ups (n=131). The logistic regression analyses regarding full-time sick leave excluded those who were on early retirement or disability pension at baseline and who had transitioned to full-time disability pension or old age pension at the one-year follow-up (n=118).

5.5.2 Study II

Missing data in instruments based on sum scores, i.e., HADS, were replaced using person-mean imputation¹⁰⁰ if missing data did not exceed 20% for each scale.¹⁰¹ Factors analysed in the univariate and multivariable logistic regression analyses were demographic (gender, age, living situation, education), medical (diagnosis, conditioning, total body irradiation, relapse, presence of cGvHD), psychological (symptoms of anxiety and depression) and satisfaction with vocational and financial situation. The logistic regression analyses were performed on

all the participants included in Study II (n=122), which excluded those on early retirement and full-time disability pension.

Table 3. Factors and variables investigated in this thesis in relation the Mehnert’s conceptual framework regarding research about work in cancer survivorship.

Mehnert’s model	Study I	Study II	Study III	Study IV
Medical factor				
Disease specific factors		<ul style="list-style-type: none"> • Diagnosis • Relapse 		
Treatment-related factors		<ul style="list-style-type: none"> • Conditioning treatment • Total body irradiation 		
Mediator variables				
Demographic factors	<ul style="list-style-type: none"> • Gender • Age • Education • Living situation 	<ul style="list-style-type: none"> • Age • Gender • Education • Financial satisfaction • Living situation 	<ul style="list-style-type: none"> • Age • Gender • Education 	
Impairments and health related factors	<ul style="list-style-type: none"> • cGvHD • Physical activity 	<ul style="list-style-type: none"> • cGvHD • Symptom frequency • Symptom distress • Symptom burden 	<ul style="list-style-type: none"> • cGvHD • General health 	<ul style="list-style-type: none"> • cGvHD • Fatigue • Physical activity • Cognitive impairments
Psychosocial factors		<ul style="list-style-type: none"> • Symptoms of depression • Symptoms of anxiety 		<ul style="list-style-type: none"> • Self-esteem • Self-confidence • Stress intolerance
Motivational factors		<ul style="list-style-type: none"> • Vocational satisfaction 		<ul style="list-style-type: none"> • Motivation to work
Work-related factors			<ul style="list-style-type: none"> • Possible adjustment to physically demanding work • Possible adjustment to mentally demanding work • Possibility to influence work conditions • Possible work adjustment when not feeling well 	<ul style="list-style-type: none"> • Possible adjustment to physically demanding work • Possible adjustment to mentally demanding work • Possibility to influence work conditions • Possible work adjustment when not feeling well • Relationship with employer • Supportive colleagues
Outcome criteria				
Work-related outcomes	<ul style="list-style-type: none"> • Sick leave 	<ul style="list-style-type: none"> • Sick leave 	<ul style="list-style-type: none"> • Return to work 	<ul style="list-style-type: none"> • Experiences of the return-to-work process after long-term sick leave

Abbreviations: cGvHD, chronic graft-versus-host disease.

5.5.3 Study III

Logistic regression analyses were performed between demographic factors (gender, age, education), medical factors (general health, presence of cGvHD) and work-related factors (adjustment to physically and mentally demanding work, possibility to influence work condi-

tions and possible work adjustment when not feeling well) and return to work >50% two years after allo-HSCT. Only those who responded to the questionnaire at baseline, at one and two years after allo-HSCT and did not report full-time disability (n=2), old age pension (n=8) or left the question regarding occupational status unanswered (n=5) at the one and two-year follow-ups were included in the statistical analyses (n=89). In the logistic regression analyses, being back at work at >50% of a full-time position indicated return to work, as this was considered a good measure of being re-established on the labour market.

5.5.4 Study IV

Qualitative content analysis is a systematic way to describe and quantify phenomena on a deeper level.¹⁰² It is a dynamic form of analysis of verbal data, focusing on differences and similarities in the data, oriented towards summarising the content in a way that enables valid and replicable inferences from data in order to provide knowledge, new insights and a representation of facts.¹⁰² The method highlights important areas of the text in order to increase understanding of the information by classifying text units into content-related categories in order to finally formulate descriptive categories of various phenomena.¹⁰³

An inductive content analysis inspired by Elo and Kyngäs was chosen to analyse the data.¹⁰³ This approach, where the details are first observed and then combined into a ‘whole’, is suitable for this study as it attempted to obtain a condensed and broad description of the phenomena involved in return-to-work after allo-HSCT.

The data were analysed in three steps: preparation, organisation and presentation inspired by Elo and Kyngäs.¹⁰³ Preparations began by reading the transcribed interviews to gain an understanding and a sense of the whole, first without any agenda, and then with the study aim firmly in mind. Thereafter, units of analysis relevant to the aim of the study were selected and digitally coloured, cut and pasted into a separate document. The next step, organisation, consisted of open coding, category formation and abstraction, allowing the categories to emerge during the analysis. Open coding is used to identify parts of the text that are meaningful and related to the purpose of the study.¹⁰³ All units of analysis were condensed and labelled with a code that remained true to the original text. All codes were continuously compared to identify differences and similarities.

This process was done individually for each of the 15 interviews. The codes were then classified and categorised into different subcategories, i.e., a group of codes sharing commonality, taking care to ensure the subcategories did not overlap. In the last step of the analysis, the subcategories were grouped together in generic categories. The generic categories were interpreted at a manifest level.¹⁰³ To strengthen the trustworthiness of the analysis, a comparison was made between the interviews and the subcategories by the first and the second author. The analysis process was reflective and considered a “work in progress.” It was a continuous process of coding, categorising and returning to the raw data when necessary to ensure that the data revealed the inherent connections and relationships. Researcher triangulation, during which the condensation, coding and categorisations of the data were discussed within the research group, occurred on a regular basis throughout the analysis phase to ensure credibili-

ty.¹⁰⁴ There were also ongoing discussions regarding pre-understanding in an attempt to avoid researcher bias. Trustworthiness and authenticity were also achieved by attempting to prioritise the voice of the participants over that of the researcher in the presentation of results and by including representative quotations.

6 ETHICAL CONSIDERATIONS

Research involving patients who are ill and going through intensive medical treatments affecting both mind and body raises ethical concerns that need to be addressed throughout the whole research process. Ethical issues, such as informed consent, autonomy and integrity were considered during the whole research project, in addition to ensuring that no participants were caused any harm. Beneficial findings leading to improved care and further discussions and analysis were considered to outweigh the potential risks for the participants.

Nevertheless, there are some ethical issues that need to be considered in this thesis. The participants have all been through an intense procedure during which they have been told that there is a risk of dying, either because of the treatment itself or the treatment not being effective, and thus, the participants can be considered as belonging to a vulnerable group of individuals experiencing ill-health. Many participants have been shown to appreciate the opportunity to share their experiences. However, they may also experience feelings of being confronted with difficult topics, both in the questionnaires and in the interviews, and this confrontation might start a process of reflection that can influence their mental health, both adversely and favourably. No medical risks associated with participation in the studies on which this thesis is based were anticipated.

It is difficult to control for individuals' emotional reactions and there is a risk of participants, who are trying to get back to a "normal" life, becoming distressed when questioned about their occupational situation, especially if they have been unable to return to work as they might have planned and hoped for. Therefore, it was important to stress that participation was voluntary and that neither present nor future care would be affected by non-participation or potential withdrawal of consent. This was clearly stated in all written information that the participants received throughout the project, including the initial information letter and informed consent form that participants signed when agreeing to participate in the research project. The initial information letter and all subsequent information sent to participants included contact details of at least two people in the research group so that participants could reach out at any time if they felt they needed support.

Individuals who were approached and invited to participate in the interview study were again reminded, both orally and in writing, of the voluntary nature of participation, in order to prevent any impression that their participation, or lack thereof, would influence their treatment or care. Interviewees were also guaranteed that any potential quotations from the interviews would be anonymised.

It was of utmost importance that all participants felt safe in the knowledge that their confidentiality was guaranteed. As soon as consent had been obtained, all participants were assigned a study code and only a selected few within the research group had access to the corresponding identification data. All questionnaire data were coded, and participants were guaranteed that all collected data would be presented at group level. In the interview study, only the interviewer had knowledge of the interviewees' personal information. All potentially identifiable information was removed from the recording and replaced with the study code

before being transcribed. All personal information and data were only collected for the explicit purpose of research. They were stored safely in accordance with regulations and safeguarded from unauthorised use.

Access to personal data was needed in order to collect data from medical records, to which the participants consented. However, only two individuals in the research group had access to the personal data.

The studies included in this thesis were all performed in accordance with the principles of the 1964 Declaration of Helsinki and its later amendments.¹⁰⁵ Approval was granted by the Regional Ethical Review Board in Stockholm, Sweden (dnr 2008/1732-31/2; dnr 2009/540-32; dnr 2015/343-32).

