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Karolinska Institutet, Stockholm, Sweden

# **A BALANCING ACT: WORK LIFE AND CHILDCARE AMONG PARENTS OF CHILDREN WITH CANCER**

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# A BALANCING ACT: WORK LIFE AND CHILDCARE AMONG PARENTS OF CHILDREN WITH CANCER

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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The thesis will be defended in public in Inghesalen, Karolinska Institutet, Stockholm, April 15<sup>th</sup> 2021, at 9:00.

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## POPULAR SCIENCE SUMMARY OF THE THESIS

Around 300 children are diagnosed with cancer each year in Sweden. A child's cancer diagnosis dramatically changes the whole family's life situation. The treatment is often long and very demanding and the risk of late effects creates uncertainty about the child's future. Increased childcare demands following the child's diagnosis may lead to long periods of work absence among the parents. In addition, parents often experience psychological distress including symptoms of anxiety and depression following the child's diagnosis, which may lead to an increased risk of sickness absence. Hence, a child's cancer diagnosis may complicate the ability of parents to balance the responsibilities as both parents and professionals. Difficulties in managing family and work life may be further affected by pre-existing income and work conditions, as well as expectations based on traditional gender roles, in which mothers often are expected to take the primary caregiving role and fathers the primary breadwinner role.

In this thesis, we investigated the socioeconomic consequences that parents of children with cancer face, with focus on sick leave (study I), division of childcare leave within couples (study II), the balance between the parent role and the work role (study III), and facilitators and barriers for parents' ability to return to work and meet financial needs (study IV). In the first two studies, statistical analyses of data from Swedish registries were conducted. The studies were based on data from 3,626 parents of children diagnosed with cancer during 2004-2009, and a matched reference group of 34,874 parents whose children did not have cancer. The data were analysed from the year before the child's cancer diagnosis and up to seven years after diagnosis. The final two studies were based on nine focus groups with 21 mothers and 11 fathers of children with cancer. The interview data were analysed using content analysis.

We found that the number of days on both sick leave and childcare leave increased dramatically among parents following a child's cancer diagnosis, and remained higher than the reference group up to six years after diagnosis. Mothers were overall on leave for more days than fathers were. We did not find considerable support that parents divide the childcare leave based on their income relative to each other. Neither did we find that parents' income development was affected by being on childcare leave. From the interviews, we found that parents felt that the child's illness had given them new perspectives on life, and that they prioritized family over work even more than before. However, to have a work life that provided a respite from the caregiving demands was also highly appreciated. The balance between family and work roles was affected by the parents' pre-existing conditions related to the family's financial resources and their work situation, but also largely to expectations grounded in traditional gender roles. The parents described that the children often experienced difficulties a long time after the cancer treatment, which in turn negatively affected their ability to balance work and parenthood.

A flexible and accommodating employer was highlighted as a key facilitator for the ability to return to work after a period of absence. To meet the financial needs of parents, coordinated and efficient support from the healthcare, governmental agencies, and employers is needed.

# POPULÄRVETENSKAPLIG SAMMANFATTNING

Varje år drabbas omkring 300 barn av cancer i Sverige. Ett barns cancersjukdom innebär att livet förändras dramatiskt för hela familjen. Tiden för behandling är ofta lång och väldigt påfrestande och därtill medför sjukdomen en stor osäkerhet för barnets framtid. Barnets behov av omvårdnad ökar ofta drastiskt, vilket kan leda till långa perioder av frånvaro från arbete eller annan sysselsättning för föräldrarna. Utöver detta så drabbas föräldrar själva ofta av psykisk ohälsa med exempelvis ångest och depression, vilket kan leda till en ökad risk för sjukfrånvaro. Barnets ökade omvårdnadsbehov och den psykiska påfrestringen kan således tänkas försvåra föräldrarnas möjlighet att balansera det ansvar de har som både föräldrar och yrkesverksamma. Svårigheter att hantera familj och yrkesliv kan ytterligare påverkas av föräldrarnas utgångsläge gällande inkomst och arbetssituation, men även förväntningar som baseras på traditionella könsroller, där mammor ofta förväntas ta största ansvaret för familj, och pappor för arbete.

I denna avhandling undersöks socioekonomiska konsekvenser som drabbar föräldrar till barn med cancer. Avhandlingen består utav fyra delstudier med fokus på sjukskrivning (studie I), fördelning av vård av barn inom föräldrapar (studie II), balansen mellan föräldrarollen och arbetsrollen (studie III), samt vilket typ av stöd som underlättar eller försvårar för föräldrar att återgå till arbete efter frånvaro och att möta sina ekonomiska behov (studie IV). De första två studierna baserades på data från svenska register. Utfallen studeras i en grupp av 3626 föräldrar till barn som diagnosticerades med cancer under åren 2004-2009 och jämförs med en matchad kontrollgrupp med 34 874 föräldrar till barn som inte har drabbats av cancer. De statistiska analyserna görs från året innan barnets diagnos och upp till sju år efter diagnos. De sista två studierna baserades på nio fokusgrupper med 21 mammor och 11 pappor till barn med cancer. Materialet från intervjuerna har analyserats genom innehållsanalys.

Vi fann att antal dagar med både sjukskrivning och vård av barn ökade kraftigt hos föräldrar efter ett barns cancerdiagnos, och att antalet dagar var högre än kontrollföräldrarnas i upp till sex år efter diagnos. Mammorna var överlag hemma mer än papporna. Vi fann inget betydande stöd för att föräldrarna fördelade tid för vård av barn baserat på sina inkomster relativt varandra, och inte heller att inkomstutveckling påverkades av frånvaro för vård av barn. Från intervjuerna fann vi att föräldrarna upplevde att barnets sjukdom hade gett dem nya perspektiv på livet, och att familjen prioriterades framför arbete i en högre grad än tidigare. Att ha ett arbetsliv som tillät en paus från föräldrarollen var samtidigt något som de värderade högt. Balansen mellan föräldrarollen och arbetsrollen påverkades även av föräldrarnas olika förutsättningar gällande ekonomi och arbetssituation, men även till stor del de förväntningar de själva hade, och möttes av från andra, som grundades i traditionella könsroller. Föräldrarna beskrev att barnen ofta hade svårigheter lång tid efter avslutad cancerbehandling, vilket i sin tur negativt påverkade föräldrarnas förmåga att balansera arbete och föräldraskapet i ett längre perspektiv.

För möjligheten att återgå till arbete efter en period av frånvaro betonade föräldrarna arbetsgivarens viktiga roll, med flexibilitet och anpassning som nyckelord. För att möta föräldrars ekonomiska behov noteras ett behov av förbättrad samordning från hälso- och sjukvården, myndigheter (i synnerhet Försäkringskassan), och arbetsgivarna.



## ABSTRACT

**Aim.** The overall aim of this thesis was to investigate the socioeconomic consequences for parents of children with cancer in Sweden. The specific aims were to increase the knowledge of (I) risk of sick leave, (II) division of childcare leave, (III) balancing work and family roles, and (IV) facilitators and barriers to return to work and meet financial needs.

**Methods.** The thesis comprises four studies. The first two studies were based on quantitative methods. The data were derived from a sample of 3,626 parents of 1,899 children who were diagnosed with cancer during 2004-2009, and a matched reference cohort of 34,874 parents from the general population. National registry data were utilized to analyze sick leave and childcare leave longitudinally. Logistic, negative binomial, beta, and linear regression analyses were conducted. The final two studies were based on qualitative methods. Nine focus group interviews with 22 mothers and 11 fathers of children with cancer were conducted. The interviews were audio-recorded and transcribed verbatim. The data were analyzed using inductive content analysis in study III, and deductive content analysis in study IV.

**Results.** In studies I and II, we found that parents of children with cancer were on sick leave and childcare leave for statistically significantly more days than reference parents from the year of the child's diagnosis and up to six years after diagnosis. Bereaved parents were at particularly high risk of sick leave. Mothers were overall on sick leave and childcare leave for more days than fathers. The division of childcare leave within a parental couple (i.e. fathers' share of the couple's total childcare leave days) was not substantially associated with the division of income within the couple (i.e. fathers' share of the couple's total income). Moreover, parents' income development was not affected by extent of childcare leave. In study III, we found that parents experienced changed perspectives and priorities after a child's cancer diagnosis. Their ability to balance work and parent roles were affected by context and conditions regarding work, economy and gender roles. Furthermore, parents described a long-term unbalance of roles. In study IV, we found that facilitators for return to work were flexibility and understanding from employers and social services, while barriers were pressures to return without consideration of the consequences. Facilitators to meet financial needs were available public, private and employer support, while barriers were a lack of organized and efficient support from employers and social services.

**Conclusions.** Parents experience considerable work disruptions for several years after a child's cancer diagnosis, due to both the child's increased care demands, as well as their own ill health. Parents ability to balance work and family was affected for a long time, while the understanding and support from employers and social services declined over time. For parents to be able to meet financial needs and return to work, more coordinated and efficient support is needed from healthcare and social services, as well as flexibility from employers.

**Keywords:** Childhood cancer, parents, sick leave, childcare leave, work-family balance, return to work, support care

## LIST OF SCIENTIFIC PAPERS

This doctoral thesis is based on the following four studies, which are referred to in the text by their Roman numerals (I-IV):

- I. Hjelmstedt, S., Lindahl Norberg, A., Montgomery, S., Hed Myrberg, I. & Hovén, E. (2017). Sick leave among parents of children with cancer – a national cohort study. *Acta Oncologica*, 56:5, 692-697
- II. Hjelmstedt, S., Montgomery, S., Nybergh, L., Hed Myrberg, I., Lindahl Norberg, A. & Hovén, E. (2020). Division of childcare leave among parents of children with a serious illness. *Journal of Family Issues*, (Epub) doi:10.1177/0192513X20940748
- III. Hjelmstedt, S., Forinder, U., Lindahl Norberg, A. & Hovén, E. A balancing act: Working and caring for a child with cancer. (Manuscript)
- IV. Hjelmstedt, S., Forinder, U., Montgomery, S., Lindahl Norberg, A. & Hovén, E. Facilitators and barriers to return to work and meet financial needs among parents of children with cancer. (Manuscript)

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## LIST OF ABBREVIATIONS

ALL	Acute lymphoblastic leukemia
CI	Confidence interval
DEGURBA	Degree of urbanization
IRR	Incidence rate ratio
LISA	Longitudinal integration database for health insurance and labor market studies (Longitudinell integrationsdatabas för sjukförsäkrings- och arbetsmarknadsstudier)
PTSD	Post-traumatic stress disorder
PTSS	Post-traumatic stress symptoms
SCCR	Swedish childhood cancer registry
SES	Socioeconomic status
TPL	Temporary parental leave

# 1 INTRODUCTION

Every year, hundreds of parents in Sweden receive the devastating and life-changing news that their child has been diagnosed with cancer. The past decades have seen major advances in treatment and subsequently increased survival rates, but children with cancer still often have to face long and demanding treatments and severe late effects. While attending to the child's illness and treatment, parents of children with cancer have to cope with both their own distress, as well as the many practical matters that the child's illness entails, which may result in major life changes. Although the child's survival may be the primary focus for parents after a child is diagnosed with cancer, it is not the only important matter. The financial situation, parents' work arrangements, and the entire family's social and psychological health need to be managed, in addition to the medical aspects. A child's illness does not occur independently of other parts of life, but needs to be incorporated into the existing organization of family life and parents' professional life. This organization might be tricky enough for any parent, and adding the pressure of a child's cancer diagnosis may create a substantial burden on the parents. Family and friends may provide essential support, but in a high-income welfare state such as Sweden, substantive support from the state can be expected as well.

In this thesis, the socioeconomic consequences of childhood cancer for parents will be analyzed and discussed. Particular focus is put on investigating the impact on work disruptions (i.e. absence from work) following a child's cancer diagnosis, and the ability to manage work and family responsibilities. Additionally, the provision of support for socioeconomic issues will be discussed, with suggestions of how the support can be improved.

## 1.1 OUTLINE OF THE THESIS

Chapter 2 begins with briefly introducing the childhood cancer situation in Sweden, as well as the current state of knowledge regarding the psychosocial and socioeconomic situation for parents of children with cancer. Next, the focus moves away from the particular childhood cancer context to aspects of parenting and working in general, including the division of work and family responsibilities, work-family balance, and work disruptions. The Swedish context and social insurance program are additionally discussed. The chapter concludes with a discussion of the rationale of the thesis. Chapter 3 presents the aim of the thesis, both the overall aim and the study-specific aims. In chapter 4, the methodology of the four studies included in the thesis is presented. A summary of the main results from the studies is presented in chapter 5. The results are further discussed in chapter 6, which also includes suggestions for future research and practice.



