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Posttraumatic stress among parents of children on cancer treatment: support, care and distress

ULRIKA PÖDER



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Abstract

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The main aim of this thesis was to longitudinally investigate the potential occurrence of posttraumatic stress disorder (PTSD) among parents of children on cancer treatment (Study I). Additional aims were to describe parents' perceptions of emotional support and satisfaction with the child's care (II), perceptions of the child's symptom burden (III), and parents' stories about having a child on cancer treatment (IV). The design was prospective, longitudinal, and data was collected at: one week, two months, and four months after the child's diagnosis and one week/six months after the end of successful treatment/transplantation. Parents (N=259) were consecutively included during the years 2002-2004 and answered questionnaires and open-ended questions over the telephone. Parenting a child with cancer is a very demanding, potentially traumatic, event. Approximately a fourth of the parents report symptoms corresponding to PTSD. The symptom level is related to being a mother, not working before the child's diagnosis, and to previous trauma experience. Less than half of those who report a need to talk with a psychologist report having had the opportunity to do so. Parents are generally satisfied with the care and report the highest satisfaction with the technical care. Emotional distress, fatigue, nutrition, and pain are, according to parents, the most problematic symptom areas for their children. Pain is identified as especially problematic. Parents in paediatric oncology care should be acknowledged as potential care-recipients. In order to prevent development of PTSD parents of children on cancer treatment should be supported to maintain an ordinary life, for example pursue work and/or activities, and to get sufficient rest. As a means towards this parents need help with e.g. household duties and childcare. In addition to this, parents in approximately two fifths of the families need extended psychosocial support aiming at reducing posttraumatic stress.

Keywords: posttraumatic stress, PTSD, symptoms, emotional support, satisfaction, childhood cancer, parents

Ulrika Pöder, Department of Public Health and Caring Sciences, Uppsala Science Park, Uppsala University, SE-75183 Uppsala, Sweden

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To my family

List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Pöder U., Ljungman G., von Essen L. Posttraumatic stress disorder among parents of children on cancer treatment: a longitudinal study. *Psycho-Oncology*. 2007 Sep 11; E-pub ahead of print, DOI 10.1002/pon.1263
- II Pöder U., von Essen L. Perceptions of support among Swedish parents of children on cancer treatment. A prospective, longitudinal study. Accepted for publication in *European Journal of Cancer Care*.
- III Pöder U., Ljungman G., von Essen L. Parents' perceptions of their children's symptoms: a prospective, longitudinal study within paediatric cancer care. Submitted.
- IV Berglund T., Pöder U., Lorenz S., von Essen L., Haglund K. Parents of children on cancer treatment: reactions, social situation and strategies to cope. Submitted.

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Abbreviations and definitions

ASD	Acute Stress Disorder
ASS	Acute Stress Symptoms
DSM-IV	The Diagnostic and Statistical Manual of Mental Disorders, 4 th edition
PTSD	Posttraumatic Stress Disorder
PTSS	Posttraumatic Stress Symptoms

Terms used in this thesis

Cases/caseness of ASD

Definition

At least moderately bothered (PTSD Checklist (PCL) - item score 3-5) by at least one of five symptoms of re-experience, three of seven symptoms of avoidance, and two of five symptoms of hyper-arousal, during the past week.

Cases/caseness of PTSD

At least moderately bothered (PCL-item score 3-5) by at least one of five symptoms of re-experience, three of seven symptoms of avoidance, and two of five symptoms of hyper-arousal, during the past month.

Custodian parents

Parents through birth or adoption.

Symptom burden

Number of symptoms and total Memorial Symptom Assessment Scale (MSAS) score, and the respective symptom subscale scores of the MSAS scale.

Introduction

The whole family becomes affected when a child is diagnosed with cancer. According to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), childhood cancer can precipitate posttraumatic stress disorder (PTSD) in parents [1]. The child's diagnosis is often the first potentially traumatic event during the disease trajectory, and several potentially traumatic events may follow [2]. The threat to life, seeing the child in pain, experiencing procedural distress, and being in emergency situations are examples of potentially traumatic events for parents. Parents' everyday lives during the child's illness are often very demanding with, for example, frequent clinical appointments, multiple hospitalizations, and administration of medication, together with the perceived need of checking the child's health status and upholding the child's intake of food and fluids, despite possible lack of appetite and a sore mouth. The demanding situation may result in increased vulnerability to traumatic events and thereby increase the risk of posttraumatic stress symptoms (PTSS) and PTSD [3-6]. The main aim of this thesis was to longitudinally investigate the occurrence of potential PTSD among parents of children on cancer treatment.

Childhood cancer

Childhood cancer is a rare event [2], and the incidence among Swedish children, age 0-19 years, is approximately 350 [7]. Childhood cancer can be classified into four main types: leukaemia (approximately 31% of all childhood malignancies), CNS-tumours (28%), lymphomas (12%), and other solid tumours (29%) [7].

The treatments, mainly chemotherapy, radiotherapy, and surgery, or a combination of these, have improved over the years, resulting in a present 5-year survival rate of approximately 75% for all childhood cancers combined [8]. Chemo- and radiotherapy are designed to destroy cancer cells. Not only these cells, but also healthy cells, e.g. haematopoietic and mucosal cells, skin cells, and hair follicles may be affected by the treatments [9].

Children and adolescents on treatment have reported a high prevalence of distress [10-12] and a high distress level [10-14], caused by pain, sleep disturbance, change in appetite, nausea, vomiting, a sore mouth, fatigue, changes in appearance, and psychological distress. Difficulty swallowing,

skin changes, and problems with urination have been reported as less common though highly distressing concerns [10]. Collins and co-workers [10] have reported a higher prevalence of symptoms among children diagnosed with a solid tumour than among children diagnosed with leukaemia, lymphoma or a CNS-tumour. Landolt and co-workers [15], on the other hand, have reported that children newly diagnosed with leukaemia are more affected by physical problems than children with CNS-tumours, with a reverse pattern one year later.

Clinical competence, continuity in staff, satisfaction with basic care needs, emotional support, information, time [16,17], and participation in decision-making [16-18] are important aspects of care for children with cancer. Amusement and being cared for by socially competent staff have also been described as important for children [16-18].

Parenting a child with cancer

Parents who have struggled to obtain the child's diagnosis [19,20] may feel relief when finally informed about it. They may also experience guilt and self-reproach about not having been effective advocates for their child during the diagnostic process [19]. Others may experience shock, numbness, and disbelief [19,21], especially if told the diagnosis shortly after the first visit to health care due to the child's symptoms [19].

When a child is diagnosed with cancer most parents become involved in the child's care, e.g. administering medications, monitoring side effects, and helping their child to handle emotional and physical concerns. Along with caring for and supporting the sick child as well as potential siblings, parents struggle to handle their own emotional distress [21-23]. Parents may experience a range of emotions at the time of diagnosis and during the early treatment phase, for example fear [21,23-26], shock [19,21,23,25], and worry about the threat to their child's life [21,23]. To face up to the demanding situation, parents may "put life on hold" [27] and ignore their own needs and feelings. This can have an impact on work and social life. Problems with relationships [25,26,28] and feelings of grief [28] may arise. Parents may use a variety of strategies to cope with the situation, for example striving for a positive focus [24,25] and to control the situation [24,26], using available support from the social network [24,25,27,29] and health care [29], using religion [25,29], taking time out from the cancer experience [21,29], handling the situation as a challenge [29], and striving to maintain normalcy [21].

Knowing that the child is getting the best available treatment and care, emotional support, information, time, and participation in care and decision-making have been reported as important aspects of care for parents of children with cancer [30,31]. Furthermore, parents have reported that the physical environment at the ward and being cared for by socially competent staff

[30] who recognise parents' needs of rest and spare-time [30,32] are important aspects of care in order for them to feel well cared for.

Swedish parents are allowed temporary parental benefit until the child reaches the age of 18, childcare allowance when a child is chronically ill, and sick-leave if their own health is affected (see <http://www.forsakringskassan.se>). However, families' income is negatively affected when a child falls ill with cancer [21,25,27,29,33-37]. This is partly due to increased expenditure, for example for transportation, parking, clinical visits, and food as well as loss of income.

Acute and posttraumatic stress

Approximately 3% of the general adult population will experience their child being diagnosed with a life-threatening illness [38]. According to the DSM-IV, this is a trauma that can precipitate PTSD [1].

Table 1. *The diagnostic symptom criteria for PTSD, according to the DSM-IV*

Symptom criteria
The traumatic event is persistently re-experienced in at least <i>one</i> of the following ways: <ol style="list-style-type: none"> 1. recurrent, intrusive distressing recollections of the event, including images, thoughts, or perceptions 2. recurrent, distressing dreams of the event 3. acting or feeling as if the traumatic event was recurring 4. intense psychological distress on exposure to reminders that symbolise or resemble an aspect of the traumatic event 5. physiological reactivity on exposure to reminders that symbolise or resemble an aspect of the traumatic event
Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least <i>three</i> of the following: <ol style="list-style-type: none"> 1. efforts to avoid thoughts, feelings, or conversations associated with the trauma 2. efforts to avoid activities, places, or people that arouse recollections of the trauma 3. inability to recall an important aspect of the trauma 4. markedly diminished interest or participation in significant activities 5. feeling of detachment or estrangement from others 6. restricted range of affect, e.g. unable to have loving feelings 7. sense of a foreshortened future, e.g. does not expect to have a career, marriage, children, or a normal life span
Persistent symptoms of increased arousal (not present before the trauma), as indicated by at least <i>two</i> of the following: <ol style="list-style-type: none"> 1. difficulty falling or staying asleep 2. irritability or outbursts of anger 3. difficulty concentrating 4. hypervigilance 5. exaggerated startle response

PTSD, as well as acute stress disorder (ASD), may occur after exposure to a traumatic event involving actual or threatening death/serious injury or threat to a person's physical integrity (criterion A1, DSM-IV), causing the person to respond with intense fear, horror, and/or helplessness (criterion A2, DSM-IV) [1]. ASD develops within a month of the trauma, and requires that the person is significantly troubled by dissociative symptoms and symptoms of re-experience, avoidance, and hyper-arousal. Symptoms of re-experience, avoidance, and hyper-arousal that persist over a month may indicate PTSD [1], see Table 1.

