Evidenztabellen zur Aktualisierung der S3-Leitlinie "Psychosoziale Versorgung in der pädiatrischen Onkologie und Hämatologie" (2019)

Bewertungskriterien (Details zum Bewertungsprozedere siehe auch Methodenbericht)

Study design

1 Systematic review or meta-analysis of controlled studies
2 Randomized controlled trial
3 Non-Randomized controlled trial
4 Observational study (cohort, cross/sectional, case-control)
5 Systematic review of descriptive or qualitative studies
6 Individual qualitative study
7 Expert opinion

- Forschungsfrage 1
- Forschungsfrage 2
- Forschungsfrage 3
- Forschungsfrage 4
- Forschungsfrage 5
- Forschungsfrage 6
- Forschungsfrage 7

Limitations - shortage of ...

sample size
sample characteristics (age, disease, gender)
control group
methods (materials, procedure)
data collection
statistical analysis
handling of missing data
sparse data
transparency of interpretation
review:
types of studies included
analysis of quality of studies
inclusion of relevant results
coherent conclusion

Limitation summery

no limitations
moderte limitations
major limitations

GRADE quality of evidence

⊕ very low
⊕⊕ low
⊕⊕⊕ moderate
⊕⊕⊕⊕ high

relevance for improvement of psychosocial

low
moderate
major

strength of recommendation

1 - weak
2 - weak
3 - strong
4 - strong

inclusion in guideline

already in guideline
new evidence/citation
new finding

Anmerkungen

Forschungsfrage (FF) 3

Aufgelistet sind Publikationen zur Forschungsfrage 3 (Belastungsfaktoren und Ressourcen). Von insgesamt 194 identifizierten Publikationen waren der Großteil Beobachtungsstudien (Fall-Kontroll-, Kohorten-, Querschnittsstudien, N=118). Aufgelistet sind hier diejenigen Studien, die von den BewerterInnen als sehr relevant für die psychosoziale Versorgung erachtet wurden, eine starke Empfehlung erhalten haben und im nachfolgenden Abstimmungsprozess von der Steuerungsgruppe in den Text eingearbeitet wurden. Die Bewertung aller anderen Publikationen aus Forschungsfrage 3 sind bei den Leitlinienkoordinatorinnen archiviert und können dort abgefragt werden.

Forschungsfrage (FF) 4

Aufgelistet sind Publikationen zur Forschungsfrage 4 (Diagnostik). Von insgesamt 117 identifizierten Publikationen waren der Großteil Beobachtungsstudien (Fall-Kontroll-, Kohorten-, Querschnittsstudien, N=95). Ein höheres Evidenzlevel erreichte nur 1 Studie (ransomisiert-kontrollierte Studie). Aufgelistet sind hier diejenigen Studien, die von den BewerterInnen als sehr relevant für die psychosoziale Versorgung erachtet wurden, eine starke Empfehlung erhalten haben und im nachfolgenden Abstimmungsprozess von der Steuerungsgruppe in den Text eingearbeitet wurden. Die Bewertung aller anderen Publikationen aus Forschungsfrage 4 sind bei den Leitlinienkoordinatorinnen archiviert und können dort abgefragt werden.

Evidenz für die Forschungsfrage 4 "Diagnostik" liefern auch die Standards 2 und 6 aus den *Pediatric psychosocial standards od care* (Wiener et al., 2015), siehe auch Anhang Methodenreport und Anhang D).

Forschungsfrage (FF) 6

Aufgelistet sind hier alle Publikationen zur Forschungsfrage 6 (Interventionen/Therapie) mit hohem Evidenzleveln (1-3). Sie wurden unter Berücksichtigung der Qualität der Evidenz sowie der Empfehlungsstärke nach Abstimmung der Steuerungsgruppe in den Text der Leitlinien eingearbeitet. Die Bewertung aller anderen Publikationen aus Forschungsfrage 6 sind bei den Leitlinienkoordinatorinnen archiviert und können dort abgefragt werden.

Evidenz für die Forschungsfrage 6 liefern auch einige Standards aus den *Pediatric psychosocial standards of care* (Wiener et al., 2015, siehe auch Anhang Methodenreport und Anhang D).

Forschungsfrage (FF) 7

Aufgelistet sind hier diejenigen Studien, die von den BewerterInnen als sehr relevant für Kernaussagen zur psychosozialen Versorgung in der Nachsorge erachtet wurden, dementsprechend eine starke Empfehlung erhalten haben und im nachfolgenden Abstimmungsprozess von der Steuerungsgruppe in den Text eingearbeitet wurden. Es handelt sich zum überwiegenden Teil um systematische Reviews.

Die insgesamt 427 Publikationen zur Forschungsfrage 7 (Nachsorge und Rehabilitation) sollen nach einer umfassenden Aufarbeitung aller identifizierten Studien in einer eigene Publikation münden, die über die Kernaussagen der Leitlinie hinausgeht (nähere Erläuterung siehe auch Methodenreport).

Evidenz für die Forschungsfrage 7 liefert auchStandard 3 aus den *Pediatric psychosocial standards of care* (Wiener et al., 2015, siehe auch Anhang Methodenreport und Anhang D).

Summery of evidence - research question 1

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
	Familiy-centered care							
1	Care that matters: Family-centered care, caregiving burden, and adaptation in parents of children with cancer	2016	Crespo, C.	Observational study (cohort, cross/sectional , case-control)	**4**		N=204 parents of children diagnosed with cancer (mothers=87.3%, leukemias 43.1%, solid tumors 22.5%, lymphomas 17.6%, CNS tumors 15.2%, LCH 1.5%; <13 52.5%, >12 47,5%, Mean age 11.19; time since diagnoses M=22.8 months), two hospitals	When parents perceived their children's health care as more family-centered, they also reported **lower caregiving burden**. Family-centered services were indirectly linked to QoL and life satisfaction through caregiving burden.
1	Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families.	2016	Lövgren, M.	Observational study (cohort, cross/sectional , case-control)	**4**	1 open-ended question from questionnaire was used for this study; content analysis	Nationwide Swedish survey of bereaved siblings, 174/240 (73%) participated. N=108 answered an open-ended question. Children diagnosed with cancer <17 years, died <25 years. Siblings: >17 years at time of data collection; 12-25 years at time of brother's/sister's death	The most common advice, suggested by 56% of siblings, **related to their own support.** One third suggested giving better medical information to siblings. Some siblings wanted to be more practically involved in their brother's/sister's care and suggested that HCPs should give parents guidance on how to involve siblings. Other common advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted. CONCLUSION: **Information, communication, and involvement should be emphasized by HCPs** to support siblings' psychosocial needs in both the health care setting and within the family.
	Communication, Shared decision-making							
1	Communication in pediatric oncology: State of the field and research agenda.	2017	Sisk, B.A.	Systematic review of descriptive or qualitative study	**5**		N=90 articles in the review	Overarching themes in this review included the persistence of information need over time, the desire for communication that ist honest, sensitive, polite, empathetic and hopeful - and the finding that high-quality communication is associated with parental peace of mind, feeling acknowledged and comforted and greater trust in physician. Parents desire honesty while maintaining hope . All studies were descriptive or correlational; none were studies of intervention; few studies addressed "managing uncertainty" or enabling patient/family self-management; **Only few studies included child's perspective.** Further work should also address the **development of multidisciplinary communication models.**
1	Strategies to facilitate shared decision-making about pediatric oncology clinical trial enrollment: A systematic review.	2018	Robertson, E.G.	Systematic review of descriptive or qualitative study	**5**	results and discussions coded line-by-line using nVivi software	N=17 studies (1990-2017)	Articles quality scores ranged from 50-100% (MMAT). Most (n=10) moderate-high 75%. Five main themes emerged: 1) decision-making as a process, 2) individuality of the process; 3) information provision, 4) the role of communication, or 5) decision and psychosocial support. Families should have adequate time to make a decision. HCPs should elicit parents' and patients' preferences for level of information and decision involvement. Information should be clear and provided in multiple modalities. Articles also recommended providing training for healthcare professionals and access to psychosocial support for families.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Familiy-centered care																					
Care that matters: Family-centered care, caregiving burden, and adaptation in parents of children with cancer	1		1												Participants mainly mothers; the ways in which the two hospital sites operationalized FCC are not covered in the study; size of the outcomes' explained variance was statistically modest.	**4**	moderate limitations	⊕ ⊕	major	**3**	new evidence/citation
Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families.															possible recall bias?	**4**	no limitations	⊕ ⊕ ⊕	major	**4**	new evidence/citation
Communication, Shared decision-																					
Communication in pediatric oncology: State of the field and research agenda.																**5**	no limitations	⊕ ⊕	major	**4**	new evidence/citation
Strategies to facilitate shared decision-making about pediatric oncology clinical trial enrollment: A systematic review.															quality of included articles was assessed with the Mixed-Methods Appraisal Tool (2 authors)	**5**	no limitations	⊕ ⊕	major	**4**	new finding

