Minor Children of Palliative Patients: A Systematic Review of Psychosocial Family Interventions

Franziska Kühne, M.Sc.,¹ Thomas Krattenmacher, M.Sc.,¹ Volker Beierlein, M.Sc.,²
Johann Christian Grimm,¹ Corinna Bergelt, Ph.D.,² Georg Romer, M.D.,¹ and Birgit Möller, Ph.D.¹

Abstract

Although the whole family is affected by a parent's palliative disease, palliative care research does not yet routinely consider patients' minor children. Children's and adolescents' psychosocial functioning may be impaired during prolonged parental disease with poor prognosis. Therefore, more and more health care providers are establishing clinical initiatives for families of palliative patients with minor children. However, the number of these family interventions, as well as their theoretical and empirical backgrounds and evidence base, has yet to be determined. The purpose of this study was to systematically review structured and published interventions for this target group, as well as empirical studies on these interventions. The evidence base and impact of interventions on families were considered. Literature published between 1980 and present focusing on psychosocial family-, child- or parent-centered interventions during palliative care was retrieved from PsycINFO®, Embase, MEDLINE®, CINAHL®, and PSYINDEX databases. Five interventions met the inclusion criteria. Programs focused on different populations, had diverse empirical and theoretical backgrounds and features, and were evaluated by studies of varying methodological quality. This systematic review illustrates the lack of well designed and elaborated intervention concepts and evaluation studies in this field, highlighting the necessity of conceptual and methodological rigor to inform clinical practice on a sustainable basis in the future.

Introduction

SEVERE SOMATIC DISEASE OF A PARENT influences the family as a whole¹—not only spouses/partners,² but also minor children.³ According to an extrapolation of data of the U.S. National Center for Health Statistics, in Western societies, 5%–15% of minor children may have a parent suffering from a severe disease.⁴ The point prevalence of severe somatic disease (i.e., life-threatening and/or severely influencing quality of life) in parents was 4.1% in a German representative study of N = 1,950 families with at least one child aged 4 to 18 years.⁵ The most common diagnoses in this sample were cancer (28.8%), cardiovascular (13.7%), and diseases of the intestinal tract (12.3%). In Western societies about 4% of children experience the death of a parent before they are 18 years old.⁶ Children of chronically ill parents show particularly more internalizing symptoms, i.e., anxious/depressive, social, and somatic problems, than children whose parents are healthy.^{5,7} Nevertheless, in specialist clinical palliative care, perhaps due to limited resources, health professionals tend to focus on primary caregivers and not on the entire family.⁸

Anticipated parental death is a crisis for every family member.⁹ Both non-ill¹⁰ and seriously ill parents¹¹ experience confusion concerning their parental competence. Child-centered parenting by healthy parents can decrease with lengthy disease of the partner.¹² In turn, both influence the adaptation of children to parental loss.^{12,13} Poorer patient prognosis, more intensive treatment, worse functional impairment, reduced mental health, and perception of parental illness as more serious are associated with negative self-reported psychosocial functioning of children of physically ill parents.^{14–17}

Children have less cognitive capacity and coping strategies than adults to deal with such a crisis.¹⁸ The predictability and stability of everyday life can disappear. Due to psychosocial stress, healthy spouses may have difficulty adequately meeting their children's needs, which may in turn exacerbate their children's situation.¹² Children fear the ill parent's death and worry about the healthy parent's well-being.¹⁹ They are afraid of the unknown as well as of not being able to effectively cope with the situation.²⁰ The association between disease severity and child functioning warrants further exploration,¹⁴ and as parental palliative disease seems to play a

¹Department of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, ²Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany.

Accepted April 29, 2012.

major role in child adjustment, reviews should account for this stage of the illness.⁷ Although of importance, other reviews explicitly exclude parental palliative disease.^{3,16}

Against this background, our review aims (1) to identify structured psychosocial interventions published and evaluated for families of palliative patients with minor children, (2) to analyze the evidence base of those interventions, and (3) to evaluate the impact of the interventions on families (if applicable).

Methods

Search strategy

When developing our concept of child-oriented medical family counseling towards a manualized interventional concept including special modules for families in palliative care in the context of a German multisite research project,²¹ this review was part of a literature search of related international interventions.

A systematic review approach^{22–24} was adapted to observational studies and descriptions of intervention concepts. English and German publications since 1980 were identified searching the databases PsycINFO, PSYINDEX, Embase, MEDLINE, and CINAHL in March 2011. The first search included the keywords (child* OR parent* OR family OR spous*) AND (terminal* OR palliative) AND (intervention* OR counsel* OR therap*). Because couple interventions were thought to possibly contain child-related issues as well, this keyword was further integrated. To cover interventions beginning in palliative care and lasting throughout bereavement, the subsequent search added the keywords (parent* death OR death of a parent OR dying parent OR bereaved child* OR child bereav*).

Hand searches were conducted in April and May 2011 through palliative care and psychooncology journals, reference lists of relevant books, included articles, and relevant review articles. An online search of relevant websites was carried out to identify evaluated intervention concepts. The full search strategy is available upon request from the first author.

Inclusion criteria and assessment of study quality

Articles were included based on these criteria:

Population: Parents with palliative-stage disease; Minor children (<18 years)

Intervention: Psychosocial interventions (e.g., counseling, psychotherapy, support groups); family, child, and parent-centered interventions; interventions delivered in any setting and by any method; content and/or time structured and formally described interventions

Outcome: Any psychosocial outcome (e.g., symptomatology, quality of life)

Studies: Evaluation studies of any quantitative or qualitative study design (with adjacent quality assessment); published since 1980; published in peer-reviewed journal or edited book; published in English (representing international research standards) or German language (author's mother tongue)

In accordance with our study questions, publications exclusively on child bereavement were excluded. Dissertation abstracts, case studies, anecdotal reports, and comments were excluded as well.

After the first elimination of studies based on title and abstract (see Fig. 1), the raters included/excluded and assessed publications independently, based on the full texts and according to a checklist requiring a decision based on each inclusion criterion (yes/no). The two trained raters were the first author (FK) and a master's psychology student with advanced methodological skills (JCG). If there were divergent assessments, consensus was achieved by discussing inclusion criteria.

According to a systematic review of tools for quality assessment of observational studies,²⁵ critical appraisal checklists provided by Cardiff University²⁶ were utilized. They were chosen because different study types are evaluated according to one common and comparable procedure. Depending on study design, raters assess specific aspects of study aims/focus, method, population, and results; they provide concluding ratings according to predefined questions. In our review, both raters independently evaluated whether or not there was evidence for the respective questions or whether there was unclear evidence. Afterwards, discordant assessments were discussed and a concluding decision was made.

Study quality will be reported, but due to small sample sizes of heterogeneous studies, no minimum-quality criterion was set for inclusion. Two independent raters assessed study quality, then discussed their findings. Interrater reliability reached a Kappa coefficient of $K = .75$, which can be categorized as good.²⁷ Data extraction and report are based on prominent publications in the field.^{16,28,29}

Results

While in total, 5 interventions described in 24 publications fulfilled the inclusion criteria and were included in this review, many interventions identified during the literature search did not fulfill the inclusion criteria. Exclusions involved not being structured by time and/or content,^{30–47} not being focused on palliative care or exclusively focused on bereavement,^{48–71} focused on early-stage cancer^{72–73} or recurrent breast cancer,⁷⁴ not including minor children/parents,^{75–78} or not being evaluated in an empirical study^{79–83} (listed regarding first inclusion criterion that did not fit). For reasons and corresponding numbers of exclusions dependent on the stage of the process, see Figure 1.

