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Adjustment and coping by parents of children with cancer: a review of the literature

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Abstract Studies published since about 1980 on psychological adjustment and coping of parents of children with cancer were reviewed. First, results concerning parental adjustment in terms of psychological distress, marital distress, and family functioning were summarized. Secondly, the use of coping strategies such as social support, communication, and search for meaning were described. Thirdly, factors that influence parental adjustment to childhood cancer, such as coping strategies and illness-related and demographic variables were discussed. All studies are

summarized in a review table, with information about the number of participating parents and children, the purpose, measures and major results. Difficulties in generalizing findings are possibly due to the heterogeneous group of children with cancer, the differences in reporting emotional problems by mothers and fathers, the difficulties in assessing illness-specific problems, and the diversity in the ways of assessing coping and adjustment.

Key words Childhood cancer · Parents · Adjustment · Coping

Introduction

For this review, empirical and descriptive studies of emotional reactions and coping behaviour of parents of children with cancer were examined. Studies exclusively concerning parental reactions to the death of their children with cancer were excluded from the review (e.g. [14, 35, 46, 66, 74]). The studies were searched by using Medline, Clinical Psychology and Psychological Abstracts with the following keywords: cancer, children, parents, coping, adjustment, anxiety and depression. References in the articles were always examined for other relevant studies. In some cases copies of material could not be obtained in The Netherlands, and they were therefore left out. Studies described in English, in articles and books, since about 1980 are presented. Before this time children with cancer were almost certain to die of their illness, so that earlier literature

focused primarily on preparation for death and dying. A review including literature of this period is available elsewhere [78].

Generally three types of studies are covered in the review: (1) only results recorded in parents are described, (2) families of children with cancer participated, and (3) primarily focused on children with cancer, but including some measurements recorded in their parents. The selection of studies in this last category has the most chance of being incomplete. The selected studies are all summarized in Table 1, in which the following information is included: the reference number of the study; the number of parents or family members participating in the study; illness-related variables of the children with cancer at time of investigation; the purpose of the study; the measures administered to the parents and the major results of the study concerning the parents. Available information about inclusion or exclusion of children with relapse or second malignan-

cies is entered for all studies. If articles refer to the same population they are described together. All abbreviations used are explained in Table 1.

The review of the literature about adjustment and coping of parents of children with cancer is divided into three parts. First, attention is given to parental adjustment in terms of psychological distress, marital distress, and family functioning. An attempt was made to describe the emotional reactions for different phases of the illness: after diagnosis, during treatment, and for long-term survivors separately. Secondly, coping resources and strategies are described. Coping is defined by Lazarus and Folkman [43] as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demand that are appraised as taxing or exceeding the resources of a person" (p. 141). It is important to make a distinction between adjustment and coping, because the two concepts have often been confounded. Through the years, the popular meaning of the term coping has come to be adaptational success, while definitions of coping must include efforts to manage stressful demands, regardless of their outcome [43]. In the last part of the review, factors that may influence

parental adjustment to childhood cancer are discussed. All results described in the literature review are summarized in some detail in Table 1.

Parental adjustment

Psychological distress

Being confronted with the diagnosis of childhood cancer in the family causes various emotional reactions. The word 'cancer' is associated with death, and for most people cancer cannot be associated with children. Researchers who have focused on parents of newly diagnosed children with cancer, or children who are in treatment, report increased emotional distress, such as anxiety or depression, in these parents against normative data [16, 50, 51]. Although different measures are used to investigate the emotional consequences, results are described together. In longitudinal studies also increased negative emotions such as anxiety, depression, insomnia or somatic and social dysfunctioning shortly after diagnosis are found [19, 48, 65, 70]. In some cases

Table 1 Studies describing emotional adjustment or coping behavior of parents of children with cancer (*index-cc* number of children with cancer on which study is based; no data of children are reported in the study, *p-cc* parents of children with cancer, ratio mothers/fathers not given, *m* mothers, *f* fathers, *couples* cases in which mother and father of a child participated, *cc* number of children with cancer who participated and of whom data are reported in the study, *tsd* time since diagnosis, *families* child, mother and/or father participated; exact numbers are not obvious, *ALL* acute lymphocytic leukemia, *AML* acute myelomonocytic leukaemia, *NHL* non-Hodgkin lymphoma, *mixed* both leukaemias, lymphoma and solid tumours, *cd* chronic diseases, *hc* healthy children)

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[1]	53 <i>index-cc</i> 53 <i>p-cc</i>	In treatment Majority leukaemia	Stress and coping behavior in relation to distance to the hospital	4 of 6 scales Parental Perception Inventory (PPI) developed from Hymovich Chronicity Impact and Coping Instrument: concerns; beliefs and feelings; coping and general information	Families living at longer distance (>100 miles) from the hospital were more often sad; concerned more about travel and information; thought support groups were more helpful, and coped more by hiding feelings, blaming someone, and wishing problems away
[2–5]	45 <i>index-cc</i> [2–4]: 42 <i>m-cc</i> 32 <i>f-cc</i> [5]: 32 <i>couples</i>	Off treatment Mixed diagnoses Age: 4–21 years	[2]: Association between major stressors, coping strategies and relationships with others [3, 4]: Satisfaction and coping in relation to medical context [5]: Childhood cancer and marital outcome	[2, 4, 5]: From interview 8 coping strategies [2–4]: Quality relationship staff [2, 5]: Marital quality [2, 6]: Perceived illness related stress [3]: Satisfaction with medical staff [2]: Relationship with friends [4]: Rated coping effectiveness [5]: Family cohesion, spouse support and medical stress	[2]: Coping strategies had a stronger effect on social relations than on the decrease of subjective stress [3]: Satisfaction predicted with 7 dimensions of quality relationship staff. Personal contact best predictor for satisfaction [4]: Passive coping related to better relation medical staff [5]: Marital quality and spouse support under stress with increase hospitalizations. Marital functioning evaluation not related to coping strategies