Summery of evidence - research question 1

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	Patients' and parents' views regarding supportive care in childhood cancer	2017	Tenniglo, L.J.A.	Individual descriptive or qualitative study	**6**	two traditional focus groups, one online focus group	N=11 adolescent patients (12-18 years, M=15; ALL=54,5, STT 27,3%, Bone tumor/Brain tumor: 9,1%), N=18 parents (9 fathers, 9 mothers, diagnoses of child 50% ALL; 11% bone tumor, 11% brain tumor, 22% SST…) of 2 dutch pediatric oncology centers	Topics of major importance were communication between patient and physician (commitment, accessibility, proactive attitude of physicians), well-timed provision of information, and the suitability and accessibility of psychosocial care. In contrast to prioritized supportive care topics by medical professionals, somatic issues (e.g., febrile neutropenia) were infrequently addressed. Patients and parents preferred to be actively involved in decision making in selected topics, such as choice of analgesics and anti-emetics, but not in, e.g., choice of antibiotics.
1	Information-sharing between healthcare professionals, parents and children with cancer: more than a matter of information exchange	2016	Coyne, I.	Individual descriptive or qualitative study	**6**	constructivist grounded theory method: individual interviews, constant comparative method	Singe-center study: cancer center in Southern Ireland; N=20 patients (7-16 years, 45% female, 30% Leukaemia, 20% CNS tumors, 25% sarcomas, 20% lymphomas; time from diagnoses 1-3 to 9-12 months); N=22 parents (77% female); N=40 health care professionals (50% nurses, 40% Physician, N= 2 social workers; N=1 Play specialist, N=1 Dietician)	The findings indicate that professionals strongly supported an open and honest approach to information-sharing; however, this viewpoint was not shared by all parents. The need to maintain hope and spirit and promote an optimistic identity influenced the amount and type of information shared by parents. Children trusted their parents to share information, and valued their parents' role as interpreters of information, advocates, and communication buffers. This study adds important insights into the complexities of information-sharing in triadic encounters. Professionals need to maintain an open mind about information-sharing strategies families may choose, remain sensitive to parents and children's information requirements and adopt a flexible approach to information provision.
1	Educating Families of Children Newly Diagnosed With Cancer	2016	Haugen, M.S.	Individual descriptive or qualitative study	**6**	3 Delphi rounds	Round 1: N=125 (80% nurses, 7% psychosocial professionals etc.), participation in Round 2: 93.3% (of N=60), Round 3: 73.3% (more than 10 years experience in pediatric oncology	The study provides multidisciplinary consensus regarding key content essentials for inclusion in **discharge education** for newly diagnosed pediatric oncology (for all and for specific groups). Psychosocial issues are listed in the top 18 topics, cognitive limitations and Rehabilitations are listed as additional topics für CNS tumor patients.
1	Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study.	2016	Bahrami, M.	Individual descriptive or qualitative study	**6**	qualitative descriptive-exploratory study	N=33 (adolescents 15-20 years=12, parents=6, oncologists=6, nurses=6)	Findings show that adolescents with cancer prefer to participate in the information-sharing process; they are faced with difficult obstacles such as their parents attitude and concerns, the culture and the medical team's shortage of time. Information-sharing process needs to be gradual and based on adolescent's need and mental capacity . It should count for familial and cultural factors.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transparency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Patients' and parents' views regarding supportive care in childhood cancer															possible selection bias due to purposive sample	**6**	moderate limitations	⊕ ⊕	major	**3**	new evidence/citation
Information-sharing between healthcare professionals, parents and children with cancer: more than a matter of information exchange	1														Limited generalisability due to single center study; predominance of nurses and physicians in HCP group - only 3 psychosocial professionals	**6**	moderate limitations	⊕ ⊕	major	**3**	new finding
Educating Families of Children Newly Diagnosed With Cancer	1														participants are 80% nurses; perspective may be different for psychosocial professionals	**6**	major limitations	⊕	moderate	**2**	
Information-sharing challenges between adolescents with cancer, their parents and health care providers: a qualitative study.	1														limited generalizability	**6**	major limitations	⊕	major	**2**	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
	Children, Adolescents, Young Adults							
1	Psychosocial Outcomes of Sharing a Diagnosis of Cancer with a Pediatric Patient	2016	Raz, H.	Observational study (cohort, cross/sectional , case-control)	**4**		N=91 adult cancer survivors (divided in 2 groups: diagnosed <12 years; diagnosed 12-18 years); N=41 female; Lymphoma 45%; Leukaemia 23%, other diagnoses 32%; mean age at diagnoses 12 years; mean current age 26 years; mean time since end of treatment: 13 years	In the group diagnosed at a younger age, those who had received "good information" (information content, timing, source) were found to have better quality of life, lower mental pain, and higher mental pain tolerance than did those in the same group (diagnosed at a younger age) who received "not good information." By contrast, in the group diagnosed during adolescence, those who had received "not good information" scored higher on these measures than did their counterparts who had received "good information." Given that information conveyed to children diagnosed with cancer can have a significant impact on survivors' quality of life, further research is needed to determine the precise information to be divulged to children at the time of diagnosis. **In the meantime, extreme caution, sensitivity, and careful judgment are required.**
1	Attitudes, Beliefs, and Trends Regarding Adolescent Oncofertility Discussions: A Systematic Literature Review	2016	Barlevy, D.	Systematic review of descriptive or qualitative study	**5**		N=96 articles	Adolescents and parents have similar informational and counseling needs. Both seek to be fully informed about cancer treatment's effects on fertility and FP options. Adolescents have varying experiences of oncofertility discussions and decision making due to sex and/or age differences. Parents and healthcare professionals **alike sometimes underestimate the importance of fertility for adolescent cancer patients.**
1	Adolescents' preferences for treatment decisional involvement during their cancer.	2015	Weaver, M.S.	Individual descriptive or qualitative study	**6**	Semantic content analysis, likert scale decisional preference score, teen advisory council	N=40 adolescents (12-18 years, 3 centers)	Adolescents indicated a spectrum of preferred decisional roles, with the most common being an actively involved role (26 of 40 or 65%), although a shared decision-making approach was still valued. Adolescents recognized that situational and social contexts might shift their preferred level of involvement in medical decisions. Although adolescents wanted to be involved in decisions, they also expressed an appreciation of family insight, parental presence, and clinician guidance.
1	Identifying a conceptual shift in child and adolescent-reported treatment decision making: "Having a say, as I need at this time"	2016	Kelly, K.P.	Individual descriptive or qualitative study	**6**	descriptive qualitative research methods	N=29 children (9-17 years) diagnosed with cancer with variable ages, gender, diagnoses, time since diagnoses, treatment experience; purposive sampling; Single-center	Children's contextually related 'Having a Say' preferences ranged from not wanting to hear information at this time, to being included in treatment discussions, to choosing a treatment option. Children reported both positive and negative effects of being involved (or not) in treatment discussions as they preferred. Children's preferences assumed the presence and involvement of their parents and doctors. Illness conditions (e.g., stage of treatment; symptom distress) informed child communication preferences more so than the child's age. The 'Having a Say' construct challenges the dominant shared TDM paradigm, which presumes it is best to involve children in their treatment decisions. Child and adolescent views of their TDM are more nuanced, children should have the right to choose not to know or not to be engaged at a given time.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Children, Adolescents, Young Adul																					
Psychosocial Outcomes of Sharing a Diagnosis of Cancer with a Pediatric Patient									1						retrospective study asked participants to answer according to recollection	**4**	moderate limitations	⊕ ⊕	major	**3**	new finding
Attitudes, Beliefs, and Trends Regarding Adolescent Oncofertility Discussions: A Systematic Literature Review														1	Studies included in recommendations are not necessarily generalizable (small sample size, pilot...); "western perspective"	**5**	moderate limitations	⊕ ⊕	major	**3**	new finding
Adolescents' preferences for treatment decisional involvement during their cancer.																**6**	no limitations	⊕ ⊕	major	**4**	new finding
Identifying a conceptual shift in child and adolescent-reported treatment decision making: "Having a say, as I need at this time"															findings are based on retrospective accounts; differences in age and course of child's illness can not be determined yet; however, careful attention to ensuring the trustworthiness of findings (methodological approach)	**6**	major limitations	⊕	major	**4**	

