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Assessment of Parental Psychological Stress in Pediatric Cancer: A Review

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Abstract

*Goals of work***.** We present an overview of the literature between 1997 and 2007 on parental stress reactions following the diagnosis of childhood cancer and we evaluate methodological strengths and weaknesses of the studies. *Methods***.** PubMed, PsychInfo and Cinahl databases were used. Sixty-seven were included in the review. *Results***.** The conceptualization of parental stress and timing of assessment varies considerably between the studies, which makes comparison difficult. Most emotional stress reactions are seen around the time of diagnosis, with mothers reporting more symptoms than fathers. As a group, parents seem relatively resilient, although a subset of parents reports continuing stress even up to five years or more post diagnosis. *Conclusions***.** The authors recommend clear definitions of parental stress, fixed points in time to assess parental stress and an approach that highlights both parental strengths and weaknesses. Improved assessment can contribute to tailoring psychological care to those parents most in need.

Introduction

The diagnosis of childhood cancer is one of the most intense, disruptive and enduring experiences that parents can have. The often unexpected and life-threatening diagnosis and the initiation of invasive medical treatment and its sequelae interfere with the entire family's normal activities and routines for a long period of time and impose stressors of varying duration, predictability and impact [25,42,58]. Since substantial progress has been made in cancer treatment and coordination of care, types of cancers that were once regarded as fatal are presently curable with treatment and have instead become chronic life-threatening diseases [17,78]. Nowadays, three out of four children diagnosed with a malignancy will survive their disease and treatment [24].

When parents are confronted with a diagnosis of cancer in their child a process starts, referred to as psychological stress [20,58,88]). In the literature, definitions of core elements of psychological stress vary considerably, often depending on the underlying theory [62].Much research has been focused on stress reactions observed in emotional manifestations of strain (anxiety, depressive symptoms) and more situation-specific emotional manifestations of strain (uncertainty, helplessness, loneliness and disease-related worry concerning future health and recurrence of the disease) [25,58,78]. Furthermore, a growing body of research has suggested that the impact of childhood cancer on the parents can well be conceptualized in terms of trauma-related symptoms or posttraumatic stress symptoms [33,82]. The outcome of the psychological stress process is generally referred to as adjustment [25,58]. The current review is based on the theory on stress and coping by [47]: when parents are confronted with a cancer diagnosis in their child (i.e. the stressor), a process starts, involving the appraisal of the stressor, followed by strain, (i.e. pressure or demand), and stress reactions, or the manifestations of strain, which become manifest as uncertainty, anxiety, depressive symptoms and posttraumatic stress symptoms.

The aims of the present review are, first, to evaluate the methodological strengths and weaknesses of studies on the emotional manifestations of strain in parents of children who have been diagnosed with cancer. Secondly, we will describe the prevalence and nature of parental strain according to disease phase (diagnosis, active treatment, maintenance and long-term survival), gender differences and risk and protective factors. Throughout the review article, we will group parental stress reactions into four main diagnostic categories, namely uncertainty, anxiety, depressive symptoms and posttraumatic stress. Recommendations will be made for future research.

Method

The following sources of published reviews have been consulted: PubMed, PsychInfo, Cinahl, The Cochrane Library and Web of Science. We prepared search filters and consulted databases to be accessed. The computer databases PubMed, PsychInfo and Cinahl were used for a search with the key words: parent, mother, father, stress reaction, psychological stress, adaptation, coping strategy, neoplasm/ psychology and pediatric cancer. Next, all reference lists of identified papers were examined and then a hand search for identified relevant studies was conducted.

The following criteria for inclusion were applied: firstly, year of publication: studies were published between January 1, 1997, and May 31, 2007, secondly, language: English language studies, thirdly, method: standardized measures of well-documented psychometric quality and the conduct of statistical tests, and lastly, aim: assessment of parental strain, parental stress reactions and the adaptation related to caring for a child with cancer. The following exclusion criteria were applied: case studies, qualitative studies, book chapters, guidelines, commentaries, and dissertations. Reference Manager Version 10 for Windows (Research Information Systems, 2001) was used as the bibliographic software package to organize the relevant references.

Results

We found four other review articles on parental stress, adjustment and coping, first of all the extensive review by Grootenhuis & Last [25] on articles published between 1980 and 1997. A recent review article with a more theoretical character [44] presents an overview of existing literature on the factors influencing parental health and well-being and a review by Bruce [12] has focused on posttraumatic stress in both childhood cancer survivors and their parents. Lastly, Peterson, Cant and Drotar [64] published a review article on the family impact of neurodevelopmental late effects in pediatric cancer survivors. Although there are overlapping issues discussed in our review article and the abovementioned reviews, we also see differences between the articles concerning aims and scope. The present review could be seen as a follow-up on the work done by Grootenhuis and Last [25], concerning articles published in the last ten years, that is between January 1st, 1997, and May 31st, 2007.

We found 79 articles with our search strategy, of which 67 articles met the inclusion criteria. Selected studies are summarized, in chronological order, in Table 1. Studies referring to the same sample are described together. The studies reported in this review are difficult to compare, because they do not only differ in design, but also in sample (both size and heterogeneity), inclusion of control groups, time of assessment, definition of core elements of psychological stress, and measurements.

Methodological issues

Terms used to describe the core elements of parental psychological stress vary considerably between the studies: from emotional strain or psychosocial difficulties to care-giving demands, from affective responses and psychological symptoms to uncertainty, anxiety, depression and posttraumatic stress disorder (PTSD), and from distress, well being and mental health to psychosocial functioning and adjustment.

One time, cross-sectional surveys were employed in the majority of studies. Although these designs are not appropriate to assess the effect of time since diagnosis, they have been used very frequently to assess parental strain in relation to disease phase. Sixteen studies (23% of the total) employed longitudinal designs in order to assess parental manifestations of strain in relation to disease phase. Six intervention studies were included, one of which employed a case control design [41] and five were randomized controlled trials (RCT) [28,34,40,71,72]. The intervention studies will not be further discussed in this review article, because this has been done in a recent meta-analysis by Pai and colleagues [62].

Sample sizes ranged considerably from 15 to 544 parents in cross-sectional studies, from 21 to 164 parents in longitudinal studies and from 18 to 252 parents in the intervention studies. While the majority of studies included both mothers and fathers, twelve studies focused solely on the mothers and two studies [55] included fathers only. Results were compared with control groups, norm groups of the measures and groups of parents of children with other illnesses.

The majority of studies used heterogeneous samples, that is, parents of children with mixed cancer diagnoses. Among the various cancer diagnoses, treatment course varies considerably, with an ensuing risk for complications such as required hospitalizations for chemotherapy, unanticipated hospitalizations for fever and/or neutropenia and varying foci for radiotherapy treatment. These treatment-related events can have a different impact on parental stress. A number of studies did focus exclusively on parents of children with leukemia [7,32,35,48]or a brain tumor [9,19].

In 26 studies parents of children who had recently been diagnosed with of cancer were included, ranging from 1 week to 6 months post diagnosis. Furthermore, 24 studies assessed parents of children in active and/or maintenance treatment, 24 studies assessed parents of children both in- and off treatment, and 26 studies solely included parents of children off active cancer therapy, that is parents of survivors. The definition of survivorship varied considerably between studies. Some researchers considered the number of months and/or years since completion of cancer treatment to be indicative of survivorhood, while others used the number of months and/ or years since diagnosis to

indicate survivorhood. Survivors ranged from 6 months to 10 years since completion of cancer treatment and from 15 months to 13 years since the diagnosis of cancer.