A PTSD prevalence ranging between 2-8% has been reported in the general population, with a higher prevalence for females [38-43]. Individuals without early symptoms of PTSD after a trauma often remain asymptomatic. Presence of ASD and persistent symptoms of dissociation and hyper-arousal have been identified as risk factors of PTSD [44] and 10-20% of those experiencing acute stress symptoms (ASS) are expected to develop PTSD [45]. It has also been shown that approximately three quarters of those with ASD develop PTSD, and that approximately half of those who develop PTSD initially have met the criteria for ASD [46].

Acute and posttraumatic stress among parents of children with cancer

To the best of our knowledge levels of acute and posttraumatic stress and the prevalence of ASD and PTSD among parents of children on cancer treatment have been investigated in very few studies. The few studies that do exist have cross-sectional designs. A 51% and 40% prevalence of ASD has been shown among mothers and fathers, respectively [6]. Findings from the same study show that 36% of the mothers and 28% of the fathers were at risk of developing PTSD. The reported prevalence of ASD is comparable with that for parents of children involved in accidents [47] and admitted to neonatal [48] and paediatric intensive care [49]. Other findings show that 67% of parents [50], 68% of mothers and 57% of fathers [4], report PTSS within a moderate to severe range. Of those, 25% of the mothers and 13% of the fathers reported severe symptoms [4], and in a Swedish study 23% of the parents reported significant traumatic stress [51]. Other findings have shown a PTSD prevalence of 30% [52] to 44% [53]. Parents of children on treatment report higher levels of PTSS than parents of children who have survived cancer [3,4] and of healthy children [3]. However, recent findings show a difference only for parents whose child has suffered a relapse when comparing levels of PTSS between parents of children on treatment and of healthy children [54].

According to a review by Bruce in 2006 [2] approximately twenty studies, the majority conducted in the US up until the year 2004, had addressed PTSS and/or PTSD in parents of survivors of childhood cancer [2]. Few were based on longitudinal designs [55-57] and none investigated the development of PTSS or PTSD. According to results from diagnostic interviews, 6% to 42% [5,52,58-60] of parents of children off treatment demonstrate PTSD. More mothers (30%) than fathers (12%) met lifetime PTSD, in that study defined as since the child's diagnosis [5]. Other findings have shown that, in comparison with parents of healthy children, parents of children off treatment report higher levels of PTSS [61,62] and a higher prevalence of PTSD [61]. A reverse pattern has also been shown: parents of long-time survivors report a lower level of PTSS compared to parents of healthy children [54].

Risk and protective factors

Individual pre-existing factors, factors related to the traumatic event including trauma responses, and post-trauma factors may affect the risk of PTSD [63]. The literature is sparse regarding risk and protective factors for ASS, PTSS, ASD and PTSD among parents of children on and off cancer treatment.

On treatment

Parent trait anxiety has been associated with ASS [6], socioeconomic factors and family function with ASS [6] and PTSS [53], and parent having experienced previous trauma has been associated with PTSS [53] among parents of children on treatment. Additionally, parent-perceived life threat at the time of the child's diagnosis, length of hospitalisation, the child's functional status [53], and relapse [54] have been associated with PTSS among parents of children on treatment.

Off treatment

Parent [64] and child age [65,66], socioeconomic factors [58], parent having experienced previous trauma [59], parent trait anxiety [56], parent emotional distress [57,65,67,68], parent-perceived life threat [55,57,58,68,69], illness uncertainty [64], parent perceptions of procedures and treatment intensity [55,56,68], the child's physical health [70], relapse [54], and time since diagnosis [54,64,65] or end of treatment [56] have been associated with PTSS among parents of children off treatment. Furthermore, family function [58,61,62,65,69,71], a supportive network [57,62,68,69], the possibility of doing things with others as well as of talking with others about cancer-related aspects [66], and a positive attitude towards health care [70] have been inversely associated with PTSS among parents of children off treatment.

Parent age [67], parent gender, parent education status, parent having experienced previous trauma, a history of psychiatric disorder within the previous year, and relapse [54], and prognosis and treatment with radiotherapy [52] have been associated with PTSD among parents of children on [52,54] and off [52,54,67] treatment.

There is very limited knowledge about which symptoms parents, according to findings from studies using multi-item measures, perceive as burdensome for their children. Studies have shown associations between perceiving one's child in distress and PTSS among parents of children with cancer [55,56,68,70,72,73]. It can be speculated whether perceiving one's child in distress increases the risk of ASS, PTSS, ASD and/or PTSD among parents. On the other hand it can be speculated whether good care and emotional support may protect parents of children from developing ASS, PTSS, ASD and/or PTSD.

The present thesis

Most parents experience many potentially traumatic events when having and caring for a child with cancer. On the basis of the available literature it seems safe to conclude that most parents possess enough resources to adapt to and cope with the situation. However, some parents experience and continue to experience distress, e.g. PTSS and even PTSD during and after the child's disease trajectory. Knowledge of risk factors and protective factors with regard to PTSS and PTSD among parents of children with cancer is sparse. The literature is especially sparse regarding parents of children on treatment. As a first step towards an increased understanding of the development of PTSD among parents of children with cancer, this thesis aims at providing an overview of the potential occurrence of PTSD among parents of children on cancer treatment and of parents' perceptions of support, care and distress.

Aims

The main aim of this thesis was to longitudinally investigate the potential occurrence of posttraumatic stress disorder (PTSD) among parents of children on cancer treatment. Additional aims were to describe parents' perceptions of emotional support and satisfaction with the child's care, perceptions of the child's symptom burden, and parents' stories about having a child on cancer treatment. The specific aims in Studies I-IV were to, among parents of children on cancer treatment:

- investigate the potential occurrence of cancer-related PTSD (Study I)
- describe parents' perceptions of emotional support and satisfaction with the child's care (Study II)
- describe parents' perceptions of the child's symptom burden (Study III)
- describe parents' stories about having a child on cancer treatment (Study IV)

Method

Design

The assessment times, sample sizes, and exclusion and refusal rates in Studies I-IV are presented below in Figure 1.

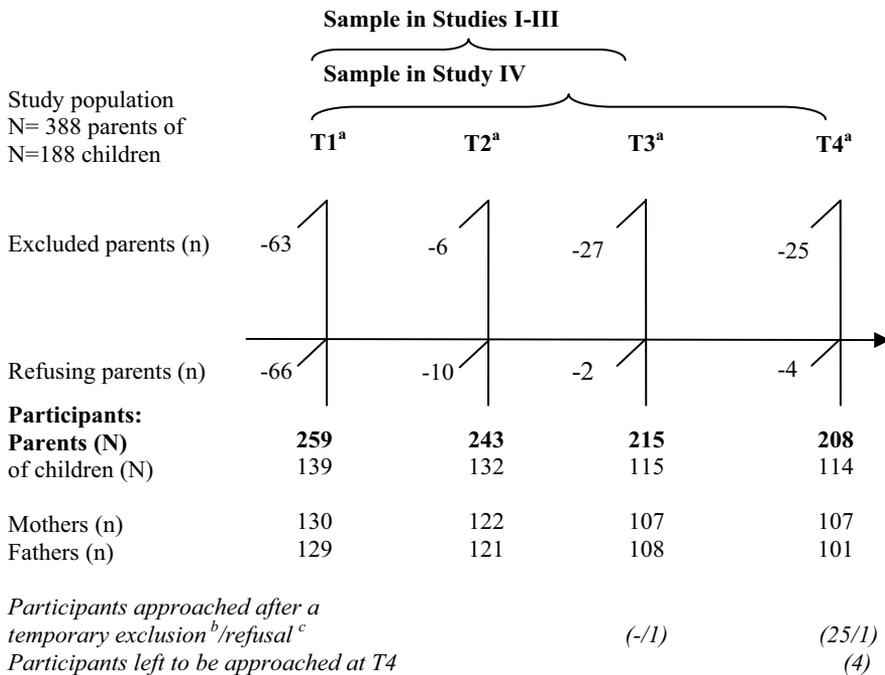


Figure 1. Assessment times, sample sizes, and exclusion and refusal rates in Studies I-IV

Notes:

^a T1=one week after diagnosis (DI); T2=two months after DI; T3=four months after DI; T4=one week after end of successful treatment/six months after bone marrow, stem cell or organ transplantation.

^b temporary exclusion at T2-T3 (n=1), or T3 (n=24), approached again at T4.

^c agreed to be asked again after preceding refusal at T2 and T3 respectively.

Data was collected within an ongoing project with a longitudinal design including seven assessments, entitled “Occurrence and development of post-traumatic stress disorder among Swedish parents of children with cancer”. The first three assessments (T1-T3) were planned in relation to the child’s diagnosis and were the same for all parents: T1=one week after diagnosis (DI); T2=two months after DI; T3=four months after DI. The following four assessments were planned in relation to the end of treatment (T4-T7) or the child’s death (T5-T7): T4=one week after the end of successful treatment (ST) or six months after bone marrow, stem cell or organ transplantation (T); T5=three months after ST or the child’s death/nine months after T; T6=one year after ST or the child’s death/18 months after T; T7=five years after ST, the child’s death or T.