Psychosocial family interventions

Table 1 gives an overview of intervention concepts including brief characterizations. Interventions were developed in the United States,^{84,85} mainly in Australia,⁸⁶ or predominantly in Europe.⁸⁷ During a conjoint European project (COSIP), three independent modifications of an intervention were developed in collaboration between partner centers.^{88–90}

Interventions addressed adolescents⁸⁹ or children and adolescents.^{84,87–90} They focused on parental physical illness,⁸⁸ cancer,^{89,90} terminal cancer,^{84,97} terminal illness,⁸⁶ or HIV/AIDS.⁹¹ Although one program was predominantly developed for adult patients and their families, we included it because one of its topics involves the "needs of younger children."⁹¹ The COSIP interventions were not exclusively designed for families in palliative care.^{88–90} Yet as in most other interventions,^{84,86,91} they include anticipatory/adaptive grief as one intervention goal. This and further intervention

FIG. 1. Flow chart of the literature search procedure.

aims (parenting competence, active coping, communication) capture the concerns of families mentioned above. All authors indicated that developmental issues are a crucial determinant of counseling.

Theoretical and empirical backgrounds were diverse, and intervention development more or less explicated (see Table 1 and Fig. 2). Important indications were illness severity,^{84,87} family functioning,⁸⁶ or disease disclosure/parental death in the course of the intervention.⁹¹ The most frequent recurrent intervention aims were parenting competence,⁸⁶⁻⁹¹ anticipatory/adaptive grief,^{84,86,88-91} active coping,⁸⁶⁻⁹¹ and communication.^{84,88-90} Intervention goals are also related to important risk and protective factors of psychosocial adaptation of minor children in cancer families, such as familial communication and functioning, parental psychological functioning, and coping strategies.^{14-16, 93, 94}

Programs were described as needs oriented,⁸⁶⁻⁹¹ preventive,^{84,86-88} or brief and focused^{84,86,88-90} by their authors. Regarding number of sessions, the length of interventions varied between short⁸⁶⁻⁹⁰ and long.^{84,91} In all cases, individual and group sessions were offered, except in one case⁸⁶ of exclusively family sessions. All interventions were face-to-face,

one provided regular telephone contacts,⁸⁴ and four were also conducted in the family home.^{84,86,89,90} One intervention did not include the ill parent on a regular basis.⁸⁴

In three interventions, an unpublished manual,⁸⁷ verbal descriptions,⁸⁴ or a published practical guide⁸⁸ describing the intervention were mentioned. If the authors had published a treatment manual,^{86,91} intervention techniques and tailoring to the treatment unit were elaborated, and both training and supervision were mandatory. Otherwise, authors listed training⁸⁷ or regular supervision.^{84,88,89} Therapists' backgrounds were mainly in social work, family therapy, and psychology or psychiatry (see Fig. 2).

Related evaluation studies

Table 2 summarizes characteristics of evaluation studies and their main results. Studies were mainly quantitative and cross-sectional (see Fig. 3). Three studies^{87,89,95} did not incorporate a control group, three compared the intervention with standard care/absence of counseling,^{90,96,97} and one with telephone monitoring.⁹⁸ Sampling was either convenience^{87,89,90,95} or randomized.⁹⁶⁻⁹⁸ Recruitment took from six

TABLE 1. INTERVENTIONS FOR FAMILIES OF PALLIATIVE PATIENTS WITH MINOR CHILDREN

Name of intervention	Authors Countries	Theoretical and empirical background	Short characterization and aims	1. parental illness 2. child and/or family characteristics 3. course 4. delivery 5. therapists, training, supervision
Children of somatically ill parents (COSIP)	Romer & Haagen 2007 ⁸⁸ Romer et al. 2007 ⁹² Germany	<p><i>Theoretical</i></p> <ul style="list-style-type: none"> developmental psychotraumatology attachment theory psychoanalytic family therapy <p><i>Empirical</i></p> <ul style="list-style-type: none"> developmental knowledge on how children cope with critical events published intervention concepts, clinical experience 	<p><i>Short characterisation by the authors</i></p> <ul style="list-style-type: none"> need-oriented, variable settings, low-threshold, preventive <p><i>Aims</i></p> <ul style="list-style-type: none"> child: cognitive comprehension, individual needs and feelings, active coping, ambivalent feelings, anticipatory grief (if applicable) parent: enhance self-perceived competence in parenting, increase healthy parent's emotional availability family: open communication, prevent dysfunctional parentification, divergent needs 	<ol style="list-style-type: none"> somatically ill parents at any treatment phase, continuing after parental death minor children (≥ 3 years old) 3–8 sessions, for 3–6 months, 50 min.; diagnostic phase (1 parents', 1 child session); intervention phase (2–6 sessions, optional family sessions) face-to-face, individual, parent or family sessions three psychodynamic child psychotherapists, regular supervisions and case reviews
	Schmitt et al. 2007 ⁸⁹ Finland	<p><i>Background</i></p> <ul style="list-style-type: none"> review of current literature and clinical experience 	<p><i>Short characterisation by the authors</i></p> <ul style="list-style-type: none"> child-centered, family approach, parent perspective, need-oriented <p><i>Aims</i></p> <ul style="list-style-type: none"> support parenthood and parenting (information, coping) raise parents' awareness of emotions and needs of children, facilitation of communication: reduction of feelings of guilt, promotion of hope, assessment of further support needs if terminal prognosis: accompany loss and grief process 	<ol style="list-style-type: none"> cancer patients minor children 5–6 sessions: 1–2 family, 1–2 couple, 1 sibling session, 1 session for each child, 1 follow-up session, 50–60 min, families choose how (family or couple session) and when to start face-to-face, each family member individually or in groups, in counselling rooms or bedside two experienced family therapists with child expertise, clinical supervision twice a month
	Thastum et al. 2006 ⁹⁰ Denmark	<ul style="list-style-type: none"> not mentioned 	<p><i>Short characterisation by the authors</i></p> <ul style="list-style-type: none"> focused, short-term, need-oriented <p><i>Aims</i></p> <ul style="list-style-type: none"> support family in taking care of children's needs parents (self-perceived competence in parenting, parental emotional availability, age-appropriate communication support network, problems) children (cognitive comprehension, individual needs and feelings, active coping, resources, possibly initiate anticipatory grief) 	<ol style="list-style-type: none"> somatically ill parents children between 8–15 yrs max. 5–6 sessions in variable settings, first 1 parent session (discussion of setting and course), family sessions afterwards, mean duration: 5 months mostly in family homes, face-to-face, parent and family sessions, children group counselling one counsellor trained in systemic family therapy and 1 of 4 counsellors being psychotherapists conducted counselling as a pair; counselling by Danish Cancer Association

(continued)

TABLE 1. (CONTINUED)