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[6]	46 <i>index-cc</i> 46 m-cc	20 cc in treatment 9 cc off treatment <1 year 17 cc off treatment >1 year Mixed diagnoses Age: 3–18 years	Relationship coping processes and adjustment	SCL-90R Ways of Coping Scale Communication Scale	Emotion-focused coping related to maladjustment. Not related to adjustment were: problem-focused coping, communication, treatment stage, demographic variables
[7]	20 cc 15 m-cc 5 f-cc	In treatment Mixed diagnoses Age: 4–19 years	Patient's and parents' causal attributions in relation to coping strategies	Causal attribution from interview Strategies for Coping with illness: Parents scale	Both patients and parents who attributed externally, used more positive typed coping strategies such as humor and support
[8]	45 <i>index-cc</i> 44 m-cc 38 f-cc (single: 4 m and 1 f)	tsd: 3–17 months In treatment Mixed diagnoses	Family coping with childhood cancer and comparison with previous studies	Coping Health Inventory for Parents (CHIP) 2 coping scales derived from CHIP	Findings CHIP comparative to other studies. Two new coping scales: encapsulation and at-risk derived from CHIP
[9]	32 families	In treatment, mixed diagnoses Age: 8–16 years	Influence of family functioning on hopelessness among children with cancer	Family Characteristics Inventory Coping Health Inventory for Parents (CHIP) Impact of Event Scale Mother-Child Relationships Evaluation Scale	No relationship between coping strategies of parents. Maintaining self-stability and understanding medical situation are related to decreased level of subjective distress about the illness for parents
[10, 11]	[10]: 55 families [11]: 61 mother-child dyads	[10]: 23 cc recent diagnosis 22 cc 1 year post diagnosis 10 cc 1 year off treatment All children ALL Relapsed excluded Age: 2.5–17 years [11]: 3 cc more in recent- and 3 cc more in 1 year post-diagnosis group	[10]: Psychiatric and family functioning [11]: Relationship maternal psychopathology and psychosocial functioning of children	Psychiatric symptomatology by structured interview (DSM-III) Beck Depression Inventory (BDI): only mothers Locke-Wallace Marital Adjustment Questionnaire Coping Health Inventory for Parents (CHIP) (only in study 10) Family Environment Scale (FES): 3 subscales Holmes-Rahe Stress Questionnaire	[10]: Between-group differences tested for all variables. Families function adequately. After completion of chemotherapy: increase in marital satisfaction, decrease in depression and familial stressors [11]: 34% of the mothers had at least one psychiatric disorder, and their children also had more problems. BDI scores of diagnosed and non-diagnosed group in normal range
[12]	63 cc only m-cc	Heterogenous brain tumours Mean time between diagnosis and testing 44 months Mean age at diagnosis: 7 years	Prediction of cognitive and behavioural outcomes of children with brain tumours by family – and illness-related variables	Coping Health Inventory for Parents (CHIP) Family Inventory of Life Events (FILE) Family Environment Scale (FES): two subscales (cohesion and control)	Mothers report average levels on FILE and FES. Lesser maternal reliance on coping strategies proved to be a family variable associated with higher intellectual functioning of children
[13]	23 <i>index-cc</i> 23 f-cc	2 months to 2 years post diagnosis Majority ALL Age: 0–17 years	Fathers' stressors and coping strategies, also related to severity of disease	Parental Perception Inventory (PPI) developed from Hymovich Chronicity Impact and Coping Instrument	Fathers' major concerns: child's future and health. Most often used coping strategy: praying. Severity of the illness of no influence on concerns and coping

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[15]	20 cc 20 sibs 19 m-cc 19 f-cc (18 couples)	In treatment Leukaemia and lymphoma Relapses excluded Age: 6–16 years	Individual, dyadic and family emotional responses to diagnosis of childhood cancer	Kinetic Family Drawing Schedule of Recent Experiences Culture-Free Self-Esteem Inventory Dyadic Adjustment Scale (DAS) Family Environment Scale (FES)	More life-events reported. No differences for mothers against norms for self-esteem while fathers had higher self-esteem. Dyads less well adjusted than married norms. Higher on all FES scales than reported norms
[16]	67 <i>index cc</i> 67 couples cc	Newly diagnosed Mixed diagnoses Age: 0–17 years	Interaction maternal and paternal coping as affected by marital distress	State-Trait Anxiety Inventory Beck Depression Inventory (BDI) Repression-Sensitization Scale (RS) Dyadic Adjustment Scale (DAS)	State anxiety scores only slightly higher than norms for mothers and fathers. Mothers also higher on trait scale than norms. One fourth of the parents report marital distress, which is predicted by both general emotional distress, discrepancy in couple's anxiety level and couple's use of sensitizing coping style
[17]	198 <i>index-cd</i> all couples 105 diabetes 34 asthma 27 epilepsy 13 leukemia 19 cardiac	Only leukaemias Mean tsd: 3.46 years Age: 4–14 years	Coping patterns in parents of children with chronic conditions in relation to child age, disease and appraisal of difficulties	Appraisal of difficulties: 15 items Coping Health Inventory for Parents (CHIP): 33 items version with own factor analysis with four factors	Parents of children with leukemia report most difficulties and report higher acceptance on medical care coping scale
[18]	30 <i>index-cc</i> 28 m-cc 23 f-cc	In and off treatment, tsd: 6 months to 2 years after end of treatment Mixed diagnoses Mean age: 10.4	Relation attribution and coping strategies	Coping Health Inventory for Parents (CHIP): 33 items version with own factor analysis with four factors Interview about attributions and perception impact	Mothers and fathers gave much lower ratings to the helpfulness of social support/information compared with the other three strategies measured with the CHIP. Fathers more often accepted no known cause than mothers. Fathers who blamed doctor for failing to diagnose experienced less help from medical staff
[19]	Based on 34 cc, of whom 13 cc participated 33 m-cc 27 f-cc 31 sibs	Longitudinal design over a period of 1 year after diagnosis at scheduled intervals Only ALL Age: 22 months to 16 years	Family's adaptation to childhood leukaemia	Family Environment Scale (FES): 6 subscales Lock-Wallace Short Marital Adjustment Test State-Trait Anxiety Inventory Psycho pathology (MMPI)	Adjustment relatively constant over time. Depression increased after one year. Families at risk: those with pre-existing problems. Families with stable relationships and support were able to maintain usual quality of life
[20, 21]	[20]: 118 cc 120 p-cc [21]: 138 cc 138 m-cc 92 hc 92 m-hc	≥ 2 years beyond any form of treatment tsd: 5–16 years Mixed diagnoses Age: 8–16 years	[20]: Concerns about surviving childhood cancer [21]: Psychological functioning of children and their parents	[20]: Impact derived from interview [21]: Family Environment Scale (FES) Derogatis Stress Profile	[20]: Parents expressed both positive and negative views. Concerns: recurrence and adjustment to impairments. Many parents grateful for surviving [21]: Only higher scores on intellectual and recreational subscales of FES for healthy mothers. No differences on Derogatis Stress Profile compared to healthy controls

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[22–25]	[22–24]: 84 <i>index-cc</i> 79 couples cc 5 single m-cc [25]: 84 cc 41 ca 38 couples ca 4 single m-ca 80 hc 43 m-hc 37 f-cc	43 cc remission: 1–5 years off treatment 41 cc relapse: in and off treatment Mixed diagnoses Age: 8–18 years	[22]: Emotional reactions of parents in relation to the survival perspective of their child [23]: Which variables from the child, and which control strategies used by parents predict emotional reactions of parents? [24]: Use of secondary control strategies [25]: Attribution of positive characteristics to the child as a particular control strategy for parents of children with cancer	[22]: Interview questions about main concerns child's illness [22, 23]: Beck Depression Inventory (BDI) Trait-Anxiety Inventory (TRAIT) Situation Specific Emotional Reaction Questionnaire (SSERQ) (feelings of loneliness, helplessness, uncertainty and positive feelings) [23, 24]: Control Strategy Scale (CSS) (secondary predictive, vicarious, illusory and interpretative control) [25]: Behavioral Assessment Scale for Parents (BAP)	[22]: Mothers and fathers of children with a relapse report more feelings of uncertainty and helplessness. Mothers of children with a relapse also report more anxiety and depression than mothers of children in remission and report more depression than found in normative data. Negative emotional consequences for fathers were only revealed with the SSERQ. Main concerns are about survival chances [23]: Anxiety and depression of total group of mothers and fathers comparative to norms. Negative emotions of mothers best predicted by having a child with a relapse and having negative expectations. For fathers negative emotions were also best predicted by having negative expectations, but also by reported feelings of depression of their child. Time since diagnosis does not predict negative emotions [24]: Parents of children in remission rely more on vicarious and predictive control (positive expectations). Interpretative control was used most frequently, based on proportional scores [25]: Parents of children with cancer attribute more cheerful behaviour to their children than parents of children with asthma or healthy children. Positive attribution of parents of children with cancer possibly contributes to their flexibility to cope with stresses of the illness
[26]	20 cc 20 c-HIV 20 hc 58 mothers 2 fathers	In treatment 1 cc with relapse tsd: 3–68 months 75% ALL Age: 4–7 years	Patterns of coping and communication among children with chronic illnesses and their parents compared with healthy controls	Coping Strategies Inventory (CSI) Disclosure diagnosis (yes/no)	Parents of children with life-threatening disease used more wishful thinking, and HIV more than cancer. Self-criticism higher in parents of healthy children. Diagnosis cancer more often known than HIV by children
[27]	25 <i>index cc</i> 25 m-cc 25 sibs cc 25 m-hc 25 sibs-hc	In and off treatment tsd: 6–41 months Mixed diagnoses Age: 2–15 years	Psychological adjustment and family functioning of siblings of children with cancer	Family Adaptability and Cohesion Scale-version II (FACES II)	More cancer families classified as rigid or chaotic, and less cancer families in the balanced range