7 RESULTS

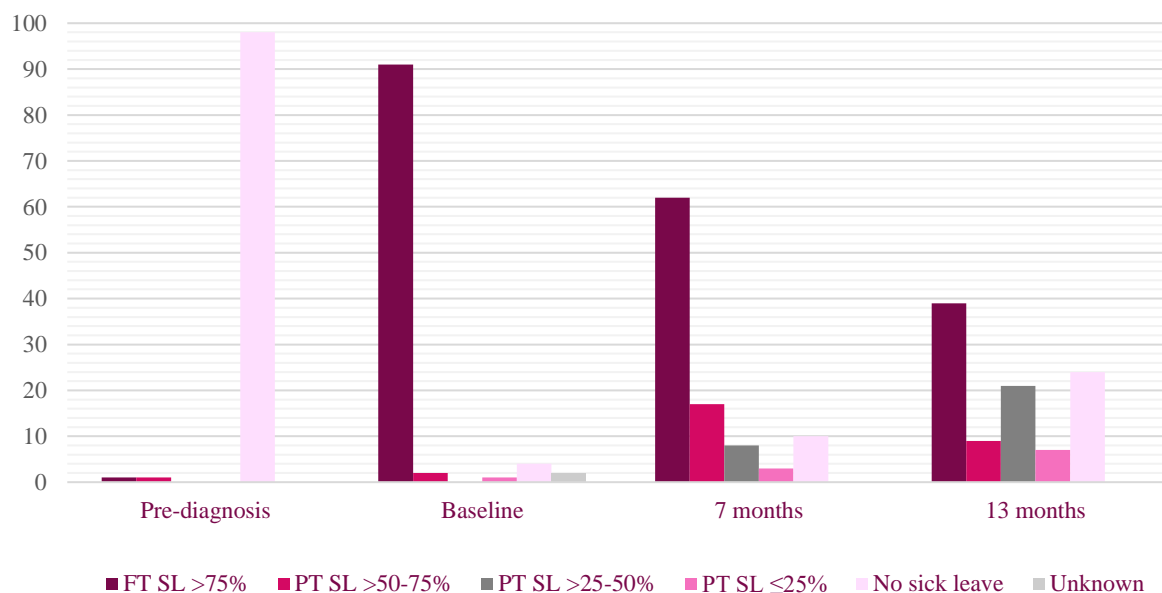
The findings are presented as a compilation of all the findings related to allo-HSCT survivors' occupational situation from Studies I – IV including a presentation of the descriptive findings and analyses of factors investigated in this thesis. The results are presented according to the two main areas of focus in this thesis – being on sick leave and returning to work, with each containing quantitative and qualitative results of the aspects affecting allo-HSCT survivors' occupational situation.

7.1 BEING ON SICK LEAVE

Studies I and II examined sick leave one year after allo-HSCT and potential factors associated with full-time sick leave one year post-transplantation.

In Study II, proportions of participants on full-time sick leave (>75), part-time sick leave (1-75%) and no sick leave were measured at pre-diagnosis, baseline (on admission to the allo-HSCT unit), seven months and one year after allo-HSCT (Figure 3). At the time of diagnosis, only 2% reported being on sick leave, whereas 98% were working full-time or equivalent. At baseline, 94% reported being on sick leave (91% full-time) and all those not on sick leave were self-employed. Seven months after allo-HSCT, 90% remained on sick leave (62% full-time), which decreased to 76% one year after allo-HSCT, of whom 39% remained on full-time sick leave.

Figure 3. Proportions of participants (%) on sick leave during the first year after allo-HSCT (n=122)



7.1.1 Demographic and medical factors

Presence of cGvHD one year after treatment was the only medical factor investigated that was found to be associated with sick leave in both Studies I and II. cGvHD was significantly associated with full-time sick leave one year after allo-HSCT in both univariate (Study I (OR 2.87; 95 % CI 1.25-6.62; $p = .01$); Study II (OR 3.07; 95% CI 1.34-7.07; $p = 0.01$)) and

multivariable logistic regression analyses (Study I (OR 3.22; 95 % CI 1.29-8.01; $p = .01$); Study II (OR 3.43; 95% CI 1.35-8.73; $p = 0.01$)).

Other medical factors investigated were haematological diagnosis, conditioning treatment, total body irradiation or relapse, were not found to be significantly associated with full-time sick leave one year after allo-HSCT. Neither were the demographic variables gender, age, education nor living situation.

cGvHD was also mentioned as a factor prolonging sick leave in the qualitative study (IV) along with other medically related issues such as susceptibility to infections and stiffness of joints. Physical limitations made the interviewees feel less capable than before diagnosis and were difficult to accept. Generic categories including subcategories of experiences related to occupational situation found in the qualitative Study IV are depicted in Figure 4.

7.1.2 Mental health

Self-reported symptoms of anxiety and depression according to HADS were investigated in Study II. Proportions of participants experiencing anxiety during the first year after allo-HSCT remained stable with approximately a quarter of participants reporting symptoms of anxiety. No significant associations were found between symptoms of anxiety at either baseline or seven months after allo-HSCT and full-time sick leave one year after treatment.

Participants reporting depressive symptoms decreased slightly from baseline (21%) to seven months after treatment (17%). Symptoms of depression at seven months was significantly associated with full-time sick leave one-year post-treatment both in univariate (OR 4.81; 95% CI 1.69-13.69; $p = 0.00$) and multivariable logistic regression analyses (OR 3.37; 95% CI 1.2-11.58; $p = 0.02$)

Findings in Study IV showed that decreased self-confidence and self-esteem due to both the treatment and long periods of sick leave affected interviewees' occupational situation regardless of their position at work, i.e., self-employed, manager or employee, although most described a gradual improvement once they were back at work.

“I have always been a person who felt very secure and strong, but now my self-confidence is a lot lower. I think it stems from my life being turned upside down and you become so incredibly fragile. And for a long time, I could hardly do anything. In the end you do not know what you can handle and manage. My decreased self-confidence and self-esteem really affected my work.” (Female, 61 years)

7.1.3 Vocational and financial satisfaction

In Study II, satisfaction with the participants' vocational and financial situation was examined. At baseline, approximately half of the participants reported low levels of satisfaction (i.e., very dissatisfied to rather satisfied) with their vocational situation (55%), which increased to 71% at seven months post-transplantation. Satisfaction with their financial situation increased from 49% at baseline to 63% at seven months after allo-HSCT.

A significant association between low vocational satisfaction at seven months post-treatment and full-time sick leave one year after allo-HSCT was found in the univariate analysis (OR 3.27; 95% CI 1.27-8.41; $p = 0.01$). No association was found between financial satisfaction and full-time sick leave.

In Study **IV**, no interviewees stated that they felt it necessary to return to work due to their financial situation. Instead, almost all participants stated that they managed well financially, although their income had decreased as a result of being on sick leave. They mentioned that they had adapted to their new situation, and several added that being on sick leave with instructions not to expose themselves to the risk of infection meant that they spent less money than would normally be the case.

7.1.4 Physical activity

In Study **I**, low physical activity was found to be associated with full-time sick leave one year after allo-HSCT in both the univariate (OR 3.28; 95 % CI 1.29-8.36; $p = .01$) and the multi-variable logistic regression analyses (OR 3.33; 95 % CI 1.21-9.17; $p = .02$).

Physical activity was also highlighted as an important aspect by several interviewees in Study **IV** and often described as a self-care strategy to improve energy levels, as many felt their energy levels decreased even further if they were not physically active during the day. Although interviewees described tiredness as causing a lack of motivation to perform any physical activities, many forced themselves to do so as they knew they would feel more energised afterwards.

7.1.5 Symptom burden

In Study **I**, the frequency and distress of 36 different symptoms were measured during the first year after allo-HSCT. The most frequently occurring symptoms were tiredness, physical weakness, disinterest in sex, susceptibility to infection, dry mouth, feeling worried and feeling low. These remained fairly stable throughout the first year.

Symptom distress varied more throughout the first year and revealed 11 different symptoms being reported as most distressing. Difficulties eating, discomfort during sex, physical weakness were reported as causing the most distress, followed by difficulties breathing, loss of appetite, mouth ulcers, sexual potency for men, fragile genital membranes, vomiting, pain and increased sputum production.

In logistic regression analyses, the overall symptom burden score, based on the combination of symptom frequency and distress from the SFID-SCT questionnaire, was analysed in relation to sick leave. A high symptom burden at the four-month follow-up was significantly associated with full-time sick leave one year after allo-HSCT both in the univariate (OR 3.17; 95 % CI 1.46-6.88; $p = .00$) and the multivariable analyses (OR 3.0; 95 % CI 1.3-6.96; $p = .01$).

