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Interventions for children of parents with cancer: an overview

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Purpose of review
The purpose of this overview is to analyze existing reviews on psychosocial interventions for children of parents with cancer and synthesize implications for further practice, interventions, and research in this field. The aim of this overview is therefore to generate systematic knowledge about what can be classed as evidence-based knowledge in this field.

Recent findings
The literature search in MEDLINE, CINAHL, PsycINFO, PSYNDEX, and PsycARTICLES resulted in three systematic reviews, which were evaluated by the AMSTAR-2-tool for quality assessment and the PRISMA-checklist for reporting. Results were analyzed through narrative synthesis due to the heterogeneity of the studies. The three systematic reviews were evaluated by the AMSTAR-2-tool for quality assessment and the PRISMA-checklist for reporting. AMSTAR-2 revealed critically low quality for all three reviews but taking into account the study situation of this scientific context, a more optimistic quality assessment can be suggested. The PRISMA checklist revealed good results. Positive evidence was found for the effect of psychosocial interventions concerning depressive symptoms, children's behavior, communication within the family, and quality of life. A comparison of the interventions is not possible due to the high degree of heterogeneity of the studies.

Summary
Following the principles of evidence-based medicine, this overview, together with clinical-practical expertise and the needs of those affected, could contribute to evidence-based care and stimulate future guidelines in this important field. The valuable engagement with questions around evidence-based practice invites professionals and researchers to enter into a common discourse to ultimately contribute to an improvement of the life situation of children of parents with cancer.

Keywords
children and adolescents, overview, parents with cancer, psychosocial interventions, recommendations for practice and further research

INTRODUCTION

Approximately 7–14% of cancer patients have children under the age of 18 [1]. The focus of institutional support, however, is mostly on those who are themselves affected by cancer, and relatives are sometimes characterized as the 'forgotten group' (2, p. 459).

Several studies show an increased risk of emotional or behavioral problems for children who have a parent with cancer [3–6]. The children are affected by fear of losing the sick parent, changes of everyday life because the sick parent is absent for treatment, possible financial worries, or changes in the physical or emotional availability of parents [6–8]. Children might react with internalized symptoms such as depression, anxiety or distress [6], symptoms of regression like enuresis [3], or externalized

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KEY POINTS

- It is of importance to recognize children of parents with cancer as an important client group in psycho-oncology. The design of interventions should be based on the (best) available evidence, and the effectiveness of one's psychosocial practice should be continuously critiqued.
- The current overview evaluates three systematic reviews in the field of interventions for children who have parents with cancer.
- The evaluated reviews are based on studies of very heterogenous quality which result in only a fairly good evaluation of the reviews even though they were undertaken according to best scientific practice.
- Evidence shows that interventions improve family functioning, children's depressive symptoms, feelings of safety, being informed, and experiencing community, but do not have a significant impact on anxiety or behavioral problems.

symptoms such as aggression [9]. However, reviews show high variability and inconsistency regarding the prevalence of symptoms [8,10–12].

Beyond the question of distress or disorder, Ellis *et al.* [13] analyzed the needs of affected children and conclude that children need appropriate information, support in communication about the issues, support by peers, support in expressing emotions, individual support in coping with the situation and special support when it comes to dying and mourning processes. The biggest support for children in need could come from their parents. Yet, the parents themselves suffer too. Family caregivers experience emotional problems, such as anxiety, depression, fatigue, and sleep problems [14]. Although 73% of patients with children wanted information about psychosocial services to support their children or parenting, family-centered support was used by only 9% of these respondents [15].

Scientific evidence on the impact of interventions for children of parents with cancer is available nationally and internationally through studies and evaluations [1,2,6,11,13]. However, studies and even reviews often appear unconnected from each other due to different research questions as well as heterogeneous study designs.

The aim of our review is therefore to generate systematic knowledge about what can be classed as evidence-based knowledge from the various study results on the effects of psychosocial interventions for children of parents with cancer. Toward this aim we have prepared an 'overview' as a systematic review of existing reviews [16,17]. Since the number of systematic reviews, which can be analyzed is quite limited, the overview covers the period between 2005 and 2020.