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[28]	10 index cc 8 couples and 2 m-cc	5 cc in treatment, 5 cc off treatment mixed diagnoses age: 2–13 years	Psychological symptoms and adjustment	General Health Questionnaire (GHQ) Leeds Self-Assessment Scale for Anxiety and Depression Semi-structured interviews	Anxiety outside normal range in 13 of 18 parents. One third of the parents ($n=6$) had communication difficulties with the staff
[29]	45 cc 45 m-cc	Longitudinal design: 2, 8, 14, 20 months after diagnosis After death still included ALL and AML Age: 4–17 years	Nature and frequency of concurrent problems	Participant observant technique	Families had concurrent stressors: medical complications, death of near persons, illness in other family member, occupational changes, financial problems. Support needed for other non-disease-related issues as well
[30, 32]	[30]: 35 families cc 13 families hc [32]: 74 families cc (including families from study [30])	Off treatment: free of disease at least 5 years, ALL, AML and NHL 1 cc relapse, age: 10–15 years [31]: Two data points: 6 months apart ($n=25$ time 2) [30]: Two data points: 1 year apart ($n=59$ time 2) 5 cc relapses	[30] Familial adjustment, adaptability and social support [32]: Adjustment, learning problems and gender	[30, 32]: Langner Symptom Checklist Family Adaptability and Cohesion Evaluation Scale (FACESII)	[30]: No differences on parental variables on time 1 between p-cc and p-hc. At time 2, mothers of children with cancer rated their families as less adaptable. Parents of survivors having educational assistance reported less family adaptability and more distress [32]: Parental ratings on both instruments within norms
[33]	32 families 33 sibs	tsd: 6 months to 3 years, in treatment; Age: 0–17 years	Sibling and parent adaptation to childhood cancer	Interviews and force-choice questions	Five family patterns: (1) increased experience of negative affect, (2) rules prohibiting emotional expression, (3) health and behaviour problems, (4) role changes, (5) increased closeness
[34]	117 cc 190 p-cc of 119-cc 101 sibs of 55 cc 13 partners of cc 22 controls	> 1 year off treatment; age: 5.6–37 years 22 cc with relapse or second malignancy	Psychological and social consequences of surviving childhood cancer	Interview Death Anxiety Questionnaire	First major study about surviving childhood cancer. Parents' marriages tended to be stable over time, low SES correlated with more adjustment problems. Major concerns: long-term effects of treatment and relapse. Hope and open communication most important coping strategies

this psychological distress was also greater than in healthy controls [48, 49, 70]. Sleep disturbances and feelings of depression remained higher against healthy controls at 8 months and 20 months after diagnosis in the studies of Magni et al. [48, 49], and depression and somatic symptoms were still higher 1 year after diagnosis [70]. A number of other studies report that parents are experiencing emotional problems 1 year after diagnosis; for example, a high percentage of mothers are diag-

nosed as overanxious [10] and fathers are diagnosed with major depression or increased feelings of depression [10, 19]. Powazek et al. [65] also report that families still experience high levels of stress 1 year after diagnosis. Fife et al. [19] report that in their longitudinal study the emotional consequences decline over time. Kupst et al. [40] showed the repeated measures from diagnosis to 10 years after treatment of perceived parental adjustment and coping adequacy. Fathers did not

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[36–40]	[36]: 43 families [37]: 64 families [38]: 64 families [39]: 60 families [40]: 28 families	Longitudinal design: 6 months, 1, 2, 6–8 years, 10 years after diagnosis Only ALL Age: 1–11 and older at start [36]: 27 cc in remission, 1 cc relapse, 15 died [37]: 52 cc in remission, 4 cc relapse, 6 dying, 2 died [38]: 64 cc newly diagnosed [39]: 44 cc in remission, 10 died, 4 relapse, 2 in remission with problems [40]: 28 cc survivors	Prospective study of family coping. Influence of several child and parenteral variables studied	Family Coping Scale: other raters Californian Psychological Inventory (CPI) Current Adjustment Rating Scale (CARS) Postdeath Adaptation Scale only in [40]: Ways of Coping Scale Brief Symptom Inventory	[36] (6–8 years after): improvement in adjustment over time. Previously found variables consequent related to good coping [37] (1 year after): Variables related to good coping: age child, coping with other family members, occupational status father, and lack of sibling problems. Intervention not related to coping [38] (6 months after): Variety of reactions but in general coped well. Intervention for mothers effective. Correlated to healthy coping: age child, previous coping, coping other family members, good support system, lack additional stresses [39] (2 years after): Variables related to good coping: quality marital and family relationship, previous coping, support system, lack additional stresses, open communication, living in the present [40] (10 years after): bi-directional relationship between survivors and mother's adjustment. Coping strategies not correlated with adjustment
[41]	(1) <i>191 index-cc</i> 188 p-cc (fam with more than ≥ 1 cc) (2) <i>38 index cc</i> 38 couples-cc 23 couples-cd	(1) cc diagnosed between 1968–1974 (2) In treatment	(1) Incidence divorce rate (2) Effect on marital relationship	(1) Divorce Survey Questionnaire (2) Psychopathology (MMPI): marital adjustment	(1) No higher divorce rate than in general population (2) cc Couples more marital stress than comparison group. Both groups more stress than normal population but less than group of marriage counselees
[42, 84]	<i>17 index-cc</i> 17 couples cc 32 couples hc (flu)	10 cc In treatment 7 cc Off treatment Age: <26 years	[42]: Sex differences in parental adjustment [84]: Parental coping, adjustment and relationship with medical personnel	Coping Strategies Inventory (CSI) Social Support Questionnaire (SSQ) Dyadic Adjustment Scale (DAS) State-Trait Anxiety Inventory Beck Depression Inventory (BDI) Quality of Medical Relationship Scale Medical Staff Rating questionnaire (by staff members)	[42]: Parents of children with cancer only higher on state. No sex differences found specific for cancer group. Mothers in both groups used more engagement coping strategies and were slightly more depressed [48]: In cancer group no decrease in distress after using adaptive coping strategies while this was found for the controls
[44]	<i>26 index-cc</i> 24 m-cc 13 f-cc	tsd: 6–35 years Mixed diagnoses Age: 8–36 years	Description concerns and needs of parents of children who survived cancer	Parents of Childhood Cancer Survivor Questionnaire Symptom Distress Checklist (SCL-90R) Lock Wallace Short Marital Adjustment Test	No psychological symptoms suggesting psychopathology: Major concerns: child's health complications and fear of relapse. Major support found from partner. Desire for long-term support