The results in Studies I-III are based on data collected at T1-T3. The results in Study IV are based on data collected at T1-T4.

Sample

Parents of children treated for cancer at four of the six Swedish paediatric oncology centres, Gothenburg, Linköping, Umeå, and Uppsala, were consecutively included. The care and treatment followed approximately the same guidelines at the four centres. Inclusion started in April 2002 and ended in February 2004, 18 continuous months at each centre. Inclusion criteria were Swedish and/or English speaking parents (including stepparents) of children, 0-18 years, diagnosed (≤ 14 days ago) with cancer (no relapse) and scheduled for chemotherapy and/or radiotherapy. Additionally, parents were to have access to a telephone. To be approached at T2 and T3 the child was to be on curative treatment. To be approached at T4 the child was to have ended treatment one week previously or, in case of transplantation six months previously. Children undergoing transplantation are under frequent observation and may require extended care the first months after transplantation. A postponed T4 assessment was therefore chosen for this subgroup. Reasons for exclusion, temporary exclusion and refusal are presented in Table 2.

The sample in Studies I-III consists of parents participating at T1-T3. One parent participating at T3 did not participate at T2, and was therefore excluded in Studies I-III. Thus, the sample consists of 214 parents of 115 children: mothers $n=107$, fathers $n=107$, see Figure 1. Eighty-four children were represented by two parents, 24 children by one parent, six children by three parents and one child by four parents. Of these, 88 were represented by their custodian parents, and two by their custodian mother and their stepfather ($n=90$ pairs in Study III). Of these pairs, seventy-five were cohabiting custodian parents ($n=75$ couples in Study I). Characteristics of participating par-

ents and their children, including the children’s treatment modalities and number of relapses, are presented in Tables 3 and 4.

The sample in Study IV consists of parents participating at T1, T2, T3 and/or T4, see Figure 1. The characteristics of participating parents and their children at T1 were almost identical for the sample in Studies I-III and for the sample in Study IV. One hundred and three children were represented by two parents, 28 children by one parent, seven children by three parents and one child by four parents at one assessment or more.

Fathers were older than mothers ($p \leq .01$) and more fathers than mothers worked full-time at T1, T2, T3, and T4 respectively ($p \leq .01$). More mothers than fathers reported that a past trauma had a possible impact on their emotional reaction ($p \leq .01$). Some parents experienced divorce, marriage, birth, accident, serious disease, or death of someone close during the study period.

Table 2. *Reasons for exclusion, temporary exclusion and refusal at T1-T4^a*

	T1 ^a	T2 ^a	T3 ^a	T4 ^a
Exclusion, n parents	63	2	1	3
>14 days after diagnosis	41			
o Logistic/administrative reasons	30			
o Not allowed to ask, doctors order/intensive care	10			
o Not reachable after provided with study information	1			
Communication difficulties	17			
No current contact with the child	5			
Child moved to a non-participating paediatric oncology centre/adult oncology care		2	1	3
Temporary exclusion, n parents	4	26	22	
Palliative care/death of the child	3 ^b	2 ^b	22 ^b	
Child had ended successful treatment	1 ^c	24 ^c		
Refusal, n parents	66	10	2	4
Not able to prioritise participation under circumstances	44	7 ^d		
Not interested	18	1	1	1 ^d
Prefers a written questionnaire	2	2		1
Doesn't feel representative	2			
Too emotional			1 ^e	
Administrative failure				2

Notes.

^a T1=one week after diagnosis (DI); T2=two months after DI; T3=four months after DI; T4=one week after end of successful treatment /six months after bone marrow, stem cell or organ transplantation.

^b parents were approached again at T5.

^c parents were approached again at T4.

^d one parent temporarily refused at T2, accepted participation again at T3, and refused participation at T4.

^e one parent temporarily refused at T3 and accepted participation again at T4.

Table 3. *Parent characteristics at T1^a in Studies I-III*

	M (SD) Range	n	%
Parent mothers/fathers ^b		107/107	50/50
Age of parent, y	36.7 (6.3) 22-55/39.1 (6.9) 22-59		
<30		28	13
30-39		113	53
≥40		73	34
Place of origin			
Nordic country		206	96
Marital status			
Married/cohabiting		191	89
Single		23	11
Custody			
Joint		197	92
Single		4	2
No custody/steparent		13	6
Education			
≤ Nine year		26	12
Upper secondary		120	56
University		68	32
Previous trauma, yes		144	67
Impact on present reaction, yes		59/38	55/36
Work status			
Full time or student (full time)		41/95	38/88
Part time		43/6	40/6
Not working ^c		23/6	22/6
Household income €			
≤ 21,500		9	4
21,600 - 32,200		28	13
32,300 - 43,000		38	18
43,100 - 53,700		86	40
≥ 53,800		49	23
No answer/don't know		4	2
Distance to oncology centre, km	150.8 (115.2) 0.1-500		

Notes:

^a T1 = one week after child's diagnosis (DI).

^b in case of a statistically significant difference ($p \geq .01$) between mothers and fathers figures for both genders are presented.

^c e.g. retirement, long-term sick-leave due to doctor's order, unemployment, parental allowance.

Table 4. *Child characteristics at T1^a in Studies I-III and treatment modalities, and number of relapses in Studies I-III^b and IV^c*

	Studies I-III		Study IV		
	M (SD) Range	n	%	n	%
Child daughters/sons		54/61	47/53		
Age of child, y	7.8 (4.9) 0.6-17.8				
0-3		26	23		
4-7		35	30		
8-12		34	30		
13-18		20	17		
Diagnosis					
Leukaemia		50	44		
Lymphoma		16	14		
CNS tumour		14	12		
Other solid tumour		35	30		
Prognosis, %					
Probability of 5 year survival	71.6 (17.9) 20-95				
>70% probability of 5 year survival		62	54		
Siblings, yes		104	90		
<u>Treatment modalities and number of relapses</u>					
Chemotherapy		115	100	139	100
Surgery		38	33	57	41
Radiotherapy		18	16	40	29
Transplantation		-	-	12	9
Relapse		2	2	9	6

Notes:

^a T1 = one week after child's diagnosis (DI).

^b Studies I-III: Data concerns the period from T1 to T3 = four months after DI.

^c Study IV: Data concerns the period from T1 to T4 = one week after end of successful treatment/six months after bone marrow, stem cell or organ transplantation.

Participants vs. non-participants

More parents of a child with a CNS-tumour (38%) than with another solid tumour (18%), lymphoma (8%), or leukaemia (7%) ($p \leq .01$) were excluded from participation. Most were excluded since more than 14 days had passed since diagnosis when it was possible to inform about the study (administrative reason).

Studies I-III

As more children with lymphoma were off treatment at T3, fewer of their parents (67%) than parents of children with another solid tumour (80%), a CNS-tumour (85%), or leukaemia (91%) ($p \leq .01$) participated in all assessments. Parents who participated in all assessments reported higher satisfac-

tion with nurses' technical skills ($p \leq .01$) than parents who did not participate in all assessments, and more parents who participated in all assessments than parents who did not reported a need for talking with "other people" (92% vs. 80%; $p \leq .01$) and benefit from talking with a social-worker (90% vs. 68%; $p \leq .01$).

Study IV

The child's prognosis was more favourable for those who participated vs. those who did not participate at T2 ($n=243$ vs. $n=16$) ($M=72.2$ vs. $M=56.2$; $p \leq .01$) and at T4 ($n=208$ vs. $n=25$) ($M=73.2$ vs. $M=60.5$; $p \leq .01$). As more children with lymphoma were off treatment at T3, fewer of their parents (69%) than parents of children with another solid tumour (80%), a CNS-tumour (84%), or leukaemia (91%) ($p \leq .01$) participated at T3.

Instruments

Parents answered questions about parent and child characteristics, see Tables 3 and 4, and the following questionnaires over the telephone (T1-T4): The PTSD Checklist Civilian version (PCL-C; T1-T4); The F-criterion questionnaire (data not presented in this thesis; T2-T4); The Comprehensive Assessment of Satisfaction with Care, Short Form, Version 4.0 (CASC SF 4.0; T1-T4); Emotional support (T1-T4); The Memorial Symptom Assessment Scale (MSAS) 10-18 (T1-T4); Perception of the effect of the child's disease on the family's daily activities (data not presented in this thesis; T2-T4). Additionally, parents were asked two open-ended questions: "Has anything special happened since the last interview (since the diagnosis at T1)?" and "Do you want to tell me something I did not ask about?" The first question was asked at the beginning of each interview and the last question at the end of each interview (T1-T4; Study IV). Children's medical data were collected from the medical charts by a coordinating nurse at each paediatric oncology centre (T1-T4).

PCL-C (Study I)

The PCL-C was translated into Swedish using a forward-backward procedure following the guidelines of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Study Group [74]. It is a self-report questionnaire constructed for screening purposes for PTSD and PTSS among the civilian population [75]. It embraces 17 items keyed to a specific trauma, in this study the child's cancer. Each item belongs to one of three subscales: re-experience (5 items; Cronbach's alpha (α) in this sample at T1-T3: .56-.83), avoidance (7; α .59-.82), or hyper-arousal (5; α .71-.86). The respondent is asked to report how much he has been bothered by each item

during the last month (at T1 during the last week) on a 5-point scale from “not at all” (1) to “extremely” (5). The total score ranges from 17 to 85 (α .80-.92).