In Study **IV**, participants described their experiences of their occupational situation 3 – 6 years after allo-HSCT, which revealed other factors of importance that were not investigated

in the quantitative studies. Symptom burden was often highlighted during the interviews, even this late in the process, and analysis of the findings divided the participants' experiences of the return-to-work process into three generic categories: coping with changes to mind and body, a changing work situation and the importance of support systems. Each generic category included four different subcategories, presented in Figure 4. The subcategory Cognitive health status was described by the interviewees as affecting their occupational situation the most, especially fatigue.

“If I can sit by myself and work in peace and quiet without any disturbing elements, then everything works well. A lot of people, meetings, in the break room, then I can feel it [fatigue] straight away. When I need to concentrate, as in a meeting, it gets difficult.” (Female, 46 years)

For participants who struggled with fatigue, working from home was a great facilitator for returning to work.

“I used to be the face of the company before I got sick. I completely avoid those things now. I used to think it was fun, but it is just too draining and takes too much energy. Now I am more into digital meetings, tasks that are suitable to do from home. There is no way I would have been able to do the assignments I used to do.” (Female, 61 years)

Intolerance to stress was also experienced by many and for those affected, it constituted a huge barrier both in the return-to-work process and in life in general.

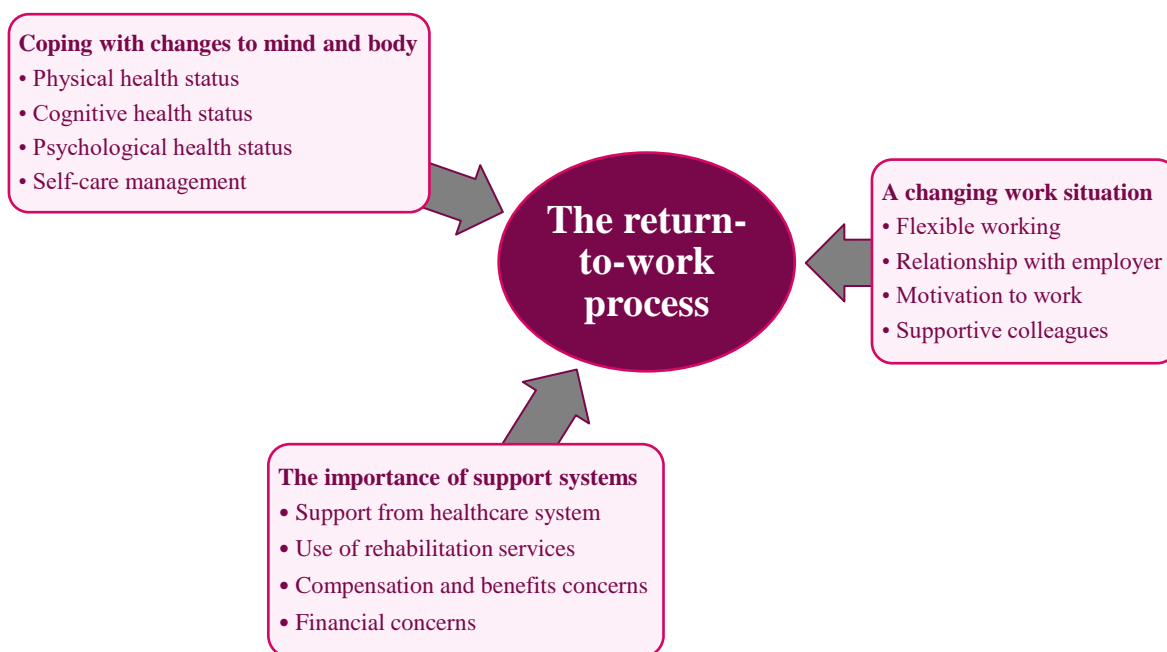
“I feel like I need more time, I have become completely allergic to stress. Before, it did not bother me, I could have tons of things to do. I just did what I had to do. Now, there is no way.” (Female, 60 years)

Other cognitive consequences mentioned were memory problems, concentration difficulties and having a “foggy” mind, all affecting return-to-work for those experiencing them.

“My physician has asked me a couple of times if I should try [return to work] but I have said that the way things are today, it will not work. I do not even function at home, so how can I go back to work? I was going to install [something] in the garden and I was trying to screw it all together while reading the instructions and... I just could not understand what it said. I sat there and read it over and over again and I just did not get it. Eventually my wife had to do it all. That felt really difficult you know, when I am the one who used to solve all these technical things before. I just felt like a complete failure.” (Male, 55 years)

Strategies for coping with cognitive impairments included mindfulness, especially important for those who struggled with intolerance to stress at work. Many also felt the need to write detailed lists and memory notes to ease their worry about not remembering what they needed to do throughout their workday.

Figure 4. Generic categories and subcategories of experiences in the return-to-work process after allo-HSCT

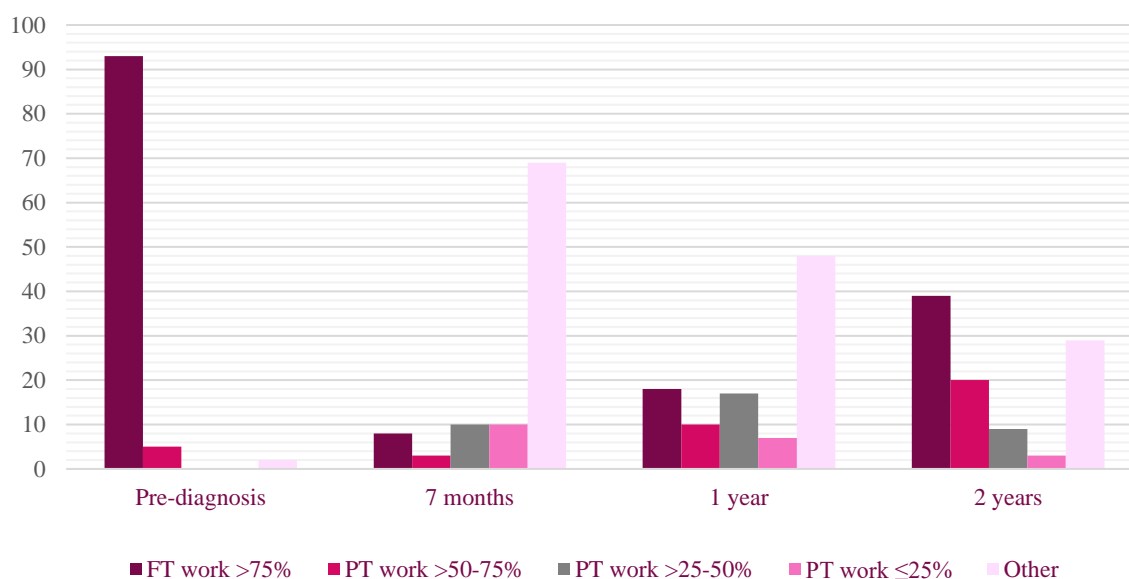


7.2 RETURNING TO WORK

In Study **III**, the rate of return to work during the first two years after allo-HSCT and potential factors at one year after treatment and their associations with the return-to-work process two years post-transplantation were examined. Study **IV** included perspectives of the return-to-work process when participants were interviewed about their experiences of their occupational situation.

Before the diagnosis of a haematological disease, 98% of all participants were working >50% of a full-time position. Seven months after allo-HSCT, 12% had returned to work >50% increasing to 28% at one year. Two years post-transplantation, 60% of participants had returned to work >50% of a full-time position and 15% had transitioned from full-time work at diagnosis to old age pension, disability pension or unemployment. Proportions of occupational situation from pre-diagnosis to two years after allo-HSCT are illustrated in Figure 5.

Figure 5. Proportions of participants return to work (%) during the first two years after allo-HSCT (n=104)



7.2.1 Demographic and medical factors

Logistic regression analyses in Study **III** showed that a higher education was significantly associated with having returned to work two years after allo-HSCT (OR 2.76; 95% CI 1.09-7.02; $p = 0.03$) (Figure 6). No statistically significant associations were found in relation to age or gender.

Similar to the results in Studies **I** and **II**, the presence of cGvHD was found to be linked to the participants' occupational situation. In Study **III**, cGvHD was significantly associated with not having returned to work two years after allo-HSCT both in the univariate (OR 3.54; 95% CI 1.38-9.1; $p = 0.01$) and multivariable analyses (OR 2.81; 95% CI 1.2-6.59; $p = 0.02$). General health one year after treatment was not found to be associated with return to work (Figure 6).

In Study **IV**, interviewees who struggled with side effects, such as cGvHD and joint stiffness, stated that they would not have been able to return to work if their job had included physically laborious tasks, while a few interviewees who were employed as manual workers explained that their main reason for being unable to return to work was their inability to carry out physically demanding tasks.

Susceptibility to infections was also described as a barrier in the return-to-work process, especially when employers were unable to adapt interviewees' workplace due to, for example, the state of the building, offer assignments suitable for working from home or assignments that did not involve physical contact with others.