## **2 BACKGROUND**

### **2.1 CHILDHOOD CANCER IN SWEDEN**

More than 300 children (ages 0-18 years) are diagnosed with cancer each year in Sweden (Lähteenmäki/SBCR, 2020). Major treatment advances in recent decades have resulted in an overall 5-year survival rate of around 85%. Nevertheless, childhood cancer is still one of the most common causes of death among children in Sweden (National Board of Health and Welfare, 2018). While adult cancer is often related to lifestyle and/or external factors, the causes of childhood cancer are largely unknown and not related to social gradient. Research, however, suggests that social gradient may impact survival, with a possible association between socioeconomic status (SES) and survival even in high-income countries (Mogensen et al., 2018). In Sweden, having parents with a lower educational level has been found to be associated with poorer survival among children with cancer (Mogensen et al., 2016).

Types of cancer among children also differ from adult cancer. The most common types of cancer among children are leukemia and brain tumors, which each constitute around one-third of all cases of childhood cancer in Sweden (Lähteenmäki/SBCR, 2020; National Board of Health and Welfare, 2018). Treatments often include chemotherapy, radiation, surgery, or a combination of these modalities, and vary in duration depending on the type of cancer. For the most common childhood cancer, acute lymphoblastic leukemia (ALL), the treatment is typically two and a half years. In the treatment of children with cancer, consideration is taken to the possible side effects of the treatments, as children who have been treated for cancer often have to deal with complications, both during the treatment but also late effects, i.e. health problems that occur months or years after treatment has ended (National Board of Health and Welfare, 2018). Survivors of childhood cancer are at risk for a range of adverse late effects. The literature shows that as many as two-thirds of survivors are likely to have one or more late effects, and that about one-quarter experience a late effect that is serious or even life-threatening (Oeffinger et al., 2006). Common types of late effects include cardiopulmonary problems, musculoskeletal problems, endocrine disorders, neurocognitive problems, osteoporosis, and second malignancies (Oeffinger et al., 2006; Robison & Hudson, 2014). Additionally, survivors of childhood cancer are at risk of psychological and social problems, which may negatively affect the overall quality of life (Robison & Hudson, 2014).

### **2.2 PARENTS OF CHILDREN WITH CANCER**

#### **2.2.1 Psychosocial impact**

A child's cancer not only affects the child, but the entire family. Despite the relatively high survival rate, the diagnosis has a major impact on the daily life of the family even long after treatment has ended, both in terms of parents' own psychological and social well-being, and the family's financial well-being. The initial reactions among parents after a child's cancer diagnosis often include shock, fear and uncertainty, and during the course of the disease parents

have reported feeling vulnerable, as well as emotionally, physically and mentally drained (Gibbins et al., 2012). The highest level of anxiety is reported around the time of the diagnosis. Although the level thereafter typically decreases, symptoms of anxiety continue to be more common among parents of children with cancer than parents of healthy children several years after diagnosis (Michel et al., 2020; Vrijmoet-Wiersma et al., 2008). Even after long periods of remission (i.e. absence of signs and symptoms of the cancer), the fear of relapse and death has been found to cause anxiety among parents (Gibbins et al., 2012; Michel et al., 2020), and a substantial subgroup of parents have been found to experience long-term psychological effects (Ljungman et al., 2014). High levels of depressive symptoms and post-traumatic stress symptoms (PTSS) have also been reported by parents of children with cancer (Michel et al., 2020; Vrijmoet-Wiersma et al., 2008). Studies conducted in Sweden have confirmed that parents of children with cancer report heightened levels of anxiety, depression and PTSS, in particular during the first years after diagnosis (Lindahl Norberg & Boman, 2008), and that mothers and bereaved parents are at particular risk of post-traumatic stress disorder (PTSD) (Ljungman et al., 2015). Factors associated with a higher level of psychological distress (such as anxiety, uncertainty, traumatic stress and depression) include the severity of the child's illness and treatment intensity, being a mother, and pre-diagnosis family stressors (Sultan et al., 2016). However, parents have also reported positive outcomes, such as changed life perspectives, personal growth and stronger family relationships (Gibbins et al., 2012; Ljungman et al., 2014; Michel et al., 2020).

Parents have reported appreciation of support from other family members, friends, health care professionals, the workplace and the general community (Gibbins et al., 2012; Kukkola et al., 2017; Pohlkamp et al., 2020; Pöder & von Essen, 2009), and social support and good family relations have been identified as protective factors for psychological functioning (Vrijmoet-Wiersma et al., 2008). The importance of supporting parents in early time-phases of the child's disease in order to avoid long-term psychological effects among parents has been stressed (Ljungman et al., 2014), but the significance of meeting supportive care needs after treatment completion has been highlighted as well (Wakefield et al., 2013). Insufficient availability of psychosocial support, and in particular an unmet need for psychological support, has been identified among Swedish parents (Kukkola et al., 2017; Pöder & von Essen, 2009). Parental distress is associated with both child distress (Bakula et al., 2019) and child quality of life (Bakula et al., 2020), which highlights the necessity of a family-focused approach to pediatric cancer care. In order to provide adequate, tailored family support, assessments of the needs of all family members have been proposed (Lövgren et al., 2020).

### **2.2.2 Socioeconomic impact**

Psychological distress among parents of children with cancer has also been found to relate to family financial difficulties (Creswell et al., 2014; Pelletier & Bona, 2015; Santacrose & Kneipp, 2019). Research on socioeconomic consequences of childhood cancer has previously been rather scarce but has gained increased attention. Assessment of financial burden has been put forth as an important part of psychosocial care for families, from diagnosis, throughout the



treatment trajectory, and into survivorship or bereavement (Pelletier & Bona, 2015). The importance of acknowledging socioeconomic consequences of childhood cancer has been highlighted in several systematic literature reviews (Pelletier & Bona, 2015; Roser et al., 2019; Santacroce et al., 2018). Childhood cancer has been found to be associated with work disruptions and adverse effects on income and/or employment among parents in Sweden (Hovén et al., 2013; Lindahl Norberg et al., 2017; Öhman et al., 2020), United States (Bilodeau et al., 2018; Bona et al., 2014; Bona et al., 2016; Dussel et al., 2011), United Kingdom (Eiser & Upton, 2007), Australia (Dussel et al., 2011; Heath et al., 2006; Kelada et al., 2020; Wakefield et al., 2014), Switzerland (Mader et al., 2017), Germany (Peikert et al., 2020) and Canada (Limburg et al., 2008; Miedema et al., 2008; Tsimicalis et al., 2012). Exceptions are studies from Norway (Syse et al., 2011), and Denmark (Mader et al., 2020), where no or only minor effects on employment and income were found. Besides work disruptions caused by the increased care burden following the child's illness, parents have also reported being absent from work due to sick leave, i.e. because of their own ill health (Eiser & Upton, 2007; Hovén et al., 2013, Peikert et al., 2020). In addition, the financial burden of childhood cancer not only consists of the indirect costs of lost wages, but also the direct costs of the child's illness, such as monetary expenditures for travel, food and medications (Eiser & Upton, 2007; Kelada et al., 2020; Miedema et al., 2008; Pelletier & Bona, 2015; Tsimicalis et al., 2012, Tsimicalis et al., 2013).

The risk factors for negative socioeconomic consequences include being a mother, lower SES, and lower age of the child at diagnosis (Roser et al. 2019; Santacroce et al. 2018). Adverse socioeconomic effects appear to be most pronounced shortly after diagnosis, but studies have found long-term adverse effects as well (Roser et al. 2019; Santacroce et al. 2018). Differences in outcomes have been found to be related to geographical region (Roser et al., 2019), which may be a result of different welfare systems and social policies. In Sweden, the social benefits have been found to account for much of the reductions in income from employment initially after the child's diagnosis, but as the social benefits diminish after a few years, the total income remained lower among mothers, but not fathers (Hiyoshi et al., 2018). The impact of social benefits in easing the parents' financial burden has also been suggested in the studies from Norway (Syse et al., 2011) and Denmark (Mader et al., 2020), with similar social welfare policies as in Sweden.

### **2.2.3 Differences between mothers and fathers**

Previous research has highlighted differences between mothers and fathers, regarding both psychosocial and socioeconomic consequences after a child's cancer diagnosis. Several studies have found mothers reporting higher levels of general psychological distress and symptoms of for example anxiety, depression (Clarke et al., 2009; Vrijmoet-Wiersma et al., 2008) and PTSS (Ljungman et al., 2015; Vrijmoet-Wiersma et al., 2008) than fathers, although many studies found that the difference diminishes over time (Clarke et al., 2009; Sultan et al., 2016). Differences between mothers and fathers in self-reports of, for instance, symptoms of anxiety and depression may, however, be a reflection of differences in reporting style and manner of

expression than actual differences with regard to experienced distress (Martin et al., 2013). Due to social and gender norms, it has been suggested that some men have greater difficulty in identifying and communicating their emotions (Addis, 2008). Indeed, fathers of children with cancer have reportedly often found it difficult to express their feelings and rather covered them up (Gibbins et al., 2012), and often received less social support (Clarke et al., 2009; Gibbins et al., 2012). Related to this are the differences that have been identified in coping styles, i.e. the strategies used to handle the difficulties related to the child's illness, where mothers reportedly have a more emotion-focused coping style and both seek and receive more social support, while fathers tend to use more problem-focused strategies (Clarke et al., 2009, Gibbins et al., 2012). Fathers also reportedly experienced being left out with regard to their contact with medical staff (Gibbins et al., 2012).

An additional possible explanation for the differences in psychosocial and socioeconomic consequences following a child's cancer may be that mothers take more responsibility for childcare compared to fathers, and are thereby more exposed to the stressors associated with caring for the child. Indeed, studies indicate that traditional gender roles tend to be reinforced after a child's cancer diagnosis, with mothers taking on the primary responsibility for childcare and fathers continuing to work to provide financially for the family (Clarke et al., 2009; Gibbins et al., 2012; Long & Marsland, 2011). There are, however, also reports of fathers not acting in a gender-stereotyped manner, but who become more involved and actively engage in the care of the child (Gibbins et al., 2012). Previous studies show that mothers reduce their level of employment to a larger extent than fathers (Bona et al., 2014; Eiser & Upton, 2007; Lindahl Norberg et al., 2017; Miedema et al., 2008, Peikert et al., 2020), and that more mothers than fathers are on sick leave (Eiser & Upton, 2007; Hovén et al., 2013). A Swiss study found that fathers of childhood cancer survivors were even more commonly full-time employed than fathers in the general population, which the authors suggests is caused by fathers having to compensate for the mothers' reduced working hours (Mader et al., 2016). In Sweden, childhood cancer has been found to have a negative effect on income from employment for both mothers and fathers, although mothers were found to have larger and more long-term reductions in income. Additionally, in comparison to a matched control cohort, mothers' employment status was found to be affected up to five years after diagnosis, while the fathers' employment status was not significantly affected at all (Lindahl Norberg et al., 2017). Another study from Sweden, however, suggests that the adverse effects on income and employment are in fact more pronounced among fathers than mothers (Öhman et al., 2020).

### **2.3 DIVISION OF WORK AND FAMILY RESPONSIBILITIES**

The division of work and family responsibilities is an important issue in many families, certainly not only in families affected by childhood cancer. Even though the past decades have seen an increased presence of women in the labor market and men engaging more in housework in Western countries (Hook, 2006; Leopold et al., 2018), women still do more housework and are involved with more childcare than men, and the progression of time alone is unlikely to

even out the uneven distribution of paid and unpaid work (Hook, 2006). Sweden have consistently been ranked at the top of several gender equality measures (Hausmann et al., 2013), and gender egalitarian ideals have been linked to a more equal division of housework and childcare (Evertsson, 2014). Despite this, traditional gendered division of housework and caregiving remain (Magnusson, 2005; Swedish Social Insurance Agency, 2013), and women in Sweden have the past years used approximately three-quarters of a couple's total parental leave, and two-thirds of childcare leave (Statistics Sweden, 2019).

Parenthood has been found to relate to an increased gender division of labor (Craig & Mullan, 2010). Parenthood has been suggested to impact wage, and a fatherhood premium have been found in Sweden in terms of wage levels in high-prestigious occupations (Magnusson & Neramo, 2017) and supervisory authority (Bygren & Gähler, 2012). Women's greater responsibility for children and household responsibilities have been suggested to be most significant for the gender pay gap in Sweden (Boye et al., 2017). A parenthood wage gap could also be considered a result of statistical discrimination (Phelps, 1972), meaning that employers assume that women are at risk of being absent from work to care for children for a long period of time, which causes women to be discriminated (Thoursie, 2005). Additionally, if fewer investments in female employees create an incentive for them to take longer maternal leaves, the effects can be self-increasing (Thoursie, 2005). The assumptions of how men and women are to divide childcare responsibilities could lead to employers favoring men because they are not expected to be absent from work for a considerable time due to childcare. So when men do take considerable time off work to care for a child, it may be seen as a signaling effect, i.e. the employer considers it to be a signal of low work commitment (Thoursie, 2005). A Swedish study found some support for this theory of signaling effects, as the association between care leave and lower wages was found to be stronger among men than women (Boye, 2015b).