The English version of the PCL-C has shown convergent validity with the Impact of Event Scale and the Mississippi Scale, which measure corresponding concepts [75,76], and satisfactory diagnostic effectiveness: it has been suggested that a score of ≥ 50 on the PCL-C indicates PTSD among war veterans [75] whereas it has been suggested that a score of ≥ 44 indicates PTSD among victims of vehicle accidents and sexual assault [77]. The PCL-C symptom criteria method [75], i.e. a score of ≥ 3 on at least one symptom of re-experience, three symptoms of avoidance, and two symptoms of hyperarousal, was used in this thesis to investigate the occurrence of ASD/PTSD, i.e. identify parents scoring as potential cases, hereafter referred to as cases, of ASD at T1 and PTSD at T2-T3. The method has shown diagnostic effectiveness for PTSD when compared to the Structured Clinical Interview for DSM-IV among mothers of childhood cancer survivors [60].

CASC SF Version 4.0 (Study II)

Parents' satisfaction with children's care was measured using the CASC SF Version 4.0 [78], a pre-model of the EORTC IN-PATSAT32 [79], consisting of 32 questions, with acceptable test-retest reliability, and convergent and divergent validity [79]. The original version was constructed as a self-report instrument. In this study the questionnaire was answered by parents according to their opinion of the child's care. At T1 parents were asked to answer the questions since the child's diagnosis whereas at T2 and T3 it was since the last interview. Responses were provided on 5-point verbal scales ranging from very poor (1) to excellent (5). The questionnaire is organised in eleven multi-item scales and three single items. The following scales are included: doctors' and nurses' technical skills (α .70-.83), doctors' and nurses' interpersonal skills (α .78-.90), doctors' and nurses' information provision (α .85-.91), doctors' and nurses' availability (α .70-.81), other hospital personnel kindness and helpfulness and information provision (only information provision is analysed due to improved consistency, α .60-.84), waiting time (α .62-.74), hospital access (excluded from analyses=low α), and the single items exchange of information (excluded from analyses=low response rate), hospital comfort/cleanliness, and general satisfaction.

Emotional support (Study II)

The emotional support questionnaire was developed by members of the research group. Parents were asked about their need for, opportunities for, and benefit from talking with doctors, nurses, psychologists, social workers, partners, friends, and other people (below referred to as sources of support).

The first question (for each source of support) assessed parents' need to talk about the child's illness. Responses were provided on a 5-point verbal scale ranging from none (1) to very great (5). A second question (for each source of support) assessed parents' opportunities to talk about the child's illness. Responses were provided on a 5-point verbal scale ranging from never (1) to very often (5). A third question (for each source of support) assessed parents' benefit from talking about the child's illness. Responses were provided on a 5-point verbal scale ranging from not at all (1) to very much (5).

During the first months of data collection parents were not asked about their need for, opportunities for, and benefit from talking to a social worker. The answering rate for the questions about this source of support is consequently somewhat lower than for the questions about the other sources of support (T1, n=192, T2, n=202, T3, n=212).

MSAS 10-18 (Study III)

The MSAS was originally developed to be answered by adults with cancer [80]. The MSAS 10-18 [10] is a modified version of the original instrument to be answered by children from approximately 10 years of age. The MSAS 10-18 consists of 30 items, and has acceptable test-retest reliability, and convergent and divergent validity [10]. In this study, the MSAS 10-18 was modified to be answered by parents of children with cancer. It was translated into Swedish using a forward-backward procedure following the guidelines of the EORTC Quality of Life Study Group [74]. In addition to the 30 items included in the original version the instrument used in this study, according to findings by Collins et al [10], embraces questions about headache and hair-loss. For each symptom parents were asked to assess whether it had been present during the last week, and if so, to rate it according to frequency, intensity, and distress. Responses were provided on 4-5-point verbal scales ranging from almost never (1) to almost always (4) (frequency scale, not applicable for nine items), from slight (1) to very severe (4) (intensity scale), and from not at all (0) to very much (4) (distress scale). For each symptom the average score for frequency (if applicable), intensity, and distress was calculated, subsequently called the symptom score [10]. The instrument embraces three subscales: The Global Distress Index (GDI; α .77-78) is the average of four frequency scores for psychological symptoms (feeling irritable, feeling nervous, feeling sad, worrying), and six distress scores for physical symptoms (constipation, dry mouth, feeling drowsy, lack of appetite, lack of energy, pain). The psychological symptoms subscale (PSYCH; α .73-77) is the average of six symptom scores (difficulty concentrating, difficulty sleeping, feeling irritable, feeling nervous, feeling sad, worrying). The physical symptoms subscale (PHYS; α .81-83) is the average of eleven symptom scores (changed taste, constipation, dizziness, dry mouth, feeling drowsy, lack of appetite, lack of energy, nausea, pain, vomiting, weight

loss). The total MSAS score (α .87-88) is the average score of all symptom scores (the aforementioned symptoms and cough, diarrhoea, difficulty swallowing, hair loss, headache, “I don’t look like myself”, insomnia, itching, less hair than usual, mouth sores, numbness/tingling in the hands/feet, problems with urination, shortness of breath, skin changes, sweating, swelling in arms/legs).

Medical data collection protocol (Study I-IV)

Medical data, e.g. about treatment modalities and relapses has been collected retrospectively to cover the time period from T1 to T4. Medical data from the time around the diagnosis was used in order to estimate prognosis. This was done by an experienced paediatric oncologist. If the diagnosis was preliminary at T1, i.e. not verified by pathological anatomical diagnosis (PAD), the diagnosis established at T2 was used.

Procedure

Parents who met the inclusion criteria received written and oral information about the study from a coordinating nurse at the respective centre within two weeks of the child’s diagnosis (Md=4 days). The same nurse asked (Md=5 days) for permission for a doctoral student or a research assistant (the interviewers) to contact the parent over the telephone, in order to ask for oral informed consent (Md=7 days). The two interviewers had no contact with the parents, besides performing the telephone interviews. Permission to contact the parent at the next data collection was acquired at the end of each interview.

The interviews took place in a median of eight days (T1), 60 days (T2), and 119 days (T3) after the child’s diagnosis, and eight days after the end of treatment/the six months-day after transplantation (T4; Md=440 days after the child’s diagnosis). The median time for the interviews was 46.2 minutes (15-185 minutes). To minimize the internal dropouts and to facilitate for the parent, the response alternatives for each questionnaire were read aloud to the parents in order of appearance, and the parents were encouraged to write these down before providing their answers. Two hundred and fifty-five of the parents answered at least one of the two open-ended questions on one occasion or more. The number of parents answering the open-ended questions at each assessment was 211 of 259 at T1 (Mothers, n=107; Fathers n=104), 213 of 243 at T2 (n=111; n=102), 178 of 215 at T3 (n=91; n=86), and 200 of 208 at T4 (n=104; n=96). The interviews were not tape-recorded.

Medical data for the children was collected from medical charts (T1-T4), on the basis of a predetermined study protocol, by a coordinating nurse at the respective centres.

Ethics

Ethical approval was obtained from the local ethics committees at the respective faculties of medicine (Diary number: Ups 02-006). Parents were guaranteed confidentiality and that the information they provided would not be disclosed to the child's health care personnel. In appreciation of participation, parents were offered a small gift after each assessment time (three centres), or after all assessments (one per assessment time, one centre).

Analyses

Statistical analyses used in Studies I-III are presented in Table 5. A p-value of $\leq .01$ was chosen, in most instances, in order to decrease the risk of Type 1 errors. In Study I a p-value of $\leq .05$ was chosen for an explorative purpose of analyses of relations between sample characteristics and ASS, PTSS, ASD and/or PTSD. Only statistically significant results will be reported in this thesis. Data in Study IV was analysed using content analysis [81].

Table 5. *Statistical analyses in Studies I-III*

	Study I	Study II	Study III
Repeated measures ANOVA ^a	x		
One-way within subject ANOVA ^a			x
One-way ANOVA ^a	x		x
Independent t-test	x		x
Dependent t-test			x
Pearson correlation	x		x
Friedman		x	
Cochrane's Q ^b	x	x	x
Mann Whitney U		x	
Chi-square	x	x	

Notes:

^a Bonferroni and t-test were used as post hoc tests.

^b McNemar's test was used as post hoc test.

Study I

The PCL-C symptom criteria method [75], i.e. a score of ≥ 3 on at least one symptom of re-experience, three symptoms of avoidance, and two symptoms of hyper-arousal, was used to identify caseness of ASD at T1 and of PTSD at T2-T3. All statistics were performed using the SPSS 11.0.3, Mac OS X version.

Study II

The scoring procedure used for the CASC SF Version 4.0 is equivalent to that recommended for the IN-PATSAT32 [79]. The transformed scores range from 0-100; a higher score indicates higher satisfaction [79]. The 5-point scales for the answers about need for, opportunities for, and benefit from talking with health professionals, significant others, and other people were transformed to dichotomous variables: 1=no/2-5=yes. If a need was reported a score for opportunity was calculated, and if an opportunity was reported a score for benefit was calculated. All statistics were performed using the SPSS 14.0 for Windows.

Study III

A symptom was categorized as frequent if rated as a lot (3 on the Likert scale) to almost always (4), intense if rated as moderate (3) to very severe (4), and distressing if rated as quite a bit (3) to very much (4) [10]. Percentages for the aforementioned symptom characteristics are based on the number of parents reporting the respective symptom as present. Symptom prevalence and the symptom characteristic distressing will be presented, together with a subsequent analysis regarding percentages of the symptom characteristic distressing based on the total sample. The symptom burden is illustrated by the mean number of prevalent symptoms, the mean for the total MSAS scale and the subscales GDI, PSYCH, and PHYS. Symptoms reported as not present were given a value of 0 for frequency, intensity, and distress in the calculations of mean values for these scales [80]. All statistics were performed using SPSS 15.0 for Windows.