Although it is often concluded that traditional measures of psychopathology may be ineffective and/or insufficiently sensitive in the assessment of psychologically 'healthy' parents in an abnormal crisis situation [6], a substantial body of research still depends on these instruments. This is also true for the studies included in this review.

However, a number of pediatric psychologists have developed and used promising disease-related measures (e.g. [22,26,54,80] and disease-specific measures [9,38,39,52] to assess parental stress reactions related to childhood illness or specifically, childhood cancer. In the majority of studies, these newly developed instruments were used alongside traditional measures on anxiety, depression, PTSS and uncertainty.

Time of assessment of parents of children with cancer ranged considerably between studies. Timing in the cross-sectional studies ranged from diagnosis to more than 7 years post-treatment. In the longitudinal studies, first assessment of parents ranged from one week post cancer diagnosis to more than 5 years post cancer diagnosis.

Emotional Manifestations of Strain According to Disease Phase

Several salient themes appear when examining emotional strain by phase of disease; these include the proportion of parents reporting strain, the correlates of stress reactions and the evolution of these reactions in time. Phases that are distinguished are the diagnostic or consolidation phase, the initial treatment phase, the active treatment phase, the maintenance phase and survivorhood. We will discuss these phases for each diagnostic category.

Uncertainty

Broadly defined, parental uncertainty in childhood cancer pertains to both acute and ongoing or pervasive fear of possible disease consequences like relapse or death [78]. In six studies, all cross-sectional, the construct of uncertainty in childhood cancer was investigated [8,19,25,55,56,73]. Uncertainty in parents of children with cancer has not been compared to uncertainty levels in parents of healthy children.

Compared to parents 1- to 5 years post-treatment, parents of children immediately after completion of treatment reported the most feelings of uncertainty [77]. Between 66% and 90% of parents reported feelings of uncertainty after termination of treatment [8]. Some parents of childhood cancer survivors may continue to be uncertain about the well being of their children many years after the cessation of treatment [25]. In the short term, high levels of uncertainty may interfere with making health decisions. In the longer term, when parental uncertainty becomes chronic, pervading the disease trajectory, it can lead to the development of posttraumatic stress symptoms [53].

Anxiety

Anxiety refers to a complex combination of emotions that include fear, apprehension, and worry. Since anxiety entails an expectation of diffuse and uncertain threat, it plays an obvious role in the experience of parents when confronted with the life-threatening diagnosis of cancer in their child. Approximately 22 studies included in this review investigated the construct of anxiety, of which 13 studies employed a cross-sectional design, 5 studies a longitudinal or prospective design, and 4 studies a RCT or case control design (see Table 1).

Anxiety occurs most frequently around the time of diagnosis and decreases over time. Parents of children newly diagnosed or in active cancer therapy reported higher levels of anxiety than parents of children off active cancer therapy, in remission, or parents whose child has relapsed [54,73,87]. In turn, parents of children with a relapse reported higher anxiety levels than parents of surviving or deceased children [86].

Longitudinal designs show that anxiety levels at diagnosis decrease across time to (near) normal levels five years post diagnosis [85,86]. Yet, symptoms of anxiety seem more common among parents of children with cancer, compared to parents of healthy children, even up to 5 years post diagnosis. This suggests that feelings of anxiety are maintained over time with a subset of parents continuing to be anxious. Prospective longitudinal research has shown that highly anxious parents are at risk for the development of posttraumatic stress symptoms [7,30]. Psychosocial functioning at six months after diagnosis seemed to predict later psychosocial functioning best [86].

Depressive Symptoms

Parents may react to the diagnosis of cancer in their children with depressive symptoms (e.g. [6,59]. Depressive symptoms include, but are not limited to, a persistent sad, anxious or empty mood, feelings of hopelessness or pessimism, feelings of guilt or helplessness, decreased energy, difficulty concentrating or making decisions, restlessness, and insomnia or oversleeping. Twelve studies included in this review investigated the construct of depression, of which 11 studies employed a cross-sectional design, 5 studies a longitudinal or prospective design, and 2 studies a RCT (see Table 1).

High levels of depressive symptoms are reported shortly after diagnosis [2,87]. Mothers of children newly diagnosed, in active cancer therapy and 1-year post diagnosis reported more depressive symptoms than mothers of children off active cancer therapy [84]. Compared to parents of healthy children, parents of children with cancer showed higher levels of depressive symptoms at multiple points from the time since diagnosis [15,59].

In mothers and fathers for whom a longer period of time had elapsed from the time of diagnosis, depressive symptoms were less common [8] but in another study parents consistently reported higher depression scores than the norm group of the questionnaire

under study [29]. Longitudinal studies suggest that depressive symptoms may be maintained over time, especially when parents initially react with moderate to severe levels of depressive symptoms. However, one cannot automatically conclude that the child's diagnosis is the cause of depressive symptoms in parents [57]. Other events, such as marital or financial problems, may also result in depressive symptoms and should be assessed simultaneously. Furthermore, because it is not possible to assess parents prior to the child's cancer diagnosis, the possibility that the depressive symptoms represent a preexisting state cannot be ruled out [51]. Depressive symptoms of the parent may interfere with, for example, health decisions, frequent clinic appointments and the parent-child relationship and communication.

Posttraumatic Stress Symptoms

Learning that one's child has a life-threatening disease is a qualifying event for posttraumatic stress disorder (PTSD) or posttraumatic stress symptoms (PTSS) [3]. Posttraumatic stress acknowledges the life threat inherent in childhood cancer while also providing a framework in which ongoing symptoms such as intrusive thoughts, arousal, and avoidance may be conceptualized and treated [33]. Twenty studies included in this review investigated PTSS or PTSD, of which 13 studies employed a cross-sectional design, 3 studies a longitudinal or prospective design, and 4 studies a RCT or case control design (see Table 1).

Approximately 68% of mothers and 57% of fathers of children currently in treatment report PTSS in the moderate to severe range [37]. Sub-clinical posttraumatic stress symptoms (PTSS) such as intrusive thoughts about cancer, physiological arousal at reminders, and avoidance of treatment-related events have been found to be even more prominent [1]. For parents of childhood cancer survivors the rates of PTSS have been found to range from approximately 10 % [36] to 42 % [19].

Parents of children recently diagnosed or currently in treatment report higher rates of PTSS and current PTSD compared to parents of childhood cancer survivors [33,40,60,66,73]. Mothers and fathers of childhood cancer survivors show significantly higher levels of PTSS and lifetime PTSD than parents of healthy children [5,11,63] but lower than symptom levels for other stressed and traumatized groups [36,43]. An extensive review article on PTSS and PTSD in childhood cancer survivors and their parents has been written by Bruce [12]. He summarized the following risk factors associated with PTSS and PTSD: female gender, greater physical late effects, increased number of prior stressful life events, perceived severity of cancer and treatment, family conflict, poor social support and emotion-focused coping.

It remains a matter of debate whether traumatic stress is a relevant model to describe the emotional reactions of parents of children with cancer [65,82]. However, symptoms of posttraumatic stress (PTS) in parents are a concern and may be an appropriate target for intervention, particularly in the period following diagnosis [66]. Early signs and symptoms of PTS require early assessment and intervention since the disruptive symptoms may linger over time in a subset of parents [4,81].