7.2.2 Work-related factors

In Study **III**, descriptive data of work-related factors one year after allo-HSCT showed that 82 – 89% were able to set their own work pace, decide when to do assignments and partici-

pate in the planning of their work. When work became too physically strenuous, 65% were able to slow the pace or perform duties in another way, while 72% were able to influence their situation if their work became too mentally strenuous. The work-related factors with the lowest scores related to possible work adjustment when not feeling well, with 59% being able to leave work and do their work at a later time and 54% were able to work from home. The proportions of all work-related factors one year after allo-HSCT can be found in Table 4.

In the statistical analyses, no factors related to self-reported work adjustment were found to be significantly associated with return to work two years after allo-HSCT.

However, the qualitative results in Study **IV** did indicate that work-related factors had an important impact on allo-HSCT survivors' return-to-work process. Several interviewees described the ability to work from home as one of the main facilitators in the return-to-work process along with being able to decide upon their work schedule and how many hours to work each day. If these adjustments to their occupational situation had not been possible, many stated that return to work would have been an even more arduous and complicated process.

“Being able to work from home and deciding myself how many hours to work have been vital to me. Otherwise, I do not think I would have been able to work as much as I do. I would never have been able to cope with having to work from the office. If I need to work a long day, I can work less another day. I do not feel completely done after six hours working from home compared to working in the office.”

For interviewees who could not work from home, the majority of the adjustments needed at the workplace were related to the participants' susceptibility to infection. This included moving into their own office from an open-plan setting, and for those in regular physical contact with others, changing to job assignments where no contact with others was necessary.

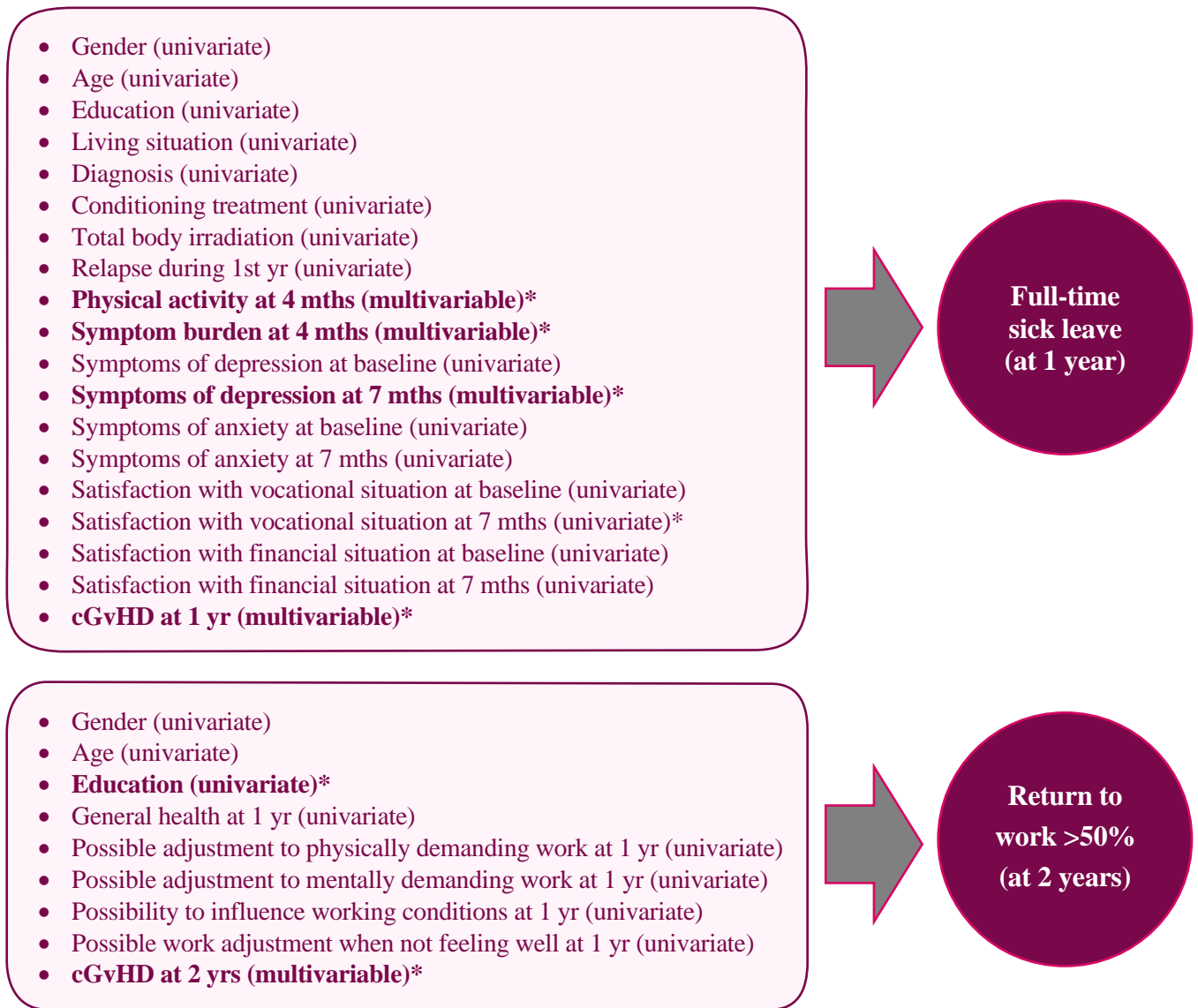
Table 4. Proportions of participants' responses to work-related questions one year after allo-HSCT for those employed before diagnosis (n=89)

Work-related questions		Total n (%)
Possible adjustment to physically demanding work		
When the work you do becomes too strenuous <u>physically</u> , is it possible for you to slow the pace or perform your duties in some other way?	Yes	51 (65)
	No	28 (35)
	Missing	10 (9)
Possible adjustment to mentally demanding work		
When the work you do becomes too strenuous <u>mentally</u> , is it possible for you to influence your situation?	Yes	57 (72)
	No	22 (28)
	Missing	10 (9)
Possibility to influence work conditions		
Can you set your own work pace?	Yes	63 (82)
	No	14 (18)
	Missing	12 (9)
Can you to some extent decide when various tasks are to be done?	Yes	65 (84)
	No	12 (16)
	Missing	12 (9)
Are you sometimes allowed to participate in the planning/organising of the work you do?	Yes	68 (89)
	No	8 (11)
	Missing	13 (9)
Possible work adjustment when not feeling well		
If you are not feeling well, can you go home and do your work at a later time?	Yes	46 (59)
	No	32 (41)
	Missing	11 (9)
If you are not feeling well, can you work from home?	Yes	42 (54)
	No	35 (46)
	Missing	12 (9)

7.3 FACTORS EXAMINED IN RELATION TO OCCUPATIONAL SITUATION

The overarching aim of this thesis was to explore the occupational situation of allo-HSCT survivors with special focus on factors associated with sick leave and return to work. Several different factors were investigated in the quantitative studies (Studies **I – III**) and an overview of these factors are shown in Figure 6, including both significant and non-significant factors examined. Significant factors in multivariable logistic regression analyses are in bold type. The figure illustrates that physical activity, a high symptom burden, symptoms of depression and the presence of cGvHD were found to be associated with allo-HSCT survivors' occupational situation.

Figure 6. Factors investigated in relation to allo-HSCT survivors' occupational situation in Studies I – III.



* $p < .05$

8 DISCUSSION

The overarching aim of this thesis was to increase knowledge and gain a deeper understanding of allo-HSCT survivors' occupational situation with a special focus on factors influencing sick leave and return to work. Overall, the results from the different studies included in the thesis revealed that allo-HSCT survivors often face long-term sick leave post-transplantation and encounter various obstacles in their return-to-work process, especially medical late effects, fatigue and symptoms of depression. Flexible working conditions, particularly in terms of time, place and assignments, were considered facilitating factors in the return-to-work process.