Study IV

Data revealed from the two open-ended questions "Has anything special happened since the last interview (since the diagnosis at T1)?" and "Do you want to tell me something I did not ask about?" was analysed using content analysis [81]. The method can be used to draw valid conclusions about a manifest message in a communication by systematic identification of specified communication characteristics. The analysis was performed in the following steps: 1) All answers were read repeatedly and separately by two persons. 2) Sentences or parts of sentences that contained information relevant to the study aim were identified (these are called recording units). Data from the different assessments was initially analysed separately. As the data from the respective assessments was found to be very similar, the data was collapsed. 3) Separately, the two persons grouped recording units into categories with preliminary descriptions reflecting central text messages. 4) The categories were compared and mutually exclusive categories were developed

and approved by three persons. 5) Descriptions of the central characteristics of each category were developed by two persons. 6) A check of the recording units and categories was carried out by one person. Repeated meetings were held with all authors in order to discuss content and descriptions of categories. None of the authors had clinical experience of paediatric oncology. However, some authors had extensive experience of working within different types of clinical care whereas others had extensive experience of analysing interview data using content analysis. The content analysis revealed answers covering: 1) parents' and 2) families' reactions and thoughts, social situation and strategies to cope and 3) families' experience of the health care system. Results regarding families' reactions and thoughts, social situation and strategies to cope and families' experience of the health care system will be presented elsewhere.

Results

Study I

Levels of ASS and PTSS and cases of ASD and PTSD

The levels of ASS and PTSS showed a linear decline over time ($p \leq .01$), and mothers reported significantly higher levels than fathers ($p \leq .01$) at all assessments, see Figure 2. The symptom criterion re-experience was fulfilled by most parents, followed by the symptom criteria hyper-arousal and avoidance.

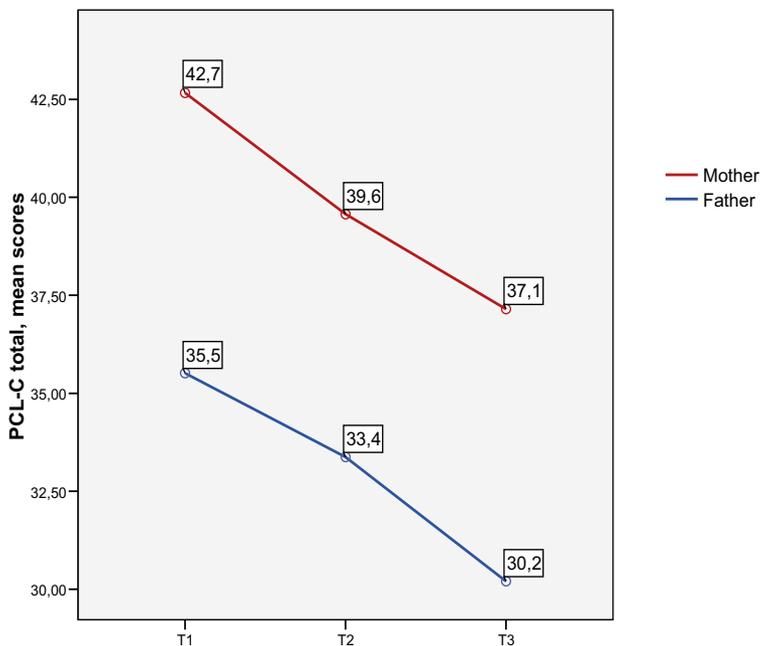


Figure 2. Mean level of symptoms among mothers and fathers at one week (T1), two months (T2) and four months (T3) after the child's diagnosis

The rate of cases at T1 (ASD) and at T2 and T3 (PTSD) was 33%, 28% and 22%, respectively. More parents scored as cases at T1 compared to at T3 ($p \leq .01$). The number of cases was higher among mothers than fathers at all

assessments ($p \leq .01$), see Figure 3. Almost half of those scoring as cases at T1 scored as cases at T3. Of those who scored as cases at T3, 70% scored as cases at T1. A small group (13%) scored as cases at all assessments.

Within the 75 couples, mothers reported a higher level of symptoms and demonstrated a higher caseness than fathers at all assessments ($p \leq .01$). At the same time, the levels of symptoms were moderately associated within couples at all assessments ($r = .29-.38$). One parent in 49% and both parents in 7% of the couples scored as cases at T1. The corresponding figures at T2-T3 were 33% and 11% at T2 and 28% and 8% at T3.

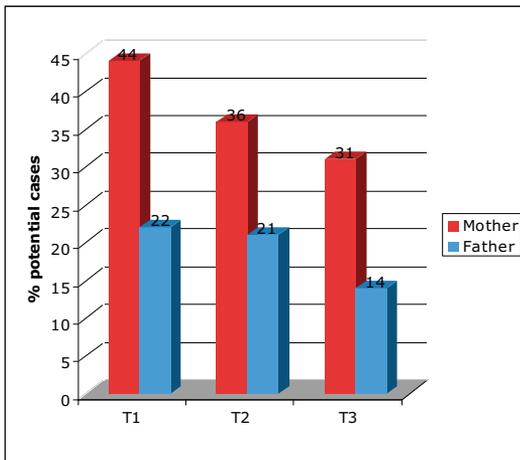


Figure 3. Percentage of mothers ($n=107$) and fathers ($n=107$) identified as cases at one week (T1), and at two months (T2) and four months (T3) after the child's diagnosis

Relations between parent and child characteristics and levels of ASS and PTSS and caseness of ASD and PTSD

The following characteristics were significantly related to level of symptoms ($p \leq .05$): not working before the child's diagnosis (T1-T3), having experienced a previous trauma believed to have a possible impact on the parent's emotional reaction at T1 (T1, T3), and the sick child being a daughter (T1). The following characteristics were significantly related to caseness ($p \leq .05$): being less than 30 years old when the child is diagnosed with cancer (T1), having one child only (T1), working less than full-time before the child's diagnosis (T1), and being of non-Nordic origin (T2).

Study II

Emotional support

The great majority of those who reported a need to talk with health professionals, significant others, and other people reported having had an opportunity to do so. However, at T1 only 28%, at T2 43%, and at T3 46% of those who reported a need to talk to a psychologist reported having had an opportunity to do so, see Figure 4. At all assessments almost all parents who reported having had an opportunity to talk to any source of support also reported having benefited from doing so.

The number of parents who reported a need to talk with a social worker, a psychologist, or other people declined over time ($p \leq .01$). No difference was demonstrated, at any assessments, between mothers and fathers with regard to the number reporting a need or an opportunity to talk with health professionals, significant others, and other people, or with regard to the number reporting benefit from having done so.

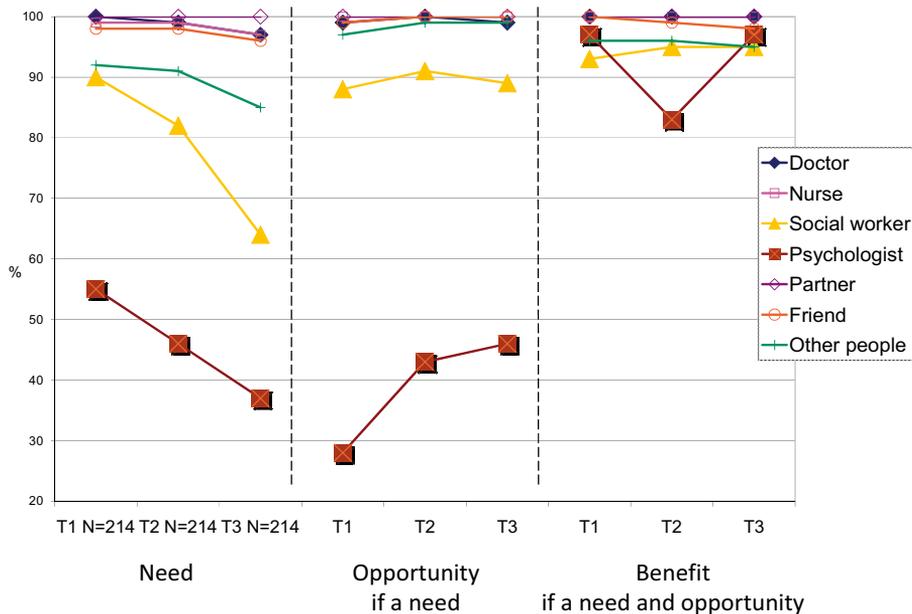


Figure 4. Parents' perceived need, opportunity if a need, and benefit if a need and opportunity¹ to talk about the child's illness at one week (T1), and two months (T2) and four months (T3) after the child's diagnosis

Notes:

¹those who reported not having taken the opportunity are not included in the analyses.

Satisfaction with the child's care

Parents reported highest satisfaction with doctors' technical skills (T1-T3) and nurses' technical and interpersonal skills (T1-T3) and availability (T1-T2). Lowest satisfaction (Md=75) was reported with aspects related to the care organisation (i.e. information at admission/discharge, waiting time, hospital comfort/cleanness) (T1-T3), doctors' information provision and availability (T1-T3), doctors' interpersonal skills (T2-T3), nurses' information provision (T1-T3), and nurses' availability (T3).