The organization of how responsibilities for paid and unpaid work are divided within families has generated much research. The specialization theory suggest that the family is a single unit in which the members attempt to maximize the household utility through specialization, which traditionally has meant women taking main responsibility for the household sector and men taking the main responsibility for the market sector (Becker, 1991). Bargaining models, on the other hand, recognize members of a family as separate agents with distinct preferences, where negotiations between parents are influenced by their bargaining power (Lundberg & Pollak, 1996). How parents divide responsibilities is thus influenced by a parent's resources and degree of dependency relative to the other parent. Previous studies have found some support for the theoretical perspective of relative resources, in which division of housework has been found to relate to the degree of dependency between members of a family, in terms of for example relative income and education (Bianchi, 2000; Brines, 1994; Evertsson & Neramo, 2004; Raley et al., 2012), although the relationship in Sweden has been found to be moderate (Evertsson & Neramo, 2007). Similar associations have been found for childcare (Amilon, 2007; Boye, 2015a; Nitsche & Grunow, 2018; Raley et al., 2012), although the association between relative resources and childcare seem to be less evident. When it comes to the division of childcare leave, studies conducted in Sweden have shown that the division of care leave is related to

women's economic dependency in that the more economically independent she is, the more care leave is used by the man (Boye, 2015a) and that care leave is used more by men when women increase their relative income and education (Amilon, 2007).

Even with an impact of resources, many studies conclude that gender plays an important role (Amilon, 2007; Evertsson & Neramo, 2004; Evertsson & Neramo, 2007; Nitsche & Grunow, 2018; Raley et al., 2012), while some have found limited support for the gender perspective (Bianchi et al., 2000). Although characteristics such as income and education are associated with equal sharing of childcare in Sweden (Duvander & Viklund, 2014; Swedish Social Insurance Agency, 2013), there remains a difference between men and women that appears to be culturally anchored and that cannot be entirely explained by the division of resources (Amilon, 2007; Swedish Social Insurance Agency, 2013). The division of labor could be seen as a reflection of prevailing cultural norms rather than a result of bargaining between individuals. According to the theory of 'doing gender', men and women do gender in their day-to-day repeated interactions so that differences between men and women are constructed in a way that they seem natural or essential, even when they are not (West & Zimmerman, 1987). In a study using data from families living in the US, Brines (1994) found support for the relative resource theory in how women act, but found that men in fact do less housework when they depend on their wife for income. This is discussed by Brines (1994) as a way of gendered compensatory behavior for their 'failed' masculinity, a way of 'doing gender'. Similar support for the 'doing gender' perspective was found in another study of families in the US, which found that women did more housework in households where the man was economically dependent than when they had equivalent earnings; this was discussed as a way to compensate the gender-deviant behavior of male economic dependency by exaggerated gender-typical behavior in housework (Evertsson & Neramo, 2004).

Although much research has been conducted on the division of work and family responsibilities, less is known of how this is organized in families with a seriously ill child. A child's serious illness may increase a family's financial burden far beyond what is an expected cost for raising a child, and the time spent on childcare is expected to increase dramatically. Taken together, arranging childcare based on economic factors may thus be even more likely than among parents in the general population. At the same time, childcare is not necessarily a typical household chore that an individual prefers to avoid (Flood & Gråsjö, 1997; Sullivan, 2013), which might be especially true when a child has a serious illness. Additionally, as parents have been suggested to take on traditional gender roles after a child's cancer diagnosis, in terms of division of childcare and paid work, economic factors may be even less influential than among parents in the general population. Lewis et al. (2000) studied decision-making among parents with disabled children in the UK and found that a gender theory approach appeared more useful than economic models. The authors suggest that challenging gendered expectations is particularly difficult for parents with disabled children due to a strong ideology of mothers as the natural caregivers for disabled or sick children (Lewis et al., 2000). The same challenges could be expected for parents of children with other serious illnesses, such as cancer, as well.

## 2.4 PARENTING STRESS AND WORK-FAMILY BALANCE

Entering into parenthood can be a stressful situation for anyone, having to adjust existing everyday life to the care demands of another person. As described above, the division of work and family responsibilities requires considerable organization. Parenting a seriously or chronically ill child often includes extraordinary caregiving demands, which may lead to particular difficulties in balancing the increased family responsibilities. Indeed, caregivers of chronically ill children have been found to endorse greater parenting stress, or stress related to the role as a parent, than caregivers of healthy children (Cousino & Hazen, 2013; Pinquart, 2017). This has been found regarding both parenting stress that is related to the child's illness, but also parenting stress related to the generic aspects of caregiving (Cousino & Hazen, 2013). Having a chronically ill child may affect parents' perception of the child's vulnerability, and increased caregiving demands may create feelings of insufficiency in managing the child's illness, which has been found to increase parenting stress (Cousino & Hazen, 2013). Parenting stress has in turn been suggested to be associated with adverse psychological adjustment in caregivers, such as increased levels of anxiety and depressive symptoms (Cousino & Hazen, 2013), and impaired parental functioning (Sulkers et al., 2015). Moreover, parents of children with health problems have been found to adopt more traditional role patterns, with mothers having high expectations on themselves as caregivers and having difficulties adjusting to the demands of their parental role (Pelchat et al., 2007), and consequently reporting higher levels of emotional stress (Pelchat et al., 2007) and parenting stress (Pinquart, 2017) than fathers.

As previously discussed, parents of children with cancer often experience extensive work disruptions. Reductions in employment and absenteeism from work, along with difficulties with dealing with unsupportive employers and finding flexible jobs, affect parents of children with other serious illnesses as well (Kish et al., 2018). Gainful employment may not only be of importance to avoid the income losses that a reduction in work hours lead to, but may also offer benefits such as self-fulfillment, companionship, emotional well-being, and a break from caregiving responsibilities (Brown & Clark, 2017; George et al., 2008; Kish et al., 2020; Lewis et al., 2000), which may be particularly welcoming when caring for a seriously ill child.

In addition, having to care for a chronically ill child has been identified as a risk factor for work-family conflict (Jansen et al., 2003). A work-family conflict occurs when the pressures from the family and work domains are incompatible, which results in an interrole conflict (Greenhaus & Beutell, 1985). A conflict can occur either in the direction of family interfering with work, or work interfering with family, and is a result of role overload. Role overload occurs when the pressure of a role increases which, due to limitations in resources such as time, hinders fulfilling the demands of other roles (Greenhaus & Beutell, 1985). Due to the major disruptions in everyday life and new caregiving tasks following a child's cancer diagnosis, difficulties with combining work and family have been reported by parents of children with cancer (Granek et al., 2012; Long & Marsland, 2011; Molinaro & Fletcher, 2018; Peikert et al., 2020; Wakefield et al., 2014). Parents not only have to reorganize existing roles and reallocate responsibilities, with mothers often assuming primary childcare responsibilities (Clarke et al., 2009; Long & Marsland, 2011; Molinaro & Fletcher, 2018), but may also have to adapt to

several new roles, such as being a therapist, teacher, or medical assistant to the child (Lindahl Norberg & Steneby, 2009).

Aside from the practical adjustments that may be needed, such as having to rearrange work hours and sacrificing career opportunities in order to meet the child's care needs (George et al., 2008; Wakefield et al., 2014), parents have also reported experiencing stress of being perceived as unreliable employees, and a lack of understanding of the precarious family situation from employers (George et al., 2008). Nevertheless, parents have also reported priorities to change in favor of spending more time with family rather than at work (Wakefield, et al., 2014). Several factors influence how the balance of work and family is affected, both individual factors (e.g. age of the child, number of children in the household, relationship status, child care availability, and perception of one's work role) and workplace organizational factors (e.g. organizational culture, policies and support at the workplace) (Brown & Clark, 2017).

## **2.5 SICK LEAVE AND RETURN TO WORK**

Another common cause for work disruptions, in addition to childcare leave, is sick leave (also referred to as sickness absence). Compared to other Western European countries, Sweden has historically had high levels of sick leave rates, with women's rates being above average, and men's below average (Angelov et al., 2011; Swedish Social Insurance Agency, 2017). Psychiatric diagnoses are increasingly common, in particular among women, but also among men (Swedish Social Insurance Agency, 2017). Higher SES is generally associated with lower sick leave rates among both men and women in Sweden, although higher education is only associated with lower rates among men but not among women (Angelov et al., 2011). Additionally, work-family conflict has been identified as associated with an increased risk of sick leave (Voss et al., 2008), although another study found this association among certain groups only (Lidwall et al., 2009). Over the past decades, women have been over-represented in sickness absence rates in Sweden, and the discrepancy has increased with time. It has been suggested that the differences relate to working conditions and the work environment of a gender-based labor market segregation (Angelov et al., 2011; Swedish Social Insurance Agency, 2018). Individuals working in human service occupations, such as healthcare, childcare, social work and educational services, are at a particularly high risk of receiving sickness benefits, and are also sectors where women are over-represented (Aronsson et al., 2018; Drake et al., 2020). It has, however, also been suggested that the most pronounced differences between men and women in Sweden are related to parenthood, with mothers being on sick leave twice as often as their partners, a difference that persists for several years (Angelov et al., 2011). Research on the association between motherhood and sickness absence in Sweden is however not conclusive, with some research suggesting that having children at home increases the risk of sickness absence, particularly among young and single women (Floderus et al., 2012), while others suggest the association is significant only among single mothers (Voss et al., 2008). Taken together, the increased psychological distress that affects

parents of children with cancer, as well as the childcare burden that goes beyond the demands of most parents, may create a particularly high risk for sickness absence.

Being on sick leave may have several negative consequences, such as adverse effects on economic and social conditions (Bryngelsson, 2009), life situation (Floderus et al., 2005), and future work ability (Gustafsson & Marklund, 2011), thus highlighting the importance of studying what factors influence an individuals' ability to return to work. Work-related conditions have been particularly emphasized as influential factors, such as a flexible work environment and supportive employers (Greidanus et al., 2018; Nybergh et al., 2020). Among Swedish employees with disorders such as depression, anxiety and stress-related disorders, which parents of children with cancer often experience, home-related aspects have been identified as important for the return to work process after sick leave, in addition to work-related aspects. Women, in particular, experienced difficulties in reducing home-related demands, which became a hindrance to their return to work (Nybergh et al., 2020). This finding further highlights the complications the particular circumstances of childhood cancer, such as very high childcare demands, may create for parents when returning to work.

## **2.6 THE NATIONAL CONTEXT**

The Swedish welfare state has traditionally been categorized as a social democratic welfare regime, characterized as universalistic and egalitarian, in which citizens have equal access to state support rather than market-based or family-based support (Esping-Andersen, 1990). As in many countries, effects on gender equality is considered when introducing policies in Sweden. In comparative studies, policies promoting female labor participation have been found to have an effect on men's time spent on unpaid work (Hook, 2006), whereas family-friendly policies, such as long parental leaves, may not have the reducing effect on gender inequality often anticipated (Mandel & Semyonov, 2005). The design and generosity of childcare policies vary across high-income countries, for example in terms of whether and if so to what extent fathers have access to parental leave (Ray et al., 2010). Parental leave policies can affect the organization of the family in different directions. A lengthy maternal leave has a negative effect on men's unpaid work time (Hook, 2006) and on women's career prospects (Aisenbrey et al., 2009), but a parental leave also eligible to fathers has a positive effect on men's unpaid work time (Hook, 2006). The negative impact on gender equality of family-friendly policies, such as a generous parental leave, could also be seen as a result of statistical discrimination. Thus, the design of social support, such as social insurance programs, may impact society in a larger context.

### **2.6.1 The Swedish social insurance system**

The Swedish social insurance system provides several financial support programs, including support for parental and sick leave. Sick leave is provided to individuals who are unable to work due to illness. For most employees, the first day of sick leave is a qualifying day, followed by 13 days of sick pay from the employer. Thereafter, the employee can apply for sickness

benefits from the Social Insurance Agency. Those who are not entitled to sick pay can apply for sickness benefits from the second day of illness. A medical certificate from the healthcare is required, but the final decision of whether one qualifies for sickness benefit is made by the Social Insurance Agency. Sickness benefit can be provided for 100, 75, 50 or 25 % of a workday. The number of days you can get sickness benefits has changed over the years included in the studies. At present, there is no limit to how many days an individual can receive sickness benefit, but during 2008-2016, there was a limit of 914 days. The assessment of the right to sickness benefit is, however, based on stricter grounds as time progresses.