METHODS

The compilation of an 'overview' (aka Umbrella Review, Meta-Review [18]) is a relatively new procedure [18]. To date, there are no agreed upon guidelines [17,19], but several recommendations for an overview [17,20▪,21,22]. We decided to apply the seven steps described by Lunny [21,22], and integrated the statements by Pollock *et al.* [17,20▪,23], for evaluating the evidence of reviews based on risk of bias and methodological quality assessments. According to the recommendation of the Cochrane Collaboration we focused mainly on the level of systematic reviews and only in in well justified exceptions on the level of primary studies [20▪].

Specification of purpose, objectives, and scope

Liberati *et al.* [24] operationalized this objective with the acronym PICOS for Population, Intervention, Comparator group, Outcome, and Study design.

Specification of eligibility criteria

According to Lunny *et al.* [21], the following inclusion and exclusion criteria can be applied: The PICO (S) components of the desired reviews and a criterion for the quality of the methodological approach in the reviews. They also take into account the number of authors involved in the respective steps of the selection process.

Search methods

In searching for relevant systematic reviews the sources to be used (e.g., databases), and the specific search strategy should be determined in advance [21].

Data extraction

According to Pollock *et al.* [17,20▪] the data should be extracted and described according to aims, date of publication and place of origin, numbers of included studies, search strategies and inclusion criteria, evaluation and statement about risk-of-bias, applied methods, and significant quantitative or qualitative findings.

Assessment of risk of bias in systematic reviews

We decided to evaluate the reviews with the AMSTAR-2 checklist [25] for the quality of the

methodology and the PRISMA checklist [26] for the quality of reporting and the risk of bias. The AMSTAR-2 checklist gives guidance on evaluating reviews according to 16 specific questions and each review can be finally evaluated in the four categories high, moderate, low, and critically low. The PRISMA checklist consists of 27 items and provides guidance on the quality of reporting.

Assessment of certainty of the evidence

Due to the expected heterogeneity of studies, we decided to discuss the certainty of the evidence on the grounds of AMSTAR-2 and PRISMA.

Synthesis, presentation, and summary of findings

In this section, information should be reported [17,21,27] describing the included reviews, methodological quality, synthesis of reviews, referring back to primary studies where needed, a summary of findings, and interpretation of findings.

RESULTS

We describe the results according to the steps by Lunny *et al.* [21,22].

Specification of purpose, objectives, and scope

With reference to the PICOS framework, the objective of the overview can be outlined as follows:

- Population: children aged between 0 and 18 who have a parent with cancer;
- Intervention: all psychosocial interventions that support children;
- Comparator group: treatment as usual or no treatment;
- Outcome: decrease or no change in distress;
- Study design: quantitative, qualitative, or mixed methods approaches.

Specification of eligibility criteria

In addition to the above-mentioned criteria, we included the following eligibility criteria: date of publication between 2005 and 2020, publication in a peer-reviewed journal reporting according to the PRISMA statement (see point 5) and published in English or German. Two of the authors (A.K. and S.P.) checked the titles and abstracts of all search results. Discrepancies were discussed until consensus was reached.

Search results

We searched the data banks of MEDLINE, CINAHL, PsycINFO, PSYNDEX, and PsycARTICLES with the following trunks:

- child* or paediatric or pediatric or offspring or adolescen* or teen*
- and
- parent* or guardian or caregiver or mother or father
- and
- neoplasm or cancer or oncol*
- and
- intervention or program or treatment
- and
- review or systematic review or meta or meta-analysis

The data search carried out in February 2020 resulted in 332 hits. After removing duplicates, 257 reviews remained. In total, 248 publications were excluded because they concerned children with the diagnosis of cancer or were not published in English or German. The nine remaining articles were read in full. Reviews which focused on grief or mourning processes, which were not clear about the scientific approach, or which did not describe an intervention were excluded. The entire process was done by two of the authors (A.K. and S.P.) independently and disagreement was discussed until consensus was reached. Three reviews remained. See Fig. 1 for the PRISMA flowchart.