Summery of evidence - research question 1

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	A participatory study of teenagers and young adults views on access and participation in cancer research	2016	Taylor, R.M.	Individual descriptive or qualitative study	**6**	participatory methods during a one-day workshop (role play, focus group etc.)	N=8 young people (18-25) with a previous cancer diagnosis aged 15-24; further consultation with 222 young people with cancer was conducted using an electronic survey (patient conference).	Further consultation showed approximately 70% wanted to find out about all available research. Workshops: 3 themes emerged: (1) Patient choice ("right to know all options"); (2) Young people suggested that non-clinical healthcare professionals should approach them about participation in research; (3) the what, when and how information was delivered was the key to assist young people in their decision. -> health care professionals need to be supported approaching vulnerable populations about research, in order to empower young people to make informed choices about research participation and to avoid inappropriate professional gate-keeping.
1	Preparing for the future: An examination of healthcare provider and patient communication regarding childhood cancer survivorship.	2015	Lamanna, J.	Individual descriptive or qualitative study	**6**	constructivist-interpretivist pradigm, audio recording and transcription, purposive sampling	N=16 childhood cancer patients (75% male, 10-22 years, mean age=16.68, Leukaemia=56%, Sarcome=19%, CNS tumor=6%); N=7 Health care professionals (N= 4 physicians, N=3 nurses, 86% female), single-center	HCP addressed more medically focused than psychosocially focused issues related to survivorship. Psychologists working in pediatric oncology settings are in excellent position to promote HCP/CCP communication on survivorship issues.
1	Children with cancer share their views: tell the truth but leave room for hope	2016	Jalmsell, L.	Individual descriptive or qualitative study	**6**	semi-structured individual interviews, analysis with systematic text condensation	N=10 children with cancer (7-17 years; single center, in active treatment)	All children expressed that they wanted truthful information and they did not want to be excluded from bad news regarding their illness. *Receiving honest and straight forward information while still being allowed to maintain hope. *Receiving information at the same time as their parents. * Receiving information at a level appropriate for the child.
1	Communication preferences of pediatric cancer patients: talking about prognosis and their future life	2017	Brand, S.R.	Individual descriptive or qualitative study	**6**	Semi-structured Interviews, directed content analysis	N=16 (mean age 13.7; 8-17 years; 56% female; 80% of those approached participated; 81% hematologic malignancy; single center)	While most pediatric cancer patients want to be involved in conversations about their cancer care, including conversations about prognosis, this is an individual and sometimes fluctuating decision, and healthcare providers should be encouraged to discuss preferences for involvement with patients and families. Participants wanted medical information to be provided to them by their healthcare providers and wanted to be direct participants in medical conversations. However, many participants displayed some ambivalence or conveyed conflicting wishes for prognostic information. For example, some participants reported that they were satisfied with what they knew, but later raised lingering questions. Open conversation anbout where to find accurate information online is recommended.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
A participatory study of teenagers and young adults views on access and participation in cancer research	1														Participants of workshop are a group of self-selected, research-aware young people; may not reflect other young people	**6**	moderate limitations	⊕ ⊕	major	**3**	new finding
Preparing for the future: An examination of healthcare provider and patient communication regarding childhood cancer survivorship.	1		1												smale sampling of HCP/PPC communication over the course of treatment and survivorship; wide range of time during which communication was observed; age heterogeneity of participants may have biased types of psychosocial topics	**6**	major limitations	⊕	major	**2**	
Children with cancer share their views: tell the truth but leave room for hope	1														small sample size; responses were remarkable similar	**6**	major limitations	⊕	major	**2**	
Communication preferences of pediatric cancer patients: talking about prognosis and their future life	1														small sample, single center, 80% hematologic malignancies	**6**	major limitations	⊕	major	**2**	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	Refinement of a Conceptual Model for Adolescent Readiness to Engage in End-of-Life Discussions.	2018	Bell, C.	Individual descriptive or qualitative study	**6**	2 in-depth cases	N=2	We proposed a linear process of readiness with 3 domains: a cognitive domain (awareness), an emotional domain (acceptance), and a behavioral domain (willingness), which preceded preparedness. RESULTS: Findings led to conceptual model refinement showing readiness is a dynamic internal process that interacts with preparedness. Current awareness context facilitates the type of preparedness discussions (cognitive or emotional). Furthermore, social constraint inhibits discussions.
1	Ethical Barriers in Adolescent Oncofertility Counseling	2016	Runco, D.V.	expert opinion	**7**		not applicable	Dealing with fertility is a tremendous burden as a part of cancer treatment and raises a significant number of ethical dilemmas. most prominent areas are discussed and examples how to address fertility preservation based of identified barriers are included.
	Parents							
1	Processing Information After a Child's Cancer Diagnosis-How Parents Learn.	2016	Rodgers, C.C.	Individual descriptive or qualitative study	**6**	individual interviews, constant comparative analysis	N=20 parents of children diagnosed with cancer in 4 US-centers at least 2 but no more than 12 months prior to study participation; purposive sampling until theoretical redundancy occurred (no new information and information did not change conclusions that had already been reached.	The insights of the study emphasizes the need for HCPs to be aware of how they provide education (in particular in regard to pacing and consistency of information). Preferred methods of learning should be identified early, parents benefit from anticipatory guidance. Education should be an ongoing process.
1	Parents' Challenges and Physicians' Tasks in Disclosing Cancer to Children. A Qualitative Interview Study and Reflections on Professional Duties in Pediatric Oncology.	2015	Badarau, D.O.	Individual descriptive or qualitative study	**6**	semi-structured interviews	N=18 parents of children with cancer; N=10 physicians - 3 pediatric units in Romania	Although physicians need to respect the wishes of children's legal representatives, they also have a duty to promote patients' best interests. We recommend that physicians employ a proactive stance in ensuring that children with cancer are appropriately informed about their diagnosis. In case of parents' arduous objections to full disclosure, an ethical consultation should be considered.
1	Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution.	2016	Snaman, J.M.	Individual descriptive or qualitative study	**6**	focus group; qualitative semantic content analysis (MaxQDA software)	N=12 bereaved parents from 1 oncology institution; death of child: 1.5 to 14 years prior to participation in focus group	Parents' responses to the prompt about typical ways the medical team communicated yielded 109 codes, which were grouped into 12 themes. The most common themes were "patient inclusion" and "explanation of medical plan," both used in 17% of responses. Responses to the prompt about positive and negative aspects of communication generated 208 codes, yielding 15 different themes. The most common theme about positive communication was the "strong relationship between family and staff." The theme "variations in care with a negative impact" was used most frequently in describing negative communication.