Name of intervention	Authors Countries	Theoretical and empirical background	Short characterization and aims	1. parental illness 2. child and/or family characteristics 3. course 4. delivery 5. therapists, training, supervision
Family Focused Grief Therapy (FFGT)	Kissane & Lichtenthal 2008 ¹⁰⁹ Kissane & Bloch 2002 ⁸⁶ Kissane 2000 ¹¹⁰ Kissane et al. 1998 ¹¹¹ Australia, USA	<i>Theoretical</i> <ul style="list-style-type: none"> Attachment theory dual-process model (Stroebe et al., 2001) Cognitive processing theory Group adaptation processes <i>Empirical</i> <ul style="list-style-type: none"> distress in palliative disease targeted interventions should focus on high-risk families (Harding & Higginson, 2003) classification of families via Family Relationships Index 	<i>Short characterisation by the authors</i> <ul style="list-style-type: none"> preventive, family-centered, brief, time-limited, focused, need-oriented delivered to high-risk families during palliative care and bereavement <i>Aims</i> <ul style="list-style-type: none"> improve family functioning (cohesion, communication, conflict resolution) promote adaptive grief (dependent on communication) support family strengths and adaptive coping 	1. terminal illness 2. children > 12 yrs, screening of families via FRI for risk of morbid bereavement: <9/12 FRI, or <4 cohesiveness (of one family member) 3. 3–4 sessions before, 3–6 sessions after death 4. 90 minutes, for 6–18 months, 4. family as a group, group therapy, face-to-face, also in family home 5. from social work, psychology, psychiatry; trained in family therapy, manual workshops, weekly peer supervision
Family Talks in Cancer Care	Bugge et al. 2009 ⁹ Bugge et al. 2008 ⁸⁷ Norway, Australia	<i>Theoretical</i> <ul style="list-style-type: none"> Family Resilience Theory (Allison et al., 2003): increase open communication, predictability, confirmation, association within family coping theory for children (Libo & Griffith, 1996): enhance experience of belonging and competence intervention for families with parental mental disease (Beardslee et al., 2003) common reactions and coping of children, adolescents, parents, families <i>Empirical</i> <ul style="list-style-type: none"> gaps in service provision 	<i>Short characterisation by the authors</i> <ul style="list-style-type: none"> child-centered, preventive, need-oriented <i>Aims</i> <ul style="list-style-type: none"> prevent psychosocial problems support communication according to child's developmental stage, coping, parenting and family resilience support family by increasing open communication, parents' understanding and support strategies for their children reframe the crisis by identifying and using family strengths seek social support increase positive interactions and mutual understanding 	1. incurable cancer 2. children 5–18 years and their families 3. five meetings over 5–6 weeks (1. family, 2. parents, 3. children, 4./5. family meeting), 4 meetings before, 1 after death 4. group and individually, family counselling, face-to-face 5. nurses, sociologist, art therapist; 8-day training course

(continued)

TABLE 1. (CONTINUED)

Name of intervention	Authors Countries	Theoretical and empirical background	Short characterization and aims	1. parental illness 2. child and/or family characteristics 3. course 4. delivery 5. therapists, training, supervision
Parental Guidance Program	Christ et al. 2005 ⁹⁸ Christ et al. 1991 ¹⁰² Christ & Siegel 1991 ⁸⁴ USA	<p><i>Theoretical</i></p> <ul style="list-style-type: none"> literature on child bereavement quality of child care after parental loss and child's relationship with surviving parent important for bereavement <p><i>Empirical</i></p> <ul style="list-style-type: none"> clinical experience, review of literature and pilot studies 	<p><i>Short characterisation by the authors</i></p> <ul style="list-style-type: none"> psycho-educational, time-limited, preventive parent guidance model: indirectly targeting children through interventions with healthy parent <p><i>Aims</i></p> <ul style="list-style-type: none"> facilitate children's mourning and adjustment to parental loss by enhancing surviving parent to sustain parental competence in child support and care, to support children to express thoughts and feelings (communication), and to maintain consistency and stability 	<ol style="list-style-type: none"> 1. parents with terminal cancer 2. children 7–17 years; healthy parent; optionally with patient 3. six months before and 6 months after parental death, 12 or more sessions, 60–90 minutes, assessment phase (2–3 meetings, feedback) and intervention phase (≥4 meetings before, 5 meetings after death) 4. mostly in patient's home, individually (well parent, children) and together, face-to-face; telephone contacts as needed bi-monthly to monthly until 14 months after parental death 5. six social workers with ≥ 5 yrs post-masters experience in medical or mental health; weekly individual and group supervision
Teens and Adults Learning to Communicate (TALC)	Rotheram-Borus et al. 1997 ⁹¹ http://chipts.ch.ucla.edu/ ⁸⁵ USA	<p><i>Theoretical</i></p> <ul style="list-style-type: none"> based on cognitive-behavioural principles, skills training model, and social learning theory targeted at universal stressors (terminal illness) and AIDS-specific factors literature review on parental adjustment to chronic and terminal illness other interventions (e.g. parental death, HIV interventions) <p><i>Empirical</i></p> <ul style="list-style-type: none"> studies on bereavement of surviving partners of gay men, research on children whose parents have a chronic or terminal illness, on AIDS-related stressors focus groups with parents with AIDS and bereaved youths, pilot-test of sessions (Rotheram-Borus et al., 1991) clinical experience 	<p><i>Short characterisation by the authors</i></p> <ul style="list-style-type: none"> need-oriented, intensive, cognitive-behavioural <p><i>Aims</i></p> <ul style="list-style-type: none"> targets of intervention: meaning, knowledge, attitudes, skills primary goal: to reduce long-term negative social, behavioural, mental health outcomes associated with parental death for adolescents by increasing coping skills parent skills: maintain emotional self-control with children, provide skills to children to avoid substance use and HIV, disclosure of illness, make custody arrangements adolescent skills: dealing with care-taking demands, maintain school performance and peer relationships, healthy bereavement 	<ol style="list-style-type: none"> 1. parents with HIV / AIDS 2. adolescents ≥ 12 yrs; low socio-economic status 3. module 1: 8 sessions, module 2: 16 sessions, module 3: 8 sessions 4. group format, individually (ill parents, adolescents, guardians) and together 5. social workers and graduate students in clinical psychology; 5-day training, ongoing supervision

FIG. 2. Features of intervention concepts (multiple answers).

months⁹⁵ to five years,^{96,98} and participation varied from 44%–57%^{87,95,96,98} to 72%–89%.^{89,90,97} There were studies with smaller,^{87,90,95} medium sized,^{89,98} and larger samples.^{96,97}

Two research projects investigated therapist fidelity.^{97,99} Participants versus nonparticipants or completers versus noncompleters were compared by three research groups.^{89,90,100} Reasons for nonparticipation were family- or disease-related burden or refusal of individual family members.⁸⁹ Parents in the counseling group were older, more often single,⁹² and reported more emotional distress.⁹⁰

Study quality was diverse. Independent of design, and referring to the critical appraisal checklists,²⁶ there were four studies of higher^{89,90,96,97} and three of lower^{87,95,98} methodological quality.

Studies considered contentment, experiences with, or implementation of the intervention more often than psychosocial outcomes (see Fig. 3). Children mentioned fear of parental death and an inability to talk to their parents about their concerns.⁸⁷ Adolescents especially experienced communication with healthy fathers as problematic.⁹⁸ When families participated in a program supporting parenting, children perceived improved parental competence and communication.⁹⁸

Altogether, participating families indicated that they were satisfied with counseling.^{90,95,97,98} In one study,⁹⁵ therapists were more critical than family members, whereas in another study⁹¹ there were no differences between therapists' and family members' ratings. In a further study, medical staff gave a more cautious evaluation.⁸⁹

In one study, mothers reported higher levels of depressiveness⁹⁰ at baseline. In the pre-post counseling comparison, parent- and child-reported depressiveness decreased.⁹⁰ Another study⁹⁶ highlighted that relationships with children were worse in dysfunctional families with parents with higher depressiveness scores. Female and older adolescents of HIV/AIDS patients reported more emotional distress.⁹⁷ Parental emotional distress predicted emotional distress in adolescents, and, if the mother was ill, adolescents reported more emotional distress and risky sexual behavior.⁹⁷ Parental physical health predicted adolescent problem behavior and parental death was associated with more emotional distress and adolescent problem behavior.⁹⁷

According to a one-group pre-post measurement, parent-reported family functioning improved after counseling.⁹⁰ In family-focused grief therapy (FFGT), families had different benefits from therapy.^{96,101} Precategorized "sullen" and "intermediate" families tended to benefit more from FFGT, whereas members of "hostile" families benefited more from individual psychotherapy. Furthermore, the most distressed family members improved significantly. Correspondingly, Christ and colleagues¹⁰² proposed a categorization of high-risk, vulnerable, and resilient families based on their clinical experience.