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[45]	20 <i>index-cc</i> 19 m-cc 1 f-cc	Off treatment Leukemia Age: 7 months to 12 years	Psychological experiences of finishing chemotherapy	Interview about feelings of fear and anxiety	Authors stress the importance of understanding anxiety if treatment is finished. Feelings of anxiety and fear for relapse are also normal emotional responses
[47]	25 families cc 16 families hc	Off treatment and free of disease >5 years Mixed diagnoses Age: 12–18 years	Late effects of surviving cancer by comparing cancer survivors with non-diseased control subjects	Family Adaptability and Cohesion Evaluation Scales (FACES III); only mothers Inventory of Parent Adolescent Communication (IPAC) Coping Strategies Inventory (CSI)	Mothers of children with cancer more rigid and less flexible. No further differences. Mothers of cancer survivors make greater use of social withdrawal as a means of coping
[48]	13 <i>index-cc</i> 12 couples 1 single m-cc 25 p-hc matched	Two data points: after diagnosis +8 months later ALL Age: 3–10 years	Psychological disturbances	Symptom Distress Checklist (SCL-90)	Higher mean scores than controls for anxiety, depression, sleep disturbances and obsessions. After 8 months still on anxiety, sleep and depression
[49]	21 <i>index-cc</i> 20 couples-cc 1 single m-cc 25 p-hc matched	Three data points: diagnosis; 8 and 20 months later Only ALL and NHL Age: 3–10 years	Longitudinal evaluation of psychological distress	Symptom Distress Checklist (SCL-90)	Same results as found in previous study. After 8 and 20 months especially sleep disturbances and depression
[50]	13 <i>index-cc</i> 13 couples-cc	After diagnosis ALL Age: 2–12 years	Relationships, psychological distress and social support	Symptom Distress Checklist (SCL-90) Social Support Questionnaire (SSQ)	Again moderate psychological distress was found. Social support buffered impact
[51]	59 <i>index-cc</i> 55 m-cc 4 f-cc	Two data points: after diagnosis +3 months Non-brain-related cancer Age: 3–18 years	Predictors of depressive symptomatology among parents of newly diagnosed children with cancer	Family Routiness Inventory Assistance provided scale Family Adaptability and Cohesion Scales (FACES-III) Beck Depression Inventory (BDI)	Mean depression scores at time 1 and time 2 in mildly depressive range. Strong relationship child behaviour problems and parental depression. Child's functional impairment and lower family cohesiveness also predictive of depressive symptoms in the mother
[52]	22 families of cc Time 1: 22 m-cc 20 f-cc Time 2: 15 m-cc 15 f-cc	Two data points: ± 1 year apart In treatment Age: 6+	Effects of disease in everyday life for patients, parents and siblings	Interview	Effects are described for the different periods parents go through. Marital relationships strengthened
[53]	10 <i>index-cc</i> 10 families	5 cc Survived 5 cc Died	Description of the impact of childhood cancer on the family (parents and siblings)	Interviews	How families perceived and responded to childhood cancer ranged from being unprepared for the diagnosis to fears of recurrence, need to normalise family life and difficulties managing siblings
[54]	175 <i>index-cc</i> 175 p-cc	ALL Diagnosed between 1973–1983	What causes childhood leukemia?	Open ended interview question	Parents describe different theories, such as environmental factors, chemical exposure and preceding illness

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[55–57]	107 <i>index-cc</i> 65 m-cc 42 f-cc	48 cc In treatment 37 cc Died 22 cc off treatment Mixed diagnoses Age: 1–20 years	[55]: Psychosocial adjustment and support [56]: Sources of support [57]: Effects treatment stage, perceived support and adjustment	Rating 11 sources of support Psychosocial Adjustment to Illness Scale (PAIS)	[55]: Predictive for poor adjustment: death of the child and younger age of the parents [56]: Needed most during illness: emotional support and counselling. Spouse, medical community and parents' mutual helpgroups most helpful [57]: See results [55]. Parents of children who died do not benefit from social support
[58]	99 cc 99 m-cc	In treatment Mixed diagnoses Excl. progressive disease Age: 8–16 years	Which variables form basis depression scores children	Beck Depression Inventory (BDI) Maternal Social Support (0–100 mm)	Low perceived social support and hospitalization of the child predict maternal depression. Only 7 of the 99 mothers exceeded clinical cut-off score
[59]	15 cc 15 m-cc 2 f-cc	Limited prognosis Age: 12–21 years	Correlates of control	Interview with 33 questions resulted in three control variables: global sense of control, control over medical decisions and control over future	Optimism and future affect were positively correlated to global sense of control and control over future
[60]	18 families cc	Remissions >4 years Majority still in treatment Leukaemias	Long-term emotional adaptation	MMPI Gough Adjective Checklist Child Behavior on 54-items Q-sort (only mothers) Parents' own attitudes (only mothers)	Descriptive results and consideration for model of life crisis points in childhood leukaemia: initial diagnosis, initial treatment, remission, relapse, terminal care and after death
[61]	44 cc 44 p-cc (mostly the mother)	2–7 years off treatment Mixed diagnoses Brain tumours excluded Mean age: 10.3 at time of diagnosis	Relationship adaptation and psychosocial outcome	Support and family functioning from interview Global adjustment from interview Impact On Family Scale: includes a coping scale	Lack of emotional support related to increased emotional distress. Mastery as a coping style was related to adaptive functioning
[62]	24 <i>index-cc</i> 45 p-cc: 21 couples cc 3 single parents	Mixed diagnoses Off treatment 2–13 years tsd: >4 years	Problems experienced by families of long-term survivors	Semi-structured interview and related questionnaire	None of the parents considered their child to be cured. Most families report some difficulties
[63]	24 <i>index cc</i> 24 m-cc 23 m-hc	Off treatment or about to enter maintenance phase Mixed diagnoses 3 cc relapse Age: >13 years	Prevalence of Posttraumatic Stress Disorder (PTSD) in mothers of survivors compared with healthy controls	Potential Stressful Events Interview Structured Clinical Interview for Diagnosis Symptom Checklist (SCL-90) Social Support (interview)	More mothers of children with cancer met criteria for lifetime PTSD, but no differences for current PTSD were found. Illness severity, level of social support, and SCL-90 severity index scores did not significantly differ in the PTSD-positive and PTSD-negative groups
[64]	30 families-cc	Mixed diagnoses 15 cc off treatment 15 cc died Age: 4–24 years	Finding criteria which predict coping behaviour in children and their families	Coping styles derived from interview	Five different coping styles distinguished: experiencing the disease as challenge, as probation, as misfortune, as fate and as punishment. Bad adaptation related to interpretation as punishment