8.1 DISCUSSION OF THE RESULTS

8.1.1 Sick leave status after allo-HSCT

The ability to return to work is a sign of recovery for many allo-HSCT patients as it is perceived as a chance to return to normality.^{19,69,71} The findings in this thesis reveal that almost all patients were on sick leave at the time of transplantation and 76% of allo-HSCT survivors remained on sick leave one year after treatment, of whom 39% were on full-time sick leave. As this longitudinal exploration of sick leave during year one after allo-HSCT is the first of its kind (Study II), no longitudinal data related to sick leave status after allo-HSCT were found with which to compare the proportions of sick leave in this thesis. A cross-sectional study found that 16% were still on sick leave at a median time of eight years after allo-HSCT²² and a longitudinal study showed that 30% of patients who had undergone an autologous HSCT due to relapse remained on sick leave after the first year (part- or full-time sick leave unknown).¹⁰⁶ Comparing allo-HSCT survivors with other cancer diagnoses can be problematic as treatment regimens vary considerably. However, studies have revealed that chemotherapy can significantly prolong sick leave and delay a return to work.^{25-27,107} The large proportion of allo-HSCT survivors who remained on sick leave in this thesis differs from e.g., breast cancer patients in Sweden, where only approximately a quarter of patients were on sick leave (with less than 10% on full-time sick leave) one year after treatment.¹⁰⁸ Furthermore, being on sick leave for longer periods of time can in itself be associated with difficulties related to return to work among patients with different types of cancer diagnoses.¹⁰⁹ Possible explanations for the high proportions of allo-HSCT survivors remaining on sick leave one year after treatment could be due to the recommendations they receive from clinicians to stay on full-time sick leave for at least six months after allo-HSCT unless they can adapt their work situation to reduce the risk of infections. In addition, patients are recommended to prolong their sick leave if they remain on full immunosuppression for GvHD six months after treatment. These recommendations are unique to allo-HSCT survivors and not applicable to other cancer diagnoses.

8.1.2 Return to work rates after allo-HSCT

In relation to active working status, 98% of survivors were in employment or equivalent at baseline. One year after allo-HSCT, just under a third of survivors had returned to work >50% along with one quarter working ≤50%. Compared to research on sick leave, there is a larger amount of research on the return-to-work process among haematological patients and estimates range from 20% to approximately 45% of survivors returning to full-time work one year after allo-HSCT in studies including both autologous and allogeneic patients.^{16,23,69,106} However, fewer allogeneic patients return to work within the first year after transplantation compared to autologous patients.⁶⁹ Estimations of return to work solely focusing on allo-HSCT survivors range from 52 to 68%^{22,68,110,111} but most of these studies do not provide a definition of return to work, perhaps including participants who had returned to work to a lesser extent than the allo-HSCT survivors in this thesis. Another explanation for the differing results regarding return to work rates could be due to the social security system in Sweden that provides financial security for all individuals who are unable to work due to illness or disability and covers approximately 80% of lost income up to a certain level.⁸⁴ This system may enable allo-HSCT to remain on some level of sick leave for longer periods of time, delaying return to work. Two years after allo-HSCT, the findings in this thesis are similar to studies exploring return to work five to eight years after treatment where 58 – 79% reported to be active at work with 27 – 32% working full-time.^{22,112}

8.1.3 Medical factors

cGvHD was significantly associated with both full-time sick leave at one year and return to work at two years post-treatment. Health related issues, such as cGvHD, have been found to delay return to work^{16,22,23} with physical recovery occurring earlier than work recovery.¹⁶ In this thesis, return to work two years after allo-HSCT was not affected by participants' general health at one year, which differs from studies suggesting that general health can influence the occupational situation of cancer survivors.^{22,85} A high symptom burden four months after allo-HSCT was also found to be associated with full-time sick leave as well as general health one-year post-transplantation. Considering that the variable symptom burden was constructed by a combination of 36 mainly physically related symptoms, the finding that cGvHD did not affect general health was somewhat surprising as cGvHD mainly manifests as physical symptoms. Previous research on whether cGvHD has an impact on allo-HSCT survivors' occupational situation has shown contradictory results, with some studies indicating that there is no association^{16,23} whereas others suggest that there is a relationship between the two.^{38,69} Early diagnosis of cGvHD together with treatment, evaluation and the use of supportive care can alleviate complications and long-term conditions,¹¹³ which may result in an improved health and return to gainful employment for allo-HSCT survivors. Although not investigated in this thesis, it appears as if cGvHD, sick leave status and return to work are interlinked and more in-depth exploration on how these variables are connected would be of interest.

8.1.4 Fatigue, tiredness and physical activity

Fatigue was one of the main barriers mentioned in the qualitative study (IV) affecting participants who had a troublesome return to work. Fatigue reduced their work ability and made them worry about being unable to cope with work. Fatigue and tiredness have been found to be among the most disruptive late effects that complicate return to work for cancer survivors^{14,18,114} including haematological malignancy,¹¹⁵ after autologous HSCT¹¹⁶ and in research combining autologous and allo-HSCT survivors.⁶⁷ Participants in this study described several strategies for coping with their fatigue, including the positive influence of physical activity that reduced their fatigue levels. The benefits of physical activity can also be seen in the results that low physical activity at four months post-allo-HSCT showed a three times greater probability of being on full-time sick leave one year after allo-HSCT, which is in line with previous research on breast cancer patients, where increased physical activity improved the return-to-work rates one year after commencement of treatment.¹¹⁷ Due to allo-HSCT survivors' limited access to activities as a result of isolation, susceptibility to infection and the various late effects impacting each individual, along with a high symptom distress making patients reluctant to engage in activity,¹¹⁸ physical activity can be difficult.¹¹⁹ One of the most frequently occurring symptom reported during the first year after allo-HSCT was tiredness. Tiredness can also have an undesirable impact on survivors' ability to engage in physical activity, while conversely, physical activity can positively affect tiredness and physical weakness,¹²⁰ symptoms that the participants in this thesis scored highly in relation to both symptom frequency and symptom distress. Gradually increasing exercise levels after allo-HSCT has been found to reduce fatigue and improve quality of life.¹²¹ Hence, exploring ways of increasing allo-HSCT survivors' physical activity would be beneficial, both to potential reduction in fatigue, but also as it has been found to have a positive effect on return to work for cancer survivors.^{122,123}

8.1.5 Mental health

Approximately 20% of the participants experienced symptoms of depression both at baseline and at seven months after treatment but only depressive symptoms at seven months were significantly associated with full-time sick leave one year after allo-HSCT. Since no data were collected pre-diagnosis, it is difficult to establish whether participants already experiencing symptoms of depression before they fell ill were the ones remaining on full-time sick leave one year after treatment. However, considering that symptoms of depression at baseline were not associated with full-time sick leave, but only at seven months post-treatment, it is likely that allo-HSCT contributed to depressive symptoms affecting full-time sick leave one year after the transplantation. In addition, only a third of the participants with depressive symptoms at baseline reported experiencing symptoms of depression one year after allo-HSCT. Although no previous research has been found that focuses on associations between sick leave and depression after allo-HSCT, unemployment after allo-HSCT has been linked to depression,⁶⁵ whereas a study performed on patients diagnosed with a haematological malignancy found no significant associations between depression and return to work.⁷⁵ However, there are several studies on non-cancer populations showing that depression

negatively affects return to work after injury or illness.¹²⁴ Despite conflicting results whether depression affects allo-HSCT survivors' occupational situation, it appears as if mental health is an important factor that should not be overlooked when discussing return-to-work opportunities after allo-HSCT and it would be worth exploring the interrelationships between mental health and occupational status in an attempt to establish whether depression is the reason for survivors remaining on sick leave or if being on sick leave is the impetus for developing depression. In addition, it is important to note that patients with cGvHD who report depression have been found to have a significantly compromised quality of life, mental health and physical functioning, along with lower overall survival.^{38,43,62,125,126} These findings increase the necessity for early identification of vulnerable allo-HSCT survivors who suffer from medical complications and mental health issues to prevent poor after effects and subsequent morbidities. Severe GvHD has also been linked to suicide, where patients have needed hospitalisation due to suicide and suicidal ideation related to GvHD,¹²⁷ reiterating the importance of early identification of survivors suffering from GvHD to provide vital support. Potential associations between symptoms of depression and cGvHD one year after allo-HSCT were not explored in this thesis; hence, there is a possibility that symptoms of depression and cGvHD may be interlinked. Additional research, especially of a qualitative nature, would be of interest to further explore how mental health affects allo-HSCT survivors along with its potential associations with medical late effects.

8.1.6 Stress intolerance

Intolerance to stress was described as a barrier that participants struggled with, as it could affect both their return-to-work process and their work ability once back at work. Similar results have been found in patients one year after treatment for a haematological malignancy, where mental stress impacted on return to work and low stress on the job facilitated work integration among autologous HSCT patients even for as long as a median of 9.5 years after treatment.¹¹⁶ Findings in this thesis show that difficulties coping with stress remain as late as three to six years after allo-HSCT, which demonstrates the necessity of supporting survivors in their management of stress. A few participants described feeling better equipped to manage stress after engaging in mindfulness. Mindfulness has been found to help cancer patients improve their quality of life and feel less vulnerable to stress,¹²⁸ suggesting that it could be advantageous to recommend mindfulness meditation exercises to allo-HSCT survivors in the hope of improving the return-to-work process.