Data extraction

We found three systematic reviews, which fulfilled all the search criteria: Alexander *et al.* [28▪▪] and Ellis *et al.* [13] from Australia, and Inhestern *et al.* [29] from Germany. All these reviews are published in English and followed the PRISMA guidelines. All three reviews aimed to assess interventions for children who have parents with cancer. Alexander *et al.* [28▪▪] focused on a review of existing interventions and their effectiveness, Ellis *et al.* [13] additionally focused on the needs of children, and Inhestern *et al.* additionally focused on barriers to implementing those interventions. Included studies varied from 8 (Alexander *et al.* [28▪▪]) to 12 (Ellis *et al.* [13]) to 16 (Inhestern *et al.* [29]). Inclusion criteria mainly differed in the time-range of publications (Alexander *et al.* from 2006 to 2018 [28▪▪]; Ellis *et al.* 1985 to 2015 [13], Inhestern *et al.* unlimited [29]) and inclusion- or exclusion of qualitative studies. The quality assessment of the included primary studies was done by the Mixed-Methods-Appraisal tool (MMAT, [30])

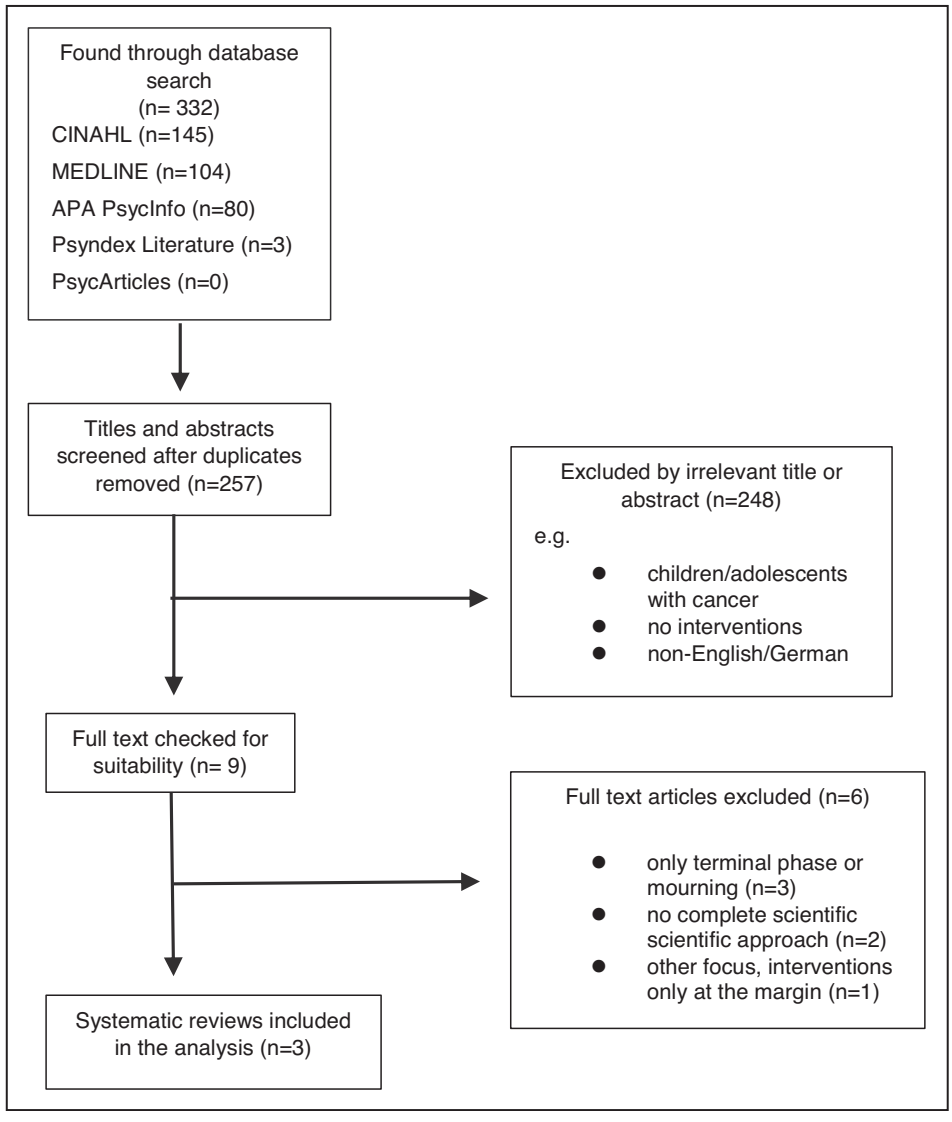

FIGURE 1. PRISMA flowchart of the literature search performed.

for the systematic reviews by Ellis *et al.* [13] and Inhestern *et al.* [29]. Alexander *et al.* used the appraisal tool developed by Keim-Malpass *et al.* [31]. Alexander *et al.* [28▪▪] included quantitative studies and studies with mixed methods, Ellis *et al.* [13] included qualitative and quantitative studies, and Inhestern *et al.* [29] included qualitative, quantitative, and mixed methods studies. All author groups pointed out the high heterogenity in the quality of included studies and decided not to calculate a meta-analysis. Alexander *et al.* [28▪▪] describe interventions with their characteristics and their contents. They describe the effects of the studies only when there is a variable on the child included. Ellis *et al.* [13] describe the needs of affected children. In the outcome description, they also include qualitative studies and nonrandomized controlled trials. Inhestern *et al.* [29] describe studies and enlarge their findings with the objective of establishing how to implement these interventions (Table 1).

Assessment of risk of bias in systematic reviews

Applying the criteria of the AMSTAR-2 checklist only, we came to the result of critically low quality for all three reviews (see Table 2) even though all the reviews were carried out to high research standards.