Parents who need to be absent from work to care for an ill child can apply for temporary parental leave (TPL) and be reimbursed with temporary parental benefit, for 100, 75, 50, 25 or 12.5 % of a workday. For most parents, the benefit is limited to 120 days per year, and can only be used by one parent at a time. Since 2005, however, parents of seriously ill children have been able to apply for an unlimited number of days, and both parents can apply for the same days. To receive temporary parental benefits for seriously ill children, a medical certificate is required. Additional benefits are available for parents who need to care for an ill child, such as additional cost allowance.

Sickness benefit and temporary parental benefit are not only available for individuals who have to be absent from work, but also those who are unable to apply for jobs and have to refrain from claiming unemployment benefits. Sickness benefit is additionally provided to individuals on parental leave who are unable to care for their child due to their own ill health. The compensation is based on the individual's current, or in some cases previous, wage. The compensation is close to 80 % of the wage, but is restricted to an income ceiling. In 2019, the income ceiling was 380,800 SEK per year (Swedish Social Insurance Agency, 2019), which can be compared to the median yearly income in Sweden for 2019, which was 337,000 SEK (Statistics Sweden, 2021).

The information provided above on the social insurance program can be found in the Social Insurance Code (SFS, 2010:10).

## **2.7 RATIONALE OF THE THESIS**

We know from previous research presented above that a child's cancer creates a psychosocially challenging situation for the parents. When the research project began, a significant gap in the knowledge of socioeconomic consequences of childhood cancer was identified, and of the studies that had been conducted, methodological weaknesses and limitations had been identified (Pelletier & Bona, 2015). Most previous studies had been cross-sectional, retrospective and based on self-reported survey data. Since then, several longitudinal cohort studies with registry data have been conducted in different countries, but results may be difficult to translate directly across countries. The studies included in this thesis aimed to contribute with knowledge about the situation for parents of children with cancer, in particular Swedish parents.



The research on socioeconomic consequences of parenting a child with cancer has mainly focused on describing the effects on income and employment, in terms of the amount of money lost or a change in employment status. With this thesis, we aimed to study the causes and consequences of work disruptions, as well as the complex relationship between work and family responsibilities, further exacerbated by a child's cancer diagnosis. Much is known of the allocation of domestic and professional labor in both Sweden and other countries, but less is known about families with seriously ill children, where the division of responsibilities for work and family may be of particular importance in everyday life, and challenging gendered expectations may be particularly difficult. Attaining a healthy work-family balance is of importance for everyone, and considering the potentially sudden and significant role pressure following a child's serious illness, additional research is required to understand the impact on work-family dynamics among parents of children with cancer.

Moreover, previous research has suggested that there is insufficient psychosocial support for childhood cancer families. In addition, a recent survey conducted on behalf of the Swedish Childhood Cancer Fund highlighted a number of weaknesses in the support provided according to parents of children with cancer (Novus, 2020). Many parents in the survey were overall satisfied with the support they had received, but the survey also exposed deficiencies, including a lack of information about available support, including financial support, an unmet need of follow-up psychological support, and discontent with the treatment from the Swedish Social Insurance Agency (Novus, 2020). Considering the extensive welfare system in Sweden, as well as the emphasis on equality in social policies, reports of insufficient support are noteworthy. Further knowledge regarding the strength and weaknesses in the support from healthcare and social services provided to childhood cancer families may provide crucial information to those who meet the parents, such as healthcare personnel, government agencies, and employers, which could hopefully facilitate the parents' challenging situation.



### **3 RESEARCH AIMS**

The overall aim of the doctoral project was to investigate the socioeconomic consequences for parents of children with cancer, and in particular the impact on paid work, childcare, and the balance between the two. The specific research aims for the four studies were:

I: To investigate the risk of sick leave due to ill health among parents following a child's cancer diagnosis, including differences between mothers and fathers, the impact of other sociodemographic characteristics, and risk of sick leave following bereavement.

II: To investigate how parental couples divide childcare after a child is diagnosed with cancer, including whether the division of childcare relates to income relations within the couple, and whether the extent of childcare leave impacts future income development.

III: To explore fathers' and mothers' experiences of parenthood and work and of balancing the dual life roles following a child's cancer diagnosis.

IV: To explore what facilitators and barriers parents of children with cancer identify for the ability to return to work and meet financial needs.



## 4 MATERIALS AND METHODS

### 4.1 STUDY DESIGN

This thesis includes both quantitative and qualitative studies. Despite the long-standing dispute between these two methods, and the ontological and epistemological assumptions traditionally related to each methodology, the value and benefits of combining both methodological approaches have been increasingly acknowledged (Danermark et al., 2002:4). Choice of method should still be established in one's ontological and epistemological starting point, which in this thesis is inspired by critical realism. The critical realist approach criticizes the traditional dichotomy of objectivity versus subjectivity in research, and advocates that "there exists both an external world independently of human consciousness, and at the same time a dimension which includes our socially determined knowledge about reality" (Danermark et al., 2002:5-6). Furthermore, it is suggested that in order to understand empirically observed events, one must also gain knowledge of the underlying mechanisms that create the events (Danermark et al., 2002:5). This approach reasons with the methodological basis of this thesis. In studies I and II, we aimed to investigate work disruptions of parents following a child's cancer diagnosis on a large scale, which was enabled by using quantitative methods. Although national registries enabled us to draw reliable conclusions on parents' work disruptions, additional approaches were needed to understand the underlying mechanisms and circumstances related to them. In studies III and IV, qualitative methods were therefore utilized to attempt to deepen our understanding of the parents' situation.

Table 1 presents an overview of study designs and methods in the four studies.

**Table 1.** Overview of study designs and methods

Study	Primary outcome	Design	Sample	Type of data	Analysis
I	Risk of sick leave	Longitudinal cohort design	3626 parents of children with cancer; 34 874 reference parents	National registry data	Logistic and negative binomial regression analysis
II	Division of childcare leave	Longitudinal cohort design	2788 parents of children with cancer; 27 110 reference parents	National registry data	Negative binomial, beta and linear regression analysis
III	Work-life balance	Inductive qualitative design	9 focus groups with 32 parents of children with cancer	Focus group interview data	Inductive qualitative content analysis
IV	Return to work and meet financial needs	Deductive qualitative design	9 focus groups with 32 parents of children with cancer	Focus group interview data	Deductive qualitative content analysis

### 4.2 STUDIES I AND II

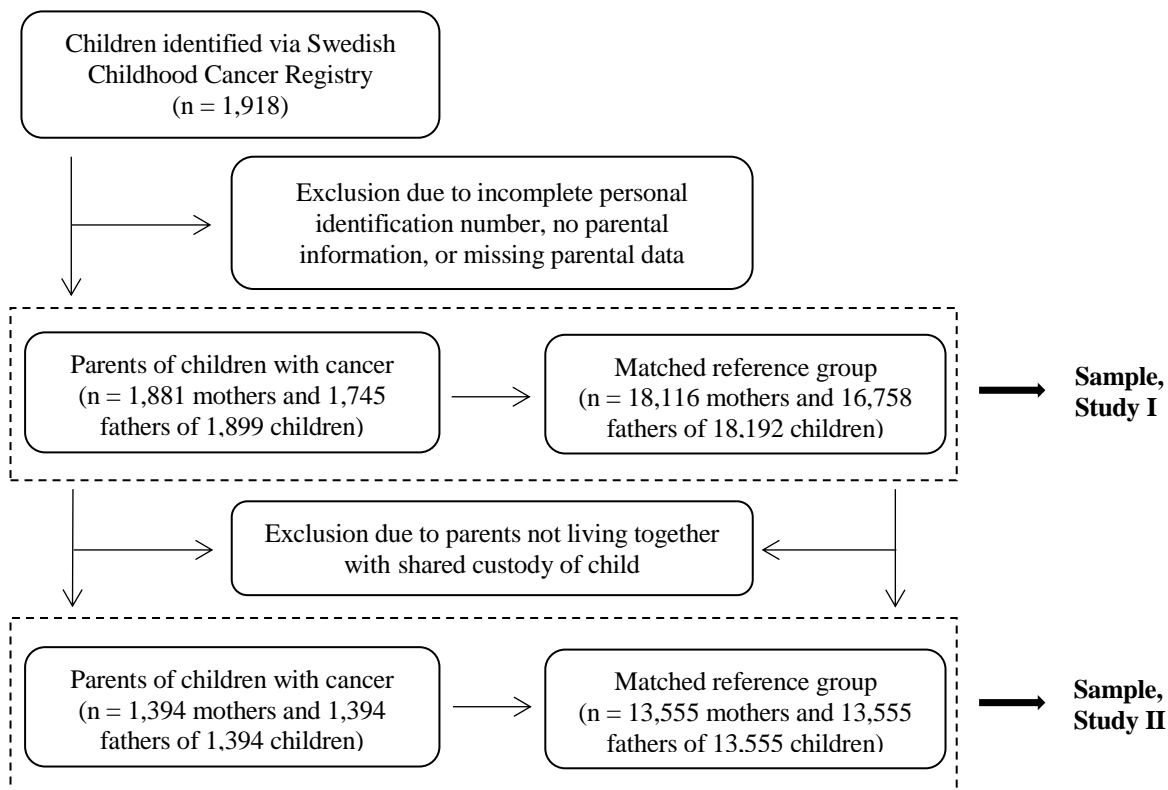
#### 4.2.1 Study sample

For studies I and II, all children ( $\leq 18$  years old) diagnosed with a primary cancer diagnosis from 2004 to 2009 were identified by the Swedish Childhood Cancer Registry (SCCR). From

the children’s personal identification number, their parents were identified by Statistics Sweden. After exclusion of children who were missing complete child or parental information, or whose parents were missing data, 1,881 mothers and 1,745 fathers of 1,899 children were included for analysis. Of those children, 298 children died during the study period. A matched general population cohort design was used with approximately 10 reference parents for each parent of a child with cancer (also referred to as control parents in study I and unexposed parents in study II), in total 34,874 reference parents. The parents were matched based on the following variables, estimated two years before child’s diagnosis (i.e. when they were likely not yet impacted by the child’s cancer): child’s year of birth, family disposable income, parental age, living arrangements, county of residence, and the number of children living at home. Sociodemographic characteristics of the sample are found in Table 2.

Study I included the entire sample described above. In study II, the focus was on behavior within couples. Therefore, only couples who were living together with shared custody were included, identified in the following steps: 1) information was available for both parents; 2) the parents had the same disposable household income; and 3) both parents were registered as cohabiting with another adult and a shared child. This resulted in a sub-sample of 2,788 parents of children with cancer and 27,110 parents in the reference cohort. Bereaved parents and their matched references were excluded from the year of the child’s death. In total, 178 children died during the study period.

A flow chart of the sampling procedure for both studies is found in Figure 1.



**Figure 1.** Study sample flow chart, studies I and II.

### **4.2.2 Statistical data analysis**

In studies I and II, the source of data on the parents was the Longitudinal Integration Database for Health Insurance and Labor Market Studies (LISA by Swedish acronym), provided by Statistics Sweden. The children's medical data were retrieved from SCCR. To ensure equivalence between the parents of children with cancer and the reference parents, the following characteristics of the groups were compared using  $\chi^2$ -tests and t-tests the year before diagnosis: income, age, education and area of residence (both studies), living arrangements and the number of children living at home (study I), and sector of employment and country of birth (study II).

In study I, the main outcome was sick leave, which was operationalized as days with sickness benefit per year. Logistic regression and negative binomial regression analyses were utilized in order to estimate the probability of receiving sickness benefit, and the incidence rate ratio (IRR) for the mean number of days with sickness benefit, respectively. The values were estimated from one year before diagnosis to seven years after. A Wald  $\chi^2$ -test was used to estimate the difference between mothers and fathers. Stratified analyses were conducted for specific sociodemographic groups (income, age, education, employment status, country of birth, living arrangement, number of children living at home, and area of residence), as well as for bereaved parents.

In study II, the main outcome was childcare leave, which was operationalized as days with TPL. Negative binomial regression analyses were used to estimate the IRR for the mean number of days with TPL per year, from the year of diagnosis to seven years after, and for comparison between mothers and fathers. The association between the division of childcare leave and division of income for a couple was estimated using beta regression analyses of the father's share of a parental couple's total income before diagnosis, and the father's share of the parental couple's total number of days with TPL after diagnosis. The association between childcare leave and income development was estimated using robust linear regression analysis of a parent's total number of TPL days from diagnosis and during the six subsequent years, and a quotient of the parent's income seven years after diagnosis and the income before diagnosis.