Parents' satisfaction with doctors' technical skills, nurses' availability, and general satisfaction with care declined over time ($p \leq .01$). No difference was demonstrated, at any assessments, between mothers and fathers with regard to satisfaction with any aspects of the child's care.

Study III

The child's symptom burden

The symptom prevalence among children, as perceived by their parents, ranged from 93% for less hair than usual at T2 to 2% for problems with urination at T2 and T3. At all assessments lack of appetite, lack of energy, and pain were reported among the five most prevalent symptoms, according to most parents. At all assessments difficulty swallowing, feeling nervous, pain, and shortness of breath were reported among the five most distressing symptoms, according to most parents reporting such symptoms. At all assessments nausea, pain and sadness were reported among the five most distressing symptoms, according to most parents in the total sample. According to parents' reports of prevalence of and distress caused by symptoms, it appears as if emotional distress, fatigue, nutrition and pain are the most problematic symptom areas. Among these, pain appears as especially problematic.

The prevalence of most symptoms and the symptom burden did, according to parents, decrease over time ($p \leq .01$). Mothers' and fathers' ($n=90$ pairs) ratings of the symptom burden for the same child were at least moderately associated at all assessments ($r=.39-.77$). Mothers reported a greater symptom burden than fathers for the same child at T3 for all MSAS scales, except for the PSYCH subscale ($p \leq .01$).

Neither parents' ($N=214$) nor mothers' ($n=107$) or fathers' ($n=107$) ratings of the children's symptom burden differed with regard to child sex, diagnosis, or prognosis. Mothers of adolescents ($n=19$) reported a higher score for the total MSAS scale compared to mothers of children 4-7 years ($n=34$) at T1 and mothers of children 0-3 years ($n=24$) at T2 and T3 ($p \leq .01$). Mothers of adolescents ($n=19$) reported a higher score for the subscale PHYS than mothers of children 7 years or younger (0-3 years, $n=24$; 4-7 years $n=34$) at T1 ($p \leq .01$).

Study IV

Parents' stories

Parents' stories, told when asked "Has anything special happened since the diagnosis/the last interview?" and "Do you want to tell me something I did not ask about?", were organised in 19 categories: parents' reactions and thoughts (5 categories), social situation (5), and strategies to cope (9), see Table 6. For a presentation of quotations, see Figure 5.

Table 6. *Parents' stories about having a child on cancer treatment. A presentation of areas and categories in alphabetic order and descriptions of category content*

Area	Categories	Category content
Reactions and thoughts	A changed view of life; Emotional distress; Emotional wellbeing; Impaired cognitive function; Impaired physical function	Positive and negative changes of expectations and priorities in life; Anxiety and mood disorders, bitterness, depression, fear and anxiety, flashbacks, guilt, loneliness, loss of temper, powerless, shock, sleeping problems, tiredness, exhaustion, uncertainty; Relief when the child finally got a diagnosis and happiness when the child feels well and the treatment has been successful; Problems with attention, concentration and memory; Gastritis, heart problems, infection, inflammation, menstrual disturbance, pain, pulmonary thrombosis, and signs of diabetes
Social situation	Isolation; Role changes; Support and lack of support from: authorities; health care; network	Isolation from friends and deprived of activities; Positive and negative experiences about the changed role as a parent, partner and self; Emotional and practical support/lack of support from authorities, i.e. employer, the local government, the national insurance office, the child's school; emotional and practical support from health care; emotional and practical support from the network, i.e. family, network, and other parents
Strategies to cope	Acceptance; Avoidance; Belief in spirituality and superstition; Focus on child; Focus on own health; "Live day by day"; Positive thinking; Preparation and fight; Support	Accepting and adapting; Avoiding troublesome thoughts and situations, not talking about the disease, and not showing the child one's own emotional distress; Believing in God, other spiritualities or being superstitious; Focusing on the child and the child's treatment and putting everything else aside; Physical exercise; Living in the moment and not foreseeing bad things; Optimism and focusing on survival; Preparing for potential negative disclosures and taking up the fight; Seeking emotional support from family, network, other parents and health care, and seeking informational support

Reactions and thoughts

A changed view of life: FT1: *You change priorities. It is more important to give priority to the family, time together and make the best use of time*

Emotional distress: MT1: *It became a double sorrow, the child is sick and I can't work*; MT4: *Thought I got a heart attack, I could not breathe, but it was anxiety neurosis*

Emotional wellbeing: MT1: *I feel more relieved now when I have got a diagnosis*

Impaired cognitive function: MT4: *I can't concentrate and I have problems when cooking and taking care of my children*

Impaired physical function: FT2: *I have to take it on my shoulders and be strong and then I get a bad stomach*

Social situation

Isolation: FT2: *You have to stay at home, and nobody can visit. It is an isolated life*

Role changes: MT2: *Even if you are not a biological parent you have feelings and can feel worry. I feel left out*; MT2: *I have grown as a parent*

Support/lack of support from authorities: FT1: *The boss supports me and I can come and go whenever I want to*; FT3: *One should not need to make war with the authorities...*

Support/lack of support from health care: FT1: *We feel dysfunctional but they don't care. It is the child who is the patient*; FT4: *The doctor and nurse, they beat everything. You can't get more support*

Support/lack of support from network: FT1: *The support we can feel is half the cure for us and for the child*; FT3: *People don't understand. They believe it's over when you come home from the hospital*

Strategies to cope

Acceptance: MT2: *If you just accept that he is sick, it feels positive that he is responding well to the treatment*

Avoidance: MT2: *I was scared of asking about the disease because I didn't want to hear bad news*

Belief in spirituality and superstition: FT1: *We have to pray to God*

Focus on child: MT2: *I put all my needs aside and totally focus on the child*

Focus on own health: MT4: *That I have been physically active has been a good way of processing anxiety and worries*

"Live day by day": MT3: *You must live in the moment. Not live as before and not in the future*

Positive thinking: FT4: *An optimistic attitude is important for recovery*

Preparation and fight: FT1: *It's time to take up the fight*

Support: FT4: *My safety valve is meeting people. I feel good when talking*

Figure 5. Examples of quotations included in each category, revealed in parents' stories about having a child on cancer treatment

Notes:

M=mother/stepmother.

F=father/stepfather.

T1=one week after diagnosis (DI); T2=two months after DI; T3=four months after DI;

T4=one week after end of successful treatment/six months after bone marrow, stem cell or organ transplantation.

Discussion

A subset of parents, more mothers than fathers, scored as cases of ASD at T1 (33%) and of PTSD at T2 (28%) and T3 (22%). The symptom levels declined over time and are related to being a mother and not working before the child's diagnosis at T1-T3 and to having experienced a previous trauma at T1 and T3. Less than half of the parents who reported a need to talk with a psychologist at T1-T3 reported having had the opportunity to do so at the corresponding assessment. Parents reported at least moderate satisfaction with all aspects of their child's care, and highest satisfaction with the technical care. Parents reported the following symptom areas as problematic for the child: emotional distress, fatigue, nutrition, and pain. Pain was identified as especially problematic. The prevalence of most symptoms and the symptom burden did, according to parents, decline over time. In comparison to fathers, mothers reported a greater symptom burden for the same child at T3. Parents described a great number of reactions and experiences as well as strategies for trying to cope with these reactions and experiences.

Acute and posttraumatic stress among parents of children on cancer treatment

Study I is the first study investigating acute and posttraumatic stress among parents over time during children's cancer treatment. The declining symptom level supports findings from studies investigating distress with cross-sectional [82,83] and longitudinal designs [84-87] and indicates that the majority of parents possess coping strategies strong enough to adapt to the situation of having and caring for a child with cancer.

A third to a fifth of the parents scored as cases during the first four months after the child's cancer diagnosis. The rate appears high considering a lifetime prevalence of PTSD of approximately 6% in the general Swedish population [42]. The findings are, however, comparable with previous reports with regard to PTSS and PTSD among parents of children on treatment [4,6,51,52]. Landolt and colleagues [53] have reported a somewhat higher prevalence of PTSD (44%) among parents of newly diagnosed children. The finding is, however, based on a small sample. About half of the parents who were identified as cases at T1 were identified as cases at T3 and among those

identified as cases at T3 almost three quarters had scored as cases at T1. The result supports previous findings about the longitudinal course of ASD and PTSD [45,46]. The predictive value of ASD and/or PTSD for PTSD after the end of treatment remains to be investigated. Meanwhile the findings suggest that ASS and ASD are not the only predictors of PTSD, and as concluded in a review by Peleg and Shalev [44], additional trauma experiences as well as insufficient support may heighten the risk of PTSD.

Potential risk and protective factors

Parent characteristics

As expected [53,59,63], parents who at T1 reported that a previous trauma possibly had an impact on their emotional reaction reported a higher symptom level than those who did not.

Mothers reported a higher level of symptoms than fathers and more mothers than fathers scored as cases. This finding does not agree with some results [4,53], but supports findings from studies in general populations [38-42] and results with regard to levels of anxiety [83,87] and depression [83] among parents of children recently diagnosed with cancer. The finding may reflect a higher vulnerability to trauma among women than men [42] and/or may be explained by the fact that women generally are more willing than men to admit discomfort [88]. Based on findings by others [89] it can be speculated whether the difference can be explained by traditional male and female role-function. Nazroo and co-workers [89] have reported that women's greater risk of depression is related to events involving children, housing, and reproduction. The fact that more fathers than mothers worked full-time may reflect that mothers, to a greater extent than fathers, were involved in events related to children and housing. Parents, regardless of gender, not working before the child's diagnosis reported a higher level of symptoms, and more among those who did not work vs. those who worked before the diagnosis scored as cases of ASD. This result may be related to previous findings, in the general population, indicating that unemployment is a risk factor for PTSD [41].