Table 3 summarizes the results of the PRISMA checklist. All the reviews report their findings at a good quality level. Inhestern *et al.* [29] published a protocol in advance and added the PRISMA checklist to their publication. Nevertheless, many items of

Table 1. Overview of the characteristics/features of the reviews on psychosocial interventions for children of parents with cancer

Authors (year of publication) *Review name*	Country	Goals/focal points	Number of included studies/ interventions	Search strategies	Inclusion criteria for studies	Methods/ quality assessment	Type of primary study results
Alexander *et al.* (2019)	Australia	(1) What interventions are available for children of parents with cancer? (2) How effective are these interventions?	8/6	7 databases (1), gray literature, hand search in 3 journals (2)	Period 2006–2018; ages 0–18 years and parents with cancer; children in focus of study, child outcome variable; English language	PRISMA procedure/ Keim–Malpass quality rating (for quantitative part)	Quantitative or mixed methods
Ellis *et al.* (2017)	Australia	(1) Overview of the psychosocial needs of children/ adolescents of parents with cancer (2) Evaluation of existing interventions	Two separate searches; for question 2: 12/12	5 Databases (3), reference lists	(1) – (2) Period 1985–2015; ages 0–18 years and parents with cancer, Intervention, RCT, non-RCT, and noncontrolled intervention study, at least one child outcome variable	PRISMA procedure/ Mixed Methods Appraisal tool	Qualitative and/or quantitative
Inhestern *et al.* (2016)	Germany	(1) Overview of interventions for parents with cancer and their children. (2) Identification of barriers and facilitating factors for utilization	Total 36, 16 with evaluation of one intervention/10 interventions	5 databases (4), systematic search of citations and reference lists, articles of previous reviews	Period open, ages 0–18 years and parents with cancer; full text availability, English or German language, structured interventions	PRISMA procedure/ Mixed Methods Appraisal tool	Qualitative, quantitative, Mixed Methods

(1) Medline, PsycInfo, ProQuest, Cochrane, CINAHL, Embase, Google Scholar; (2) Journal of Psychosocial Oncology, Psycho-oncology, Cancer; (3) Medline, CINAHL, PsychInfo, EMBASE, Social Work Abstracts; (4) CINAHL, Embase, Medline, PsycInfo, Psyndex.