Emotional Manifestations of Strain and Gender of the Parent

Stress reactions can take different forms in fathers and mothers and it may be relevant to identify these differences in order to deliver specific interventions. Twenty-three studies included in this review compared emotional manifestations of strain in mothers and fathers of children with cancer, of which 13 studies employed a cross-sectional design, 9 studies a longitudinal or prospective design, and 1 study employed a RCT (see Table 1).

Gender Differences in Uncertainty, Anxiety, Depression and PTSS

Evidence for gender differences in parental uncertainty in childhood cancer has not been well established. In one study, mothers of children in remission or with a relapse reported higher levels of uncertainty than fathers [26]. Mothers of children newly diagnosed, in remission, relapsed or off treatment report higher levels of anxiety and depressive symptoms than fathers of children with cancer [32,59,84,86,87], whereas other researchers found no gender differences [18,29]. In one study that focused on fathers who identified themselves as the primary caregiver, elevated rates of depressive symptoms were found more in fathers than mothers [10]. Perhaps being the primary medical caregiver adds to the strain instead of the gender of the parent?

With regard to PTSS and PTSD, mothers have been reported to display more symptoms than fathers [1,12,66,87], especially re-experiencing and arousal symptoms. However, other studies show relatively equal levels of PTSS and rates of current PTSD [33,49,66]. Gender differences in the experience of PTSS may be related to the time of evaluation: over time, only the fathers' symptoms decreased, whereas the mothers' symptoms remained high [49].

In agreement with gender studies on the prevalence of psychological problems in the general population, mothers of children with cancer tend to report more and higher levels of symptoms than fathers. However, it is still not clear whether the differences between mothers and fathers in these studies represent different stress reactions to childhood cancer or are related to general population differences between men and women [76]. Women seem more willing to report discomfort than men. Therefore, gender differences may be due to reporting style [23]. Another explanation may be that mothers more often have the main responsibility for the care of the child with cancer and fathers are more peripherally involved in childcare. The question remains whether it is necessary and possible to tailor interventions to specific needs of mothers and fathers of children with cancer.

Risk factors

Since parents of children with cancer are at risk for the development of disruptive emotional manifestations of strain, which persist over time among a subset of parents, it seems important to obviate risk factors early in order to detect and support parents most at risk for later maladjustment. Several variables have been indicated as risk factors for the development of emotional manifestations of strain.

Risk factors include, but may not be limited to, the following findings: Parents who display the most and highest levels of emotional manifestations of strain at diagnosis continue to experience the highest levels of symptoms, even after treatment ends. Certain demographic characteristics have been identified as risk factors: Parents of children with cancer who are less educated and parents with lower SES [32] or parents with a 'perceived unsatisfactory financial status' [48] report more depressive symptoms.

Trait anxiety has been identified as a predictor of post-treatment PTSS for mothers [7] and for both mothers and fathers [30,43,81]. No association with treatment intensity and minimal associations with time since diagnosis have been found [37]. Child behavior problems [6] were found to be predictive of parental depressive symptoms. High levels of care giving demands, past traumatic life events, and less perceived social support have also been identified as risk factors for the development and maintenance of emotional manifestations of strain.

Attention should be given to parents with pre-existing psychological problems, because they may be less able to deal with the crisis of having a child with a life-threatening disease. Knowledge of risk factors may help identify those parents most in need of psychological care and interventions, preventing these parents from developing disruptive emotional manifestations of strain beyond the 'normal' reactions to the life-threatening diagnosis of cancer.

Protective factors

Several studies have focused on protective factors and on parental adjustment rather than parental stress. We will summarize the positive effect that coping strategies, social support and family relations are shown to have on parental adaptation.

Coping Strategies

Because stressors change with the different phases of cancer, studies on parental coping strategies should be classified according to the phase of cancer [21,83]. Moreover, the adaptive value of a coping strategy is likely to be dependent upon the phase of cancer. Studies addressing changes in coping strategies over the course of childhood cancer are relatively scarce [83]. Avoidance seems to be functional in the early phase of childhood cancer when parents are overwhelmed with stressors. However, in face of active treatment and maintenance, avoidant behavior of the parent has been related to elevated levels of emotional manifestations of strain e.g., anxiety and depression [30,59].

According to Grootenhuis and Last [26], low levels of predictive control coping (i.e. finding it difficult to have positive expectations about the course of the disease), were related to higher levels of emotional manifestations of strain in mothers and fathers of children in remission or with a relapse. More frequent use of active problem focused coping strategies (e.g., acting immediately, being goal oriented), and less frequent use of palliative reactions, avoidance behavior, passive reactions and expressing negative emotions were associated with less depressive symptoms and anxiety in parents of children in active cancer treatment and children that are cancer-free [59].

We recommend longitudinal studies with repeated measures within the same cohort over time to examine which coping strategies are likely to be maladaptive during a particular phase of childhood cancer and require early assessment in order to prevent further psychological problems.

Social Support

Social support seems to have a moderating effect on the impact of anxiety, depressive symptoms and posttraumatic stress symptoms [5,15,18,50,61,76]. Higher levels of perceived social support have been associated with less anxiety [15,59,61,76], lower PTSS levels [5,36]and better adjustment to medical disease [27]. On the other hand, a small network size, more perceived social constraint and a less perceived sense of belonging have been associated with more PTSS in parents of pediatric cancer survivors [7,12,43,76].

Assessing and evaluating both the parent's specific needs for support and the availability of support is important to meet those needs throughout the course of childhood cancer [31].

Family Relations

The family plays an important role in the psychological functioning of both the parents and the child with cancer [5,36,42,69]. Good family relations, adequate family coping and stable family functioning have been reported [36,46,74,75] in studies with a systemic focus. However, marital distress [87], poor family functioning and poor family relationships have been reported as well [80].

Although in most studies family functioning has been investigated as an outcome variable, some studies consider family functioning as a predictor variable for parental adjustment to childhood cancer [25]. Less family cohesion, satisfaction, adaptability and communication have been correlated to parental anxiety and therefore indirectly predicted PTSS [43]. Screening for family functioning, at diagnosis, seems important to identify strengths that can serve as buffers to cope with the stressors to come.

Discussion

The diagnosis and treatment of cancer in one's child can cause long-lasting psychological effects in a parent. Feelings of uncertainty, anxiety, depressive symptoms, and posttraumatic stress symptoms are most prevalent shortly after the parents are confronted with the diagnosis of childhood cancer. These emotional manifestations of strain decrease to near normal levels over time in the majority of the parents, but have been found to persist in a substantial proportion of the parents, even many years post-treatment. Furthermore, as is often found in the general population, mothers tend to report more and higher levels of symptoms than fathers with respect to anxiety, depression and PTSS. These differences may well be related to the traditional distribution of care-giving tasks and responsibilities. Also, since women seem more willing to report discomfort than men, gender differences may also be due to reporting style [23]. The question remains whether these gender differences are meaningful and, consequently, whether mothers require specific intervention efforts.

Assessment of parental stress reactions is important to identify those parents most in need. The following risk factors have been indicated: female gender, pre-existing psychological problems, high trait anxiety, low social economic status and financial worries, child behavior problems, high perceived care-giving demands, and less perceived social support. Certain coping strategies, such as active problem solving seeking, social support and optimism can serve as protective factors. Specific strengths of the family should be identified and used. Parents might well benefit from a tailored intervention based on strengths and weaknesses that is targeted to their specific needs with respect to the phase of childhood cancer [28,30,34,76,80].