In counseling for parents with AIDS/HIV and their adolescent children,^{103,97} although both groups profited in various domains, positive effects seemed to last for the first two years, primarily for the program's duration. At six years¹⁰⁴ there were still positive effects in the intervention group, although only evident in secondary outcomes.

Discussion

Few interventions with various backgrounds

There is a small number of structured, published, and evaluated interventions for families of palliative patients with minor children. Their theoretical and empirical background varies, as well as the comprehensibility of their design. Furthermore, in the field of interventions for children of cancer patients, programs are seldom developed according to evidence-based or theory-driven frameworks.¹⁶ Our review reveals that successful interventions begin in palliative care and last throughout bereavement.^{84,86,91} Publishing manual-based interventions is a means of quality management, as authors describe important aspects of their interventions more thoroughly. Number of treatment sessions varied in accordance with different populations and conceptualizations. One research group offered booster sessions, but did not control for participation.⁹⁷ Therefore, our findings support the conclusion of other authors who stress the necessity of an investigation of effective "doses" of support in family caregiver palliative care research,⁸ also with due regard to minor children.

In accordance with empirical results regarding risk factors,^{7,15,16} participating parents were more often single,⁸⁹ emotionally more distressed,⁹⁰ and children mentioned fear of parental death.⁸⁷ Therefore, it is promising to support the most distressed subgroups and to respect resilience in well-functioning families.^{89,105} It needs to be defined whether psychosocial burden means symptomatology, limited functioning, decreased health-related quality of life, or family functioning.⁸⁹ Kissane and colleagues (2007)¹⁰⁰ propose routine screening of family functioning to facilitate recognition of high-risk families. The authors prefer individual therapy for members of hostile families in the light of potential negative effects within the scope of a preventive model.

Defining the appropriate time point for screening is very important, because parental palliative disease is not a single event but a phase of familial transition.¹⁰ Self-assessed need hints at individual shock and psychosocial burden, and should coincide with offering support.⁸⁹ Periodic assessment and clinical experience are important further ways of determining distress.⁸⁹ Consistent with the fact that "there is no one-size service that fits all"^{106(p. v)}, research should unravel effective aspects of treatment.²⁹

TABLE 2. EVALUATION STUDIES ON INTERVENTIONS FOR FAMILIES OF PALLIATIVE PATIENTS WITH MINOR CHILDREN

Name of intervention First author	1. approach 2. study design 3. control group 4. measurement 5. recruitment	Instruments (respondents)	1. population 2. sample selection 3. participation	Children 1. sample size 2. age mean 3. gender	Parents/family 1. sample size 2. disease 3. age mean 4. gender	Main results (descriptively or qualitative categories)* Main significant results ($p < .05$) ^o
Children of somatically ill parents (COSIP)	Paschen et al. 2007 ^{o5} 1. quantitative 2. cross-sectional 3. none 4. after termination 5. six months	<ul style="list-style-type: none"> • FBB (evaluation of intervention, A, Pt, WP, T) • SBI (treatment goals, self-constructed, A, Pt, WP) 	1. physically ill parents 2. convenience sampling 3. 50% (n = 25) families	1. n = 14 children 2. 11 years (SD = 4) 3. 58% female	1. n = 13 fathers, n = 14 mothers 2. 77% cancer 3. 43 years (SD = 6) 4. 50% mothers	<i>Overall contentment with counselling*</i> <ul style="list-style-type: none"> • parents: mean 3.3 (range 0–4); children: mean 3.2; therapists: mean 2.2 <i>Most important intervention goals*</i> <ul style="list-style-type: none"> • parents: parental competence, emotional availability; children (11–18 years): active coping • therapists: anticipating bereavement (not specified in family questionnaires for ethical reasons), cognitive understanding of children
Schmitt et al. 2007 ^{o9}	1. quantitative 2. cross-sectional 3. none 4. during (families) resp. at end of project (staff) 5. 2 years (patients)	<ul style="list-style-type: none"> • connectedness and attitudes towards project of staff (self-construction) • sociodemographic data on patients 	1. cancer families 2. convenience sampling 3. 79% (n = 109) of staff, n = 37 families	1. n = 69 children 2. 11 years (SD = \$) 3. 57% female	1. n = 37 patients, n = 22 spouses 2. 59% breast cancer 3. counselling group 45 years (SD = 7) 4. patients 86%, spouses 23% female	<i>Staff*</i> <ul style="list-style-type: none"> • 49% (n = 53) of staff members thought that patients benefited from counselling • 39% (n = 42) were more aware of patients' children <i>Families*</i> <ul style="list-style-type: none"> • 6.5% of all new patients had minor children, 76% wished last family session to be offered to every new patient • main reasons for non-participation: 23% accumulation of at least 3 obstacles (distance, exhaustion, small children, ...), 23% husband or children did not want to take part <i>Significant results^o</i> <ul style="list-style-type: none"> • parents in counselling group were older, more often single parents • non-counselling families were recomposed more often
Thastum et al. 2006 ^{o0}	1. quantitative, qualitative 2. pre-post, cross-sectional 3. non-counselling group 4. before and after 5. autumn 2003–4	<ul style="list-style-type: none"> • BDI, FAD (Pt, WP) • BYI, IPPA, Kindl (C, A) • FBB (C, A, Pt, WP, T) • interviews (C, A, Pt, WP, T) 	1. physically ill parents, children 8–15 years 2. convenience sampling 3. 89% (n = 24) of counseled families	1. IG n = 34, CG n = 21 2. 11 years (SD = 2) 3. IG 38% female, CG 62% female	1. IG n = 24, CG n = 16 families 2. not mentioned 3. not mentioned 4. IG 59% mothers, CG 55% mothers	<i>Counselling vs. non-counselling group^o</i> <ul style="list-style-type: none"> • parents in counselling group had higher BDI scores, higher baseline BDI of mothers <i>Pre-post measures in counselling group^o</i> <ul style="list-style-type: none"> • parents: decrease in BDI, improvements in FAD scales • children: decrease in BYI ($\eta > .19$, large effect) <i>Satisfaction with counselling^o</i> <ul style="list-style-type: none"> • mothers mean 3.5, children rated it lower than parents <i>Qualitative data*</i> <ul style="list-style-type: none"> • on parent's and children's opinions, family problems, central focus, not achieved goals • reasons for seeking counselling: parental insecurity, lack of communication, interpersonal conflict, role changes

(continued)

TABLE 2. (CONTINUED)