8.1.7 Work-related factors

That no work-related factors were found to be significantly associated with return to work is surprising, considering the amount of research on cancer survivors suggesting otherwise. In Study III, results revealed that 82 – 89% of the participants were able to set their own work pace, decide when to do their work assignments and be part of planning their work. Since such a large proportion of the participants already had the opportunity of such flexible working conditions, identification of significant associations between work-related factors and return to work could be difficult due to the sample being too small and/or not including

enough participants who did not have the opportunity to adjust their work situation. However, a higher educational level showed a significant association with return to work two years after treatment, which contradicts earlier findings from a study including both allogeneic and autologous HSCT-survivors where no associations between educational level and occupational situation were found.²³ The majority of the participants in this thesis had a higher educational level. Hence, a possible explanation for the significant results in this thesis could be that individuals with a higher educational level were employed in positions that were frequently more flexible compared to employment that does not necessitate higher levels of education, as employer accommodation, including flexibility, has been found to be a strong predictor of return to work among cancer survivors.¹⁴ In addition, a higher educational level has been found to have an impact on perceived quality of life after allo-HSCT¹¹¹ and further exploration into whether quality of life is improved due to a return to work or whether return to work rates are higher for those who report a higher quality of life before returning to work would be of interest.

In qualitative findings in Study **IV**, allo-HSCT survivors stated that they would have found it difficult to return to work if they had been unable to adjust their work situation regarding flexibility, such as hours worked and tasks to be performed. Interestingly, no significant associations between work-related factors one year after allo-HSCT and return to work two years after treatment were found in the quantitative analyses. These results contradicts several studies on return to work after cancer that have shown that adjustments at work increases the likelihood of return to work¹²⁹⁻¹³¹ and that lack of work adjustment increases the risk of sick leave.^{132,133} A reason for these differing results could perhaps be that adjustments to the allo-HSCT survivors' occupational situation in this thesis have already been implemented in other forms than the factors investigated, such as having the opportunity of working less than 50% and remaining on some level of sick leave. Resignation from work during the course of allo-HSCT treatment has also been found to be fairly high as 41% of participants in a Japanese study decided to resign from work, with the highest incidence of reported resignation being after discharge post-allo-HSCT.¹³⁴ Perhaps these issues are not as common in Sweden due to the social security system that allows for work adjustments in the form of working less hours while remaining on some level of sick leave. Previous research has also showed that it is common for allo-HSCT patients to experience serious adverse financial consequences.^{67,76} Therefore, it is worth noting that satisfaction with their current financial situation was not associated with full-time sick leave and almost all participants in Study **IV** stated that they were able to adapt to their new situation and were financially comfortable. This may again be due to the Swedish context including the national social insurance system that financially compensates patients for loss of earnings following injury or illness.

8.1.8 Facilitating return to work

The predominant facilitator in the return-to-work process in Study **IV** was the opportunity for flexible working, not only in relation to working hours but also the structure of the working day. The opportunity to set their own starting and finishing times and being part of the decision-making process regarding their work activities enabled an earlier and more straightfor-

ward return to work. In addition, being allowed to decide themselves on their rate of return to work in incremental stages gave the participants a sense of control and without it, their return to work could end up being unsuccessful. Flexible working also allowed the participants to plan their days and prioritise their workload, which especially reduced their levels of fatigue and stress; thus, increasing their quality of life. Strengthening these findings is a recent study investigating return to work after allo-HSCT, which found that flexible work schedules and reduced working hours increased the likelihood of return to work from 52% to 76% five years after treatment,¹³⁴ as well as flexible work being a facilitating factor in the return-to-work process among patients with other cancer diagnoses,^{3,14,18} including autologous HSCT patients.¹¹⁶

The need for flexible working for a successful return to work emphasises the importance of a good relationship with a supportive employer. Most participants described that they had supportive employers with whom they had a good communicative relationship. Previous studies into other cancer diagnoses have also concluded that a supportive employer can facilitate return to work, as a non-supportive work environment and lack of understanding from supervisors were negatively associated with return to work.^{67,135-138} In line with studies of head and neck cancer survivors¹³⁵ and autologous HSCT patients,¹¹⁶ decreased self-esteem and self-confidence in relation to work were experienced by a few participants in Study **IV** but these issues were alleviated by supportive employers with whom they had a good communicative relationship. Other studies have also found that cancer survivors often overestimate their work ability upon return to work and take on too much too quickly, which can be demoralising and lead to failures in the return-to-work process.¹³⁹⁻¹⁴¹ However, this was not found in this thesis, but rather, the participants described that they were not feeling stressed over when and how to return to work but instead took their time in making their decisions to ensure that the timing of return to work suited them, which was often the result of their relationship with a supportive employer. In contrast to previous studies, most participants did not experience any pressure from their employer to return to work,^{18,137} which may have been due to their motivation and willingness to achieve a successful return to work.

Working from home was considered one of the most important facilitators in the return-to-work process and several participants stated that they would not have been able to return to work without the possibility of working from home. Not only did it minimise the risk of infections, which many survivors are fearful of due to their compromised immune system, but it also allowed for even greater flexibility in working hours and activities, making it easier for participants to engage in self-care management, such as scheduling in physical activity and/or rest as needed during the day. Interestingly, working from home also seemed to decrease the need for rest compared to in-office working. Previous studies in cancer survivors have also found that the flexibility of working from home and being able to alter one's schedule facilitated return to work.^{135,137,142} Qualitative studies in patients with a haematological malignancy, autologous HSCT patients and research including both autologous and allo-HSCT survivors have also revealed that flexibility pertaining to time and work conditions and environmental factors, such as being able to work from home, were major positive factors

that facilitated return to work.^{67,115,116,143} In addition, a recent study revealed that work adaptations increased the rate of return to work for allo-HSCT survivors from 52% to 76% at a median of five years after allo-HSCT, but did not state the type of work adaptations.¹³⁴ Considering the rapid adaptations needed due to the forced transition to working from home during the COVID-19 pandemic, hopefully allo-HSCT survivors will benefit from employers' experiences of these adaptations and increase their possibilities of working from home. Nevertheless, there are aspects to consider regarding working from home. Recent research shows that employees' family-work conflict, leisure time and social isolation were negatively related to working from home.¹⁴⁴ However, self-leadership and autonomy were positively related^{144,145} and perception of productivity level among workers remained unchanged when compared to in-office productivity, with females, older and high-income workers even reporting increased productivity when working from home.¹⁴⁶ Furthermore, allowing for flexible working conditions could possibly reduce the risk of low vocational satisfaction affecting full-time sick leave one year after allo-HSCT, which was found to be the case in Study II. Similar results have also been shown six weeks post-surgery in patients with breast cancer where low vocational satisfaction predicted non-return to work 10 months after surgery⁸⁰ and long-term sick leave for non-cancer patients.^{78,79} However, it is difficult to ascertain whether low vocational satisfaction is due to being on sick leave or vice versa, as vocational dissatisfaction may be dependent on whether the patient has employment to return to.

8.1.9 Support in the return-to-work process

Findings in this thesis show that even three to six years after allo-HSCT, survivors are still affected by late adverse effects of their treatment that influence return to work. In an effort to support survivors in the return-to-work process, signs and symptoms, especially of medical and treatment-related factors, impairments and health status, as well as psychosocial factors, need to be identified at an early stage and supportive strategies implemented to guide survivors on how to manage and overcome their difficulties. Research on cancer survivors states that guidance from healthcare professionals^{137,147} and information for employers should be improved.¹³⁷ In line with previous studies,^{18,147,148} most participants in this thesis rarely discussed return to work with healthcare professionals, which is consistent with research showing that only 54% of cancer survivors indicated that conversations regarding work-related issues with healthcare professionals had been helpful.¹⁴⁷ However, in view of the work-related factors that survivors described as facilitating their return to work, it is clear that it is necessary for employers to be made aware of survivors' experiences of return to work to gain insights into the importance of their support regarding potential work adaptations. In addition, increasing healthcare professionals' awareness of allo-HSCT survivors' return-to-work process is essential, as barriers to return to work can be identified early. This could allow for care plans being implemented that include interventions to support survivors in overcoming or limiting these barriers. A systematic review of existing interventions aimed at enhancing return to work in cancer patients showed mixed results regarding interventions' effectiveness. Interventions based on patient education and teaching self-care behaviours found similar

return-to-work rates compared to standard care, while multidisciplinary interventions involving physical, psycho-educational and/or vocational components led to higher return-to-work rates.¹⁴⁹ Furthermore, a multidisciplinary rehabilitation programme for cancer patients combining personal counselling on work-related issues with a specialised oncology occupational physician and supervised physical exercise in a clinical setting during chemotherapy is likely to result in return to work in addition to reduced fatigue, increased work ability and quality of life.¹⁵⁰ Considering that the findings in this thesis show that allo-HSCT survivors experience similar barriers in the return-to-work process as patients with other cancer diagnoses, together with physical activity reducing fatigue, multidisciplinary interventions consisting of occupational counselling, preferably including contact with the employer, and physical activity could prove beneficial for allo-HSCT survivors' return-to-work process. In addition, this thesis shows the importance of always including the allo-HSCT survivors in the discussions and planning of their return to work. Not only to discern the difficulties they are facing in order to implement support strategies, but also because participants felt respected and listened to, as well as giving them a feeling that they could maintain some control over their situation, which for some increased their motivation to return to work.