In most of the studies included in this review parents of children with heterogeneous diagnoses were assessed, making comparisons difficult. Different rates of uncertainty, anxiety and other stress reactions may be directly associated with the child's type of cancer (e.g. parenting a child with standard risk ALL versus a child with a malignant brain tumor). The inclusion of predominantly white parents and the assessment of either mothers alone or parents as a couple causes bias and generalization problems. The inclusion of non-native speaking parents continues to be a difficulty, although efforts are being made to translate assessment instruments and intervention programs for these groups, e.g. [70,71].

A wide variety of assessment measures to measure parental emotional manifestations is seen across studies. As has been stated by many others, relevant, reliable, and valid assessment tools for parents of children with cancer are critically important in advancing the field of pediatric psychology because they can provide further evidence of the impact of childhood chronic disease on parents, as well as the potential need for and impact of psychological interventions [25,45,79]. However, parents of children with cancer are coping with an abnormal situation and therefore existing instruments may fail to assess their specific problems [25]. This can lead to "pathologizing" parental adaptation to childhood illness, which can have negative effects such as increased stigma and a de-emphasis on parents' daily functioning [67].

Disease-related and disease-specific measures can provide valuable, additional information when administered together with general measures [80]. It would be beneficial to both research and patient care to make use of the strengths of each different type of instrument. Sound psychometric properties of disease-related and disease-specific measures still need to be established and comparison groups are often small. Multi centered research and (inter) national collaboration is needed to obtain larger samples and to validate disease-related and disease-specific questionnaires developed by others or –better yet- to develop new measures together. The DISABKIDS project [13] and the KIDSCREEN project [68] are excellent examples of successful international collaborative projects yielding valid and reliable assessment tools to measure health related quality of life in children with chronic conditions. Unfortunately oncology was not incorporated in these projects.

Looking back on the last ten years in pediatric psycho-oncology research, there is a trend toward larger studies; almost half (32) of the studies included at least 100 parents (in most cases both mothers and fathers were included). The proportion of longitudinal studies seems to rise somewhat (14 % in the Grootenhuis & Last review versus 23% in the present review), but the majority of designs is still cross-sectional. This seems somewhat surprising, because in almost all articles the necessity of longitudinal designs is argued.

Recommendations

The present review study reveals potential areas of improvement in future research. In the 67 studies included in this review a variety of definitions of the core elements of the psychological stress process have been used, often described together and simply referred to as 'stress'. It is important to clarify what is meant by 'stress' and to specify the temporal course of a stressor [45]. To facilitate communication and collaboration it is necessary to be more specific in the terminology used to describe the psychological reactions of both parents and patients, and to make a clear distinction between stress as a primary reaction and psychological stress as an outcome. Investigators must determine whether they are interested in the person's appraisal of the stressors, or simply in the occurrence of verifiable events. Another issue is the temporal course of the illness or condition itself, since the phase of an illness guides the 'timing' of the assessment [16]. These aspects need to be specified before proceeding further with the study design and measurement strategy. In many instances, it matters whether the investigator is interested in processes that occur at the time of disease onset, in the period following initial diagnosis, during the

course of treatment, when complications arise (such as a relapse) or in the longer term.
It seems we have no more need of more cross-sectional research in this area, given its limitations. Repeated, ongoing assessment with longer time frames remains necessary to follow parents prospectively through the different phases of illness, treatment and long-term survival. It is recommended that a consensus be established on the optimal points in time to assess emotional reactions in parents following the diagnosis of cancer in their child. If assessments would take place for example one, six and 12 months after diagnosis, at the end of treatment and one and/or two years after the cessation of treatment, the comparison of results from research would be facilitated and patient and parent care would be enhanced. Assessment shortly after diagnosis provides important information on the initial reactions of parents. However, clinical practice has shown that assessment within four weeks after diagnosis is difficult, because parents are often too overwhelmed to take the time to fill in questionnaires. Assessment at six and twelve months post diagnosis will give insight in parental stress over time according to different disease phases. The end of treatment brings new challenges for parents and longer term follow-up is necessary to keep track of the parents who still report high stress levels.
After identifying those parents most in need of more intensive psychological care, the next step is to deliver feasible, limited, brief interventions for sub-clinical manifestations of psychological distress. Intervention research is a growing area in pediatric psychology and despite the many methodological challenges; efforts should be made to implement and evaluate existing intervention programs to prove effectiveness. This can only be done through (inter)national cooperation and well-developed study designs.
Furthermore, it is recommended that investigators routinely describe their reasons for using particular assessment tools or questionnaires, which should be embedded in an underlying theoretical model. Researchers seldom document their arguments for the selection of assessment measures used in their studies. This is unfortunate, because it would give more insight in the underlying theoretical model and it could facilitate discussion and communication among peers. One should also consider that measures could be used for different purposes. Important questions are: What does this measure do best? Is it a screening tool? Is it able to establish a diagnosis or to obtain a detailed picture of the problem? Is suitable for evaluating treatment outcome? [45]. Method and measure should match the study's purpose. A screening instrument is not intended to analyze a person, but to direct scarce professional time to cases meriting more in-depth study or support [14]. Development of brief screening instruments is important to identify parents at risk for preexisting, ongoing and escalating emotional manifestations of strain [39].
Lastly, instead of 'pathologizing' parents by classifying them as anxious or depressed [67], it would be more helpful to investigate parents' quality of life. Parental adjustment to childhood illness should be considered as a normative process involving additional daily responsibilities, limitations in major life roles and increased strain in close relationships. What is asked of parents is much more than in a normal parenting situation and acknowledging this would help parents cope better with the difficult and stressful situations with which they are confronted.

Table 1. Summary of Studies assessing Parental Psychological Stress in Childhood Cancer, in Chronological Order