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[65]	35 families cc: mainly mothers 'view'	Only ALL Three data points: diagnosis, 6 and 12 months later Age: 5 years and older	Delineate characteristics of families at high risk for emotional difficulties	Clinical Analysis Questionnaire (only mothers) Coping Operations Preference Enquiry (COPE) Mother/Child relationship Inventory	During first 6 months reduction of maternal anxiety, but remained high at six months. One year after diagnosis high level of stress but adequate functioning. Fathers more closed communication about the illness
[68]	484 <i>index-cc</i> 90% m-cc	Mixed diagnoses	Parents' causal attributions	Open ended interview question about comments or concerns concerning causes childhood cancer	Major themes: environmental exposures, family health history
[69]	42 families cc 42 families hc 56 sibs-cc 54 sibs-hc	At least 2 years after diagnosis- Leukemia only Age: 4–16 years	Children's and family's adjustment	Family Concept Inventory (over age 10)	Families of children with cancer saw themselves as being less effective and as more worried
[70]	22 <i>index-cc</i> 22 m-cc 19 f-cc matched with 21 m-hc 17 f-hc	Two data points: after diagnosis and 1 year later Mixed diagnoses Brain tumours excluded Age: 4–16 years	Prospective study of the psychological adjustment of parents and families of children with cancer	General Health Questionnaire (GHQ) General Functioning Scale of the Family Assessment Device	After diagnosis mothers experienced more anxiety, insomnia, somatic and social dysfunction than healthy mothers. At 1 year follow-up more depression and somatic symptoms. A similar pattern, although with lower scores, for fathers was found
[71]	81 families cc including sibs	Follow-up study Mixed diagnosis 17 cc in treatment 24 cc first remission 14 cc long term survivors 11 cc relapse 15 cc died	Psychological changes over time	Interview	High frequency of emotional disturbances among parents. Marital problems in almost half of the families, especially after diagnosis. Complete return to normal life after remission hardly ever occurred
[72]	26 <i>index-cc</i> 26 couples-cc (fathers did not complete whole data-set)	Majority ALL 6 months to 2 years past diagnosis Age: 2–12 years	Communication patterns between parents	Beck Depression Scale (BDI) Langner Symptom checklist Janis Personality Inventory (self-esteem) 8 scales derived from interview e.g. about communication and coping	For mothers, open and frequent communication positively affected emotional well-being. Communication with spouse important. Mothers rated family climate more positive and rated patient better adjusted than fathers
[73]	63 <i>index-cc</i> 63 m-cc 49 f-cc matched with 64 m-hc 62 f-hc	Off treatment: <1 year to 15 years Mixed diagnoses, including histiocytosis (18%) Age: 3–18 years	Psychological distress and social support	Center for Epidemiological Studies Depression Scale (CES-D) State-Trait Anxiety Inventory Provisions of Social Relations (PSR) Marital Questionnaire (subscale)	No differences in depression and anxiety versus controls. Parents with less support more at risk for depression and anxiety. Perceived social support especially for mother related to less distress
[75]	51 families	38 cc 5 years off treatment 13 cc died	Long-term adjustment and coping	Family Adjustment Scale (FAS) Current Adjustment Scale (CAS): three coping strategies	After 5 years consistency of family functioning over time. Parents with a child that died had more problems adjusting over the long term. Better adjusted families were able to place experience in proper perspective, seek professional help, coped effectively and learned additional coping skills

Table 1 Continued

Study (reference)	No. and groups	Characteristics of the children with cancer	Purpose	Measures parents	Major results concerning parents
[76]	30 cc 30 m-cc 17 f-cc	Off treatment: 22–128 months Mixed diagnoses: brain tumours excluded Age: 8–19 years	Posttraumatic stress symptoms	Post Traumatic Stress Reaction Index State-Trait Anxiety Inventory Appraisal of life threat and intensity treatment	Posttraumatic stress symptoms did not correlate with diagnosis, time since end of treatment. Maternal symptoms correlated with anxiety, child's appraisal of treatment severity and duration of treatment
[77]	21 families cc 17 families hc	In and off treatment tsd: 2–124 months Mixed diagnoses Age: 6–12 years	Life change events and coping behaviors	Family Inventory of Life Events and Changes (FILE) Family Crisis Oriented Evaluation Scale (F-COPES)	Families with a child with cancer experienced more stressful life events but no differences in coping behaviour between the two groups were found
[79, 80]	[79]: 68 <i>index-cc</i> 130 parents (68 m-cc and 62 f-cc) [80]: 70 <i>index-cc</i> 133 parents (69 m-cc and 64 f-cc)	Time off treatment: 6 months to 7 years Diagnoses: leukaemia and lymphoma 7 cc with relapses Age: 8–12 years	[79]: Family planning and emotional consequences [80]: Late psychological consequences of children with cancer and study of risk factors	[79, 80]: Four categories measuring impact: Uncertainty Loss of control Self-Esteem Negative feelings (6 sub-scales) [79]: interview questions about family planning	[79]: Reproductive planning affected in one third of families. Affected families reported more loss of control and negative feelings [80]: Uncertainty and loneliness most reported. Risk factors for late problems: e.g. low SES, mothers, no religion, concurrent stresses. No effect of treatment found on consequences. No decline in problems over time
[81]	82 cc 77 couples-cc 4 single m-cc 1 single f-cc	32 cc in treatment 50 cc off treatment 10 cc with relapse Mixed diagnoses Age: 4–16 years	Relationship open communication and emotions	Interview Utrecht Coping List (UCL) Parental Attitude Research Instrument (APARI) State Anxiety Inventory Stress and psychosomatic stress reactions	Parental psychological and psychosomatic stress compared to general Dutch population. Mothers experience more negative emotions when asking and expressing emotions about the child's illness. Only slight relationship found between communication and coping styles
[82]	57 <i>index-cc</i> 57 couples	In and off treatment Mixed diagnoses Age: $\pm$ 4–19 years	How does being married affect the provision of social support functions	Mannheim Interview on Social Support	Determinants of overall and specific support networks largely couple specific. Confidants differ for mothers and fathers
[83]	85 <i>index-cc</i> 93 p-cc (mostly mothers)	Off treatment tsd: 3–15 years Mixed diagnoses	Concerns and needs of parents of long term survivors	Developed questionnaire about needs and concerns Ratings of support	Major concerns: child's ability to marry and have children, risk of relapse, and relationship with siblings. Need for ongoing support medical team and need for written material expressed

^a Studies using the same data set are described together

differ over time in the perceived adjustment and coping adequacy. For mothers it was found that coping adequacy decreased between 6 and 10 years after treatment. When the chemotherapy is terminated parents may experience increased feelings of anxiety [45]. Low scores on depression scales have also been found for parents of children with cancer in treatment [16, 58].

Other studies, which included children with cancer both in and off treatment, also found increased psycho-

logical stress in the parents with children in active treatment [28, 42]. Brown et al. [11] found that 34% of the mothers of children with cancer in various phases of their child's disease, were diagnosed with a psychiatric disorder. Women diagnosed with a psychiatric disorder had higher depression scores on the Beck Depression Inventory (BDI) than mothers who were not diagnosed with a psychiatric disorder. The scores of mothers both with and without a psychiatric disorder were in the nor-

mal range, however [11]. On the other hand, no differences were found between parents of children with cancer against normative data about psychological and psychosomatic stress by Van Veldhuizen and Last [81]. The majority of the children participating in their study were off treatment. A few investigators analysed within-group differences based on the treatment phase of the child. Brown et al. [10] found that mothers of children who were off treatment had significantly lower depression scores than mothers of newly diagnosed children, and mothers of children 1 year after diagnosis. Morrow et al. [57] also found that parents of children who were off treatment had the lowest scores on a measure investigating the psychological adjustment to the illness. Van Dongen-Melman et al. [80] reported that late psychological consequences did not differ for parents with children off treatment less than 2 years ago, between 2 and 5 years ago, and for parents of children off treatment more than 5 years ago. Lack of prediction of time since diagnosis has also been found by Grootenhuis and Last [23].