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Refinement of a Conceptual Model for Adolescent Readiness to Engage in End-of-Life Discussions.	1															**6**	major limitations	⊕	moderate	**1**	
Ethical Barriers in Adolescent Oncofertility Counseling																**7**	major limitations	⊕	major	**2**	
Parents																					
Processing Information After a Child's Cancer Diagnosis-How Parents Learn.															Study sample includes only parents of children on an inpatient oncology unit and children in the study were hospitalized two weeks or longer. Other patient groups (e.g. outpatients) should be the focus in future studies.	**6**	moderate limitations	⊕ ⊕	major	**3**	new finding
Parents' Challenges and Physicians' Tasks in Disclosing Cancer to Children. A Qualitative Interview Study and Reflections on Professional Duties in Pediatric Oncology.	1														limited generalizability: small sample, center-specific cultural factors, possible selection bias; perspective of children is missing	**6**	major limitations	⊕ ⊕	moderate	**2**	
Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution.	1														small sample from 1 center	**6**	major limitations	⊕	major	**2**	

Summery of evidence - research question 1

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys.	2016	Snaman, J.M.	Individual descriptive or qualitative study	**6**	focus groups	N=11 (85% of the recruited); 82% mothers; First focus group: death of child M=6 years prior; 2nd focus group M=4.8 years prior;	Four main concepts were identified within the parental narratives, including the importance of strong and ongoing relationships between providers and bereaved families, the importance of high-quality communication, the effect of negative experiences between providers and families on parental grief, and the importance of the institution's role in the grief journeys of bereaved parents.
1	Just gripping my heart and squeezing': Naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting.	2017	Nelson, M.	Individual descriptive or qualitative study	**6**	emotional touchpoint storytelling	4 bereaved families	Recipients perceive their emotional experiences as mainly originating from the news itself, and perceived consequences of it, rather than its delivery. Strong emotional reactions during the interaction are not necessarily an indicator of ineffectual delivery. Findings provides support for the importance of providing time, focused attention an d repeated opportunities to ask questions in the practice of breaking and news.
1	Evaluation of parents' decision-making in oncologic pediatric treatment.	2016	Bandinelli, L.	Individual descriptive or qualitative study	**6**	cross-sectional descriptive study of mixed approach, questionnaires and semi-structured individual interviews	N=10 parents (of 12 invited) of pediatric cancer patients (3-17 years, mean age=7.8; 70% ALL); 90% mothers	It was observed that, in spite of emotional difficulties, parents have proved able to decide on issues related to the treatment of their children, having enough autonomy for decision-making.
1	The Information Needs of South African Parents of Children With Cancer	2016	Maree, J.E.	Individual descriptive or qualitative study	**6**		N=13 parents of academic hospital in Johannesburg	Four themes emerged from data: shock of the diagnosis, information needs about the disease and investigation, living with the treatment and communication of the information; there was no consensus on which information was needed at specific points in time and parents had different opinions on how information should be made available to them.
1	I have to live with the decisions I make': laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses	2017	Bluebond-Langer, M.	expert opinion	**7**		not applicable	Description and recommendation of an approach to engage parents in conversations about care and treatment that recognises and appreciates the dilemmas which clinicians and parents face and in so doing provides a way for everyone to live with the decisions that are made.
	Relationship Health-Care-Provider - Patient							
1	The Doctor-Patient Relationship in the Adolescent Cancer Setting: A Developmentally Focused Literature Review	2015	Siembida, E. J.	Systematic review of descriptive or qualitative study	**5**		N=25 articles included in review (from 1268 identified)	Three important conclusions emerged: (1) discrepancies among adolescent patients, parents, and providers about the desired extent of involvement in treatment-related decisions; (2) patient desire for developmentally and culturally appropriate information provision; and (3) the desire and preference for how information is delivered, with recognition that these preferences may change with age.