All regression models in studies I and II were adjusted for covariates, and additional inclusion criteria for specific analyses were applied when appropriate (see corresponding articles for further details). Independence was assumed for observations between matched groups. The dependence within groups and subjects and groups over time was accounted for using cluster-robust standard errors. Estimates with  $p < 0.05$  were considered statistically significant. The statistical analyses were conducted using the statistical software STATA and R. Further details of the data analysis in studies I and II can be found in the respective article.

### **4.2.3 Methodological considerations**

The inclusion of a cohort of reference parents in the quantitative studies, who were individually matched based on a number of key characteristics, enabled us to account for several pre-existing conditions that might have influenced the outcome. By using registry data, we avoided

the risk of recall bias, and the risk of either selection bias or information bias was considered low, as the data from LISA is comprehensive and based on reliable sources, without indication of systematic errors (for more information about LISA, see Statistics Sweden, 2016). Avoiding these systematic errors strengthens the validity of the studies. However, the validity is also dependent on how well the variables actually measure the intended outcomes. The data from LISA covers a large number of variables, but certain assumptions and adjustments of the variables still had to be made before conducting the analyses in order to fit the research aims, such as how we measure income, how employment status affects other variables, changes in social insurance legislation, etc. This is further elaborated on in the respective articles. We attempted to account for these assumptions and adjustments by making sensitivity analyses or controlling for certain variables. It is, however, important to keep this in mind, in particular when comparing the results to other studies.

The robust methodological design of the quantitative studies, including a sample representing a range of sociodemographic characteristics, is favorable for the generalizability. It should be noted, however, that only different-sex parental couples were included in the sample. Seeing as the division of childcare responsibility has been suggested would differ in same-sex couples (Evertsson & Boye, 2018), including that group in the study would have contributed with an interesting dimension and improved the generalizability of the studies. We were fortunate to be able to use data from the SCCR, with high completeness and coverage (Lähtenmäki/SBCR, 2020). Due to this, almost all children diagnosed with cancer during 2004-2009 were included, and the sample thus covered a variety of cancer diagnoses, favoring the generalizability of the studies to the general childhood cancer population. The heterogeneity of childhood cancer was, however, not accounted for, as we did not differentiate between different diagnoses in the analyses or other illness/treatment-related characteristics. Although the studies focused on parents of children with cancer, we believe that much of the results are not uniquely related to cancer, and could thus be generalized to a larger population of parents of children with a serious illness. Finally, assessing the generalizability of the studies has to be done in the light of the national context. The Swedish welfare system that enables parents to be on sick leave and temporary parental leave can be compared to the systems in some other Northern European states, but stand in contrast to many others.

### **4.3 STUDIES III AND IV**

#### **4.3.1 Participants and recruitment procedure**

Studies III and IV are based on focus group interviews. Nine focus groups with in total 32 parents of children with cancer (21 mothers; 11 fathers) were conducted. We aimed to capture the experiences of parents with varying characteristics, both in relation to socioeconomic and demographic factors, but also in relation to a child's diagnosis and treatment status (i.e. if parenting a child in active cancer treatment, a childhood cancer survivor, or following bereavement). The participating parents were recruited with the help of the Swedish Childhood



Cancer Fund. We presented the study at their national and local meetings, and advertised in their newsletters, webpages and Facebook-pages. Participants were additionally recruited via a recommendation from other participating parents. Parents who expressed interest in the study were given further information as well as an invitation to participate.

The focus groups were homogeneous and contrasting in terms of parent sex, with six groups consisting of only mothers and three groups consisting of only fathers. In relation to other sociodemographic factors, as well as the child's diagnosis and health status, the groups were heterogeneous. Characteristics of the entire sample are presented in Table 2. Three parental couples were represented by both parents, but in different groups. All participants were part of a different-sex parental couple. Some parents were still with the other parent of the child, while others had separated.

**Table 2.** Sociodemographic characteristics of sample for studies I-IV

		Studies I & II <sup>a</sup> – Parents of children with cancer (n=3,626) <sup>b</sup>		Studies I & II <sup>a</sup> – Reference parents (n=34,874) <sup>b</sup>		Studies III & IV – Parents of children with cancer (n=32) <sup>c</sup>	
		Mean		Mean		Mean	
Age		38		38		42	
Sex	Women	1881	52	18116	52	21	66
	Men	1745	48	16758	48	11	34
Education	Basic/Secondary	2703	75	26260	75	10	32
	Post-secondary	831	23	7911	23	21	66
	Other/Missing	92	3	703	2	1	3
Employment	Employed	2992	83	28724	82	24	75
	Not employed	572	16	6008	17	4	13
	Other/Missing	62	2	142	1	4	13
Area of residence <sup>d</sup>	Cities/Towns and suburbs	2479	68	24001	69	26	81
	Rural areas	1085	30	10731	31	6	19
	Missing	62	2	142	1		
Child's age at diagnosis		Median 7				Median 5	
	Child's diagnosis	No	%	No	%	No	%
	Leukemia	527	27			13	41
	CNS tumors	512	28			8	25
	Other	860	45			11	34

Note: Sum may vary due to rounding

<sup>a</sup>Additional selections were made for the final sample of study II, see section 4.2.1.

<sup>b</sup>Measured one year before diagnosis

<sup>c</sup>Measured at time of interview

<sup>d</sup>According to Eurostats description of Degree of Urbanisation (DEGURBA) (Eurostat, n.d.)

### **4.3.2 Interview procedure and content analysis**

The focus groups consisted of 2-5 parents of children with cancer, a moderator and an observer. Depending on what was most convenient for the participating parents, the focus groups took place in conference rooms either at the researchers' office, or at hotels. In two of the focus groups with fathers, one father in each group participated via video-link. One focus group, with three mothers, was conducted entirely via video-link.

During the introduction of the interview, the moderator repeated the aim of the research project, explained that the focus group was intended to be a discussion between the participants, and emphasized that all kinds of experiences and thoughts were encouraged to share. The interviews began with the participants briefly introducing themselves to the group. The moderator thereafter asked open-ended questions related to the two study aims, such as questions about their work situation, how they divided responsibilities for work and childcare, and how they perceived the support they received.

The focus groups were on average 1 hour and 55 minutes long. The interviews were audio-recorded and transcribed verbatim. The final data consisted of 17 hours and 15 minutes of recorded interviews, which was the base for both study III and study IV, albeit with different study aims. In both studies III and IV, the data were analyzed through qualitative content analysis. The analysis approach was, however, different for the two studies.

In study III, an inductive analysis approach was used (Graneheim & Lundman, 2004; Graneheim et al., 2017), meaning that the analysis was data-driven (Graneheim et al., 2017). The analysis began with reading through the transcripts. Sentences and paragraphs connected to parents' experiences of balancing work and family roles were highlighted as meaning units, which were thereafter extracted into codes. Next, the codes were compared for similarities and differences, grouped and abstracted into seven subcategories and three categories.

In study IV, a deductive analysis approach was used (Elo & Kyngäs, 2008), meaning that the analysis was concept-driven (Graneheim et al., 2017). Based on previous literature about psychosocial support for childhood cancer families and return to work after work disruptions, twelve codes were constructed a priori. The transcripts were read through, and meaning units were highlighted and coded. The codes were thereafter organized within a pre-constructed matrix of analysis. Next, the codes were grouped into categories and abstracted into four generic categories concerning facilitators and barriers for returning to work and meeting financial needs.

### **4.3.3 Methodological considerations**

When assessing the strengths and weaknesses of the methodology for the qualitative studies, it is important to consider the common overall concept of trustworthiness, including components of credibility and transferability (Graneheim et al., 2017). Credibility considers how well the data and method of analysis address the aim of the study. Considering that the common aim of the studies was to explore the parents' experiences and thoughts, we concluded that focus

groups were an appropriate method. Focus groups enable parents to interact with each other and use the other's experiences to reflect further on the mechanisms behind their own motivations and behavior (Morgan, 1997:15; Wibeck, 2000:40). Focus groups can also be a favorable method when sensitive issues are discussed (Wibeck, 2000:128). However, the interaction between participants may also be influenced by the group norm, with participants fearing to deviate from the norm (Morgan, 1997:15; Wibeck, 2000:128). Therefore, we continuously emphasized to the participants that we were interested in all kinds of experiences, and worked actively to include all participants in the discussions, which was also one of the key tasks of the observer. Assessment of the end result is that the participants engaged actively in the discussions, both when they agreed with each other and when they did not. The parents repeatedly stressed the importance of the study topic, and were eager to discuss a matter that they often perceived had previously been overlooked.

The credibility of the study is also related to whether the selection of participants is appropriate in order to meet the aim of the study. As is common when doing group interviews with people who share a common experience, a purposeful sampling method was used (Patton, 2015:283-4). We wanted participants who shared the experience of being the parent to a child with cancer, but aimed to capture the experiences of a variety of people in terms of sociodemographic characteristics and regarding the child's illness and treatment status. When deciding the sample size we did not necessarily aim to achieve saturation, but rather an attempt to capture an adequate sample, a variability of relevant events, and high quality data (Malterud et al., 2016). As is often recommended, we decided to keep the focus groups homogeneous and contrasting in terms of sex (Morgan, 1997:36). This decision was based on the expectation that some issues discussed could potentially revolve around gender roles, and that separating men and women could facilitate the discussions.

The appropriate number of participants in a focus group has been disputed, and depends both on how involved the participants are as well as the character of the study topic (Morgan, 1997:42; Patton, 2015:475). Our focus groups comprised 2-5 participants, which is fewer than is often recommended. However, we assessed after a few interviews that because of the nature of the topic discussed, more than five participants in each group might be inappropriate. A larger group size might have made the discussions less open, and not provide enough time for each participant to share their story. Due to difficulties in finding a time and place for all participants, five participated via video-link. Although it should be acknowledged that this might have led to possible differences in group dynamics, our assessment of using this method was that there was surprisingly little difference compared to face-to-face participation.

Transferability considers to what extent the study results can be transferred to other contexts (Graneheim & Lundman, 2004). We fared well in capturing parents with various sociodemographic characteristics, thus improving transferability. We did, however, not include parents who were not Swedish-speaking, which is a limitation of the study. As the participants themselves contacted us about participating in the study, there is a risk of the participants representing unusual experiences that they wanted to share, but the nuanced interview data

suggest we were able to capture a variety of experiences as well. As with the quantitative studies, only different-sex parental couples were represented. As the influence of gender roles was frequently discussed, having same-sex parental couples represented would likely have made the results more transferable to a general population of parents. Regarding transferability to other medical contexts, many experiences of parenting a child with cancer can likely be transferred to parenting children with other serious illnesses as well. As discussed previously regarding the generalizability of the quantitative studies, the national context is of major importance, and the results may differ from studies conducted in countries with less generous national welfare and different labor laws.

Part of trustworthiness is the transparency of whether the results are the voice of the participants or the interpretation of the researchers (Graneheim et al., 2017). In study IV the analysis was kept close to the text with a lower level of interpretation and abstraction, whereas in study III, the analysis was still conducted on the manifest content, but with a higher degree of both interpretation and abstraction. For qualitative research with interpretative ambitions, the reflexivity is considered important in order to properly assess the scientific quality, meaning that the researchers need to understand and be clear with their own pre-understanding, perspective, and how that may affect the research process (Graneheim et al., 2017; Patton, 2015:70-4). My own background includes working at the Social Insurance Agency, and experiences from the other researchers involved include many years of research of psychosocial aspects of childhood cancer, as well as social work with childhood cancer families. These experiences may be reflected both during the interview process, as well as during the analysis. This does not necessarily have to be negative, as the researchers' previous experiences may guide them to focus on the topics that they know parents have previously emphasized as important (Wibeck, 2000:88). In order not to compromise the credibility of the analysis because of the potential influence of the researchers' pre-understanding, a number of measures have been taken. For instance, several researchers, with different backgrounds, have been involved in all parts of the research process, from interviewing to analyzing, and any disagreements have been discussed until consensus has been achieved. The use of quotations and examples from the coding process to exemplify the interpretations is another measure that has been taken to strengthen the credibility of the analysis.

However, even though I acknowledge the impact a researcher's pre-understandings may have on the analysis, I do not believe that the results are entirely dependent on it. As discussed at the beginning of this chapter on methods, this point of departure for this thesis is that even though our perception of reality may be socially influenced, the reality still exists independent of us as observers. The participants provided rich and nuanced content, and I am confident in the ability to draw conclusions from their accounts about important aspects of their reality.