Name of intervention First author	1. approach 2. study design 3. control group 4. measurement 5. recruitment	Instruments (respondents)	1. population 2. sample selection 3. participation	Children	Parents/family	Main results (descriptively or qualitative categories)* Main significant results ($p < .05$)°
				1. sample size 2. age mean 3. gender	1. sample size 2. disease 3. age mean 4. gender	
Parental Guidance Program Christ et al. 2005 ⁹⁸	1. quantitative 2. RCT 3. telephone monitoring 4. t1 pre, t2 7 months, t3 14 months post death 5. five years	• CDI, STAI, SEI (C) • CBCL (parent- proxy) • POPM (parenting, self- construction, C)	1. parental cancer, prognosis ≤ 6 months, intact families 2. randomly 3. 57% (n = 104) families completed t1, t2 and/or t3	1. IG n = 75, CG n = 22 2. not mentioned 3. 48% girls	1. not mentioned 2. terminal cancer 3. not mentioned 4. 58% mothers (WP)	<i>Results</i> ° <ul style="list-style-type: none">• worse perception of communication: older children with surviving fathers• children in IG perceived parental competence and general communication as better at t2 and t3 than children in CG• parents in IG were very (69%) or somewhat (31%) satisfied with focus on children's needs and concerns
Family Focused Grief Therapy (FFGT) Kissane 2006 ⁹⁶ Kissane 2003 et al. ¹⁰¹	1. quantitative 2. RCT 3. standard PC (33%) 4. baseline, t2 6 months, t3 13 months post bereavement or termination 5. 1996–2001	• FES, FAD, BDI, BSI, SAS, BPQ (C, A, Pt, WP)	1. prognosis < 6 months, living partner, child ≥ 12 years, FRI score 2. randomly 3. of 183 eligible families, 44% (n = 81) consented	<i>baseline data</i> 1. n = 165 children 2. 29 years (SD = 9) 3. 52% female	<i>baseline data</i> 1. IG 53 families, CG 28 families 2. cancer 3. patients 57 years (SD = 8), spouses 56 years (SD = 9) 4. patients 49%, spouses 47% female	<i>Baseline</i> ° <ul style="list-style-type: none">• FRI: intermediate (51%), sullen (26%), hostile (23%) of families• intermediate < sullen < hostile: cohesion, expressiveness and conflict (FES) deteriorate; psychological distress (BSI) increases; social functioning (SAS) deteriorates; family functioning (FAD) deteriorates• in the depressed members (BDI case) of dysfunctional families: worse relationships with children <i>Follow-up: mean changes between IG and CG for all members</i> ° <ul style="list-style-type: none">• BSI gain in scores at t3 were small: d = .26 (sullen d = .32, intermediate d = .19, hostile d = .18)• BDI at t2 sullen d = .44, intermediate d = .30• top 10% of family members: BSI/BDI improved at t2 and t3 in IG <i>Children*</i> <ul style="list-style-type: none">• mention concerns (e.g. fear of parental death, inability to talk to parents)• experiences with the intervention: more open communication, predictability, family strengths, increased knowledge, feeling important to family, coping <i>Parents*</i> <ul style="list-style-type: none">• support (communication, parenting, in dealing with emotions), help (identify resources, strengthen family, plan future)
Family Talks in Cancer Care Bugge et al. 2009 ⁹ Bugge et al. 2008 ⁸⁷	1. qualitative 2. cross-sectional 3. none 4. up to 6 weeks after termination 5. Oct 2005 – Aug 2006	• in-depth interviews (C, A, Pt, WP)	1. patients with incurable cancer and at least 1 child aged 5–18 years 2. convenience sampling 3. 6 of 11 invited families (54%)	1. n = 12 2. 9 years 3. 8 girls, 4 boys	1. n = 6 patients, n = 13 parents 2. incurable cancer 3. 42 years 4. 7 fathers, 6 mothers	

(continued)

TABLE 2. (CONTINUED)

Name of intervention	1. approach 2. study design 3. control group 4. measurement 5. recruitment					Main results (descriptively or qualitative categories)*		
	First author	Instruments (respondents)	1. population 2. sample selection 3. participation	Children 1. sample size 2. age mean 3. gender	Parents/family 1. sample size 2. disease 3. age mean 4. gender	Main significant results (p < .05)°		
Teens and Adults Learning to Communicate (TALC)	Rotheram- Borus et al. 2004 ¹⁰⁴ , 2003 ¹⁰³ , 2001a ¹⁰⁸ , 2001b ⁹⁷ , 2001b	• adolescents: BSI, SES, stressful family events, conduct problems (self- construction), Texas Grief Inventory, Somasick Scale	1. parents with HIV/AIDS, adolescents 2. randomly 3. 72% of eligible parents	baseline data 1. IG n = 206, CG n = 207 2. 15 years (SD = 2) 3. 50% female	baseline data 1. IG n = 153, CG n = 154 2. HIV/AIDS 3. 38 years (SD = 6) 4. 80% female	Over 2 years° <ul style="list-style-type: none">participants: liking, trust, group cohesion at end of each session: mean 4.5–4.8 (range 1–5)parents and adolescents: BSI: over 15 months greater reductions in IG, but not latermultiple problem behaviour (parents and adolescents), conduct problems (adolescents): decreased more over 3–24 months in IGless family stressors, higher self-esteem across 2 yrs in IG Over 2 years (effect of bereavement)° <ul style="list-style-type: none">parental physical health predicted adolescent problem behaviour, parental emotional distress predicted emotional distress in adolescents, IG: fewer problem behavioursif parent died, more emotional distress and more problem behaviours of adolescent 2–4 years°decrease in IG in adolescents' problem behaviour, conduct problems, emotional distress, negative family events over approx. two years, but increase or n.s. differences later At 6 years° <ul style="list-style-type: none">IG: more likely to be in school or employed, less likely to receive public welfare during past 6 months, less somatic symptoms, less alcohol consumption		

A-adolescents, C-children, CG-control group, IG-intervention, Pt-patients, T-therapists, WP-well parents.

FIG. 3. Features of evaluation studies (outcomes, design, approach; multiple answers; RCT, randomized controlled trial).

Diverse evidence base

As there is only a handful of methodologically sound studies,^{89,90,96,97} the evidence base of child-centred interventions in families with parental palliative disease is rather low. This also applies to studies on children of cancer patients in general, where intervention studies are mostly poorly constructed.^{28,94} Methodological shortcomings include widely used cross-sectional designs, lack of control groups, heterogeneous questionnaires that cannot be easily compared, inconsistent treatment exposure, and overall, rather low participation rates.

In one study, patients refused participation because of organizational and disease-related burdens,⁸⁹ which is perhaps a core feature of the population studied and may require flexibility on the part of therapists and researchers. Sampling bias arises from convenience sampling^{87,89,90,95} and clinical personnel that potentially screened out more dysfunctional families.⁸⁶ Furthermore, certain subgroups participated less, such as avoidant families,⁸⁶ or fathers and Spanish-speaking mothers in another study.⁹⁷ Depending on parental disease, samples were of higher^{86,89} or lower⁹⁷ socioeconomic status.

Researchers relied on self-report data and often used additional self-established measures. A great deal of effort was invested in large-scale studies, but most comparisons were nonsignificant, perhaps due to poor sensitivity of the applied measures. Given the deteriorating physical condition of the palliative patient, the focus on improvement of most instruments should perhaps be reconsidered, since psychosocial stabilization is an important treatment goal in itself in these families. Likewise, resilience is still rarely taken into account in studies on families of palliative patients with minor children.

Most participants were satisfied with the interventions.^{90,95-98} Although social desirability is quite likely, contentment with a program is an important prerequisite for building a therapeutic working alliance. The evaluation studies included in this review indicate that the identified interventions for families of palliative patients and their minor children tend to improve communication, depressiveness, and

family functioning.^{90,96-98} Nevertheless, due to theoretical and methodological weaknesses, these findings should be considered in the context of the respective evidence base.

Conclusions

Parental palliative disease can be a particularly critical situation for dependent children, and long-lasting illness is associated especially with internalizing child symptoms.^{7,16} Although there is a variety of family, child and parent-centered concepts, only five structured and published interventions met our inclusion criteria. As presented, successful interventions already begin in palliative care and last throughout bereavement, transferring interventions into manual-based forms adds to quality management, and supporting the most distressed subgroups presents an adequate approach.