Nowadays more children with cancer are surviving their illness, and an increasing number of studies have focused on the emotional consequences of (long-term) survivors and their parents. A 5-year period without treatment can be considered as a criterion for surviving childhood cancer, although several investigators also consider children shorter off treatment as survivors. Based on the results of these studies, parents do not experience emotional disturbances compared to healthy controls or normative data [21, 30, 32, 40, 44, 73]. However, if illness related concerns are taken into account these parents seem to experience feelings of loneliness and uncertainty [22, 80], posttraumatic stress symptoms [63], and fear for relapses, worries about infertility, and uncertainties about the future are very common [20, 22, 34, 44, 53, 83].

Parents do also report positive responses if questioned about the impact of the illness. Positive responses of parents are about their good support systems, about new values or attitudes, re-evaluation of their goals, or a report that they value life more [17, 20, 22, 62]. Another issue sometimes mentioned is increased closeness in families [33] or a strengthened marital relationship [34, 52]. In this case family- and marital functioning are positively affected, whereas negative effects have been described as well.

Marital distress and satisfaction with the marital relationship

A child's illness can have a negative effect on the parents' marriage and result in the experience of marital distress. In general parents do experience marital distress, especially after the diagnosis [10, 71], but no high-

er divorce rates have been found [34, 41]. Two inventories have been used several times in studies with parents of children with cancer to assess marital problems, namely the Dyadic Adjustment Scale and the Locke-Wallace Marital Adjustment Scale. No differences were found from the normal populations in studies in which marital problems were investigated with these self-report measures [42, 44]. Barbarin et al. [5] reported that most couples experienced their marriages as reasonably satisfactory and their partners as supportive. A considerable number of studies found an increased incidence of marital distress [15, 16, 19, 41, 71] and impaired sexual relationships after diagnosis [28, 77], or preferences for marital counselling [62].

Family functioning

In most studies investigating parental and familial adjustment, family functioning has been investigated as an outcome variable. In some studies, however, family function has been considered as one of the predictors for parental adaptation to the child's illness [51]. They found for example, that lower family cohesiveness was predictive for maternal depression. In this review, however, family functioning is considered as an adaptation outcome. Two measures are commonly used to study family functioning, the FES (Family Environment Scale) and the FACES (Family Adaptability and Cohesion Scale).

The FES is composed of 10 dimensions, which are conceptually grouped into three underlying domains of family functioning: relationship, personal growth, and systems maintenance. The ten subscales contain: cohesion, expression, conflict, independence, organization, control, activity-recreational orientation, moral-religious emphasis, achievement orientation and intellectual/cultural orientation. Findings with the FES show that over time, family organization and control increase compared with the diagnostic period [10, 19]. Greenberg et al. [21] only found significant differences on the subscales intellectual/cultural orientation and activity-recreational orientation, compared with a healthy comparison group for parents of long-term survivors, whereas Carlson-Green et al. [12] did not find any differences from normative data. Only Cornman [15] found that scores of parents of children with cancer in treatment were significantly higher on every FES subscale than the reported norms.

The FACES is based upon the importance of cohesiveness and adaptability in family functioning. Four levels of cohesion (disengaged, separated, connected, and enmeshed) and four levels of adaptability (rigid, structural, flexible and chaotic) are distinguished. Cohesion and adaptability are combined to yield three types of families: balanced, mid-range and extreme.

The scales are useful in differentiating functional and dysfunctional families. Adaptability and cohesion in families of children with cancer appear to be consistent with norms [27, 30, 32, 51], although some patterns of less adaptability were found by Kazak and Meadows [30]. Horwitz and Kazak [27] found that more families of children with cancer obtained either very high or very low adaptability scores. Madan-Swain et al. [47] found that the mothers in cancer families designated themselves as more rigid and less flexible on the adaptability levels than the mothers of the non-diseased control subjects.

Other studies that investigated family adjustment found that family functioning was satisfactory [5, 9] and consistent over time [75]. Family problems later in time were also found [69, 70], however.

Coping resources and strategies

After a careful search of the literature on the use of coping scales in paediatric oncology, it appeared that three scales were used in more than one study. These are: The Coping Health Inventory for Parents (CHIP), the Ways of Coping Scale and its adapted version, the Coping Strategy Inventory (CSI), and the Social Support Questionnaire (SSQ). In several studies coping scales derived from interviews, or questions about the use of a possible coping strategy, were used. Various conceptualizations of coping strategies can be identified from the various scales: emotion- and problem-focused coping, positive-typed and negative-typed coping, regression-sensitization, or disengagement and engagement coping. Although the use of denial is often raised as a possible coping strategy, the use of denial is seldom investigated.

Communication

Communication is often mentioned in the literature as a coping strategy used by parents of children with cancer [6]. Communication can have different meanings. Apart from open communication about the illness with the child [26, 81], communication with important others about emotional experiences [44], and understanding of the medical situation through communication with other parents and the medical staff can also be distinguished. Communication with the medical staff is one of the three scales of the CHIP. Brown et al. [10] found that parents often relied on understanding the medical situation through communication with the medical staff, while Eiser et al. [18] found the contrary. They found that both mothers and fathers gave much lower ratings to the helpfulness of social support/information compared with the other three strategies measured with the CHIP.

Relationships with the medical staff are important for parents of children with cancer. This was shown by Eiser and Havermans [17], who found that parents of children with leukaemia and parents of children with cardiac conditions gave higher endorsement to items about the importance of medical care than did the parents of children with other conditions. Other researchers addressed the importance of the parent-staff relationship. The quality of the parent-staff relationship was best predicted by positive personal contact, whereas communication with the medical staff did not predict dimensions of satisfaction [3]. Barbarin and Chesler [4] also found that less well-educated and those parents using passive coping, reported better relationships with the medical staff. This could not be found by Wittrock et al. [84]. Shapiro and Shumaker [72] found that mothers had more open and more frequent communication with the sick child than fathers did. Communication and support are related to one another, because with communication parents can search for information or get support [13, 59].

Social support

Social support refers to the perceived availability of friends and family to help a person cope with the stress [61]. In several studies parents report that support from family and friends was very helpful to them [36, 39]. Morrow et al. [56] report that next to the spouse, the medical community and other parents in the mutual help group were the most helpful sources of support as perceived by the parents. No significant differences were found in the patterns of social support among parents with children in different stages of treatment. Larson et al. [42] found that both mothers of children with cancer and those of healthy controls were receiving more overall informational and emotional support than did fathers. Mothers appear to use social support more than fathers do [42]. Veiel et al. [82] published similar results. Wives appeared to have larger everyday kin networks and more frequent contact with relatives.

Search for meaning

In threatening situations people search for reasons for the occurrence of events. These kind of causal attributions are motivated by efforts to understand and make sense of events and thus to cope emotionally and gain some sense of control [7]. Bearison et al. [7] found that internal types of attribution, and especially self-blame were reported most often. Eiser et al. [18] also found self-blame to be a common attribution for mothers. Fathers were more likely than mothers to accept that there was no reason for the child's illness [18]. In the

study of McWhirter and Kirk [54] many families had ideas about why their child had leukaemia. The most common ideas concerned the influence of environmental factors. Concerns about environmental exposures and about family health history were the most prominent ideas about causality in the study of Ruccione et al. [68].