Person-centred care implies that healthcare professionals focus their care on the needs of the individual and is based on the individual's unique experiences and ability to participate in their care.¹⁵¹ Adverse late effects, symptom burden and their impact on health and quality of life are important parts of person-centred care,⁵⁷ and the dialogue between the patient and the healthcare team needs to be systematic, continuous and dynamic⁵¹ in order to prevent, reduce and manage the side effects and other adverse consequences as early as possible after allo-HSCT. Research highlights the importance of implementing models to identify patient-reported outcomes in a person-centred way; thus, facilitating communication between the patient and healthcare professionals.^{151,152} For example, symptom burden was reduced when routine symptom monitoring was implemented in the care of autologous and allo-HSCT patients¹⁵³ emphasising the importance of healthcare professionals systematically measuring and monitoring allo-HSCT survivors' health status, both physical and mental, through continuous dialogue. Seeing that some of the core responsibilities of nursing includes prevention of illness and care of the ill, registered nurses are especially important in supporting patients in their recovery.

Despite longer recovery periods compared to many other cancer diagnoses, allo-HSCT survivors are motivated to return to work and experience similar barriers and facilitators in their return-to-work process as other cancer survivors with fatigue, tiredness and intolerance to stress being particularly difficult to overcome. However, although many allo-HSCT survivors often encounter challenges in their return-to-work process, it should be noted that not all survivors experience difficulties, as there are survivors who seem content with their occupational situation, both among those who work full-time and those who work part-time. Nevertheless, for survivors experiencing difficulties, barriers in the return-to-work process need to be identified at an early stage in order for appropriate interventions to be implemented that can support survivors achieving a successful return to work. Additionally, employers need to be

made aware of allo-HSCT survivors' potential barriers in the return-to-work process and allow for a flexible approach to work, including the option of working from home and the need to make essential adjustments in the workplace.

8.1.10 Conceptual framework

According to Mehnert,¹⁴ developing a better understanding of cancer and treatment induced work-related problems facilitates cancer survivorship research. Examining the occupational situation of cancer survivors from a multidisciplinary perspective, including psychosocial, neurophysiological, sociological, financial and health perspectives, is critical for improving the understanding and assessment of central aspects of occupational issues in cancer survivorship.¹⁴

This thesis is an attempt at identifying factors of importance for allo-HSCT survivors' occupational situation guided by Mehnert's model related to research about work in cancer survivorship (p. 9).¹⁴ Recognising the different aspects involved in the return-to-work process will not only lead to more accurate and reliable assessments of the needs of allo-HSCT survivors, resulting in improved occupational rehabilitation, but also provide vital information to healthcare professionals and employers on how to best support survivors through the process. Comparing the results of the studies on which this thesis is based on to Mehnert's model, the areas that appear to have a greater impact on allo-HSCT survivors' occupational situation are impairments and health status, especially cGvHD, fatigue, a high symptom burden and not being physically active, and psychosocial factors, including symptoms of depression and intolerance to stress. Work-related factors emerged as important factors for allo-HSCT survivors' occupational situation on an individual basis in the qualitative study, but no significant associations between occupational situation and work-related factors were found in the quantitative studies.

In relation to demographic factors, gender and age were not found to be factors affecting occupational situation after allo-HSCT, which contradicts previous research indicating that cancer survivors, including allo-HSCT survivors, of female gender and older age are less likely to return to work,^{22,23,68} as well as being more likely to work part time at a median time of eight years after treatment²² or remain on sick leave for longer periods of time.¹⁵⁴ Treatment-related factors, such as conditioning treatment and total body irradiation, and the disease specific factors diagnosis and relapse were investigated in Study I to see whether they influenced full-time sick leave at one year after treatment, but none of these factors was found to be a predictor. Relapse during the first year after allo-HSCT was not associated with full-time sick leave one year after transplantation, whereas previous research in autologous HSCT patients has shown that relapse of the primary disease was associated with a lower likelihood of return to work in the first year after treatment,⁶⁹ as well as a decreased rate of return to work for patients who were on sick leave at the time of relapse.¹⁰⁶ The results suggest that those included in this thesis who relapsed during the first three years after allo-HSCT were treated successfully, as they were able to participate in the studies. Unsuccessful treatment of relapse after allo-HSCT often results in death, which led to a lack of data at follow-ups in this thesis.

Return to work after allo-HSCT can be a complicated process in which several aspects need to be considered, including the interactions between the various aspect involved. In order to develop and implement interventions and rehabilitation programmes, it is necessary to gain a multifaceted understanding of cancer and treatment-induced physical, cognitive and psychosocial consequences and their combined impact on allo-HSCT survivors' occupational situation.

8.2 METHODOLOGICAL CONSIDERATIONS

8.2.1 Design and sample

The longitudinal perspective in this thesis allowed insights into which factors were associated with sick leave at one year and return to work two years after allo-HSCT, as such a design is useful for studying changes over time and potential causal relationships.¹⁵⁵ There were six data collections points throughout the study period, four of which occurred during the first year, which is considered to be a time when change is rapid, and thus requiring more frequent data collection time points to examine patterns and make accurate predictions. Studies **I – II** focused on the early recovery phase after allo-HSCT (first year), which is beneficial as this period has been less studied. Many other studies including allo-HSCT survivors are cross-sectional and generally focus on data one year after or beyond allo-HSCT.

The sample in this thesis only consisted of participants who had undergone allo-HSCT. Many studies within the stem cell transplantation field include both autologous and allo-HSCT patients, which can be problematic as the two treatments are different, especially in relation to side effects and complications. The sample size, however, might be considered relatively small but since only approximately 400 allo-HSCT are performed annually in Sweden and the specific inclusion criteria, along with the severity of the participants' diagnoses and treatments, an eligible sample of 321 potential participants, out of whom 237 agreed to participate, should be recognised as relatively large for this patient group. A serious challenge of longitudinal designs that needs to be taken into consideration is attrition.¹⁵⁵ Due to the nature of the intense treatment and the subsequent consequences faced by the participants, attrition was also found to be an issue in this thesis as 55 participants died during year one, 18 during year two and six during year three; thus, reducing the available sample throughout the study period. The smaller sample sizes available for statistical analyses in the different studies can affect the statistical power of the studies and increase the risk of type II-errors and there is a possibility that larger sample sizes could have discovered significant associations where none were found. In addition, analyses investigating the effects of cGvHD should be interpreted with caution as there is a risk that participants who suffered from severe cGvHD may have died, opted out of the study or from responding at one or more time points due to feeling unwell. Indicative of this is the relatively small number of participants in this thesis diagnosed with cGvHD (approximately 25%) and the absence of participants diagnosed with severe cGvHD when previous figures show that up to 65% of allo-HSCT patients develop cGvHD.^{38,41} Despite the low proportion of participants diagnosed with cGvHD, significant associations were found in relation to both sick leave at one year and not returning to work at

two years after allo-HSCT. This only strengthens the conclusion that cGvHD plays a key role in allo-HSCT survivors' occupational situation.

A comparison between respondents and non-respondents at baseline showed that women participated to a higher degree than men, but no differences were found in relation to age or diagnosis. The lack of information regarding occupational status among non-respondents in the studies is problematic, especially as the reasons for not participating are unknown. This may have resulted in a lack of data from the most severely affected participants, both in terms of diagnosis and/or treatment as well as occupational situation, if they were not capable of responding due to their health status.

The criterion-based sample in the qualitative study (IV) was drawn from the population of the larger questionnaire study. This type of sampling method was chosen as it contributed to a deeper understanding of thoughts, feelings, perceptions and experiences related to a troublesome return to work. However, by only selecting those who were classified as experiencing a troublesome return to work, the sample only included allo-HSCT survivors who were working part time or not at all. Excluding those who were able to return to work more rapidly resulted in the study focusing more on a problematic return to work. Thus, analysis of aspects and factors that could have supported return to work was limited as such data were not collected. The study would most probably have yielded different findings if the sample included individuals who experienced a straightforward return to work. This could also have contributed to some of the discrepancies found between the quantitative studies where the group-based questionnaire data did not reveal any associations between work-related factors and return to work, whereas the interviewees in the qualitative study frequently highlighted work adjustment and flexibility as fundamental for a successful return to work. Acquiring samples using a criterion-based method also increases the risk of the sample not representing the population. Although the sample contained an even gender distribution and was relatively diverse regarding time since allo-HSCT, most of the participants were of an age where they had already experienced a long and fulfilling career. In addition, most participants in this study were in employment that for the most part was flexible to changes in their work situation regarding working hours and possibilities to work from home. A larger proportion of participants who were not as established on the job market and could not easily adapt their work situation may have yielded different results.