As with research on interventions for cancer families with minor children,^{3,4,15,28} there is a lack of well-designed and elaborated intervention concepts and evaluation studies in palliative care. Future empirical studies are facing the tasks of screening for high-risk families and individuals according to self-assessed need and clinical assessment; of study recruitment against the background of physical deterioration of the patient; of defining appropriate outcome criteria (e.g., stability, resilience); and of selection and development of sensitive outcome measures. Stringent development of specific interventions for families of palliative patients with minor children is necessary and needs to be theoretically clear, empirically substantiated, clinically sensible, and supported by methodologically sound intervention studies. This can help to explain and establish what and why psychosocial professionals do what they do.

Acknowledgments

We would like to thank Doreen Kopper for her assistance with literature search and acquisition, and Monica Blotevogel for English copyediting. The study is part of the German multisite research project "Psychosocial Services for Children of Parents with Cancer" supported by German Cancer Aid (Deutsche Krebshilfe, grant #108303). In this multisite project the following institutions and principal investigators are collaborating:

- Dept. of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, University Medical Centre Hamburg-Eppendorf (Prof. Georg Romer);
- Inst. of Medical Psychology, University Medical Centre Hamburg-Eppendorf (Prof. Uwe-Koch-Gromus);
- Dept. of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, Charité University Medical Centre, Berlin (Prof. Ulrike Lehmkuhl);
- Dept. of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, University Medical Centre, Leipzig (Prof. Kai v. Klitzing);
- Inst. of Medical Psychology, University Medical Centre, Leipzig (Prof. Elmar Brähler);
- Dept. of Psychosomatic and General Clinical Medicine; University Medical Centre, Heidelberg (Prof. Wolfgang Herzog);
- Dept. of Child and Adolescent Psychiatry, University Medical Centre, Heidelberg (Prof. Franz Resch);

- Dept. of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, Otto-von-Guericke University, Magdeburg (Prof. Hans-Henning Flechtner).

Author Disclosure Statement

No competing financial interests exist.

References

1. Rolland JS: Parental illness and disability: A family systems framework. *J Fam Ther* 1999;21:242–266.
2. Pitceathly C, Maguire P: The psychological impact of cancer on patients' partners and other key relatives: A review. *Eur J Cancer* 2003;39:1517–1524.
3. Diareme S, Tsiantis J, Romer G, Tsalamani E, Anasontzi S, Paliokosta E, Kolaitis G: Mental health support for children of parents with somatic illness: A review of the theory and intervention concepts. *Fam Syst Health* 2007;25(1):98–118.
4. Worsham NL, Compas B, Ey S: Children's coping with parental illness. In: Wolchik SA, Sandler IN (eds): *Handbook of Children's Coping: Linking Theory and Intervention, Issues in Clinical Child Psychology*. New York: Plenum Press, 1997, pp. 195–213.
5. Barkmann C, Romer G, Watson M, Schulte-Markwort M: Parental physical illness as a risk factor for maladjustment in children and adolescents: Epidemiological findings from a national survey in Germany. *Psychosomatics* 2007;48(6):476–481.
6. Pearlman MY, Schwalbe KD, Cloitre M: Managing behavior problems in grieving children. Grief in childhood. In: Pearlman MY, Schwalbe KD, Cloitre M (eds): *Fundamentals of Treatment in Clinical Practice*. Washington DC: American Psychological Association, 2010, pp. 123–145.
7. Sieh DS, Meier AM, Oort FJ, Visser-Meily JMA, Van der Leij DAV: Problem-behavior in children of chronically ill parents: A meta-analysis. *Clin Child Fam Psychol Rev* 2010;13:384–397.
8. Hudson P, Payne S: Family caregivers and palliative care: Current status and agenda for the future. *J Palliat Med* 2011;14(7):1–6.
9. Bugge KE, Helseth S, Darbishire P: Parents experiences of a family support program when a parent has incurable cancer. *J Clin Nurs* 2009;18(24):3480–3488.
10. Siegel K, Raveis VH, Bettes B, Mesagno FP, Christ G, Weinstein L: Perceptions of parental competence while facing the death of a spouse. *Am J Orthopsychiatry* 1990;60(4):567–576.
11. Altschuler J, Dale B: On being an ill parent. *Clin Child Psychol Psychiatry* 1999;4(1):23–37.
12. Saldinger A, Porterfield K, Cain AC: Meeting the needs of parentally bereaved children: A framework of child-centered parenting. *Psychiatry* 2004;67(4):331–352.
13. Christ GH, Siegel K, Christ AE: Adolescent grief: It never really hit me...until it actually happened. *JAMA* 2002;288(10):1269–1279.
14. Huizinga GA, Visser A, Van der Graf WTA, Hoekstra HJ, Stewart RE, Hoekstra-Weebers JEHM: Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer. *Psychooncology* 2011;20:730–737.
15. Visser A, Huizinga GA, van der Graaf WTA, Hoekstra HJ, Hoekstra-Weebers JEHM: The impact of parental cancer on children and the family: A review of the literature. *Cancer Treat Rev* 2004;30:683–694.
16. Osborn T: The psychosocial impact of parental cancer on children and adolescents: A systematic review. *Psychooncology* 2007;16:101–126.
17. Visser A, Huizinga GA, Hoekstra HJ, Van der Graf WTA, Hoekstra-Weebers JEHM: Parental cancer: Characteristics of parents as predictors for child functioning. *Cancer* 2006;106:1178–1187.
18. Saldinger A, Cain A, Kalter N, Lohnes K: Anticipating parental death in families with young children. *Am J Orthopsychiatry* 1999;69(1):39–48.
19. Christ GH, Siegel K, Freund B, Langosch D, Hendersen S, Sperber D, Weinstein L: Impact of parental terminal cancer on latency-age children. *Am J Orthopsychiatry* 1993;63(3):417–425.
20. Saldinger A, Cain A, Porterfield K: Managing traumatic stress in children anticipating parental death. *Psychiatry* 2003;66(2):168–181.
21. Romer G, Kühne F, Bergelt C, Möller B: Seelische Gesundheitsvorsorge für Kinder krebserkrankter Eltern. Manualisiertes Interventionskonzept kindzentrierter medizinischer Familienberatung [Mental healthcare for children of parents with cancer. Manualized interventional concept of child-oriented medical family counselling]. *Psychotherapeut* 2011;56(5):400–408.
22. *Cochrane Handbook for Systematic Reviews of Interventions* 4.2.6 [updated September 2006]. Higgins JPT, Green S (eds). In: *The Cochrane Library* 4:6. Chichester, UK: John Wiley, 2006.
23. Kunz R, Khan KS, Kleijnen J, Antes G: Systematische Übersichtsarbeiten und Meta-Analysen. Bern, CH: Huber, 2009.
24. Bausewein C, Simon S: Serie: Methodik in der palliativmedizinischen Forschung - Systematische Übersichtsarbeiten. *Palliativmedizin* 2010;11(5):202–205.
25. Sanderson S, Tatt ID, Higgins JPT: Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: A systematic review and annotated bibliography. *Int J Epidemiol* 2007;36(3):666–676.
26. Cardiff University. Critical Appraisal Checklists. www.cardiff.ac.uk/insrv/libraries/sure/sysnet/criticalappraisalchecklist.html. (Last accessed March 28, 2011).
27. Grouven U, Bender R, Lange S: Der Kappa-Koeffizient [The kappa coefficient]. *Dtsch Med Wochenschr* 2007;132: e65–e68.
28. Niemelä M, Hakko H, Räsänen S: A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer. *Psychooncology* 2010;19:451–461.
29. Hodges LJ, Walker J, Kleiboer AM, Ramirez AJ, Richardson A, Velikova G, Sharpe M: What is a psychological intervention? A metareview and practical proposal. *Psychooncology* 2011;20:470–478.
30. Adams-Greenly M, Moynihan RT: Helping the children of fatally ill parents. *Am J Orthopsychiatry* 1983;53(2):219–229.
31. Adams-Greenly M, Beldoch A, Moynihan R: Helping adolescents whose parents have cancer. *Semin Oncol Nurs* 1986;2(2):133–138.
32. Black A, Wood D: Family therapy and life threatening illness in children or parents. *Palliat Med* 1989;3(2):113–118.
33. Black D: Family intervention with families bereaved or about to be bereaved. In: Papadatou D, Papadatos C (eds):