Reference Design	Aim	Parent (n)	Child Characteristics	Parent Measures	Findings
Allen et al., 1997 [47] Cross Sectional	Investigate the impact of cancer diagnosis on psychological wellbeing of children and parents	34 M 27 F	Mixed diagnoses Median time post diagnosis 3 weeks	STAI BDI	Parental anxiety was higher than norms. M were most anxious. There were no gender differences found in depression
Barakat et al., 1997 [48] Cross Sectional	Compare PTSS in cancer survivors and parents with healthy children and parents	309 M 213 F	Mixed diagnoses Survivors Mean yr off treatment 5.8	PTSD-RI STAI IES FACES ALTTIQ SNRDAT	M and F had higher levels of PTSS than controls. Past perceived life threat and social support were contributors to PTSS
Grootenhuis & Last, 1997b [49] Cross Sectional	Determine which variables predict emotional adjustment of parents	84 M 79 F	Mixed diagnoses In & off treatment Mean mo post diagnosis: 51 1. Remission 54 2. Relapse 47	BDI TRAIT SSERQ CSS	A lack of positive expectations about the course of the illness was most strongly related to negative emotions. Having a child with a relapse predicted helplessness and uncertainty for M. Depression in the child was related to uncertainty of the father
Kazak et al., a. 1997 [29] b. 1998 [30] Cross Sectional	a. Examine psychological sequalae survivors and their parents compared to healthy controls b. Compare symptoms of anxiety and PTSS	a-b. 130 M 96 F	a-b. ALL & ANLL Survivors Mean yr off treatment 5.8	a. FACES SNRDAT a-b. IES STAI PTSD-RI	a. No differences in family functioning and social support a-b. More PTSS in M and F of survivors
Moore & Mosher, 1997 [50] Cross sectional	Examine adjustment responses of mothers and children (self care and anxiety) to cancer	74 M	Mixed diagnoses In & off treatment	STAI DCAPQ	M of children off treatment showed better adjustment responses than M of children in treatment. Basic conditioning factors predict adjustment responses. A relationship between mother/child adjustment was found
Sawyer et al., a. 1997 [51] b. 1998 [52] c. 2000 [53] Longitudinal	a. Follow prospectively adjustment of children and parents first 2 years post diagnosis b. Examine relation parent and family adjustment post diagnosis and adjustment of the child 2 yr post c. Assess psychological adjustment of children treated for cancer and their parents	a-b. 38 M 31 F c. 39 M 31 F	a-b-c Mixed diagnoses In & off treatment T1: mean weeks post diagnosis 5 a. T2: 1 & 2 yr post T1 b. T2: 2 yr post T1 c. T2-T5: 1, 2, 3 and 4 yr post T1	a-b-c FAD-GFS GHQ	a. Children and parents reported more emotional distress than controls post diagnosis. N of problems declined the first year and stabilized at comparable level with controls b. Distress level M post diagnosis were potential important influence on child adjustment c. Parents and children reported more psychological problems than controls post diagnosis. In the longer term, there were no differences in the number of problems
Hoekstra-Weebers et al., 1998 [24] RCT	Evaluate psycho educational intervention program parents of children with cancer	20 M 19 F	Mixed diagnoses In treatment T1: ≤ 14 days, T2: 6 and T3: 12 mo post diagnosis	STAI-State SCL90 SSL-D GHQ-12 Intensity Emotions List	Although there was a positive clinical evaluation, the structured intervention program was no more effective than standard care
Hoekstra-Weebers et al., a. 1998 [54] b. 1999 [55] c. 2001 [56] Wijnberg-Williams et al., d. 2006 [57] e. 2006 [58] Prospective	a. Examine gender differences in adaptation to diagnosis, and relation with coping style of parents of children with cancer b. Examine risk variables for future, immediate and persistent psychological distress parents c. Investigate level support and concurrent, prospective effects support on functioning parents d. Explore effects social support on psychological distress of parents of pediatric cancer patients e. Examine change and gender differences in self reported distress	a-b-c. T1: 85 M 79 F T2-T3: 66 M 62 F d-e. T4: 58 M 57 F	a-b-c. Mixed diagnoses In treatment T1: ≤ 14 days, T2: 6 and T3: 12 mo post diagnosis d-e. Survivors Deceased T4: 5 yr post diagnosis	a. SCL90 b. STAI-Trait SIB QREE RSES a-b. UCL a-b-c-d-e. GHQ-12 b-c-d. SSL-I SSL-D e. SCL90 STAI-State	a. More psychiatric symptoms and psychological distress at diagnosis, no gender differences. Distress declined with time. Few gender differences coping b. Trait anxiety was the strongest predictor of distress. Social support additional risk factor F. Previous life events and assertive behavior additional risk factors M c. Most support at diagnosis. Decrease of support with time but parents were equally satisfied. Dissatisfaction with social support and negative interaction was a risk factor for F, not M. Well adjusted M got more support than M who remained clinically distressed d. Decreased distress and support T1-T4. No change in satisfaction support and negative interaction. Dissatisfaction with support and negative interactions affected distress F, not M e. Decreased distress, psycho-neurotic symptoms and anxiety to normal level T4, except on GHQ. M more anxiety than F. Parents of children who relapsed reported more anxiety than parents of survivors or deceased children
Kazak et al., 1998 [30] Cross Sectional	Predict PTSS in parents of childhood cancer survivors	320 M 224 F	Mixed diagnoses Survivors Mean yr off treatment 5.7	PTSD-RI STAI FACES SNRDAT ALTTIQ	Anxiety was the strongest predictor of PTSS. Other contributors were: perceived life threat, treatment intensity and social support
Kazak et al., 1999 [20] Case control	Piloting Surviving Cancer Competently Intervention Program (SCCIP). Evaluate changes in PTSS, anxiety and family functioning	19 M 13 F	Mixed diagnoses Survivors Off treatment	PTSD-RI IES STAI-State FLS	PTSS and anxiety decreased in the participants. Changes in family functioning were difficult to discern