Table 2. Overview of the evaluation of the reviews with AMSTAR-2

Review AMSTAR-2 Question	Alexander *et al.* (2019)	Ellis *et al.* (2017)	Inhestern *et al.* (2016)
Q1 Research question and inclusion criteria with PICO	Y	Y	Y
Q2 Methods were established prior to conduct; deviation justified	N	N	Y
Q3 Explanation of selection of study designs	Y	N	Y
Q4 Comprehensive literature search strategy	pY	pY	pY
Q5 Duplicate study selection	Y	Y	Y
Q6 Duplicate data extraction	N	N [1]	Y
Q7 List of excluded studies and justification	N	N	N
Q8 Description of included studies in adequate detail	Y	Y	pY
Q9 Assessing of RoB in individual studies	N [2]	Y [3]	Y [3]
Q10 Sources of funding of the included studies	N	N	N
Q11 With meta-analysis: methods used to combine appropriate	n.a.	n.a.	n.a.
Q12 With meta-analysis: assess the potential RoB-impact of studies	n.a.	n.a.	n.a.
Q13 Account of RoB of studies when interpreting/discussing the results	N	Y [4]	N
Q14 Satisfactory explanation for/discussion of heterogeneity in results	Y	Y	Y
Q15 With meta-analysis: publication bias assessed and discussed	n.a.	n.a.	n.a.
Q16 Conflict of interest stated	Y	N [5]	Y
Summe (Yes = 1, partial Yes = 0,5)	6,5	6,5	9

Y = Yes, pY = partial Yes, N = No, n.a. = not applicable, as no meta-analysis was performed. (1) no indication of this in the text; (2) the germinal mal patch instrument could not be identified as sufficient for a pY or Y response; (3) use of MMAT (see AMSTAR-2 guidance document, Shea *et al.*, 2017); (4) leaned toward yes because publication bias discussed; (5) no indication of how conflicts of interest were handled.

the PRISMA checklist could not be applied due to the high heterogenity of primary studies and the limitation of having to do a meta-analysis.

Ellis *et al.* [13] and Inhestern *et al.* [29] applied the MMAT-quality tool [30] for evaluating the risk of bias. Alexander *et al.* [28▪▪] applied the Keim-Malpass-tool [31], but we could not find sufficient information. More details can be seen in Table 4.

Assessment of certainty of the evidence arising from the overview

The heterogeneity of primary studies is quite diverse, and primary studies with a qualitative or mixed-method approach were sometimes included. Therefore, the formalistic evaluation of the three reviews is low with Inhestern *et al.* receiving a better evaluation than the other two reviews. However, all three reviews applied the best scientific standards and therefore the quality evaluation in the current scientific context has to be regarded as the best possible.

Synthesis, presentation, and summary of findings

Due to the heterogeneous nature of the primary studies, all three selected reviews report the results of the individual studies on a case-by-case basis.

Alexander *et al.* [28▪▪] found positive results related to changes in children's depressive symptoms. Here, the components of psychoeducation, supportive counseling, improvement in coping skills, and communication seem to be helpful. However, this only refers to two of the eight studies. The authors point out that these components are broadly defined, and no study examines their specific contribution to the effect of the intervention. No significant results were found for the domain of children's anxiety by Alexander *et al.* [28▪▪] except in the domain of the subscale of cancer-related worry and in relation to the more general factor of psychological stress.

Ellis *et al.* [13] divide the included studies into categories of study design [qualitative, randomized controlled studies (RCT), and non-RCT]. Mixed-methods design studies are categorized as the most relevant to the data. The authors report positive outcomes in child and parent mood, child behavior, and family communication, with these improvements produced by interventions of varying duration and intensity. The nonsignificant results of the studies are mentioned only in the description of each study but are not revisited in the summary and discussion.