- Children and Death*. Washington, DC: Hemisphere Publishing Corp., 1991, pp. 135–143.
34. Blackford KA: Strategies for intervention and research with children or adolescents who have a parent with multiple sclerosis. *Axone* 1992;14(2):50–54.
 35. Chowns G: 'No, you don't know how we feel': Groupwork with children facing parental loss. *Groupwork An Interdisciplinary Journal for Working with Groups* 2008;18(1):14–37.
 36. Christ GH, Christ AE: Current approaches to helping children cope with a parent's terminal illness. *CA Cancer J Clin* 2006;56(4):197–212.
 37. Dunning S: As a young child's parent dies: Conceptualizing and constructing preventive interventions. *Clin Soc Work J* 2006;34(4):499–514.
 38. Kennedy C, McIntyre R, Worth A, Hogg R: Supporting children and families facing the death of a parent: Part 1. *Int J Palliat Nurs* 2008;14(4):162–168.
 39. Kennedy C, McIntyre R, Worth A, Hogg R: Supporting children and families facing the death of a parent: Part 2. *Int J Palliat Nurs* 2008;14(5):230–237.
 40. Lewandowski J: A parent has cancer: Needs and responses of children. *Pediatr Nurs* 1996;22(6):518–521.
 41. Lewis FM: Strengthening family supports. *Cancer and the family*. *Cancer* 1990;1(65):752–759.
 42. Lydon A, Hennings J, Ryan Woolley: Evaluation of a British child bereavement service: The user's perspective. *Palliat Support Care* 2010;8:297–303.
 43. Lewis PG, Lippman JG: *Helping Children Cope with the Death of a Parent: A Guide for the First Year*. Westport, CT: Praeger Publishers/Greenwood Publishing Group, 2004.
 44. Rauch PK, Muriel AC, Cassem NH: Parents with cancer: Who's looking after the children? *J Clin Oncol* 2002;20(21):4399–4402.
 45. Segal J, Simkins J (eds): *Helping Children with Ill or Disabled Parents: A Guide for Parents and Professionals*. London: Kingsley, 1996.
 46. Saldinger A, Cain AC, Porterfield K, Lohnes K: Facilitating attachment between school-aged children and a dying parent. *Death Stud* 2004;28(10):915–940.
 47. *Cancer and the family life cycle: A practitioner's guide*. Veach TA, Nicholas DR, Barton MA. New York: Brunner-Routledge, 2002.
 48. Cable D: Book review: *Remembering My Special Person: An Activity Book for Children Experiencing the Death of a Loved One*. *Am J Hosp Palliat Care* 1998;15(1):61.
 49. Carroll ML, Griffin R: Reframing life's puzzle: Support for bereaved children. *Am J Hosp Palliat Care* 1997;14(5):231–235.
 50. Corr CA: Support for grieving children: The Dougy Center and the hospice philosophy. The staff of the Dougy Center. *Am J Hosp Palliat Care* 1991;8(4):23–27.
 51. Costa L, Holliday D: Helping children cope with the death of a parent. *Sch Couns* 1994;28(3):206–213.
 52. Gersten JC, Beals J, Kallgren CA: Epidemiology and preventive interventions: Parental death in childhood as a case example. *Am J Community Psychol* 1991;19(4):481–500.
 53. Goldman L (ed): *Life and Loss: A Guide to Help Grieving Children*. Bristol, UK: Routledge, 2000.
 54. Grollmann EA (ed): *Bereaved Children and Teens. A Support Guide for Parents and Professionals*. Boston: Beacon Press, 1995.
 55. Heiney SP, Lesesne CA: Quest. An intervention program for children whose parent or grandparent has cancer. *Cancer Pract* 1996;4(6):324–329.
 56. Hilliard RE: The effects of music therapy-based bereavement groups on mood and behavior of grieving children: A pilot study. *J Music Ther* 2001;38(4):291–306.
 57. Hoke LA: A short-term psychoeducational intervention for families with parental cancer. *Harv Rev Psychiatry* 1997;5(2):99–103.
 58. Holland J: How schools can support children who experience loss and death. *Br J Guid Counc* 2008;36(4):411–424.
 59. Lohnes KL, Kalter N: Preventive intervention groups for parentally bereaved children. *Am J Orthopsychiatry* 1994;64(4):594–603.
 60. Lutzke JR, Ayers TS, Sandler IN, Barr A: Risks and interventions for the parentally bereaved child. In: Wolchik SA, Sandler IN (eds): *Handbook of Children's Coping: Linking Theory and Intervention, Issues in Clinical Child Psychology*. New York: Plenum Press, 1997, pp. 215–243.
 61. Mark BS: The death of a parent: The spirit of healing through individual and group therapy. In: Lanham, MD, Jason A (eds): *The Handbook of Infant and Adolescent Psychotherapy: New Directions in Integrative Treatment*, Volume 2. Northvale, NJ: Aronson, 1997, pp. 319–331.
 62. McGlaufflin H: What one small hospice learned from its grieving children's program. *Am J Hosp Palliat Care* 1994;11(2):36–39.
 63. Moyer JA: Bannock bereavement retreat. A camping experience for surviving children. *Am J Hosp Care* 1988;5(2):26–30.
 64. Pearlman MY, Schwalbe KDA, Cloitre M: *Grief in Childhood: Fundamentals of Treatment in Clinical Practice*. Washington, DC: American Psychological Association, 2010.
 65. Pfeffer CR, Jiang H, Kakuma T, Hwang J, Metsch M: Group intervention for children bereaved by the suicide of a relative. *J Am Acad Child Adolesc Psychiatry* 2002;41(5):505–513.
 66. Sandler IN, Ayers TS, Romer AL: Fostering resilience in families in which a parent has died. *J Palliat Med* 2002;5(6):945–956.
 67. Sandler IN, Ayers TS, Wolchik SA, et al.: The family bereavement program: Efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. *J Consult Clin Psychol* 2003;71(3):587–600.
 68. Sontag MA, Nadig J, Henry L: The Children's Grief Workshop: Social work practice in hospice. *Am J Hosp Palliat Care* 1994;11(3):23–29.
 69. Traeger J: Supporting your grieving child. *J Palliat Med* 2011;14(1):116–117.
 70. Tonkins SAM, Lambert MJ: A treatment outcome study of bereavement groups for children. *Child Adolesc Social Work J* 1996;13(1):3–21.
 71. Walsh-Burke K: Family communication and coping with cancer: Impact of the We Can Weekend. *J Psychosoc Oncol* 1992;10(1):63–81.
 72. Davis Kirsch SE, Brandt PA, Lewis FM: Making the most of the moment: When a child's mother has breast cancer. *Cancer Nurs* 2003;26(1):47–54.
 73. Lewis FM, Casey SM, Brandt PA, Shands ME, Zahlis EH: The enhancing connections program: Pilot study of a cognitive-behavioral intervention for mothers and children affected by breast cancer. *Psychooncology* 2006;15(6):486–497.
 74. Northouse LL, Walker J, Schafenacker A: A family-based program of care for women with recurrent breast cancer and their family members. *Oncol Nurs Forum* 2002;29(10):1411–1419.