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys.	1														reduced generalizability due to small sample, single-institution	**6**	major limitations	⊕	moderate	**2**	
Just gripping my heart and squeezing': Naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting.	1														small numbers, one center-study - limited generalizability	**6**	major limitations	⊕	moderate	**2**	
Evaluation of parents' decision-making in oncologic pediatric treatment.	1														small sample, single-center	**6**	major limitations	⊕	moderate	**1**	
The Information Needs of South African Parents of Children With Cancer	1														only small South African population of 1 institution, cared for by the same health care team was studied; different childhood cancers, different treatment phases;	**6**	major limitations	⊕	moderate	**1**	
I have to live with the decisions I make': laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses																**7**	major limitations	⊕	moderate	**2**	
Relationship Health-Care-Provider - Patient																					
The Doctor-Patient Relationship in the Adolescent Cancer Setting: A Developmentally Focused Literature Review																**5**	no limitations	⊕ ⊕	major	**3**	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	Towards understanding problems in the parent-practitioner relationship when a child has cancer: meta-synthesis of the qualitative literature	2016	Davis, S.	Systematic review of descriptive or qualitative study	**5**		N= 10 papers for meta-study	All papers but one conceptualised problems in the parent-practitioner relationship as conflict or relational problems, attributing these to differences between parents and practitioners in roles and perspectives, or in power and authority. Only little consideration of psychological factors (e.g. conflict as a consequence of parental fear). This review exposed potential influence of researcher's prior assumptions on their methods and therefore on their findings.
1	Relationships between oncohematopediatrics, mothers and children in communicating bad news	2017	Afonso, S.B.	Individual descriptive or qualitative study	**6**	participant observation and open interviews	N=5 doctors, N=4 residents, N=5mothers of children under treatment; more than 100 hours of observation; single center	The main results showed: intense exchanges on BN among professionals; relapse of children who were evolving positively as the most difficult news; constant update of BN facing terminally ill children; quality of communication influencing the treatment; professionals permanently balancing between closeness and distance from patients and evidence of the their irreplaceable role to secure the family and the child
	Transcultural care							
1	Facading in transcultural interactions: examples from pediatric cancer care in Sweden	2016	Pergert, P.	Systematic review of descriptive or qualitative study	**5**	secondary analysis of data	second analysis of 5 focus groups with health care professionals (N=35), individual interviews with nurses (n = 12) and foreign-born parents (n = 11)	**Facading** emerged as the **core category** and is the act of showing an outer appearance that will influence other people's interpretations. In transcultural interactions, facading might be misinterpreted because of different meanings of facading across cultures. A lack of awareness of one's own facading and possible interpretations can constitute obstacles to transcultural caring relationships. Conclusion: General knowledge of the culture ist not enough but transcultural learning includes knowledge of the individual patient. To gain a true dialogue communication tools such as interpreters could be used.
	Psychosocial Standard of Care							
1	Psychosocial standards of care for children with cancer and their families: A national survey of pediatric oncology social workers	2018	Jones, B.	Observational study (cohort, cross/sectional , case-control)	**4**	Survey; single-group design	N=107 pediatric oncology social workers; 81 institutions, 30 US states	Social work provided at most institutions, primarily by social workers and child life specialists; many of the 2015 Standards are not being systematically implemented; areas for improvement: funding for psychosocial support staff and programs, incorporation of standardized assessment measures, assessment for financial burden throughout treatment and beyond, consistent access to psychology and psychiatry, integrated care for parents and siblings, more inclusion of palliative care services from time of diagnosis.
1	Pediatric psycho-oncology care: standards, guidelines, and consensus reports	2015	Wiener, L.	Systematic review of descriptive or qualitative study	**5**		N=27 articles about psychosocial care (1980-2013): 5 standards, 19 guidelines, 3 consensus-based reports;	None was sufficiently up tp date, comprehensive, specific enough, or evidence- or consensus-based to serve as a current standard for psychosocial care.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Towards understanding problems in the parent-practitioner relationship when a child has cancer: meta-synthesis of the qualitative literature																**5**	major limitations	⊕	moderate	**3**	
Relationships between oncohematopediatrics, mothers and children in communicating bad news	1				1										small sample in single center; presentation of methodology and results not completely transparent (description of participants, results of observations vs. results of interviews)	**6**	major limitations	⊕	moderate	**1**	
Transcultural care																					
Facading in transcultural interactions: examples from pediatric cancer care in Sweden														1	small sample size of analyses studies	**5**	moderate limitations	⊕ ⊕	moderate	**3**	new evidence/citation
Psychosocial Standard of Care																					
Psychosocial standards of care for children with cancer and their families: A national survey of pediatric oncology social workers															Multiple responses from 17 institutions; self-report data; cross-sectional (snapshot); results do not capture the level/quality of care provided in delivery of each Standard	**4**	no limitations	⊕ ⊕	major	**4**	new finding
Pediatric psycho-oncology care: standards, guidelines, and consensus reports																**5**	no limitations	⊕ ⊕	major	**4**	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	The Impact of Cancer and its Treatment on the Growth and Development of the Pediatric Patient	2017	Brand, S.	expert opinion	**7**	Non-systematically review	not applicable	Providing education, anticipatory guidance, and individualized support to child and their families is a psychosocial standard. Pediatric patients of all ages cope and adjust better to all phases of treatment when their care is delivered in a developmentally-informed and psychosocially thoughtful way. An integrated multidisciplinary psychosocial support team is facilitative in anticipating and meeting the needs of pediatric cancer patients and has recently become a psychosocial standard of care.
	Others							
1	The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase	2015	Kars, M. C.	Individual descriptive or qualitative study	**6**	multicenter qualitative study; second individual interviews, with one or both parents, were held in seven cases (n=12) and in one case a third interview (parental process); 37 interviews in palliative phase, 20 soon after the child's death	N=34 (in total 57 interviews), female=17(50%), age: <30=2(5.9%), 30-39=17(50%), 40-49=14(41.2%), >50=1(2.9%) child: female=7(41%), age: <1=2(11.8%), 1-4=5(29.4%), 5-11=5(29.4%), 12-15=3 (17.6%), >16=2(11.8%) Leukemia/Lymphoma=6(35.3%), Medulloblastoma=2(11.8%), Neuroblastoma=1(5.9%), Renal tumor=1(5.9%), Hepatocellular carcinoma=2(11.8%), bone tumor/soft tissue sarcoma=4(23.5%), Germ cell tumor=1(5.9%)	3 aspects played a role in the parents ability to represent "the voice of the child" **(1)** the context in which parents had access to "the voice of the child": - involvement in the child's life: as a parent, and because of their intense involvement in their child's life, they knew and could understand what the child needed - feeling responsible for paying attention to the child's voice: most considered it a part of parenthood to be aware ofthe child's perspective, to pay attention to it, and to provide support and guidance in response to the child's signs (2) strategies to **understand the child's inner perspective:** - direct (asking the child directly) and indirect strategies (spontaneously said by the child (in the past), nonverbal signs, ..) - deciding on which strategy to use: indirect were the least onerous for the child but required efforts from the parents; asking is the most direct and reliable way but parents sometimes feel some reticence about starting a conversation --> tendency to use indirect strategies, in both very young and very ill children (3**) taking the child's perspective into account:** -diversity in putting forward "the voice of the child": Some parents hardly addressed their child's perspective at all, even when asked for it, whereas others spontaneously put forward the child's perspective again and again. - threatened by the child's perspective: parents could acknowledge the child's perspective as long as it was not too threatening for the parents themselves. --> an open communication is helpful for both child and parents, even in EOL situations

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
The Impact of Cancer and its Treatment on the Growth and Development of the Pediatric Patient																7	major limitations	⊕	major	**2**	
Others																					
The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase									1						Analysis was conducted post-hoc- the data collection was aimed primarily at exploring the “lived” experience of parents. Parents were not asked directly to reflect on their ability to take the child’s perspective into account.	6	moderate limitations	⊕ ⊕	moderate	**3**	new evidence/citation

Summery of evidence - research question 1

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample	findings
1	Good death for children with cancer: a qualitative study.	2015	Ito, Y.	Individual descriptive or qualitative study	**6**	In-depth interviews, qualitative content analysis	N=10 pediatric cancer survivors, N=10 bereaved family members, N=20 medical professionals (oncologists, nurses, psychologists, palliative care physicians, music therapists, teachers, rehabilitation staff)	Thirteen characteristics of a good death were identified: (i) sufficient opportunities to play freely, (ii) peer supporters and (iii) continued access to the patient's usual activities and relationships were found to be most important. The findings suggest the importance of providing an environment that is as similar as possible to patients' ordinary lives.