Inhestern *et al.* [29] divide the studies into the categories of family-centered, parent-centered, and

Table 3. Overview of the assessment of reviews using the PRISMA checklist (Moher *et al.*, 2009/2011)

Review Reported on page #			
PRISMA checklist question	**Alexander *et al.* (2019)**	**Ellis *et al.* (2017)**	**Inhestern *et al.* (2016)**
Title			
F1 Title identified as systematic review and/or meta-analysis	1812	1	1
Summary			
F2 Structured abstract with keywords as complete as possible (1)	1812 [6]	1 [6]	1–2 [6]
Introduction			
F3 Scientific background and rationale	1813	1	2–3
F4 Precise specification of the question with reference to PICOS (2)	1813	1 [6]	1 [6]
Methods			
F5 Specification of protocol and registration	n.r.	n.r.	3
F6 Selection criteria: characteristics of studies (PICOS) and reports (3)	1813	3	3 + S2
F7 Information sources (e.g., databases, contact with authors) with dates	1813	2–3	3
F8 Complete electronic search for at least one database	1813	3	S1
F9 Description of the study selection process (4)	1814	3–4	4–5
F10 Description of methods of data extraction from reports and data acquisition from investigators	1814	4	4–5
F11 Data details: listing and definition of all data	1816	4 ff.	5
F12 Methods for assessing risk-of-bias in studies	1814–15	3–4	5
F13 Key effect estimators	n.a.	n.a.	n.a.
F14 Description of the synthesis of results, meta-analysis if applicable	1815–16	4	5–6
F15 Risk-of-bias across studies (5)	n.a.	n.a.	n.a.
F16 Methods for additional analyses	n.a.	n.a.	n.a.
Results			
F17 Selection process of studies, preferably with flowchart	1814	4–5	6
F18 Representation of the features according to which data were extracted	1816	6ff., 9ff.	Tables 1–3
F19 Risk-of-bias within the studies	1815 p.p. [7]	6.ff. p.p. [7]	6/S3 p.p. [7]
F20 Presentation of the results of the individual studies	1815/16ff.	6ff., 9ff.	6–10; Tables 1–3
F21 Presentation of the meta-analysis	n.a.	n.a.	n.a.
F22 Risk-of-bias across studies	n.a.	n.a.	n.a.
F23 Results of possible additional analyses	n.a.	n.a.	n.a.
Discussion			
F24 Summary of main findings including strength of evidence and relevance to target groups	1819 [8]	15 [8]	15–17 [8]
F25 Discussion of study-level limitations, targeting criteria, overview	1817	18	15–17
F26 Interpretation of results, implications for further research	1820	18–19	17
Financial support			
F27 Sources of financial or other support; function of funders, if any	n.r.	19 p.p. [9]	17

n.a. = not applicable; n.r = not reported; p.p. = partially present. For the items: (1) background, objectives, data sources, selection criteria, participants and interventions, quality assessment, synthesis methods, results, limitations, conclusions; (2) P = population/participants, I = interventions, C = comparator group/comparisons, O = outcome/target criteria, S = study designs; (3) e.g., period of studies, language, publication status; (4) preselection, eligibility, inclusion in systematic review, meta-analysis if applicable; (5) e.g., publication bias, selective reporting within studies; for the responses: (6) not entirely complete; (7) limited, part of quality assessment, no classic RoB estimate as no meta-analysis; (8) naming certainty of evidence limited; (9) role of supporters* not described.

child-centered interventions. The authors report that participants perceived the interventions as helpful, and experienced positive outcomes in terms of quality of life, mental health/mental distress, improved understanding and more open communication among families.