Reference Design	Aim	Parent (n)	Child Characteristics	Parent Measures	Findings
Barakat et al., 2000 [59] Longitudinal	Explore impact PTSS on long- term, psychological functioning of cancer survivors and M	65 M	Mixed diagnoses Survivors T1: Mean mo off treatment 58 T2: 18 months post T1	T1: PTSD-RI IES ALLTIQ T2: BSI LES	PTSS at T1 predicted general adjustment at T2, approximately 18 months later
Dockerty et al., 2000 [60] Cross Sectional	Assess mental health parents of children with cancer, compared to healthy controls	218 M 179 F	Mixed diagnoses In treatment	GHQ-12 VAS CAGE LTE-Q B-SSQ	Significant but small differences in mental health M and F of children with cancer compared to controls. Parents of children with cancer are relatively resilient
Manne et al., 2000 [61] Cross Sectional	Investigate individual differences in coping style, lifetime traumatic events, social support and PTSS	72 M	Mixed diagnoses Survivors Mean yr off treatment 2.5	PCL-C ISEL MBSS LEC	13.5 % of the M had symptoms indicative of cancer related PTSS Perceived social constraints and 'lack of belonging' were associated with PTSS.
Sloper, 2000 [62] Longitudinal	Investigate psychological distress in parents and relations between illness variables, appraisal, psychosocial resources and coping strategies	68 M 58 F	Mixed diagnoses In & off treatment T1: 6 mo and T2: 18 mo post diagnosis	T1-T2: MI T1: FES SSRM-SNSS BLCS WCQ	51% M and 40% F reported high distress levels at T1 and T2. M: Appraisal of strain, ability to deal, more self-directed coping and family cohesion were predictive of distress. F: risk employment problems, number of hospitalizations, appraisal and family cohesion were predictive of distress
Best et al., 2001 [31] Longitudinal	Evaluate association parental anxiety during treatment childhood leukemia and PTSS post treatment	66 M 47 F	ALL & AML T1: In treatment T2: Mean yr off post T1 3.7	T1: PPQ T2: STAI-State PAAS IES-R PTGI SNRDAT	Anxiety during treatment was a predictor of PTSS for M, not F. Anxiety, self-efficacy, posttraumatic growth and time since treatment were associated with avoidance
Frank et al., 2001 [63] Cross Sectional	Determine whether cognitive appraisals, perceptions of child behavior and social support predict affective responses differentially for M and F	77 M 48 F	Mixed diagnoses In & off treatment Mean yr post diagnosis: M: 2.7 and F: 2	BDI STAI ASQ CHIP	Parents did not differ on any of the variables. There were differential predictors of affective responses for mothers and fathers
Fuemmeler et al., 2001 [33] Cross Sectional	Examine PTSS and general distress among parents of children with a brain tumor	18 M 10 F	Brain tumor Off treatment Mean yr post diagnosis 6.8	PDS BSI PPUS WCQ	Parents of survivors of brain tumor were found to be at risk for PTSS and general distress. Uncertainty in illness was a primary risk factor for adjustment problems
Goldbeck, 2001 Longitudinal [64]	Study effect coping dissimilarity within couples on QoL of parents of children with cancer, compared to parents of children with diabetes or epilepsy	25 M 25 F	Mixed diagnoses In treatment Mean weeks post diagnosis: T1: 1-2 T2: 8-12	ULQIE CHIP TCS	Parents of children with cancer used more rumination, defense, information seeking, and less social support seeking than controls. M more frequent and effective coping strategies than F, but no differences in QoL. Coping dissimilarity F and M has a differential effect on family members
Mu et al., 2001 Cross Sectional [65]	Examine impact of stress experienced by M during cancer treatment of the child	100 M	Mixed diagnoses In treatment Mean length of treatment 12 mo	STAI-State PPUS BAS SMS	Sense of mastery was a mediator for uncertainty and anxiety. Uncertainty was a good predictor for boundary ambiguity
Iqbal & Siddiqui, 2002 [32] Cross Sectional	Determine frequency of depression in parents of children with ALL	37 M 23 F	ALL Off treatment First remission within last month	SCID-IV MMSE	Depression found in 34 parents, more common among M, less educated parents, lower SES
Goldenberg-Libov et al., 2002 [66] Cross Sectional	Examine prevalence and predictive factors of PTSD and PTSS in M	49 M	Mixed diagnoses Survivors Off treatment	SCID-PTSD PSEI	20 % M current and 27 % M lifetime PTSD. The number of low magnitude stressors past year, the perception of the cancer threat and income were contributors to the prediction of PTSS
Mu et al., 2002 [67] Cross Sectional	Examine stress impact on F caring for children undergoing cancer treatment	76 F	Mixed diagnoses In treatment Mean weeks in treatment 15	STAI-State PPUS PMS	Uncertainty and level of education were good predictors of anxiety
Sahler et al., 2002 [21] Two-arm RCT	Examine feasibility and effects Problem Solving Skills Therapy (PSST) with M of newly diagnosed children	50 M	Mixed diagnoses In treatment Mean weeks from diagnosis to T1: PSST 8.9 Controls 9.3	POMS SPSI-C	M in PSST-intervention condition showed enhanced problem-solving skills and decreased negative affectivity compared to controls
Santacroce, 2002 [68] Cross Sectional	Describe relations between uncertainty, anxiety and PTSS in parents	12 M 3 F	Mixed diagnoses In treatment Mean weeks post diagnosis 5	STAI-State PTSD-RI PPUS	Level of uncertainty was lower than expected. Anxiety level was comparable to hospitalized persons with anxiety disorders. Level of PTSS was higher than parents of survivors. There was a significant relation between anxiety and PTSS
Yeh, 2002 [69] Cross sectional	Investigate gender differences stress in parents of C with cancer diagnosis	164 M 164 F 1. 48 M & F 2. 43 M & F 3. 23 M & F 4. 47 M & F	Mixed diagnoses In & off treatment 1. Diagnosis ≤ 2 mo 2. In remission 3. Relapse 4. Off treatment	PSI-SF MSS SCL35-R	M reported higher distress levels than F. Parents of children newly diagnosed with cancer showed higher levels of depression, anxiety, stress and marital dissatisfaction
Boman et al., a. 2003 [70] b. 2004 [71] Cross Sectional	a. Understand reactions M and F of children with cancer b. Compare incidence disease- related distress symptoms in M and F of children with cancer and parents of children with diabetes	a-b. 146 M 118 F	a-b. Mixed diagnoses In & off treatment Mean mo post diagnosis 34	a-b. PPD-C	a. Distress levels (loss control, self-esteem, anxiety, depression, sleep disturbance, psychological and physical distress) were lower with more time elapsed since diagnosis b. Parents of children with cancer reported higher levels of anxiety, depression, loneliness, psychological and physical distress than parents of children with diabetes

Reference Design	Aim	Parent (n)	Child Characteristics	Parent Measures	Findings
Brown et al., 2003 [72] Cross Sectional	Examine adjustment among cancer survivors and M. Determine differences in PTSS relative to healthy comparisons	52 M	Mixed diagnoses Survivors Mean yr off treatment 5	PTSD-RI FILE FES	M of children with cancer reported more PTSS and more recent and past stressful life events than controls
Han, 2003 [73] Cross Sectional	Identify factors that influence maternal psychosocial adjustment to childhood cancer	200 M	Mixed diagnoses In treatment Relapse	FILE PAIS VAS CHIP PRQ	Stress, coping, social support and time since diagnosis significant were correlates of maternal psychosocial adjustment
Kazak et al., 2003 [74] Prospective	Identify risk level for psychosocial distress in families of children newly diagnosed cancer	103 M 15 F 2 Grand mothers	Mixed diagnoses In treatment T1: Mean days post diagnosis 9 T2: Mean mo post diagnosis 4	PAT	The PAT identified three subsets of families with increasing psychosocial distress at diagnosis
Steele et al., a. 2003 [75] b. 2004 [76] Longitudinal	a. Examine maternal distress initial 6 mo post diagnosis, and relation between changes distress and parenting strategies b. Identify distress patterns initial 6 months and examine patterns as predictors of child distress	a-b 65 M	a-b Mixed diagnoses In treatment Mean weeks post diagnosis: T1: 2-5 T2: 12-14 T3: 22-24	a-b. PSI POMS-SF a. CBS PDI b. PSS	a. The perceived and affective distress M decreased. Consistency of parenting fluctuated. Other parenting strategies and caregiver burden remained stable b. Four patterns of maternal distress. The high maternal stress group reported higher emotional distress in their child at T1, 2 and higher somatic distress at T3
Streisand et al., 2003 [77] Cross Sectional	Examine relation pediatric parenting stress and family functioning	96 M 20 F	Mixed diagnoses In/off treatment Mean mo post diagnosis 38	PIP FAD	Increased pediatric parenting stress is associated with poorer family functioning outcomes
Trask et al., 2003 [78] Cross sectional	Examine relations distress, coping, social support and family adaptation within pediatric cancer population and parents	28 M 1 F	Mixed diagnoses In/off treatment Mean mo post diagnosis 18	BSI FACES CSI	Low-level distress was reported, with a positive relation between parent-child adjustment. More use of adaptive coping strategies. Distress was associated with a reduced use of adaptive strategies
Barrera et al., 2004 [79] Cross Sectional	Determine if cancer diagnosis brings unique adjustment challenges	69 M	Mixed diagnoses In treatment Diagnosis ≤ 3 weeks	BDI STAI SCL90-R: GSI FIRA-G WCQ	M of children with cancer reported more depressive symptoms, emotion focused coping, and social support than controls. M of children with cancer had more adjustment difficulties uniquely related to child behavior
Von Essen et al., 2004 [80] Cross Sectional	Investigate well-being and burden of symptoms among parents of children with cancer	118 M 83 F	Mixed diagnoses In & off treatment Diagnosis within one mo	GQOLI	F had a higher mental wellbeing. M reported more symptoms of depression. Parents in treatment reported lower social and mental wellbeing and more depressive symptoms than parents off treatment
Hung et al., 2004 [81] Cross Sectional	Evaluate whether stress differs between parents of children with physical disability and parents of children with cancer	89 Parents	Mixed diagnoses In treatment Newly diagnosed or relapse	PSI-SF	Parents of children with cancer reported higher levels of stress than parents of children with a physical disability
Kazak et al., 2004 RCT [18]	Evaluate reduction of PTSS related to cancer	146 M 106 F	Mixed diagnoses Survivors 1-10 yr off treatment	IES-R PTSD-RI STAI-State	There were significant reductions in intrusive thoughts among fathers in the experimental group (SCCIP)
Kazak et al., 2004 [19] Cross Sectional	Describe rates and concordance of PTSD and PTSS in adolescent cancer survivors and M and F	146 M 103 F	Mixed diagnoses Survivors Mean yr off treatment 5	IES-R PTSD-RI SCID-PTSD	M and F reported relatively equal rates of PTSS and current PTSD. Nearly 30% M met criteria since diagnosis, with 13% currently In nearly 20% families at least one parent had current PTSD. At least one family member had re-experiencing symptoms
Lähteenmaki et al., 2004 [82] Longitudinal	Evaluate impact of childhood cancer on the life of the parents	21 Parents	Mixed diagnosis In treatment T1: 3 mo and T2: 12 mo post diagnosis	STAI-State Non-standardized questionnaire	In the beginning the high loss income and strain were intolerable. Negative view of own health but positive attitude on family life and spousal relation. Standardized anxiety assessment failed to show increase
Magal-Vardi et al., 2004 [83] Longitudinal	Assess development psychiatric morbidity, evaluate HRQoL and specify traumatic events leading to PTSS	20 M 16 F	Mixed diagnoses In treatment T1: < 2 weeks, T2: 1 mo and T3: 6 mo post hospitalization	DTS	20 % of the parents showed signs of PTSS within the first two weeks after diagnosis. No change in maternal PTSS, a decrease in PTSS in fathers. Several events were identified as causes
Quin, 2004 [84] Cross Sectional	Examine long-term psychosocial effects of cancer on children and families	74 M 46 F	Mixed diagnoses Survivors Off treatment	GHQ COPE	Shortly after treatment: isolation, vulnerability and ongoing worries were reported. Gender differences in coping. Majority of the parents readjust to ordinary family life post treatment
Svavarsdottir, 2004 [85] Longitudinal	Identify time-consuming and difficult care giving tasks experienced by M and F	T1: 25 M 20 F T2: 22 M 18 F T3: 21 M 15 F	Mixed diagnoses In/off treatment Recurrence ≤ 6, ≤ 18, ≤ 24 mo diagnosis- study baseline	CMCCQ GWB	Emotional support was the most time consuming and difficult task for M & F. M: manage behavioral problems and structure-plan family activities. F: manage work-organize care and give emotional support to the partner
Alderfer et al., 2005 [86] Cross Sectional	Identify and describe potential PTSS patterns within couples	49 M 49 F	Mixed diagnoses Survivors Mean yr off treatment 5.3	PTSD-RI IES-R SCID-PTSD FLS	5 Clusters of PTSS were found. The majority of the families have at least one parent with moderate-severe PTSS