Summery of evidence - research question 1

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Good death for children with cancer: a qualitative study.	1														Small sample size; none of the participants was actually dying pediatric cancer patient	**6**	major limitations	⊕	moderate	**2**	

research question	title of study	year of publication	first author	study design	remark on study design	sample
	Palliative care: Structure, standards, education					
2	Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review	2016	Weaver, M.S.	Systeamtic review or meta-analysis of controlled studies	lack of global generalization, lack of diversity of perspective and selection bias for most of reviewed studies	Out of 216 studies identified -> N=72 papers were included
2	Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology.	2017	Levine, D.	Observational study (cohort, cross/sectional, case-control)		N=129 patient-parent dyads (N=61 girls; Mean age=14.0; Braintumor 16%, Leukemia=29%, Lymphoma=20%, Solid Tumor=32%; time since diagnoses=1-12 months; N=114 mothers); 3 sites; 92.1% positive response rate
2	A prospective study on the characteristics and subjects of pediatric palliative care case management provided by a hospital base palliative care team	2017	Jagt-van Kampen, C.T.	Observational study (cohort, cross/sectional, case-control)	hree month prospective stud	N=455 contacts with parents of N=70 parents (27 malignant disease, 43 non-malignant disease)
2	Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team.	2015	Kassam, A.	Observational study (cohort, cross/sectional, case-control)		N=75 bereaved parents (response rate 54% of 140 eligible parents; mothers=81,3%); Median age of children at diagnosis = 6 yrs;
2	Summary of Pediatric Palliative Care Team Structure and Services as Reported by Centers Caring for Children with Cancer	2018	Weaver, M.S.	Observational study (cohort, cross/sectional, case-control)		N=142 surveys from 18 countries and 39 states
2	Mental Health Services for Parents Who Lost a Child to Cancer: If We Build Them, Will They Come?"	2015	Lichtenthal, W. G.	Observational study (cohort, cross/sectional, case-control)	multicenter study	N=120 bereaved parents between 6 months and 6 years after their loss
2	Constitution of a New Specialised Pediatric Home Care Team - First Year Experience	2016	Hauch, H.	Observational study (cohort, cross/sectional, case-control)	Documentation of the structure of the palliative team for children; retrospective evaluation of patient data	N=35 (45%=Oncology; 55% other chronic disease); Age: 0,3-29, M=11,7

Summery of evidence - Research question 2

title of study	findings
Palliative care: Structure, standards, education	
Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review	A standardized approach the benefits who whole and yet can be tailored to the individual should be considered. Youth with cancer and their families should be introduced to palliative care concepts early in the disease process, regardless of disease status. They should receive longitudinal psychosocial support and developmentally appropriate end of life care in a standardized format with the flexibility of individualization.
Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology.	Pediatric oncology patients experience a high degree of symptom-related suffering early in cancer therapy, and very few patients or parents in this study expressed negative attitudes toward early palliative care. Palliative care was first defined as: a group of clinicians with expertise in symptom management and a goal of improving QoL; after learning that PC teams also provided end-of-life care are participants (15% of patients, 14,7% of parents) reported that this would have made them less willing to meet with a PC team. 26.4%/17.8% indicated it would make them more willing. Children were significantly more likely to endorse PC intervention if pain or symptom management was a problem. Our findings suggest that pediatric oncology patients and families might benefit from, and are not a barrier to, early palliative care integration in oncology.
A prospective study on the characteristics and subjects of pediatric palliative care case management provided by a hospital base palliative care team	All different disciplines of the PPCT were regularly consulted, except for the chaplain. With an easy accessible team with a highly pro-active approach, availability from 8 am to 9 pm seems sufficient to accommodate patient's and parent's needs. More anticipation seems required for socio-economic topics. This insight in pediatric palliative case management can provide guidance in the development of a new PPCT.
Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team.	Parents were significantly more likely to receive five communication elements if their child was referred to a palliative care team. These elements are: discussion of death and dying with parents by the healthcare team ($P<0.01$); discussion of death and dying with child by the healthcare team when appropriate ($P < 0.01$); providing parents with guidance on how to talk to their child about death and dying when appropriate ($P < 0.01$); preparing parents for medical aspects surrounding death ($P = 0.02$) and sibling support ($P = 0.02$). Children were less likely to be referred to a palliative care team if they had a hematologic malignancy.
Summary of Pediatric Palliative Care Team Structure and Services as Reported by Centers Caring for Children with Cancer	Children and adolescents with cancer do not yet receive concurrent palliative care as a universal standard. Three-fourths of sites reported having a PPC program available for the pediatric cancer population at their center. Six percent of respondents perceived pediatric oncology patients and their families "always" were introduced to palliative care concepts and 17% reported children and families "always" received communication about palliative principles. The most prevalent barriers to palliative care were at the provider level.
Mental Health Services for Parents Who Lost a Child to Cancer: If We Build Them, Will They Come?"	Forty-one percent of bereaved parents were currently using mental health services (talk therapy, psychotropic medication, and/or a support group), most commonly within the first 2 years after their loss. Talk therapy was the most frequently used service, although 36% of parents who discontinued therapy did so because it was not helpful. Forty percent of parents who wanted bereavement support reported they were not receiving services. The most common barriers to service use were that it was too painful to speak about the loss (64%) and too difficult to find help (60%). Barriers to service use must be addressed, particularly for those with more debilitating grief symptoms and for minorities.
Constitution of a New Specialised Pediatric Home Care Team - First Year Experience	Successful realization of a palliative team for children is possible in a short time. The need for social counseling, hospice care, nursing and psychological support has been assessed to be significantly higher than existing care services, in particular psychological support (= coverage gap of a clinically-counseled palliative psychologist involved in the team).