Other coping strategies distinguished

Several other findings about coping strategies are mentioned in the literature. Hardy et al. [26] found that parents of children with a life-threatening disease more often relied on wishful thinking, whereas Madan-Swain et al. [47] found that parents of children with cancer used withdrawal more often. Praying and religion have also been considered as coping strategies [2, 13]. Cayse [13] found that praying was most often used as a coping strategy by the fathers in their study. Other researchers have proposed coping strategies themselves, sometimes based on a model or derived from existing scales. For example Birenbaum [8] derived two new coping scales from the CHIP, *encapsulation* (normalization and controlling the meaning of the experience through cognitive functions or behaviours such as realistic appraisal, optimistic viewpoints) and *at risk* (vigilance to minimize threat by complying with treatment and protecting the child). With these defined coping strategies, particular behaviours of the parents of children with cancer, such as compliance with treatment, can be better understood. Petermann and Bode [64] derived different coping styles based on interview material.

Some of the studies report about coping in terms of emotion or problem-focused coping strategies. Barbarin and Chesler [2] distinguished three problem-focused coping strategies (information seeking, problem solving and help seeking) and five emotion-focused coping strategies (maintaining emotional balance, relying on religion, being optimistic, denial and accepting). In their study about marital functioning, they found that wives more often used religion and information seeking, whereas husbands more often used denial [5]. No correlations were found between the use of the eight coping strategies [4]. Baskin et al. [6], however, found a positive correlation between the use of problem- and emotion-focused coping. Larson et al. [42] found that both mothers of children with cancer and mothers of healthy children, used more engaged coping, that is more active, oriented, coping, than fathers did. Grootenhuis et al. [24] used the model of Rothbaum et al. [67], in which primary and secondary control are outlined in strategies of predictive, vicarious, illusory and interpretative control, to describe parental efforts to cope with childhood cancer. Secondary control strategies are comparable to emotion-focused coping strategies.

Manifestations of secondary interpretative, illusory, predictive and vicarious control strategies were operationalized and assessed. Mothers appeared to rely more on interpretative and illusory control than fathers do, while parents of children in remission relied more on predictive (having positive expectations) and vicarious control (attributing power to the doctor) than parents of children with a relapse. Parents with a lower educational level tended to rely more on all control strategies with the exception of interpretative control.

Hoping for a miracle, wishful thinking and attributing special characteristics to the child as a proof that the child is one of the survivors are illustrations of illusory control in its secondary form and was investigated as a coping strategy. By attributing positive characteristics to their child, parents create an image of the child as being vital, hence fostering the illusion that fate will be kind to them. The parents need to believe that the child is strong, because if the child can handle the situation, it increases their confidence that the child will survive. We found support for parents' attribution of positive characteristics to their children with cancer. We discovered that parents of children with cancer attributed more cheerful behaviour to their children than parents of children with asthma and healthy children do [25].

Factors influencing adjustment

Coping resources and strategies

Social support seems to have a 'buffering' effect on the impact of the stress especially after diagnosis and during treatment [50, 55, 58]. For parents whose child was out of treatment, only support from relatives appeared to be helpful, and parents whose child had died did not benefit from any source of social support [57]. Sex differences are visible as well. Social support proved to be inversely related to depression and anxiety for both the parents, but social support appears to be of greater importance for mothers than for fathers [73].

A positive association for both parents has been found between open and frequent disease-specific communication and enhanced psychological and physical well-being [34, 72]. Spousal communication also seems positively correlated with marital satisfaction [72], although Barbarin and Chesler [2] found that being optimistic was the only coping strategy significantly correlated with marital quality. Dahlquist et al. [16] found that marital distress was predicted by a combination of general emotional distress, the discrepancy between the couple's state anxiety levels and the use of sensitizing coping strategies.

Other coping strategies that seem to be related to better adjustment are external types of attributions and

acceptance of the physicians' advice that the cause was unknown [7], and higher mastery [61]. Blotcky et al. [9] found that parental coping behaviours of maintaining self-stability and understanding their children's medical condition measured with the CHIP, were related to less distress. Petermann and Bode [64] identified five coping styles and found that if families see the disease as a challenge, families are more stress-resistant and stable. Whenever parents continue to be hopeful this protects them from negative emotions. The protection of having a positive outlook or being optimistic has been described [2, 34, 60] and confirmed as one of the major predictors of positive adjustment [23].

A negative correlation, reflecting maladjustment and the use of particular coping strategies has also been found. Increased depression and anxiety were correlated with disengaged coping styles [84] and emotion-focused coping [6]. In some studies no relations between coping strategies and adjustment are reported. Barbarin and Chesler [2] state that parents report high level of stress and say that they cope well, but no correlations were found between coping strategies and adjustment. Baskin et al. [6] found that problem-focused coping and communication were not related to adjustment.

Characteristics of the children

No effect from sort of diagnosis and treatment on emotional outcome of parents have been found [6, 16, 80]. The perceived illness severity by fathers also was not related to negative emotions [13]. The number of hospitalizations however, appeared to be predictive for decreased marital quality [4] and maternal depression [58]. The child's functional impairment proved to be related to maternal depression [51] and to increased problems in parents [80]. A lesser survival perspective, that is having a child with a relapse or second malignancy, was related to more emotional problems in both mothers and fathers [22]. Stuber et al. [76] found a positive correlation between maternal posttraumatic stress symptoms and duration of treatment. Time of assessment proves to be an important predictor for parental distress. Most emotional problems are measured after diagnosis of the child's illness, and if the child is in treatment. These findings have been described above in the paragraph about psychological distress.

Other child-related variables apart from the illness that may influence parental adjustment, are the age or the emotional reactions of the children themselves. A relation between the age of the children and adjustment was found by Kupst et al. [37]. Families with older children tended to be coping better than those with younger children 1 year after diagnosis. This was not found by Leventhal-Belfer et al. [44], but they found

that mothers of boys viewed their son's cancer history as having a greater impact on them. That parents of male patients reported higher levels of depression was also found by Manne et al. [51]. Mulhern et al. [58] found that the mother's self-report of depressive symptoms was predicted by low perceived social support, and this was associated with higher levels of child depression. Difficulties in adjustment of the children or the child's behaviour problems also seemed to be a predictor for adjustment problems of the mothers [11, 40, 51]. In one study only evidence was found for uncertainty of fathers in relation to the depressive symptoms of the children [23].

Characteristics of the parents

With regard to age and socio-economic status (SES) of the parents, especially SES seems to be of importance in the adjustment of parents of children with cancer. Risk of reporting problems by parents of children with cancer with a low SES, or lower income, has been found in several studies [6, 34, 73, 80]. Mothers with lower SES reported higher degrees of emotion-focused coping, and this coping style was associated with increased maladjustment [6]. Hardy et al. [26] found that parents with lower SES level had more self-criticism than did the other parents in their study. Morrow et al. [57] are one of the only research groups who report that younger parents (younger than 30 years) had significant greater psychosocial adjustment difficulties. Being married is another factor that may influence parental adjustment. Speechley and Noh [73] found that married subjects tended to have moderately lower levels of depression and anxiety than those who were currently not married. More specifically, it was found that being married was more protective for fathers. Families who changed their family planning as a consequences of childhood cancer in the family experienced more loss of control and negative feelings than families who were not affected by family planning [79].

Of the parental variables, gender has received most attention, although in only two studies have sex differences been the major issue [42, 72], and only a few studies systematically analysed and reported sex differences. Fathers reactions differ in several ways. Of fathers increased drinking and avoiding discussion of the subject is described [60]. There is an increasing evidence of differences in levels of depression and anxiety for mothers and fathers [16, 22, 28, 42, 49, 73] although these differences do not always reach significance. These differences, however, are present in the general population as well [42]. The reasons for the differences could be caused by fathers' tendencies to deny, or failure to report distress, and do not necessarily indicate that fathers experience less distress.