Reference Design	Aim	Parent (n)	Child Characteristics	Parent Measures	Findings
Kazak et al., 2005 [23] RCT	Report initial feasibility and outcome of pilot study SCCIP-Newly Diagnosed	9 M 8 F 1 Grand mother	Mixed diagnoses Newly diagnosed In treatment	T1: ASDS T2: STAI-State IES-R	Reduced anxiety and PTSS after completion of intervention (SCCIP-ND) was reported
Kazak et al., 2005 [87] Cross Sectional	Investigate PTSS in parents of C in treatment and association with treatment intensity and time since diagnosis	119 M 52 F	Mixed diagnoses In treatment Mean mo post diagnosis 15	PTSD-RI IES-R	All but one parent reported PTSS. Mean scores indicated moderate PTSS. Two parent families: 80% at least one parent with moderate-severe PTSS. M and F reported more distress than controls. Minimal associations with time since diagnosis. No association with treatment intensity
Norberg et al., a. 2005 [88] b. 2005 [89] Cross Sectional	a. Consider range of parental coping strategies. Examine relation between coping strategies and anxiety and depression b. Examine relations between anxiety, social support seeking and perceived social support M and F survivors	a. 224 M 171 F b. 103 M 81 F	a-b. Mixed diagnoses a. In treatment a-b. Off treatment b. Survivors	a. ZDS a-b. STAI-State UCL b. Social Support Scale	a. No difference in the frequency of coping strategies. More active problem focusing, less avoidance and passive reaction were related to lower levels of anxiety and depression. Contextual demands influence relation coping-anxiety-depression b. A positive relation between support seeking and perceived support was found. Negative relation between anxiety and support seeking, stronger for M than F
Norberg et al., 2005 [90] Cross Sectional	Investigate traumatic stress in parents of children in active treatment versus off treatment	230 M 183 F	Mixed diagnoses In & off treatment Mean mo post diagnosis 19	IES-R	More intrusion and arousal parents of children in treatment. No difference between parents of children with and without a relapse. Post treatment: being immigrant and less educated, higher risk elevated stress. M more stress than F
Phipps et al., a. 2005 [91] b. 2006 [92] Cross Sectional	a. Examine PTSS levels in children and parents as a function of time elapsed post diagnosis and by use of parent versus child report for assessing patient PTSS b. Examine levels PTSS in children with cancer and their parents as function of adaptive style	a. 1. 35 Parents 2. 34 Parents 3. 30 Parents b. 99 M 18 F 4 Step- or Grandparents	a-b. Mixed diagnoses 1. In treatment, ≥ 2-≤ 6 mo post diagnosis 2. In/off treatment, 18-30 mo post diagnosis 3. Off treatment, ≥ 5 yr post diagnosis 4. Off treatment, ≥ 5 yr post diagnosis and age ≥ 18	a-b. IES-R PTSD-RI b. WAI	a. Parents of children recently diagnosed reported higher PTSS levels than parents of survivors. b. Low anxious and repressive parents reported lower PTSS levels than high anxious parents