Summery of evidence - Research question 2

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transparency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Palliative care: Structure, standards, education																					
Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review																1	moderate limitations	⊕ ⊕ ⊕	major	3	new finding
Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology.									1						cultural bias, recall bias	4	no limitations	⊕ ⊕ ⊕	major	4	new finding
A prospective study on the characteristics and subjects of pediatric palliative care case management provided by a hospital base palliative care team															single center	4	moderate limitations	⊕ ⊕	major	4	new finding
Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team.									1						limited generalizability due to single institution study and possible selection bias	4	moderate limitations	⊕ ⊕	major	3	new finding
Summary of Pediatric Palliative Care Team Structure and Services as Reported by Centers Caring for Children with Cancer									1						response rate could not be calculated; survey relied on self-report rather than program investigation; possible selection bias	4	moderate limitations	⊕ ⊕	major	3	new finding
Mental Health Services for Parents Who Lost a Child to Cancer: If We Build Them, Will They Come?"	1														Possible healthy selection bias (parents who were excluded or declined may've been more distressed); no formal psychiatric diagnoses (data collection was self-report).	4	moderate limitations	⊕ ⊕	moderate	3	new evidence/citation
Constitution of a New Specialised Pediatric Home Care Team - First Year Experience	1		1												no standardized instruments	4	major limitations	⊕	major	3	

Summery of evidence - Research question 2

research question	title of study	year of publication	first author	study design	remark on study design	sample
2	What are Palliative Care Physicians for Adults Taught on Palliative Care for Children? Paediatric Aspects in Palliative Care Curricula for Adults	2016	Schiessl, C.	Systeamtic review of descriptive or qualitative study		N=30 out of 86
2	Parental experiences with a paediatric palliative care team: A qualitative study	2017	Verberne, L. M.	Individual descriptive or qualitative study	interviews, thematic analysis	N= 42 parents of 24 children supported by a multidisciplinary pediatric care team (Univ. children's hospital)
2	"Stories Take Your Role Away From You": Understanding the Impact on Health Care Professionals of Viewing Digital Stories of Pediatric and Adolescent/Young Adult Oncology Patients	2017	Laing, C. M.	Individual descriptive or qualitative study	philosophical hermeneutic approach - focus group	N=12 health care professionals from various disciplines and sites
2	Pediatric Oncology Providers’ Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor	2018	Szymczak, J.E.	Individual descriptive or qualitative study	semistructured qualitative interviews	N= 16; Gender: Female=12 (75); Area of practice: Neuro-oncology 3 (18.8); Bone marrow transplant 4 (25); Solid tumor 4 (25); General oncology 5 (31.3); Professional role: Attending physician 8 (50); Fellow physician 2 (12.5); Nurse practitioner 1 (6.3); Social worker 2 (12.5); Psychologist 2 (12.5);Child life specialist 1 (6.3)
2	Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families	2016	Kaye, E.C.	Expert opinion		not appilcable
2	Pediatric palliative oncology: the state of the science and art of caring for children with cancer	2018	Snaman, J. M.	expert opinion		

title of study	findings
What are Palliative Care Physicians for Adults Taught on Palliative Care for Children? Paediatric Aspects in Palliative Care Curricula for Adults	Worldwide 30 PCC were identified, with only 15 curricula mentioning any PaedPC issues. Developmental issues, special role of parents, ethical issues etc. were seldom mentioned. Basic aspects of pediatric palliative care as an "add-on" to adult palliative care is insufficient. Ideal goal is that children should be cared for by PaedPC teams.
Parental experiences with a paediatric palliative care team: A qualitative study	Parents valued (I) continuity and coordination of care and reliable point of contact, (II) pracitical support an (III) team member's sensitive and reliable attitude. Parents increasingly valued team over time.
"Stories Take Your Role Away From You": Understanding the Impact on Health Care Professionals of Viewing Digital Stories of Pediatric and Adolescent/Young Adult Oncology Patients	Findings revealed that HCPs found digital stories to be powerful, therapeutic, and educational tools. Health care providers described uses for digital stories ranging from education of newly diagnosed families to training of new staff. Several offered the idea of using them instead of support groups, it was stated, that they allows space for other family members. Moreover digital stories support patient engagement and the recognition of patient voice.
Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor	Results: 16 providers were interviewed (10 physicians, one nurse practitioner, two social workers, two psychologists, and one child life specialist). Three core perceptions emerged: 1) the PPCS offers a diverse range of valuable contributions to the care of children with advancing cancer; 2) providers held favorable opinions about the PPCS owing to positive interactions with individual palliative care specialists deemed extraordinarily emotionally skilled; and 3) there is considerable emotional labor involved in calling a PPCS consult that serves as a barrier to early initiation. The pediatric oncology providers in this study held a highly favorable opinion about their institution's PPCS and agreed that early consultation is ideal. However, they also described that formally consulting PPCS is extremely difficult because of what the PPCS symbolizes to families and the emotional labor that the provider must manage in introducing them. Interventions to encourage the early initiation of palliative care in this population may benefit from a focus on the emotional experiences of providers.
Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families	Importance of early integration of pediatric palliative care (PPC) for children with high-risk cancer as an interdisciplinary endeavor.
Pediatric palliative oncology: the state of the science and art of caring for children with cancer	This review focuses on advancements within several key areas of the field, specifically regarding investigation of the communication needs and preferences of patients and families, exploration of educational initiatives and interventions to teach PPO principles to clinicians, study of patient-reported and parent-reported tools to better assess and manage refractory symptoms, and development of novel models to integrate palliative care within pediatric oncology.

Summery of evidence - Research question 2

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
What are Palliative Care Physicians for Adults Taught on Palliative Care for Children? Paediatric Aspects in Palliative Care Curricula for Adults																5	no limitations	⊕ ⊕	major	4	new finding
Parental experiences with a paediatric palliative care team: A qualitative study	1														one-center study limiting generalizability of results; + mothers and fathers, wide variation of disease and phase of palliative trajectory	6	moderate limitations	⊕ ⊕	major	3	new finding
"Stories Take Your Role Away From You": Understanding the Impact on Health Care Professionals of Viewing Digital Stories of Pediatric and Adolescent/Young Adult Oncology Patients	1															6	major limitations	⊕	moderate	2	
Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor	1				1										a qualitative design at a single site, limited generalizability to settings beyond the hospital where this study was conducted; sample may be biased; sample size is small; no representive sample	6	major limitations	⊕	moderate	2	
Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families																7	major limitations	⊕	moderate	2	
Pediatric palliative oncology: the state of the science and art of caring for children with cancer																7	major limitations	⊕	moderate	2	

research question	title of study	year of publication	first author	study design	remark on study design	sample
	Structure, Organisation, evaluation					
2	Predictors of Patient Satisfaction in Pediatric Oncology	2017	Davis, J.	Observational study (cohort, cross/sectional, case-control)		1244 satisfaction surveys (4 pediatric hematology/oncology practices); 2012-2014
2	Strategies facilitating practice change in pediatric cancer: a systematic review	2016	Robinson, P.D.	Systeamtic review of descriptive or qualitative study		24229 citations identified -> 60 studies included
2	Development of Quality Metrics to Evaluate Pediatric Hematologic Oncology Care in the Outpatient Setting	2017	Teichman, J.	Individual descriptive or qualitative study	Delphi Process	7 medical doctors, 3 nurses
2	Multidisciplinary pediatric brain tumor clinics: the key to successful treatment?	2015	Abdel-Baki, M. S.	Expert opinion		not applicable
	Implementations of psychosocial standards, integrations of psychosocial care					
2	Implementing the psychosocial standards in pediatric cancer: Current staffing and services available	2017	Scialla, M. A.	Observational study (cohort, cross/sectional, case-control)		N=99 pediatric oncologists, N=132 psychosocial leaders and N=58 administrators in pediatric oncology of 144 US programs; response rate: 72%
2	Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States	2017	Scialla, M.A.	Observational study (cohort, cross/sectional, case-control)		N=99 oncologists, N=132 psychosocial leaders, N=58 administrators from 144 pediatric oncology treatment programs from 44 states and the District of Columbia; response rate 72%