Life events and concurrent stressors

Life events can be defined as dramatic events evolving from social and interpersonal transactions. While dealing with childhood cancer in the family, parents of children with cancer will be confronted with other life events, such as changes in the health or death of other close relations. In one of the first major studies investigating concurrent stresses in the families of leukaemic children [29], it was found that the majority of the families were also confronted with one or more other problems. These other problems could be categorized as: major complications related to the child's illness, death of another befriended child with leukaemia or other significant person, concurrent illness in other family members, occupational changes, and financial problems. Financial problems have an enormous impact on families, and are experienced, for example, by families living at long distances from the hospital [1]. Overholser and Fritz [61] who correlated financial burden in a family with cancer against several measures of psychosocial functioning in the family, found that financial burden was related to setbacks in the mother's work role. More mothers suffered career setbacks than fathers did. Lack of additional stresses has repeatedly been found to be associated with better adjustment by Kupst et al. [38, 39].

Thoma et al. [77] found that parents of children with cancer experienced more stressful life events than did parents with physically healthy children. Brown et al. [10] found that familial stressors are especially experienced by parents of newly diagnosed children. A similar finding was reported by Cornman [15]. She found that both mothers and fathers reported an increase in current life stresses, which would indicate they were at moderate to major risk for health changes within the following 2 years. Increased risk of reporting problems, as a result of a chronic disease in a family member other than the child surviving cancer, and concurrent stresses, was also found by Van Dongen-Melman et al. [80].

Conclusion

Although adjustment and coping have been studied extensively, the findings are often conflicting. These inconsistent findings can be attributed to several underlying problems.

Inclusion of the children

As becomes clear from the research overview, the criteria for inclusion of children with cancer are often heterogeneous. Children are included at different ages, with

different diagnoses (sometimes only children with leukaemias, in other studies all diagnoses) and stages of treatment (in and off treatment) which makes comparison of the findings difficult. Findings of several studies are based on small populations of children with cancer. Even if studies seem to consider a comparable population, for example long-term survivors, the definition of a long-term survivor appears to be different. Inclusion of children in these studies vary from children who ended treatment 7 months to decades before. Illness-related variables, such as diagnoses, number of hospitalizations or physical impairments, which may influence adjustment and coping have been studied, but these studies are sparse. Little attention is paid to the particular consequences for parents of children with a relapse. With the increasing number of children who survive their illness, the number of children surviving a relapse also increased, but this increase is not reflected in the population characteristics. Only a few studies mention the number of children with relapses included in their population.

Inclusion of the parents

Another difficulty in the study of coping and adjustment, lies in the inclusion of mothers and fathers. There is an increasing evidence of differences in levels of experience or reporting of depression and anxiety for mothers and fathers. However, many studies have assessed coping and psychological consequences for parents as a couple or most frequently just for mothers. The problems faced by mothers and fathers vary because they are likely to encounter different experiences in the course of the illness. For example, mothers have a more intense involvement with the sick child and fathers have more concerns about competing obligations between work and family [31]. These differences may contribute to the different levels of distress. On the other hand, men and women differ in expressing and reporting of emotions. Although less often addressed, difficulties also exist in the statistical analyses with inclusions of mothers and fathers, because dependence exists between the data.

Assessment

Identifying emotional problems for parents of children with cancer appears to be dependent on the time of assessment and the instruments used. Psychological problems of parents were formerly assessed from descriptive interview material, but standardized measures are now used. Several of these standardized instruments assess psychopathology, such as depression and anxiety, and a variety of scales are used. Although it is often sug-

gested that serious psychological problems are not evident for parents of children with cancer, this seems true only to some extent. If results of studies with children in equivalent treatment status are compared (that is in and off treatment) some obvious research findings come into view. After diagnosis, parents do experience increased emotional distress, which is often higher than in parents of healthy controls. Increased psychological distress is still evident after 1 year. Although mean scores are higher than the normal ranges, they are indeed not as high as would be expected considering the stressful circumstances. This can partly be attributed to the inappropriateness of instruments to measure the impact of childhood cancer [80]. Parents of children with cancer are coping with an abnormal situation and therefore existing instruments may fail to assess their specific problems. Differences in the reported feelings of uncertainty and helplessness only became apparent between fathers of children with cancer in remission and fathers of children with a relapse when an illness-related questionnaire was used, and not with anxiety and depression questionnaires [22]. Decline of emotional problems is evident if parents of children with cancer who are no longer in treatment are included. The only group of parents for whom invariably no serious psychological problems are found on general questionnaires compared with healthy controls, are those of children who are off treatment or who are long-term survivors.

Definitions of coping and adjustment

Although coping is often investigated, this is often only based on scales derived from interview questions. Furthermore, similar to the measurement of adjustment, many different coping scales are administered. Comparisons between findings of studies with different coping scales is more difficult, because the scales use different conceptualizations and often combine different coping strategies. Another problem is that of the definition of coping and adjustment. In several studies adjustment and coping are used interchangeably, or coping scales are confounded with items about adjustment. Interpretations of 'good coping' which emerged are, for example, positive-type coping strategies such as humour, seeking support or mastering [7] or high scores on scale that should be considered as measuring adjustment [36, 40]. Although Kupst and her colleagues did a commendable job in studying coping in parents of children with cancer over more than 10 years, their assessment of coping and adjustment lead to troublesome interpretations. The difficulties are partly due to the ratings of coping by staff members and the lack of conveniently available coping scales when they started their project. Different definitions of adjustment may also

lead to conflicting recommendations in the literature. Although several research groups recommend psychosocial care programmes, almost no empirical studies of supportive programmes aimed at effective coping or decreasing emotional distress are available. Only Kupst et al. [37] investigated whether a psychosocial intervention could affect coping with the disease, but no effects were found.

Implications for future research

The problems that have been summarized above have implications for future research. The majority of the studies presented in this review have included parents of fewer than 50 children with cancer. To include a substantial sample of parents of children with cancer it is necessary to conduct multi-centre studies. With the inclusion of a larger population more attention can also be given to within-group differences. Other limitations of the presented studies that should be taken into account are the inclusion of a predominantly white population, and the cross-sectional design of many studies. Because in many studies the majority of the participants are white, the results of these studies cannot necessarily be generalized to parents of children with cancer from other ethnic or cultural communities. A cross-sectional design restricts conclusions about how emotional consequences for parents of children with cancer change over time. These limitations ask for prospective and longitudinal studies, which also include families with other ethnic or cultural backgrounds.

We conclude that parents of children with cancer are coping with an abnormal situation and that existing instruments may therefore fail to assess their specific problems. Hence, it seems essential to investigate parental adjustment to childhood cancer not only with standardized instruments, but also with illness related questionnaires. Whenever researchers are interested in measuring coping and adjustment, it is of major importance to use coping scales that include items with no relation to outcome. This is of importance because if a coping construct is to be used to predict outcome, separation of coping efforts from their outcome is necessary.

Finally, we would like to draw attention to the lack of intervention studies in paediatric oncology. Since there are hardly any empirical studies available about supportive programmes aimed at effective coping or decreasing emotional distress, the implementation and evaluation of intervention programmes could well be an important research area in the future.

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