It can be speculated whether work outside the home may provide distraction as well as support from workmates. It has been reported that mothers who work outside the home manage the loss of a child better than mothers who do not work outside the home [90]. The finding suggests that occupying more roles than the parent role may protect against distress. However, findings by others [91] indicate that having a job to manage outside the home together with having a caregiver responsibility may contribute to increased distress. Findings from Study IV illustrate that parents experience a flexible approach regarding sick-leave and work as supportive. As the family's situation is strongly affected by the child's disease and treatment [92], flexible

approaches to work and sick-leave should be emphasised. This may in turn also decrease parents' financial worries, which were reported in Study IV as well as in previous studies [21,25,27,29,33-37].

The child's symptom burden

Pain is the only symptom reported among the five most prevalent as well as the five most distressing symptoms by most parents at all assessments in Study III. On the basis of this finding pain is identified as the most problematic symptom. This finding supports previous reports [10,11,93-98] demonstrating that pain is a major problem within paediatric cancer care. The finding may be of clinical importance as previous results suggest that a child's pain may cause ASS in a child, with the parents' symptoms of ASD as a mediating factor [99]. It is not unreasonable to believe that this may apply to other symptoms than pain. If so, it may have serious consequences for parents as well as children, as Study III and other studies [10-14,93,96] show that children on cancer treatment experience a wide range of symptoms. This reasoning may explain findings showing that children's retrospective appraisal of treatment intensity is related to PTSS among children and mothers [100].

The fact that more fathers than mothers worked outside the home at all assessments may imply that mothers spent more time than fathers with the ill child, which may have resulted in a greater awareness of the child's symptom burden. Furthermore, at all assessments, more mothers than fathers scored as cases and mothers reported a higher symptom level than fathers. The symptoms include hyper-arousal, e.g. being watchful or on guard, and may have resulted in an over-sensitization to their child's symptoms after some months. One of these circumstances, or a combination of the two, may have resulted in a difference with regard to mothers' and fathers' reports of their child's symptom burden four months after diagnosis. Perceiving one's child suffer from symptoms may cause distress, which in turn may have an impact on how the child's symptoms are perceived. Unpublished data from the project indicates a moderate association between parents' symptom levels and the reported symptom burden of the child at T1-T3. Furthermore, parents who scored as cases reported a higher symptom burden than those who did not. On the basis of this finding we hypothesize that seeing one's child suffer increases the risk of parents developing PTSS and that these symptoms in turn have an impact on parents' perceptions of their children's symptoms.

Support and care

Parents in Study IV provided very positive descriptions of the emotional support they had received from the health care staff. They expressed that their emotional needs had been taken into consideration. However, some parents in Study IV described a lack of emotional support from health care,

indicating that parents' wellbeing was not always fully acknowledged by the staff. According to the principles of family-centred care, all family members should be recognized by the health care staff as potential care recipients [101,102], and their possible emotional, physical, and social needs should be attended to [102]. Today, Swedish paediatric care follows the principles developed by the Nordic Association for the Needs of Sick Children (NOBAB, see <http://www.nobab.se/standard/standbakgr.html>), based on the UN Convention on the Rights of the Child (see <http://www.rb.se/eng/ChildRights/>). The NOBAB charter for children at hospital (see <http://www.nobab.org/nobabcharter.html>) underscores that the child's as well as his/her family's emotional and physical needs should be acknowledged. The results from Study II show that parents were at least moderately satisfied with all aspects of the child's care and most satisfied with the technical care. This is encouraging since it has been reported that parents of children with cancer perceive the staff's clinical competence as highly important in order to make them feel that their child is well cared for [30]. The psychosocial aspects of the child's care, e.g. information and the staff's interpersonal skills and availability, were given somewhat lower values. Previous studies, performed within various paediatric hospital settings, have illustrated similar areas as potentially problematic [103-108]. When interpreting the results it should be taken into consideration that it is based on parents' self-reports and does not necessarily reflect the care that was provided. The findings do, however, suggest that there is room for improvement with regard to the psychosocial care and information in Swedish paediatric oncology care.

A traumatic stress perspective

According to a so-called traumatic care model, developed by Kazak and co-workers [109], all family members' emotional distress and care needs should be attended to when a child is acutely or chronically ill, e.g. diagnosed with cancer. Psychosocial care corresponding to the family members' psychosocial function and needs should be provided. The care can, according to Kazak and co-workers [109], be provided at three levels: universal, targeted, and clinical care. The levels are independent of trauma phase and families may pass between levels during the course of the child's disease trajectory. Universal care should aim at reducing traumatic experiences, increasing a sense of safety and control, and preventing distress. Universal care should be provided to all families. Targeted and clinical care includes increased psychosocial support, aiming at reducing distress, for example by helping the family to cope with disease- and treatment-related suffering [109]. Considering the results from Study I parents in approximately 40% of the families should, at some time during their child's treatment period, be provided with targeted or clinical care. In these families one or both parents scored as cases of PTSD two and/or four months after the child's diagnosis.

Preliminary data from a three-session cognitive behavioural therapy intervention, aiming at reducing anxiety and PTSS among caregivers of children newly diagnosed with cancer, shows promising results [110]. Parents, regardless of level of PTSS, were randomized into two groups. The control-group was provided with standard psychosocial care whereas the intervention group was helped to understand how beliefs about the cancer and its treatment influenced them, and to anticipate the impact of cancer on the family over time. The results showed a decline of PTSS in the intervention group, whereas the level of PTSS increased in the control group [110]. The data indicates that it is possible to reduce PTSS among parents of children on cancer treatment. Interventions provided early during the child's disease trajectory may reduce the number of parents who need targeted and clinical care later during the child's disease trajectory. This may be beneficial not only from the individual's personal perspective, but also from the society's health economic perspective [111,112].

Encouraging ordinary life

The great majority of the parents who reported a need to talk with health care professionals (besides psychologists), significant others, and other people also reported having had an opportunity to do so. However, taking parents' stories into consideration, parents' also felt lonely and isolated from friends as well as deprived of hobbies and work. The child's illness together with the isolation from friends and activities may cause double sorrow [28] and may have a direct and/or indirect negative impact on parents' psychological [44,57,87,113] as well as physical health [32,35]. Taken together, the findings from Studies I-IV suggest that parents of children with cancer should be encouraged and supported to, at least to a certain extent, maintain an ordinary life including work and activities. This corresponds to the recommendations of today's clinical care. However, parenting a child with cancer is a very demanding, even potentially traumatic, event [109], and parents may perceive a strong need to be close to their sick child at all times [26,28]. Consequently, some parents may have difficulties in following the aforementioned recommendations. These parents should be offered support from health care to do so. For instance, health care staff could help parents to activate the social network to provide instrumental support, e.g. with household management and child-care. Such actions may result in time for work, activities, as well as for rest. Parents should also be helped to accept such support. Those who do not have a social network should, if possible, be helped to create such support, e.g. from parents in the same situation. If this is not possible parents should be provided with instrumental support by health care and/or social authorities to maintain an ordinary life. Such support can help parents to maintain multiple roles, e.g. to continue work and to engage in activities believed to be beneficial for emotional wellbeing [57,87,90,114]. Social as well as physical activities have been described as enhancing posi-

tive affect [115], which in turn may help to cope with negative emotions in stressful situations [116] and consequently prevent development of PTSS and PTSD.

Increased psychosocial support

It is thought-provoking that less than half of the parents who reported a need to talk with a psychologist reported having had the opportunity to do so. When considering this it should be acknowledged that almost all parents who reported having had an opportunity to talk to a psychologist reported having benefited from doing so. Unpublished data from the project indicates that parents identified as cases of PTSD reported a higher need than non-cases to talk to a psychologist and other health care professionals. Preliminary results also show that parents identified as cases of PTSD reported a higher benefit than non-cases from doing so. The findings illustrate that a subgroup of parents of children diagnosed with cancer experiences a need to talk to a psychologist. In order to possibly prevent persistent distress and even development of PTSD among these parents it should be possible within paediatric cancer care to provide parents with the opportunities for increased psychosocial support, e.g. counselling.

Methodological considerations

The main strengths of the studies in this thesis are the large and population-based sample, including an equal number of mothers and fathers from different areas in Sweden and the longitudinal design covering four assessments, from the child's diagnosis to the end of treatment. All participants were included at approximately the same time during the course of the child's disease, and of the eligible parents 73% participated in the first three assessments. The overall refusal rate was low, especially considering the parents' very complex life situation.

Exclusion and refusal

The number of exclusions predominantly depends on the time criterion (i.e. time from the child's diagnosis), which caused a higher exclusion rate among parents of children with a CNS-tumour compared to among parents of children with other cancer types. As the time period between a diagnosis of a CNS-tumour and the subsequent decision about treatment modality often extends over more than one week, the original time criterion was extended from one to two weeks. In addition, to reach as many parents as possible, parents of children with a CNS-tumour were eligible for participation regardless of treatment modality at T1: the original criterion was that the child should be scheduled for chemotherapy. Despite these efforts the exclu-

sion rate became higher for parents of children with a CNS-tumour. The results concerning the subgroup of parents of children with a CNS tumour, regardless of mode of treatment, will be presented elsewhere.