Reference Design	Aim	Parent (n)	Child Characteristics	Parent Measures	Findings
Sahler et al., 2005 [22] RCT	Replicate PSST with larger and more diverse sample. Test Spanish version and examine moderators effectiveness PSST	217 M	Mixed diagnoses In treatment Mean weeks to randomization: 9	POMS BDI-II IES-R NEO-FFI SPSI-R	M in PSST showed enhanced problem-solving skills and decreased negative affect compared to controls. Effects were largest immediately after training
Stam et al., 2005 [93] Cross Sectional	Investigate HRQoL of children and emotional reactions of parents shortly after treatment	124 M 111 F	Mixed diagnoses Mean mo off treatment 2	GHQ-30 SSERQ	Parents of children with cancer reported more psychological distress than norms. More loneliness, helplessness and uncertainty was reported than parents of children 1-5 yr post cancer treatment
Barakat et al. [94], 2006 Cross-sectional	Describe posttraumatic growth (PTG) and its association with various variables	146 M 107 F	Mixed diagnoses Mean years off treatment: 5,3	PCS-scale from ITSIS ALTTIQ IES-R	A majority of the parents and adolescents in the study reported PTG. Greater perceived treatment severity and life threat was associated with PTG.
Bonner et al. [95], 2006 Cross-sectional	Develop a disease related measure of parent adjustment : PECI	157 M 38 F 7 grandm.	Brain tumors In/off treatment	BSI CGSQ IES IFS PECI	The PECI was proven to be reliable and valid. Four factors emerged: Guilt and Worry, Emotional Resources, Unresolved Sorrow and Anger and Long-term Uncertainty.
Lou, 2006 [96] Cross-sectional	Exploring factors related to the psychological wellbeing of parents of children with cancer	23 M 7 F 1 grandf	Leukemia In treatment, 1-44 mo since diagnosis (M 9.6)	PCI, GHQ	Parents are at risk for poor psychological well being related to financial problems and a lack of self-oriented coping approaches
Norberg et al., 2006 [97] Cross-sectional	Examine relationships between anxiety, seeking social support and perceived social support	103 M 81 F	Mixed diagnoses Off treatment	UCL STAI PPUS	Parent's subjectively perceived support appears to be more important for anxiety regulation than their support-seeking coping.
Phipps et al., 2006 [98] Cross-sectional	To examine symptom levels of PTS in children with cancer and their parents as a function of patient and parent adaptive style	99 M 18 F 4 other	Mixed diagnoses In/off treatment	IES-R, WAI	Parents identified as low anxious or repressors self-reported lower levels of posttraumatic stress (PTS) than high anxious parents. They also reported lower levels of PTS in their children
Bonner et al., 2007 [99] Cross-sectional	Evaluate the psychosocial functioning of fathers as primary caregivers of pediatric oncology patients	23 F 23 M	Mixed diagnoses In/off treatment	BSI IES IFS CGSQ PECI	The majority of parents were above normative means on measures of psychological distress. A large proportion of fathers reported elevated levels of depression
Robinson et al., 2007 [100] Cross-sectional	Identify factors that influence the association between parent and child distress	94 M 67 F	Mixed diagnoses In treatment	SCL-90 R FES NNSI CBCL	Children whose parents were distressed were more likely to be distressed . Subgroups of children were found to be more vulnerable to the father's distress

Note. ALL, Acute Lymphocytic Leukemia; ALTTIQ, Assessment of Life Threat and Treatment Intensity Questionnaire; AML, Acute Mylogenic Leukemia; ANLL, Acute Nonlymphoblastic Leukemia; ASDS, Acute Stress Disorder Scale; ASQ, Attributional Style Questionnaire; BAS, Boundary Ambiguity Scale; BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; BLCS, Brief Locus of Control Scale; B-SSQ, Brief Social Support Questionnaire; C, Child (ren); CAGE-Q, Screening test alcohol abuse; CARS, Current Adjustment Rating Scale; CBS, Caregiver Burden Scale; CES-D, Center for Epidemiological Studies Depression Scale; CGSQ, Caregiver Strain Questionnaire; CHIP, Coping Health Inventory for Parents; CMCCQ, Care of My Child with Cancer Questionnaire; COPE, Coping-scale; CSI, Coping Strategies Inventory; CSS, Control Strategy Scale; DAS, Dyadic Adjustment Scale; DCAPQ, Dependent Care Agent Performance Questionnaire; DTS, Davidson Trauma Scale; F, Father; FACES, Family Adaptability and Cohesion Evaluation Scale; FAD, Family Assessment Device; FCS, Family Coping Scale; FES, Family Environment Scale; FILE, Family Inventory of Life Events Environment and Change; FIRA-G, Family Index of Regenerativity and Adaptation-General; FLS, Family Life Scales; FRI, Family Routines Inventory; GHQ, General Health Questionnaire; GSI, Global Severity Index; GWB, General Well-Being Schedule; GQOLI, Göteborg Quality of Life Instrument; HDRS, Hamilton Depression Rating Scale; HRQoL, Health Related Quality of Life; IES, Impact of Event Scale; IOFS, Impact on Family Scale; ISEL, Interpersonal Support Evaluation List; IRSS, Illness Related Social Support Scale; ITSIS, Impact of Traumatic Stressorts Interview Schedule; JCS, Jalowiec Coping Scale; LEC, Life Events Checklist; LES, Life Experience Survey; LTE-Q, List of Threatening Experiences Questionnaire; LWMA, Locke Wallace Marital Adjustment Scale; M, Mother; MBSS, Miller Behavioral Style Scale; MI, Malaise Inventory; MMSE, Mini Mental State Examination; MQ-OS, Marital Questionnaire-Overall Satisfaction Scale; MSS, Marital Satisfaction Scale; N, Number; NEO-FFI, NEO-Five Factor Inventory; N.o.s., Not otherwise specified; NSSI, Norbeck Social Support Questionnaire; PAAS, Pediatric Anxiety and Avoidance Scale; PAIS, Psychosocial Adjustment to Illness Scale; PAT, Psychosocial Assessment Tool; PCI Parenal Coping Inventory; PCL-C, Post-traumatic Symptom Disorder Checklist-Civilian Version; PDI, Parenting Dimensions Inventory; PDS, Posttraumatic Stress Diagnostic Scale; PGIHQ, Patient Generated Index Health Questionnaire; PIP, Pediatric Parenting Stress; PMS, Pearlin Mastery Scale; POMS, Profile of Mood Scale; PPQ, Perception of Procedures Questionnaire; PPD-C, Parental Psychological Distress in Childhood Cancer; PPIS, Parental Perception of Illness Severity scale; PPUS, Parent's Perception Uncertainty in Illness Scale; PRQ, Personal Resource Questionnaire; PSEI, Potential Stressful Events Interview; PSI, Parenting Stress Index; PSR, Provisions of Social Relations; PSS, Perceived Stress Scale; PSST, Problem-Solving Skills Training; PTGI, Post Traumatic Growth Inventory; PTSSD-RI, Posttraumatic Stress Disorder Reaction Index; QoL, Quality of Life; QREE, Questionnaire of Recently Experienced Events; RCT, Randomized Controlled Trial; RS, Modified Repression-Sensitization Scale; RSES, Rosenberg Self-Esteem Scale; SCCIP (-ND), Surviving Cancer Competently Program (-Newly Diagnosed); SCID-PTSD, Structural Clinical Interview for DSM-IV Section Posttraumatic Stress Disorder; SCL90-R, Symptoms Checklist-90-Revised; SES, Socioeconomic Status; SIB, Scale for Interpersonal Behavior; SMS, Sense of Mastery Scale; SNRDAT, Social Network Reciprocity and Dimensionality Assessment Tool; SRRS, Social Readjustment Rating Scale; SSQ, Social Support Questionnaire; SSL-D, Social Support List Interactions; SSL-I, Social Support List Discrepancies; STAI, Spielberger's State Trait Anxiety Inventory; SPSI-C, Social Problem-Solving Inventory-Cancer; SPSI-R, Social Problem-Solving Inventory-R; SSERQ, Situation Specific Emotional Reaction Questionnaire; SSRM-SNSS, Social Support Resources Measure-Support Network Satisfaction Scale; TRAIT, Dutch version Trait Anxiety Inventory; TCS, Trier Coping Scales; UCL, Utrecht Coping List; ULQIE, Ulm Quality of Life Inventory for Parents of a Chronically Ill Child; VAS, Visual Analogue Scales; WAI, Weinberger Adjustment Inventory; WCQ, Ways of Coping Questionnaire; yr, year

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