Despite the heterogenity of primary studies, we conclude that interventions do have a positive

Table 4. Citation matrix to show the overlap of primary studies

	Authors/review	Alexander *et al.* (2019)	Ellis *et al.* (2017)	Inhestern *et al.* (2016)
1	Azarbarzin *et al.* [33]	X		
2	Davey *et al.* [34]	X	X	X
3	Hauken *et al.* [35]	X		
4	Kobayashi *et al.* [36]	X		
5	Lewis *et al.* [37]	X	X	X
6	Lewis *et al.* [38]	X		X
7	Shallcross *et al.* [39]	X		
8	Thatsum *et al.* [40]	X	X	X
9	Bugge *et al.* [41]		X	X
10	Bugge *et al.* [42]			X
11	Christ *et al.* [43]		X	X
12	Greening *et al.* [44]		X	
13	Heiney and Lesesne [45]		X	
14	John *et al.* [46]		X	X
15	John *et al.* [47]			X
16	Naudi [48]		X	
17	Semple and McCaughan [49]		X	X
18	Taylor-Brown *et al.* [50]		X	
19	Werner-Lin and Biank [51]		X	
20	Davis-Kirsch *et al.* [52]			X
21	Kissane *et al.* [53]			X
22	Kissane *et al.* [54]			X
23	Paschen *et al.* [55]			X
24	Niemela *et al.* [56]			X
25	Tucker *et al.* [57]			X

impact on children. A more specific analysis of the effects of each type of intervention could not be made.

CONCLUSION

The Cochrane Collaboration describe one of the aims of an overview to represent the body of evidence of existing systematic reviews. This aim could be met, even though an evidence summary proved difficult due to the heterogenity of the studies included. The recommendation building up on homogeneous reviews with high methodological quality in an overview could not be met. The factor of narrative synthesis of results can mitigate this circumstance somewhat. With the selection of the AMSTAR-2 instrument (quality of implementation) and the PRISMA checklist (quality of reporting), established and relatively well validated assessment instruments were chosen. Both are characterized by a detailed and differentiated consideration of different quality criteria.

Out of the 332 articles found in the literature search, three systematic reviews were included in the final analysis. Subsequent assessment of the methodological evaluation using the AMSTAR-2 checklist revealed a critically low quality for all three reviews [25]. However, taking into account the study situation of this scientific context, a more optimistic quality assessment with the result 'satisfactory' can be suggested. Shea *et al.* [6] emphasize that not only the AMSTAR-2 criteria should be taking into account, but the scientific context should also be considered. It should be mentioned that the quality of primary studies was very heterogeneous, so a systematic review will be limited in its quality. The quality of reporting for all three reviews was found to be good, as assessed by using the PRISMA checklist. The review by Inhestern *et al.* [29] scored slightly better than Alexander *et al.* [28▪▪] and Ellis *et al.* [13] in both the AMSTAR-2 and PRISMA quality ratings. Due to the lack of certainty in the evidence, no generalizable conclusions about the effectiveness of interventions could be made. However, the reviews report positive changes from the interventions in children's depressive and stress-related symptoms [28▪▪], in children's behavior and family communication [13], in quality of life,

psychological distress, and a better understanding of their parents' cancer [29]. Concerning the interventions, it can be cautiously concluded that those interventions that focus on the entire family system seem to be effective. The most common content components of interventions are as follows: Building coping skills, expressing/managing feelings, psychoeducation, and improving communication. Because the setting varied throughout the studies, no valid conclusions can be made about the appropriate duration of interventions. In addition, the interventions were experienced as helpful by the affected individuals themselves [29]. No changes were reported concerning anxiety [28▪▪].

The biggest challenge in this field of research is the implementation of reliable, valid studies that meet the criteria of children in a situation of existential threat, as well as maintaining high ethical standards. An intervention with a waiting control design has a considerable ethical dilemma.

It might be questioned whether an overview in this field is adequate. The Cochrane Collaboration's claim to use homogeneous reviews with high methodological quality in an overview could not be met [20▪]. However, the overview meets the requirement of clinical–psychological intervention development and research to align interventions with the current state of research [32] and care. Thus, our overview has the potential to provide input for the development of recommendations for action that could influence future guidelines for practice and research in this important field.

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Conflicts of interest

There are no conflicts of interest.

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- ▪ of special interest
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