#### **4.4 ETHICAL CONSIDERATIONS**

The studies included in this thesis have ethical approval from the Regional Ethical Review Board in Stockholm [2011/804-31/5; 2013/757-32; 2014/1634-32; 2019-03277].

For the first two studies, national registry data were used. All data were de-identified, with a code key kept by Statistics Sweden, separately from the data, which was destroyed after five years. The analyses were conducted on a group level, and no research subject can be identified from the results. The likelihood of a breach of integrity or privacy was thus considered low. As is common with registry data (Ludvigsson et al., 2015), informed consent was not considered necessary. Asking all research subjects for consent would be close to impossible for practical reasons, and would entail the risk of losing a very large part of the study sample, which could lead to selection bias and loss of statistical power, and thus compromise the quality of the research (Ludvigsson et al., 2015). Therefore, the benefits of using registry data without consent was considered greater than the potential risks.

Parents who contacted the research group about participation in focus groups were given written information about the study, including information regarding confidentiality and anonymity. The information was provided again verbally at the beginning of the interviews. The participants provided written informed consent, and were informed that they could withdraw from the study at any point in time. Confidentiality was emphasized and participants were asked not to share information outside the group. The results from the focus groups are presented so that the participants are kept anonymous. Only member of the research group had access to the audio-recorded data.

It should be acknowledged that the research subjects in this thesis, i.e. the parents of children with cancer, are a potentially vulnerable group, who shall be treated with respect to their situation and with caution as to whether the research could cause any discomfort for them. For the studies based on registry data, the risk of the research causing discomfort among the research subjects was minimal, as they were not directly approached and results were presented at group level. During the focus groups, however, there was a risk that the discussion would cause reactions of discomfort among the participants, although as participation was purely voluntary, they were most likely prepared to talk about their experiences when they expressed interest in participating. The possibility for parents to share their experiences could also be perceived as something positive rather than negative, which is also supported by studies that have found participation in research to be perceived as something valuable among bereaved parents (Dyregrov, 2004; Kreicbergs et al., 2004). During the focus group interviews, the participants continuously emphasized the importance of the research topic and expressed hope that their contribution to the research could lead to improvement for others in their situation, suggesting that they perceived the benefits of participating being greater than the potential risks.

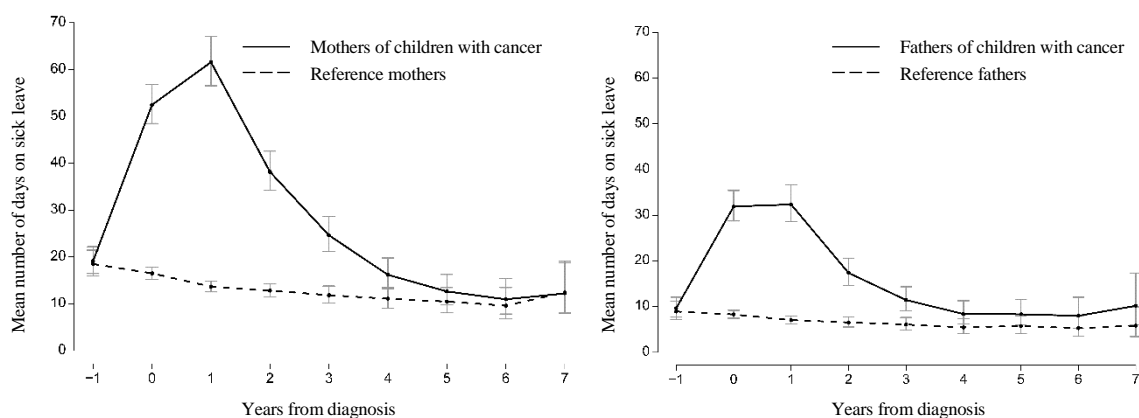


## 5 RESULTS

### 5.1 STUDY I: RISK OF SICK LEAVE

In study I, the following research questions were addressed: 1) Does childhood cancer increase the risk of sick leave among parents? 2) Are there any differences in the risk of sick leave between mothers and fathers? 3) Are sociodemographic characteristics associated with the risk of sick leave? 4) Does bereavement increase the risk of sick leave?

During the year of the child's cancer diagnosis, around 42 % of mothers and 33 % of fathers received sickness benefit. The proportions receiving any sickness benefit were statistically significantly higher ( $p < 0.01$ ) than among the reference parents from diagnosis and the subsequent four years among mothers, and three years among fathers. When comparing the mean number of days with sickness benefit, adjusted for covariates, the rates were significantly higher than among reference parents from the year of diagnosis to five years post-diagnosis among mothers, and six years among fathers (Table 3). Figure 2 presents the mean number of days with sickness benefit, for mothers and fathers separately.



**Figure 2.** Mean number of days on sick leave among parents of children with cancer ( $n=1,881$  mothers; 1,745 fathers) and reference parents (18,116 mothers; 16,745 fathers), including 95 % confidence intervals, from one year before diagnosis to seven years after

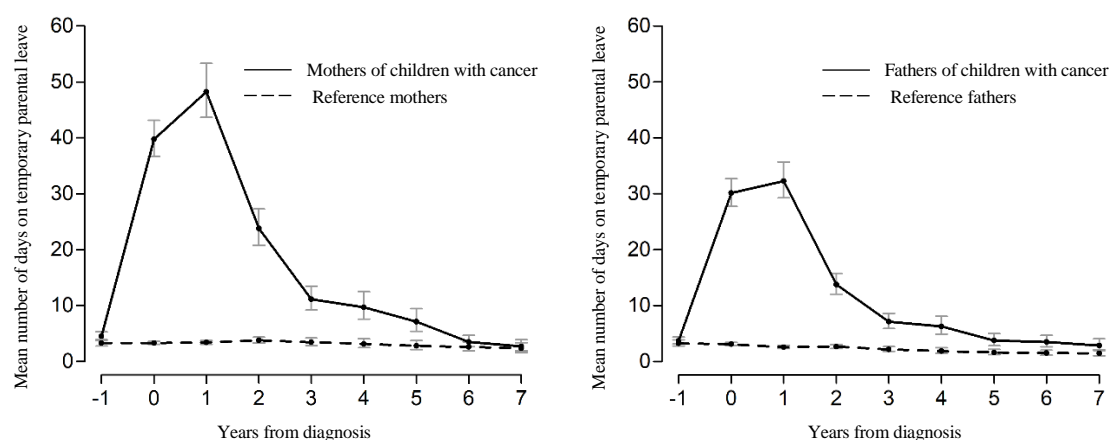
Although mothers were on sick leave for significantly more days than fathers following a child's cancer diagnosis (Figure 2), so were the mothers in the reference group. The relative effect of a child's cancer diagnosis was thus not significantly larger among mothers than among fathers.

Among mothers of children with cancer, the risk of sick leave relative to reference mothers one year after diagnosis was rather similar across the sociodemographic strata. Among fathers, however, the relative risk of sick leave was particularly high among those with a high income, higher education, who were employed, and who were born in Sweden. Bereaved parents were particularly likely to receive sickness benefit. At the year of the child's death, around 76 % of bereaved mothers and 67 % of bereaved fathers received sickness benefit. The rates remained significantly higher than among reference parents up to three years after the child's death.

## 5.2 STUDY II: DIVISION OF CHILDCARE LEAVE

In study II, the following research questions were addressed: (1) Do mothers and fathers of children with cancer divide childcare leave equally before and/or after the child’s diagnosis, and does the division differ from parents in the general population? (2) Is there an association between the division of income and the division of childcare leave within parental couples of children with cancer? (3) Is there an association between the extent of childcare leave and income development among parents of children with cancer?

Expectedly, the number of days on TPL increased dramatically following a child’s cancer diagnosis among both mothers and fathers and remained statistically significantly higher for five years post-diagnosis among mothers, and six years post-diagnosis among fathers (Figure 3 and Table 3).



**Figure 3.** Mean number of days on temporary parental leave among parents of children with cancer (n=1,394 mothers; 1,394 fathers) and reference parents (13,555 mothers; 13,555 fathers), including 95 % confidence intervals, from one year before diagnosis to seven years after.

Overall, mothers had more TPL days than fathers had (Figure 3). However, around the time of diagnosis, there was no significant difference in the number of days on TPL between mothers and fathers. Compared to the reference parents, the gender gap was larger among parents of children with cancer before the diagnosis, but smaller a few years after diagnosis.

At the year of diagnosis, a weak but statistically significant non-linear association (u-shape) was found between the division of income and division of childcare leave among parents of children with cancer. Overall, however, the results did not provide sufficient evidence that the division of income affects the division of childcare within couples with children with cancer.

The accumulated number of days did not have a statistically significant effect on income development among parents of children with cancer. Among the reference parents, a small but statistically significant negative effect ( $p < 0.05$ ) was found among both mothers and fathers.



**Table 3.** Incidence rate ratios (IRR) and 95% confidence intervals (CI) for the mean number of days on sick leave and temporary parental leave among parents of children with cancer compared to reference parents.

Years from diagnosis	Mothers			
	Sick leave <sup>a</sup>		Temporary parental leave <sup>b</sup>	
	IRR <sup>e</sup>	95 % CI	IRR <sup>f</sup>	95 % CI
-1	1.08	0.91-1.27	1.33**	1.11-1.58
0	3.35***	3.02-3.72	14.69***	12.85-16.80
1	4.50***	4.02-5.04	17.75***	15.03-20.97
2	3.08***	2.69-3.53	7.28***	5.93-8.94
3	2.14***	1.79-2.56	4.27***	3.03-6.02
4	1.50***	1.19-1.88	3.05***	2.32-4.01
5	1.33*	1.00-1.77	3.48***	2.06-5.87
6	1.26	0.86-1.84	1.38	0.98-1.96
7	0.93	0.59-1.45	0.91	0.64-1.31

Years from diagnosis	Fathers			
	Sick leave <sup>c</sup>		Temporary parental leave <sup>d</sup>	
	IRR <sup>e</sup>	95 % CI	IRR <sup>f</sup>	95 % CI
-1	1.11	0.86-1.43	1.07	0.91-1.25
0	5.42***	4.63-6.35	13.22***	11.27-15.52
1	6.29***	5.24-7.54	17.35***	14.35-20.97
2	3.48***	2.75-4.40	7.10***	5.53-9.11
3	2.09***	1.56-2.81	4.51***	2.97-6.85
4	1.66**	1.15-2.39	4.65***	2.94-7.38
5	1.72*	1.12-2.66	2.54***	1.77-3.65
6	1.70*	1.05-2.77	2.41**	1.40-4.15
7	1.74	0.96-3.13	1.90	0.79-4.58

Note: Year '0' = year of child's diagnosis. \*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

<sup>a</sup> n = 1,881 mothers of children with cancer; 18,116 reference mothers.

<sup>b</sup> n = 1,745 fathers of children with cancer; 16,758 reference fathers.

<sup>c</sup> n = 1,394 mothers of children with cancer; 13,555 reference mothers.

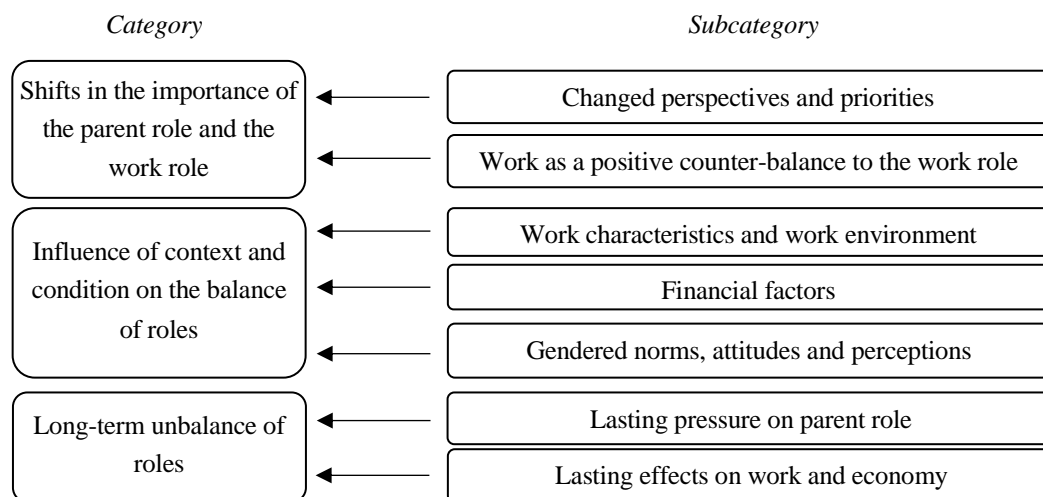
<sup>d</sup> n = 1,394 fathers of children with cancer; 13,555 reference fathers.