Data collection and analyses

It can be speculated whether the changes over time with regard to the investigated variables are at least partly due to repeated assessments [117]. The opportunity for parents to repeatedly talk about their situation might result in a favourable outcome for parents' psychological wellbeing. Whether this is the case is currently being investigated in a separate study within the project. In the event the parent scored prevalence of a symptom (score 3-5) on the PCL-C, follow-up questions for that specific item were posed. There is a possibility that parents perceived this procedure as a burden and therefore avoided scoring items higher than 2 at the following assessments. This corresponding risk may exist for the MSAS 10-18. Additionally, it should be taken into consideration that all self-report data was collected over the telephone. It has been shown that people tend to report better psychosocial function and fewer problems via the telephone than via mailed questionnaires [118-120]. Taking these aspects into consideration it seems reasonable to assume that the findings from Studies I and III are slightly skewed towards the positive side. This may also apply to parents' ratings of satisfaction with care and perceived support in Study II, which additionally may be affected by a hesitation to express negative opinions due to potential feelings of dependency and vulnerability [121]. However, as neither of the two persons who gathered the data had any contact with the parents, besides performing the interviews over the telephone, we consider this risk to be minimal.

The PCL-C

It would have been optimal to identify PTSD with a diagnostic interview for PTSD. However, as potential participants lived from the very north to the south of Sweden and as we, when planning the project, did not consider it feasible to conduct a diagnostic interview for PTSD over the telephone we chose to use the PCL-C to identify PTSD. The PCL-C is constructed for screening purposes for PTSD and PTSS [75] and does not assess all criteria for a PTSD diagnosis, including the A-criteria. It has however been shown that it provides an appropriate estimate of PTSD among parents of children with cancer [60] as well as in other populations [75,77]. Today we are aware of the possibility of performing a diagnostic interview over the telephone. If the project had been planned today, at least a subgroup of the participants would have been asked to participate in such an interview for PTSD and to answer the PCL-C. This procedure would not only help to draw a more firm conclusion with regard to the occurrence of PTSD among parents of children

on cancer treatment but would also illuminate the diagnostic effectiveness of the Swedish version of the PCL-C.

The internal consistency of the total PCL-C and the sub-scales improved over time, which may illustrate that the PTSD symptomatology among parents of children on cancer treatment becomes more manifest with time. And, the internal consistency of the PCL-C is somewhat lower for fathers than mothers at all assessments. On the basis of the internal consistency values, it can be concluded that the PCL-C is somewhat less reliable when screening for PTSD among parents shortly after a child's cancer diagnosis than some months later and somewhat less reliable when screening for PTSD among fathers than among mothers of children on cancer treatment.

The CASC-SF

It could be argued that the conceptualisation of less than optimal satisfaction used in this study, i.e. 75 on a scale ranging from 0-100, is misleading. A score of 75 does not indicate dissatisfaction. However, dissatisfaction with care is seldom reported [121], and the areas identified as less than optimal may be the areas which need improvement in health care.

Content analysis

Data from the different assessments was initially analysed separately. However, as the data from the respective assessments was very similar, data was collapsed. Two persons conducted the great majority of the interviews and researchers with considerable experience of content analysis and with different pre-understanding took part in the analysis. Due to the sample and the design and the way data was analysed it is assumed that the investigated phenomena, i.e. parents' stories about having a child on cancer treatment, have been investigated and described thoroughly. However, the fact that parents' answers were not tape-recorded and that follow-up questions were not asked may imply that some information is missing in the presentation of the findings.

Statistical significance

Statistical significance shows if a difference or an association exists between variables at a certain level of probability but does not describe the magnitude or the clinical importance of the difference or association. The magnitude or the clinical importance of a difference can be described by the effect size [117]. In some instances, for example if mortality is the outcome, a small effect size ($d=0.2$) can be of great importance [122]. For psychosocial variables, like those investigated in the present thesis, a greater effect size (at least $d=0.5$) is desired, in order to achieve a so called minimally important difference. On the basis of a review of the literature it has been concluded that half a SD corresponds well with an effect size of 0.5 and that, in most circumstances, the threshold of discrimination for changes in health-related

quality of life for chronic diseases appears to be approximately half a SD [123]. The findings from Study I showed a statistically significant difference over time with regard to levels of PTSS. However, small effect sizes were demonstrated between the respective assessments (T1-T3) ($d=0.12-0.25$) and the differences between the assessments were less than half a SD. Preliminary results, on the basis of data collected at later assessments, show a decline with regard to the level of PTSS of more than half a SD at three months after the end of treatment, in comparison with the first assessment. The corresponding effect size is large ($d=0.86$). On the basis of the magnitude of the differences and the corresponding effect sizes it may be concluded that the level of PTSS among parents is fairly constant during the child's treatment trajectory and does not decline until three months after the end of treatment. This conclusion does not correspond with the conclusion put forward in Study I. The reasoning shows the importance of how data is analysed and of how conclusions, and the following implications, are reached.

Ethical considerations

Despite parents' very complex life situation, few parents refused participation at T1 and further participation once included in the project. This indicates that, although the interview embraced a great number of questions, most parents did not find participation too burdensome. Some parents even expressed that they found the interviews very valuable. This made us question if participation in the project might have had a positive effect on parents' well-being. Therefore, as mentioned previously, a separate study aiming at investigating whether this is the case is currently undertaken within the project.

Conclusions and implications

Parenting a child with cancer is a very demanding, potentially traumatic, event. Approximately a fourth of the parents report symptoms corresponding to PTSD. The symptom level is related to being a mother, not working before the child's diagnosis, and to previous trauma experience. Less than half of those who report a need to talk with a psychologist report having had the opportunity to do so. Parents are generally satisfied with the care and report the highest satisfaction with the technical care. Emotional distress, fatigue, nutrition, and pain are, according to parents, the most problematic symptom areas for their children. Pain is identified as especially problematic.

Parents in paediatric oncology care should be acknowledged as potential care-recipients. In order to prevent development of PTSD, parents of children on cancer treatment should be supported to maintain an ordinary life, for example pursue work and/or activities and to get sufficient rest. As a means towards this parents need help with e.g. household duties and child-care. In addition to this, parents in approximately two fifths of the families need extended psychosocial support aiming at reducing posttraumatic stress.

Future perspectives

The present thesis presents findings regarding the first four months of the children's cancer treatment and the first week off treatment. Findings from the next three assessments within the project will further describe the development of PTSD among parents of children with cancer, and will e.g. reveal whether ASD/PTSD during the early part of the child's cancer trajectory predicts later or chronic PTSD. The findings will also describe whether, and if so to what extent, parent gender, work situation and previous trauma experience and/or perceptions of support, care, and the child's symptom burden predict later or chronic PTSD. Future analyses will not only focus on differences between subgroups but also on identifying subgroups of parents who react to a child's cancer diagnosis in different ways.

PTSD is the most costly anxiety disorder [124]. However, the economic consequences of PTSD among parents of children with cancer have not been documented. Within the ongoing project the health-economic costs for those who are PTSD negative, PTSD positive and not treated for it, and PTSD positive and treated for it are investigated five years after the child's diagno-

sis. Furthermore, in a separate study the clinical efficacy and cost-effectiveness of an Internet-based cognitive behavioural therapy treatment for PTSS and PTSD will be evaluated.

Svensk sammanfattning

Den här avhandlingen presenterar resultat från ett pågående projekt "Förekomst och utveckling av posttraumatiskt stressyndrom". Det övergripande syftet var att undersöka möjlig förekomst av posttraumatiskt stressyndrom (PTSD) hos föräldrar till barn som genomgår behandling mot cancer (Studie I). Syftet var också att beskriva föräldrars uppfattning av känslomässigt stöd och tillfredsställelse med barnets vård (II); uppfattning om barnets symtombörda (III) samt föräldrars berättelser om hur det är att vara förälder till ett barn som genomgår behandling mot cancer (IV).

Data insamlades under åren 2002 till 2007, vid en vecka, två månader och fyra månader sedan barnet fått sin diagnos samt en vecka/sex månader efter avslutad behandling/transplantation. 259 föräldrar till 139 barn besvarade olika frågeformulär samt frågor med öppna svarsalternativ, vid upprepade tillfällen via telefonintervjuer.

Att vara förälder till ett barn med cancer är mycket påfrestande. Ungefär en fjärdedel av föräldrarna rapporterar symptom motsvarande PTSD, vilket t.ex. innebär att återuppleva svåra minnen, känna sig känslomässigt avtrubbade, vara extra vaksam, ha svårt att sova och/eller ha koncentrationssvårigheter. Att vara mamma, att inte arbeta före barnets diagnos samt att ha upplevt en tidigare traumatisk händelse ökar risken för dessa besvär. Färre än hälften av de föräldrar som rapporterar behov av att prata med psykolog rapporterar att de har fått tillfälle till detta. Föräldrarna är överlag tillfredställda med barnets vård och rapporterar högst tillfredsställelse med vårdens tekniska aspekter. Känslomässiga besvär, trötthet, nutrition och smärta är, enligt föräldrarna, de mest problematiska symtomområdena för deras barn. Smärta tycks vara det mest problematiska området.

Föräldrar inom barnonkologisk vård borde ses som potentiella vårdtagare. För att förebygga utvecklande av PTSD borde föräldrar till barn som genomgår cancerbehandling få stöd att, åtminstone till en viss del, kunna upprätthålla sitt vanliga liv, t.ex. fortsätta arbeta och/eller fortsätta med sociala och fysiska aktiviteter, samt för att få tillräckligt med vila. För att möjliggöra detta behöver föräldrar praktisk hjälp, t.ex. med hushållsarbete och barnpassning. Föräldrar i ungefär två femtedelar av familjerna uppskattas behöva utökat psykosocialt stöd för att handskas med den posttraumatiska stress de upplever i samband med sitt barns sjukdom.

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