8.2.2 Data collection

The use of clinically diagnosed cGvHD data in this thesis should be considered advantageous as many other studies only use self-reported data, which could be deemed uncertain due to subjectivity. In the logistic regression analyses, the presence rather than severity of cGvHD was analysed, perhaps influencing the cGvHD results. However, severity of cGvHD was also analysed and showed similar results despite the lack of participants with severe cGvHD, and thus, strengthening the findings in this thesis related to cGvHD. Similarly, the likelihood of participants being classified as having symptoms of depression in Study II might be over-estimated as depressive symptoms were measured using the HADS self-assessment scale and

not diagnosed by a clinician. However, HADS has been found to have excellent case finding abilities in many settings.⁹⁰

The SFID-SCT questionnaire in Study **I** was chosen because it was originally developed in the Swedish language and covers 36 relevant symptoms following allo-HSCT. The questionnaire consists only of single items and has not been psychometrically validated, which is a potential threat to internal validity. Nevertheless, it has previously been used in several Swedish studies^{22,54,86,87} and in the studies on which this thesis is based on, all items were experienced by at least one participant at all time points.

In Study **IV**, a possible limitation is the extended inclusion period due to the COVID-19 pandemic along with most of the data being collected during the pandemic, which meant that circumstances at work had changed for some of the participants as it had enabled them to work from home more easily. This could have biased the discussions during the interviews by emphasising the facilitating nature regarding return to work. Important to note, though, is that many participants who found working from home a crucial factor in their return-to-work process had already had the opportunity to work from home before the pandemic.

There is no established way to conduct research on sick leave status and return to work and different definitions, cut-offs etc. are used in both national and international settings. For example, in Study **III**, the definition of return to work was being back at work >50% as this can be considered as being re-established on the labour market. However, other studies measure return to work differently by examining return to work as a yes or no question without taking part-time work into consideration, using different cut-off points specifying when return to work has taken place or defining return to work as a specified period of time without receiving any sickness benefits. These discrepancies in research related to occupational situation, including the different study contexts, can complicate the possibilities to compare results; thus, threatening external validity. Nonetheless, research into occupational situation is important despite these challenges, as it generates invaluable knowledge for a successful recovery.

9 CONCLUSIONS

Similar to previous research among survivors of cancer,^{67,135,137,156-158} the findings in this thesis revealed that work was still an important aspect for the participants after allo-HSCT, that work added meaning to their lives and allowed them to feel useful to society and that they were motivated to return to work, although they may face various obstacles in their effort to do so.

A large proportion of allo-HSCT survivors are still on full-time sick leave one year after treatment and cGvHD and depressive symptoms may be associated with sick leave. A high symptom burden and low physical activity four months after allo-HSCT were also associated with full-time sick leave and poor general health one year after transplantation. Furthermore, return to work was found to be a lengthy process for many allo-HSCT survivors, where cGvHD and a higher educational level are of a greater importance than adjustments to the work situation in the return-to-work process two years after allo-HSCT.

Careful monitoring and management of both physical and psychosocial adverse effects and their consequences are essential in the care provided by healthcare professionals working closely with allo-HSCT survivors. Implementing appropriate self-assessment instruments could be beneficial, as such measures can help identify and enable strategies to reduce late effects, which could improve patients' perception of health and facilitate recovery, including an increased likelihood of a successful return to work and transition into survivorship.

For patients, healthcare professionals and employers to better address the needs of allo-HSCT survivors in their professional life, a profound understanding of cancer and treatment-induced physical, cognitive and psychosocial late effects and their impact on daily activities is fundamental for the development of educational, rehabilitative and occupational interventions. In addition, it is important to listen to each individual and take his/her own assessments of barriers and facilitators into account as allo-HSCT survivors have different individual needs. This could all be achieved by ensuring a person-centred rehabilitation approach to guide and support survivors in the return-to-work process, and thus, regain an important aspect of everyday life.

Involvement is needed not only from the healthcare system but also social insurance agencies, employers and colleagues to be able to support allo-HSCT survivors in coping with feelings of social exclusion, decreased self-esteem as well as quality of life. Survivors need to be physically and mentally prepared for the return-to-work process, but also for the possibility of not being able to return to work. However, it is important to note that not all allo-HSCT survivors experiences difficulties in their return-to-work process. Having the ability to predict the length of sick leave and potential obstacles in return-to-work process after allo-HSCT could help prepare higher-risk patients for long-term sick leave and a delayed return to work and allow for interventions to be implemented to restore their quality of life, including a more satisfactory occupational situation.

10 CLINICAL IMPLICATIONS

The findings in this thesis contribute to a better and deeper understanding of what allo-HSCT survivors can expect in terms of sick leave and return to work during their recovery. This is valuable information not only for allo-HSCT survivors, but also for their families, healthcare professionals, employers and society in order for adequate multidisciplinary support to be provided. The majority of allo-HSCT patients are diagnosed with a haematological disease when actively engaged in working life, causing disruption in their lives, and it is important that survivors are informed about all the various aspects that can affect their lives after such an intense treatment. Not receiving valuable and up-to-date information regarding the impacts of allo-HSCT on their working life can cause disappointment and resentment due to unrealistic expectations, which in turn can affect their psychological well-being long after allo-HSCT.

It is important for healthcare staff to closely monitor and manage the consequences of cGvHD and be observant of and find appropriate care strategies for patients showing symptoms of depression in the aftermath of allo-HSCT. In addition, an increased awareness regarding the consequences of symptoms after allo-HSCT is necessary for both allo-HSCT survivors and healthcare professionals in order to ease patients' symptom burden.

Implementing multidisciplinary interventions incorporating occupational counselling that involves the healthcare system, allo-HSCT survivors and, importantly, their employers, is an encouraging approach in achieving a successful return to work, especially when acknowledging and allowing for the individual needs of allo-HSCT survivors. When comparing Mehnert's model related to research about work in cancer survivorship¹⁴ (p. 9) to the results found in the studies included in this thesis, it is apparent that many factors affecting allo-HSCT survivors' occupational situation correspond with several factors and variables included in Mehnert's model, demonstrating that allo-HSCT survivors face many of the same challenges as other cancer survivors. Identifying the various aspects involved in allo-HSCT survivors' return-to-work process, including their interaction, will provide information that is essential for determining when and in which areas supportive strategies are required. Thus, identifying allo-HSCT survivors at risk of long-term sick leave and/or an unsuccessful return to work, in addition to the affected factors involved in the process, may help to improve survivors' rehabilitation and increase their quality of life, including their occupational situation.

11 FUTURE PERSPECTIVES

Examining sick leave and return to work in allo-HSCT survivors further along the trajectory than in this thesis would be of interest to ascertain whether sick leave status and/or return-to-work alter over longer periods of time. In a cross-sectional study regarding allo-HSCT survivors' occupational situation, results showed that 52% had returned to full-time employment at a median of eight years after the transplantation.²² This indicates that a substantial proportion of allo-HSCT survivors remain on some level of sick leave long after their transplantation. Findings in this thesis showed that over a third of the participants were working part-time two years after the transplantation and, thus, additional longitudinal studies following participants for longer than three years would be interesting to examine if return-to-work rates fluctuate over time or become stable at a certain point. It could also provide valuable information regarding the factors that were found to affect allo-HSCT survivors' occupational situation and whether they remain the same or change with the passing of time. Furthermore, exploration into potential associations between different predictor variables in this thesis, such as cGvHD, physical activity, symptom burden, symptoms of depression etc., could provide more in-depth knowledge as to which and when different variables affect each other. This would be particularly interesting to investigate on an individual level as the focus of the results in this thesis are on a group level. Another interesting perspective would be to combine data from all six different allo-HSCT centres in Sweden, or register data based on occupational situation of allo-HSCT survivors reported to and by the Social Insurance Agency, as this would allow for larger sample sizes. This would be particularly interesting in relation to work-related factors, as previous findings, in contrast to results in this thesis, have shown work adjustment to be a key factor in the return-to-work process for patients diagnosed with cancer.

Other interesting results outside the scope of this thesis emerged in the examination of various factors affecting allo-HSCT survivors. For example, distress related to nutritional concerns during the first year after allo-HSCT was reported at several time points. Poor nutritional intake during and after allo-HSCT can have a negative impact on recovery as there is an established link between nutrition and the immune system, where malnourished patients are at greater risk of developing GvHD,^{159,160} as well as increase the risk of mortality.¹⁶¹ In addition, distress relating to sexuality was also found to be an issue of concern throughout the first year with three of the five highest ranking distressing symptoms being related to sexual difficulties. These findings were not discussed in this thesis as they were not relevant to the aim but considering that these factors can have a profound impact on allo-HSCT survivors' well-being, they deserve further exploration.

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