<sup>e</sup> Adjusted for income, parent's age, living arrangement, education, employment status, country of birth, area of residence, children living at home, and calendar year.

<sup>f</sup> Adjusted for the number of children aged 0-6 years, sector of employment, age, education, income from employment and calendar year >2005/≤2005.

### 5.3 STUDY III: WORK-LIFE BALANCE

The aim of study III was to explore fathers’ and mothers’ experiences of parenthood and work and of balancing the dual life roles following a child’s cancer diagnosis. The analysis resulted in three categories and seven subcategories, see Figure 4.



**Figure 4.** Categories and subcategories of parents’ experiences of balancing work and family roles

The first category ‘Shifts in the importance of the parent role and the work role’ includes subcategories ‘Changed perspectives and priorities’ and ‘Work as a positive counterbalance to the parent role.’ Parents expressed having changed their perspectives regarding being working parents, and prioritized time with their family more after the child’s diagnosis. They felt they had become better parents, more present in their children’s lives, but also more worried as parents. Moreover, parents described that they had become careful not to waste their life on work, and better at setting boundaries at work. However, parents also emphasized the importance of the work role to avoid feeling trapped in the parent role. Work provided them with opportunities to be treated as a professional and be someone else than only a parent of a child with cancer.

The second category ‘Influence of context and conditions on the balance of roles’ includes subcategories ‘Work characteristics and work environment’, ‘Financial factors’, and ‘Gendered norms, attitudes and perceptions’. Parents with emotionally or socially demanding jobs had difficulties in acting as sympathetically as they wanted because they compared other people’s problems with their own situation. Parents expressed difficulties in leaving work behind them, even if it was temporary, because of the fear of neglecting their careers, or because of bad conscience towards colleagues who had to cover for them. How much support the employer displayed mattered for their ability to balance work and family. Family finances affected the balance between work and family by forcing some parents to work because of financial difficulties, even though they wished to spend the time with their child. Differences between how mothers and fathers handled the balance between work and family were

discussed. Mothers expressed reacting to the child’s diagnosis with a more natural, protective instinct than the fathers. They also experienced being treated differently by others, where mothers were expected to take full responsibility for the childcare, and being questioned for wanting to work. Fathers, on the other hand, did not feel included in the child’s care by the healthcare staff, and were not given as much emotional support or room for grief as the mothers.

The third and final category is ‘Long-term unbalance of roles’, which includes subcategories ‘Lasting pressure on parent role’ and ‘Lasting effects on work and economy’. Parents, in particular mothers, described how they still struggled with the demands of the parent role, because of their own impaired physical and psychological health, the child’s continued care needs, the diminishing understanding from others, and insufficient support systems. Balancing work and family was additionally complicated by continued difficulties of returning to work while at the same time still suffering financially due to the child’s illness.

#### 5.4 STUDY IV: RETURN TO WORK AND MEET FINANCIAL NEEDS

In study IV, the following research question was addressed: What facilitators and barriers do parents of children with cancer identify for their ability to return to work and meet financial needs? The analysis resulted in four categories, see Table 4.

**Table 4.** Categories of facilitators and barriers to returning to work and meeting financial needs

	<i>Return to work</i>	<i>Meet financial needs</i>
<i>Facilitators</i>	Flexibility and understanding from employers and social services	Available public, private and employer support
<i>Barriers</i>	Pressure to return without consideration of the consequences	Lack of organized and efficient support from employers and social services

Facilitators for a return to work were abstracted into the category ‘Flexibility and understanding from employers and social services’. The flexibility of the social insurance system in Sweden enabled parents to combine work with childcare leave or sick leave, and with aid from the healthcare providers to return to work in a controlled manner. Still, factors related to the workplace were particularly important for parents’ ability to return to work. Flexible work arrangements, regarding time, location, and the extent of social interactions needed, were an important facilitator. The parents were helped by supportive employers who allowed the parents to decide when and at what pace to return to work, and who offered support from occupational health services. Open communication with colleagues was also described as a facilitator for a return to work. However, regardless of the employers and social services, a return to work was still dependent on the child’s health and care needs.

Barriers to a return to work were abstracted into the category ‘Pressure to return without consideration of the consequences’. Parents’, in particular the mothers’, ability to return to work was hindered by the extensive childcare demands still present even a long time after the child’s treatment had ended. Mothers in particular also expressed having impaired physical and psychological health as a result of the child’s illness, which reduced their work ability. Certain types of work were particularly challenging to return to, such as work with little flexibility, and tasks that required being social and/or compassionate. A toxic work environment with negative communication and unsupportive and impatient employers constituted a barrier. Parents also perceived a lack of understanding and flexibility from social and healthcare services, who rushed the parents back to work in a manner that often became counterproductive.

Facilitators to meet financial needs were abstracted into the category ‘Available public, private and employer support’. The social insurance system was an important facilitator that enabled parents to take a leave from work and be compensated for the loss of income, as well as for some of the increased expenses related to the child’s illness. However, having private insurance was still emphasized as an important facilitator that kept parents from financial disaster. Employers that let parents keep their full pay without having to work full time, or even at all, were also facilitators.

Barriers to meet financial needs were abstracted into the category ‘Lack of organized and efficient support from employers and social services’. Parents’ expressed that the complicated bureaucracy and the lengthy processes of the Social Insurance Agency and other agencies became a barrier to meet financial needs. Overall, many parents considered the support to lack coordination and proper organization. Some parents felt their employment situation was not compatible with the social insurance system, and others experienced discrimination by their employers, which worsened their financial situation.

## 6 DISCUSSION

This thesis aimed to investigate the socioeconomic consequences for parents of children with cancer, with particular focus on work disruptions and how the child's illness affect the dynamics of childcare and work responsibilities. Indeed, our studies show that a child's cancer diagnosis creates a demanding situation for parents, with both short-term and long-term challenges. They have to adapt to a new, complex life situation, with implications on childcare, work life, family finances, and health.

The findings concur with much previous research that suggest that parents suffer several socioeconomic consequences following a child's cancer diagnosis (Roser et al., 2019; Santacroce et al., 2018). The results of the studies in this thesis further demonstrate that parents experience considerable work disruptions, both childcare leave due to child's ill health and sick leave due to own ill health, for a substantial time after a child's cancer diagnosis. Mothers were overall on both sick leave and childcare leave for more days than fathers. We found that after the initial shock of the child's diagnosis, parents continued to struggle with the impact of the increased childcare pressure on the balance of work and family. Parents prioritized time with family higher, similar to what has been reported by parents in studies conducted in other countries (Kelada et al., 2020; Peikert et al., 2020; Wakefield et al., 2014). Still, the parents in our studies expressed appreciation of the respite from childcare that the work role provided, which has been expressed by parents of children with other illnesses as well (Kish et al., 2020). Balancing work and family was influenced by pre-existing financial and occupational conditions, as well as expectations based on gender roles. The difficulties in balancing work and family remained for a long time, due to child's continued ill health, parents' impaired mental health, and lingering financial and occupational adverse effects. The importance of flexible work arrangements and supportive employers was particularly stressed by parents when discussing their ability to return to work. In order to meet financial needs and return to work, parents emphasized the need for a more coordinated and organized support from both social services and employers.

Sick leave rates among parents were significantly higher than among reference parents for several years following a child's cancer diagnosis. The possibility to be on sick leave may be crucial to heal from the negative impact the child's illness may have on parents' health. To limit the negative effects of being on sick leave for a long time (Bryngelsson, 2009; Floderus et al., 2005; Gustafsson & Marklund, 2011), a gradual and controlled return to work was expressed as desirable among parents in our focus groups. An important finding from study III was that this, unfortunately, was more difficult for some parents. In particular, those working in human service occupations in our focus groups expressed difficulties in returning to or remaining in work due to not having the emotional capacity to care for others. As is the case in the general Swedish population (Aronsson et al., 2018), these kinds of occupations were more common among the women in our groups. A study on the Swedish working population suggested that although long hours of caring for children were found to be associated with higher odds of emotional exhaustion, combining family caregiving with human service work

does not explain the higher risk of sickness absence among human service workers (Drake et al., 2020). The higher risk of sickness absence among human service workers has instead been explained by psychosocial workplace factors and organizational resources, with emotional demands and low work-time control as particularly influential factors (Aronsson et al., 2018). Emotional demands and low control have been put forth as hindering a return to work as well (Nybergh et al., 2020). This further highlights the role of the employer in parents' return to work in a sustainable manner after a child's cancer diagnosis. Adjusting work-time control is difficult in certain occupations, but employers could still attempt to allow more work-time flexibility within the constraints of that particular type of work. Flexible work arrangements, such as ability to choose when, where and how to perform their work, were identified as facilitators for return to work in study IV. Employers could further explore the ability to allow for flexibility in the level of emotional demands. For example, parents in our focus groups expressed gratitude when they could rearrange work assignments and let colleagues do specific tasks that they perceived as particularly emotionally demanding.

It is evident from the studies that there is an impact of traditional gender roles on parents' work disruptions and how they manage work and family responsibilities after a child is diagnosed with cancer. Both sick leave rates and childcare leave rates were higher among women than men in our sample, which mirrors the pattern in the general population (Angelov et al., 2011; Swedish Social Insurance Agency, 2013). During the focus groups, when discussing the uneven distribution of childcare between mothers and fathers, it was consistently suggested that this was a result of women earning less than men, which then led to a division of childcare that resulted in the least severe financial strain on the family. We did, however, not find sufficient support for this reasoning when we investigated the association between income division and childcare division within couples in study II. Related to this was the discussion among mothers in some of the focus groups that mothers are more 'natural' caregivers than fathers, and also that they met expectations from others to act in a gender-typical manner in terms of work and family responsibilities. This indicates support of the findings found in earlier studies that traditional gender roles after a child's cancer diagnosis might in fact be reinforced (Clarke et al., 2009; Gibbins et al., 2012).

That income is secondary to parent gender as explanatory factor for skewed childcare division has been suggested in the general Swedish population as well (Swedish Social Insurance Agency, 2013). Rather than income differences, it could be differences in work characteristics between men and women that impact mothers' and fathers' work disruptions after a child's cancer diagnosis. The results from the studies showed that flexibility at work was a key facilitator for parents to remain in or return to work, and having flexible work arrangements was most frequent among the fathers. Workplace flexibility has been emphasized as an important factor for the ability of parents of children with disabilities to balance work with family demands (Brown & Clark, 2017) and for return to work among parents of children with cancer (Kelada et al., 2020), and female-dominated jobs are often characterized by low flexibility (Kjellson et al., 2014; Magnusson, 2019).

Results from both the second and third studies suggest that the differences between mothers and fathers in the extent of childcare leave vary during the illness trajectory. Mothers were on childcare leave for more days than mothers in the reference group even the year before the diagnosis. As symptoms of the child's illness may have been apparent before diagnosis (Dang-Tan & Franco, 2007), we assume that this is related to that the child required increased care even before the cancer diagnosis was made, although this was not reflected in the fathers' childcare leave. At the year of diagnosis, there was no significant difference between the mothers and fathers of children with cancer, which is supported by the findings of the focus group discussions. The parents talked about how they both had dropped everything else completely when the child was diagnosed, and focused entirely on the child. But as time progressed, it was described that many fathers returned to work before the mothers. This concurs with the results from the second study, where the difference in days on childcare leave between mothers and fathers became significant again the year after diagnosis. These results suggest the possibility that the crisis of a child's diagnosis allow parents to deviate from the traditional responsibilities attributed to them, or allows for 'doing gender' differently, for a period of time before they return to more traditional patterns. Additionally, in study II we found no results suggesting that being on childcare leave affected fathers' income development, suggesting that it did not signal low work commitment in the same manner as has been suggested for fathers in the general Swedish population (Boye, 2015b).

Several interesting aspects of the impact of SES were found in studies I, III and IV. We found that the effect of a child's cancer diagnosis on a father's risk of sick leave, relative to fathers in the general population, is highest among fathers with a high income, higher education, who are employed, and who are born in Sweden. These factors are generally not considered to be risk factors for sick leave (Angelov et al., 2011). This implies that a child's cancer diagnosis might affect the risk of sick leave more evenly throughout the SES spectrum. Family SES might, however, impact how the work absence affects the family's ability to meet financial needs and attain a healthy work-life balance. Previous research has found lower SES to be a risk factor for more severe financial difficulties among parents of children with cancer (Kelada et al., 2020; Lindahl Norberg et al., 2017; Roser et al., 2019). Indeed, parents in our focus groups also discussed how financial struggles before diagnosis further aggravated their situation after diagnosis, and those who had private savings were grateful for the relief from financial stress it offered. In addition, SES is related to work flexibility (Magnusson, 2019), which may further complicate the socioeconomic situation for parents with lower SES. Importantly, some parents with limited assets expressed how they had been forced to go back to work in order to sustain a reasonable financial situation, even though they had preferred to be with their child. That there are parents in Sweden who need to prioritize work over caring for an ill child for financial reasons is noteworthy, and warrants further investigation into how to better meet the needs of those who require socioeconomic support the most.