75. Duggleby W, Wright K, Williams A, Degner L, Cammer A, Holtslander L: Developing a Living with Hope Program for caregivers of family members with advanced cancer. *J Palliat Care* 2007;23(1):24–31.
76. Johnson JL, Norby PA: We Can Weekend: A program for cancer families. *Cancer Nurs* 1981;4(1):23–28.
77. McIntyre R (ed): *Nursing Support for Families of Dying Patients*. London, UK: Whurr Publishing, 2002.
78. Rosenbaum E, Garlan RW, Hirschberger N, Siegel AL, Butler LD, Spiegel D: The Life Tape Project: Increasing family social support and symbolic immortality with a brief existential intervention for cancer patients and their families. *Omega (Westport)* 2006;53(4):321–339.
79. Bedway AJ, Smith LH: “For kids only”: Development of a program for children from families with a cancer patient. *J Psychosoc Oncol* 1996;14(4):19–28.
80. Call DA: School-based groups: A valuable support for children of cancer patients. *J Psychosoc Oncol* 1990;8(1):97–118.
81. Greening K: The “Bear Essentials” program: Helping young children and their families cope when a parent has cancer. *J Psychosoc Oncol* 1992;10(1):47–61.
82. Gunther M, Crandles S, Williams G, Swain M: A place called HOPE: Group psychotherapy for adolescents of parents with HIV/AIDS. *Child Welf* 1998;77(2):251–271.
83. Taylor-Brown J, Acheson A, Farber JM: Kids Can Cope: A group intervention for children whose parents have cancer. *J Psychosoc Oncol* 1993;11(1):41–53.
84. Christ GH, Siegel K: Parental death: A preventive intervention. *Recent Results Cancer Res* 1991;121:426–431.
85. Intervention Manual Project TALC. chipts.cch.ucla.edu/interventions/manuals/intervhra1.html. (Last accessed July 15, 2011.)
86. Kissane DW, Bloch S: *Family Focused Grief Therapy: A Model of Family-Centered Care During Palliative Care and Bereavement*. Buckingham, UK: Open University Press, 2002.
87. Bugge KE, Helseth S, Darbyshire P: Children’s experiences of participation in a family support program when their parent has incurable cancer. *Cancer Nurs* 2008;31(6):426–434.
88. Romer G, Haagen M: *Kinder körperlich kranker Eltern*. Göttingen: Hogrefe, 2007.
89. Schmitt F, Manninen H, Santalahti P, Savonlahti E, Pyrhonen S, Romer G, Piha J: Children of parents with cancer: A collaborative project between a child psychiatry clinic and an adult oncology clinic. *Clin Child Psychol Psychiatry* 2007;12(3):421–436.
90. Thastum M, Munch-Hansen A, Wiell A, Romer G: Evaluation of a focused short-term preventive counseling project for families with a parent with cancer. *Clin Child Psychol Psychiatry* 2006;11(4):529–542.
91. Rotheram-Borus MJ, Murphy DA, Miller S, Draimine BH: An intervention for adolescents whose parents are living with AIDS. *Clin Child Psychol Psychiatry* 1997;2(2):201–219.
92. Romer G, Saha R, Haagen M, Pott M, Baldus C, Bergelt C: Lessons learned in the implementation of an innovative consultation and liaison service for children of cancer patients in various hospital settings. *Psychooncology* 2007;16:138–148.
93. Wong M, Looney E, Michaels J, Palesh O, Koopman C: A preliminary study of peritraumatic dissociation, social support, and coping in relation to posttraumatic stress symptoms for a parent’s cancer. *Psychooncology* 2006;15:1093–1098.
94. Su Y, Ryan-Wenger NA: Children’s adjustment to parental cancer. A theoretical model development. *Cancer Nurs* 2007;30(5):362–381.
95. Paschen RS: Evaluation eines präventiven Beratungskonzeptes für Kinder körperlich kranker Eltern. *Psychotherapeut* 2007;52:265–272.
96. Kissane DW, McKenzie M, Bloch S, Moskowitz C, McKenzie DP, O’Neil I: Family focused grief therapy: A randomized, controlled trial in palliative care and bereavement. *Am J Psychiatry* 2006;163(7):1208–1218.
97. Rotheram-Borus MJ, Stein JA, Lin YY: Impact of parent death and an intervention on the adjustment of adolescents whose parents have HIV/AIDS. *J Consult Clin Psychol* 2001b;69(5):763–773.
98. Christ GH, Raveis VH, et al: Evaluation of a preventive intervention for bereaved children. *J Soc Work End Life Palliat Care* 2005;1(3):57–81.
99. Chan EK, O’Neill I, McKenzie M, Love A, Kissane, DW: What works for therapists conducting family meetings: Treatment integrity in family-focused grief therapy during palliative care and bereavement. *J Pain Symptom Manage* 2004;27(6):502–22.
100. Kissane DW, Lichtenthal WG, Zaider T: Family care before and after bereavement. *Omega (Westport)* 2007;56(1):21–32.
101. Kissane DW, McKenzie M, McKenzie DP, Forbes A, O’Neil I, Bloch S: Psychosocial morbidity associated with patterns of family functioning in palliative care: Baseline data from the Family Focused Grief Therapy controlled trial. *Palliat Med* 2003;17(6):527–537.
102. Christ GH, Siegel KF, Mesagno FP, Langosh D: A preventive intervention program for bereaved children: Problems of implementation. *Am J Orthopsychiatry* 1991;61(2):168–178.
103. Rotheram-Borus MJ, Lee M, Leonard N, Lin Y-Y, Franzke L, Turner E, Lightfoot M, Gwadz M: Four-year intervention outcomes of an intervention for parents living with HIV and their adolescent children. *AIDS* 2003;17(8):1217–1225.
104. Rotheram-Borus MJ, Let M, Lin YY, Lester P: Six-year intervention outcomes for adolescent children of parents with the human immunodeficiency virus. *Arch Pediatr Adolesc Med* 2004;158(8):742–748.
105. Harding R, Higginson IJ: What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003;17(1): 63–74.
106. Monroe B, Kraus F (eds): *Brief Interventions with Bereaved Children*. Oxford University Press, New York, 2010.
107. Visser A, Huizinga GA, Hoekstra HJ, Van der Graf WTA, Gazendam-Donofrio SM, Hoekstra-Weebers JEHM: Emotional and behavioral problems in children of parents recently diagnosed with cancer: A longitudinal study. *Acta Oncol* 2007;46:67–76.
108. Rotheram-Borus MJ, Lee MB, Gwadz M, Draimin B: An intervention for parents with AIDS and their adolescent children. *Am J Public Health* 2001a;91(8):1294–1302.
109. Kissane DW, Lichtenthal WG: Family focused grief therapy: From palliative care into bereavement. In: Stroebe MS (ed): *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention*. Washington, DC: American Psychological Association, 2008, pp. 485–510.
110. Kissane DW: A model of family-centered intervention during palliative care and bereavement: Family Focused

- Grief Therapy (FFGT). In: Baider L, Cooper CL, Kaplan De-Nour A (eds): *Cancer and the Family*, 2nd ed. Chichester, UK: Wiley, 2000, pp.175–197.
111. Kissane DW, Bloch, McKenzie M, McDowall AC, Nitzan R: Family grief therapy: A preliminary account of a new model to promote healthy family functioning during palliative care and bereavement. *Psychooncology* 1998;7(1): 14–25.

Address correspondence to:

Franziska Kühne, M.Sc.

Department of Child and Adolescent Psychiatry,
Psychotherapy, and Psychosomatics
University Medical Center Hamburg-Eppendorf
Martinistraße 52, 20246 Hamburg
Germany

E-mail: f.kuehne@uke.de