One can derive from this that the families with high SES are more prepared for financial difficulties, and therefore will not be affected as much. However, what we found from the focus groups was that these families often have arranged their life based on a higher income, and that

they also face difficulties in their new situation in terms of paying loans and other expenses based on the higher income, considering that the social benefits do not cover loss of income above an income ceiling. Importantly, as was additionally exposed in the focus group discussions, an individual with a reasonably high income may still be financially vulnerable if there is a lack of job security. For example, reflecting the experiences of the participants, someone who has worked full-time, but who works ‘on call’ and without a full-time employment contract, may be put in a grim financial situation if they have to take a lengthy leave of absence, without being sufficiently covered by social insurance, and without any mandatory support from the employer. Individuals with this particular vulnerability due to lack of job security can be compared to what have been called the ‘precariat’, a social class characterized by precarious working conditions, which have been discussed as an emerging problem in many countries (Standing, 2013). Thus, when discussing risk factors for financial burden, SES may definitely be of significance, but might not suffice, and including job security and coverage in the social insurance program may be just as important.

The welfare system, and in particular the social insurance system, was stressed as an essential source of financial support for parents. The high rates of both sickness benefits and childcare benefits depict the scope of work disruptions following a child’s cancer diagnosis, but this also highlights how many parents have in fact received necessary support from the social insurance system. The importance of this support for the possibility for parents to uphold a reasonable financial standard cannot be understated. However, our results also exposed how the bureaucracy surrounding the social insurance was so cumbersome that it became a hindrance for parents in their attempt to avoid severe socioeconomic consequences. Similar portrayals of the interaction with the Swedish Social Insurance Agency have been expressed by other individuals on sick leave due to mental disorders, with complex regulations and erratic decisions that became a hindrance for their recovery and return to work (Nybergh et al., 2020). Similar to the parents in our focus groups, a need for concrete help with bureaucratic demands were expressed (Nybergh et al., 2020).

## **6.1 CONCLUSIONS**

The conclusions drawn from the studies included in this thesis are presented here separately for each study.

From the first study, we conclude that the risk of sick leave among parents increases following a child’s cancer diagnosis, and remains heightened compared to reference parents up to six years subsequently. Although the prevalence of sick leave was higher among mothers, both mothers and fathers experienced a similar increase in sick leave days relative to the reference parents. The risk relative to reference parents was particularly high for fathers belonging to a higher SES. Moreover, bereaved parents were at particular risk of being on sick leave.

From the second study, we conclude that the increase in childcare leave prevalence among parents after a child’s cancer diagnosis remains higher compared to the reference parents up to



six years after diagnosis. Just as among the reference parents, mothers were overall on childcare leave for more days than fathers, with a larger gender gap the year before diagnosis than among reference parents. The division of childcare leave was not substantially associated with the division of income within parental couples. Neither did the extent of childcare leave associate with income development among parents of children with cancer.

From the third study, we conclude that balancing work and parenthood after a child's cancer diagnosis includes many challenges for parents. Many parents experience a change of perspective, prioritizing time spent with family over work. At the same time, the demanding parent role can become overwhelming, which made work a positive counterbalance. Balancing work and parenthood was influenced by several conditions, such as work characteristics and pre-existing financial situation. Parents were also affected by the gender-based expectations of how they were to manage work and family. It is furthermore clear that the child's illness continued to make a mark on the parents' ability to balance work and family for a considerable time, while the support from others at the same time decreased.

From the fourth study, we conclude that the ability to return to work is facilitated by flexibility and understanding from employers and social services, and in particular supportive employers who accommodate the needs of the parent. Pressure from employers and social authorities to return to work, despite lingering high childcare demands and impaired own mental health, could be counterproductive for the ability of parents to return to work. The ability to meet financial needs was facilitated by having access to social insurance, but private insurances were also emphasized as crucial. Barriers to meeting financial needs were mainly derived from a lack of organized and efficient support from employers and social services.

The way to move forward from these conclusions is discussed below, with suggestions for both future research and future practice.

## **6.2 SUGGESTIONS FOR FUTURE RESEARCH**

This research was conducted in the light of identified gaps in knowledge of the socioeconomic consequences for parents of children with cancer and what impact they might have, in particular with regards to methodological limitations identified in previous research (Pelletier & Bona, 2015). We were pleased to find that the design and methodology used in the first study were considered to be of the highest scientific quality (Roser et al., 2019). Future research should continue to strive for the highest possible scientific quality, including usage of the many reliable and comprehensive registries available today, especially in Sweden. Registries, however, also have their limitations. For example, during the focus group discussions, it was clear that many of the parents were absent from work without applying for benefits, an absence that would not necessarily be visible in registries. Given the increased understanding that was provided to us by conducting qualitative studies, mixed-method studies could also be used to a larger extent in order to grasp the entire experience of parents of children with cancer, which may not be possible in quantitative or qualitative studies only.

A disease, such as cancer, does not exist in one's life separate from the rest of everyday life. From a scientific point of view, it would thus be motivated to make use of the many theoretical frameworks regarding causes and consequences of work absence, as well as the division of responsibilities for work and family, in order to understand the behavior and experiences of the families living with the disease. Interdisciplinary research could provide new insights beyond the medical context in which much research on the topic is currently conducted.

As has been stated several times in this thesis, the national context needs to be considered when comparing research. Still, comparisons between countries could also create an interesting base for evaluation of different support measures, and lessons could be learnt from other contexts. In addition, even though the results on sick leave and childcare leave in studies I and II are specific for Sweden, they still tell us something about parents' health and work ability, and the children's care demands, which can be expected to be similar in other countries as well, regardless of what kind of social support is provided.

Childhood cancer is a heterogeneous group of diagnoses, and illness and treatment characteristics (e.g. treatment modality/intensity, length of treatment, type of cancer) may have a large impact on the child's future health, and hence the childcare burden imposed on parents. Future studies could benefit from including illness and treatment-specific factors, as well as late effects assessments, to investigate differences in socioeconomic outcomes among parents. Furthermore, considering the difference between mothers and fathers found in registry data, as well as the importance of gender roles discussed in focus groups, studying socioeconomic consequences among same-sex parental couples of seriously ill children would likely provide new and interesting insights into the influence of sex and gender in parenting seriously ill children. Additionally, only Swedish-speaking parents were included in our focus group. To include parents who are not Swedish-speaking in future studies would be very informative, especially as one can suspect that understanding information and receiving adequate support might be particularly difficult for this group.

Last but not least, a principal element throughout the literature as to how parents of children with cancer are affected socioeconomically, including the studies presented in this thesis, is the conclusion that these issues need to be taken into consideration in the care of childhood cancer families, in order to avoid additional problems for families who are already struggling to keep their life together. Our focus groups revealed a frustration among the parents that these issues were not taken seriously and that they were often left on their own to cope with the socioeconomic consequences that the child's disease entailed. Future research should move forward from presenting the consequences parents might face, to identifying the tools that can actually facilitate the parents' situation. This could go beyond the context of childhood cancer and include parents of other serious illnesses as well.

### **6.3 SUGGESTIONS FOR FUTURE PRACTICE**

During all of the discussions in the focus groups, the important role of the Social Insurance Agency was emphasized. It was clear that the administration of both sickness benefits and childcare benefits had differed between the parents, which can partly be explained by that their children were treated during different years. For example, some had experienced that the administration of childcare benefits had been conducted by a specific unit of insurance administrators, who they could contact directly, while others had not been provided this service and felt that the insurance administrators lacked knowledge of their particular situation. To have access to a unit specialized in childcare benefits for parents with seriously ill children, with a specific contact person for the parents, is indisputably preferred. It would be even better if the insurance administrators could work with all types of benefits that parents of seriously ill children require, including additional cost allowances and parents' sickness benefits. This kind of cohesive administration would likely be preferred for anyone seeking any kind of benefit from the social insurance, not only parents of ill seriously ill children, and might unfortunately not be feasible in practice. But for many parents of children with a serious illness in Sweden, there is a sense of frustration over unstructured support from the Social Insurance Agency.

Another central theme of the focus groups was the lack of organized support that some parents experienced from the social workers. The social workers present in all childhood cancer care centers in Sweden have several different tasks, and while many parents had appreciated the support from the social worker, other parents experienced that the social workers were too overwhelmed to help them properly. Perhaps the role of the social worker today is too wide, or alternatively misunderstood by the parents, as they expected the social worker to help them with everything from applying for benefits, arranging special medical equipment, and at the same time being their therapist. Practical and emotional support does not necessarily have to be confined to the same person. Similar observations of mismanaged expectations of social workers have been made in other countries as well (Wakefield et al., 2013). An additional important consideration that could be made regarding the healthcare providers is whether mothers and fathers are in fact treated equally, given that the parents in our focus group expressed that the fathers were still not equally included in the care of the child, or provided psychological support, as much as the mothers.

In Sweden, rehabilitation coordinators have recently been introduced as a new occupation within healthcare, with the role of supporting an individual with the sick leave and rehabilitation process, and offering coordination for a return to work after sick leave, in cooperation with relevant actors (SFS, 2019:1297). Based on the many accounts of the lack of organized and coordinated support for the parents in our focus groups when returning to work, this new role of rehabilitation coordinators could be an excellent step in the right direction. In addition to those who are to prepare for a return to work after a period of sick leave due to their own ill health, this research highlights the need for a similar coordinating role when returning to work after caring for a seriously ill child for a long period of time.

Beyond the involvement of rehabilitation coordinators, the occupational health service could preferably be more extensively involved in the parents' return to work as well. Several parents thought it would be beneficial if the occupational health service in the organization where they were employed contacted them early on after the child's diagnosis, to evaluate the parents' possible engagement at work, and how to return in a suitable manner for both employee and employer. Parents may definitely need to be on childcare or sick leave following a child's cancer diagnosis, but as our focus groups found the workplace often created a much-needed space for parents to be something more than only parents of a child with cancer, early communication with the occupational health services may create an opportunity for parents to not be completely cut off from their work. Additionally, employers should consider the possibility of allowing for as much flexibility as possible in work arrangements, within the boundaries of that particular work.

As has been highlighted in previous research as well (Pelletier & Bona, 2015; Wakefield et al., 2013), a long-term approach when designing support for childhood cancer families is imperative. In this thesis, we have found that parents are affected for many years after the child's diagnosis in terms of work absence, both due to the child's ill health and the parents' ill health. Additionally, there was much emphasis in the focus group discussions on how the impact of the child's illness on the parents' working life, and life in general, continued, even long after treatment had ended. In order to provide appropriate support for childhood cancer families, it is necessary to acknowledge and understand how the child's illness affect all parts of the family's life, and for an indefinite period of time.

The goal of this research is ultimately to improve the wellbeing of families affected by childhood cancer. Achieving this goal would not only be beneficial for childhood cancer families, but identifying how support can be improved could be valuable for families with children affected by other serious illnesses as well. The results of our studies demonstrate that there is room for improvement regarding the support provided to families to reduce the socioeconomic consequences of a child's cancer diagnosis on the parents. Evidence of inconsistent access to support furthermore highlight that there is a need to look into how the psychosocial support can be standardized. This work would benefit from examining how the published pediatric Standards of Psychosocial Care (Wiener et al 2015) are implemented in practice. As an important component of comprehensive psychosocial care (standard number 5), risk for financial hardship should be assessed in all families (Pelletier & Bona, 2015; Wiener et al 2015). Supported by the findings of the studies in this thesis, such an assessment should include risk factors such a pre-existing financial conditions and employment (status, security and work arrangements). The recommendation is to offer targeted referral for financial counselling and supportive resources based on the financial assessment. Furthermore, it is recommended that that reassessments are performed throughout the cancer treatment trajectory and into survivorship or bereavement (Pelletier & Bona, 2015). Indeed, the results of our studies highlight the importance of offering longitudinal support (including both governmental support and support from healthcare), but how to best offer this support needs further investigation. How to best integrate the pediatric Standards of Psychosocial Care into existing

clinical practice have been discussed (Wiener et al. 2020), although not specifically for the standard financial hardship. Besides making an assessment of the quality of care provided, key factors for successful implementation is stakeholder involvement (first and foremost the parents), and attention and willingness to change clinical practice from key healthcare professionals (Wiener et al., 2020).



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