title of study	findings
Structure, Organisation, evaluation	
Predictors of Patient Satisfaction in Pediatric Oncology	Most important predictor of overall patient satisfaction were cheerfulness of practice, wait time and staff working together.
Strategies facilitating practice change in pediatric cancer: a systematic review	No specific strategy type was successful at improving patient outcomes. Literature describing strategies to facilitate practice change in pediatric cancer is emerging. However, major methodological limitations exist.
Development of Quality Metrics to Evaluate Pediatric Hematologic Oncology Care in the Outpatient Setting	After two Delphi-rounds thirteen metrics were chosen for the final list based on highest scores and eliminating redundancy: patient communication/education; pain management; delay in access to clinical psychology, documentation of chemotherapy, of diagnosis/extent of disease, of treatment plan and of follow-up scheme; referral to transplant; radiation exposure during follow-up; delay until chemotherapy; clinic cancellations; and school attendance. This study provides a model of quality metric development that other clinics may use for local use.
Multidisciplinary pediatric brain tumor clinics: the key to successful treatment?	Multidisciplinary clinics have become standard of care for cancer patients, including those with brain tumors; Multidisciplinary clinics require support from institution and hospital as well as haven multiple specialities; within Multidis. clinics patients should have access to support groups, family support and counseling, school support. More research is needed in order to optimize patient care.
Implementations of psychosocial standards, integrations of psychosocial care	
Implementing the psychosocial standards in pediatric cancer: Current staffing and services available	Over 90% of programs have social workers and child life specialists who provide care to children and their families. Fewer programs have psychologists (60%), neuropsychologists (31%) and psychiatrists (19%). Challenges are primarily based on pragmatic issues related to funding and reimbursement.
Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States	Participants indicated that psychosocial care consistent with the standards was usually or always provided at their center for most of the standards. Only 55,6% of the oncologists and 45,6% of the psychosocial leaders agreed that their psychosocial care was comprehensive and state of the art. Psychosocial care was most often provided when problems were identified, rather than proactively. There is evidence for the value of more integrated models of psychosocial services.

Summery of evidence - Research question 2

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Structure, Organisation, evaluation																					
Predictors of Patient Satisfaction in Pediatric Oncology															voluntary survey -> response bias?; no further information about patients	4	moderate limitations	⊕ ⊕	major	3	new evidence/citation
Strategies facilitating practice change in pediatric cancer: a systematic review																5	no limitations	⊕ ⊕	moderate	1	
Development of Quality Metrics to Evaluate Pediatric Hematologic Oncology Care in the Outpatient Setting	1														size of consensus group (N=10 from one center), patient and family perspective not incorporated	6	major limitations	⊕	moderate	2	
Multidisciplinary pediatric brain tumor clinics: the key to successful treatment?																7	major limitations	⊕	major	2	
Implementations of psychosocial standards, integrations of psychosocial care																					
Implementing the psychosocial standards in pediatric cancer: Current staffing and services available									1						limitations: It is likely that nonresponding programs have fewer psychosocial staff members; there could be response or desirability bias; when psychosocial staff members are shared with other departments, it is not clear from these data how that portion of time is allocated and if those staff members are always available when needed;	4	moderate limitations	⊕ ⊕	major	4	new finding
Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States															limitation: centers with fewer resources or without psychosocial staff may not have participated; there may be response or social desirability bias in the data	4	moderate limitations	⊕ ⊕	major	4	new finding

research question	title of study	year of publication	first author	study design	remark on study design	sample
2	Understanding Effective Delivery of Patient and Family Education in Pediatric Oncology - A Systematic Review From the Children's Oncology Group	2016	Rodgers, C.C.	Systeamtic review of descriptive or qualitative study	Review according to GRADE criteria, based on evidence ten recommendations were identified	N=83 out of 3552
2	The integration of psychology in pediatric oncology research and practice: collaboration to improve care and outcomes for children and families	2015	Kazak, A.	Expert opinion		not applicable
2	Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps	2016	Kirch, R.	Expert opinion	key findings of joint workshop with 100 multidisciplinary experts	N=100 experts (clinicians and researchers, funders of research, parent and family stakeholders, patient advocacy, representatives from the Children's oncology group, pharmaceutical companies etc.)
	Hospital environment					
2	How Do Adolescents Affected by Cancer Experience a Hospital Environment?	2018	Peeters, K.	Individual descriptive or qualitative study	semi-structured interviews	N=10 (14-25 years, N=9 girls/women)
	Education for staff, staff support practices, work-related stress					
2	Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomised trial	2017	Gouveia, L.	Ranomized controlled trial		N=63 HCP (33.3% nurses, 44.4% nursing students, 11.1% medical doctors, N=3 occupational therapist, N=3 physiotherapist, N=1 social worker)
2	Preventing work-related stress among staff working in children's cancer Principal Treatment Centres in the UK: a brief survey of staff support systems and practices	2016	Beresford, B.	Observational study (cohort, cross/sectional, case-control)		N=19 UK children's cancer principal treatment centers (=100%)
2	Educational Needs of Health Professionals Caring for Adolescents and Young Adults with Cancer	2018	Bradford, N.K.	Observational study (cohort, cross/sectional, case-control)	Online and paper survey	health professionals involved in AYA care; 2013: 122 participants; 2017: 73 participants

title of study	findings
Understanding Effective Delivery of Patient and Family Education in Pediatric Oncology - A Systematic Review From the Children's Oncology Group	Based on the evidence, 10 recommendations for practice were identified. These recommendations address delivery methods, content, influencing factors, and educational interventions for parents and siblings. There is a strong recommendation that written material, short verbal discussions, and audio recordings of the diagnostic discussion be used to provide education to pediatric patients newly diagnosed with cancer, and their parents and siblings.
The integration of psychology in pediatric oncology research and practice: collaboration to improve care and outcomes for children and families	Seven key contributions of psychologists to collaborative and integrated care in pediatric cancer are described: managing procedural pain, nausea, and other symptoms; understanding and reducing neuropsychological effects; treating children in the context of their families and other systems (social ecology); applying a developmental perspective; identifying competence and vulnerability; integrating psychological knowledge into decision making and other clinical care issues; and facilitating the transition to palliative care and bereavement. Psychologists who are integrated into treatment teams have opportunities to provide preventive care in collaboration with other team members.
Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps	Workshop outcomes emphasized the need for new pediatric cancer drug development and identified critical opportunities to prioritize palliative care and psychosocial support as an integral part of pediatric cancer research and treatment, including the necessity for adequately resourcing these supportive services to minimize suffering and distress, effectively address quality-of-life needs for children and families at all stages of illness, and mitigate the long-term health risks associated with childhood cancer and its treatment. Next steps include dismantling existing silos and enhancing collaboration between clinical investigators, disease-directed specialists, and supportive care services; expanding the use of patient-reported and parent-reported outcomes; effectively integrating palliative and psychosocial care; and clinical communication skills development.
Hospital environment	
How Do Adolescents Affected by Cancer Experience a Hospital Environment?	Adolescent patients primarily look for connections with life outside the hospital. The hospital confronts them with different obstacles, most of which appear to relate to difficulties concerning the loss of these connections. These obstacles include a lack of freedom, control, and autonomy; limited social interaction with friends; inability to participate in daily activities; boredom; and a lack of privacy. There is a need for a hospital environment dedicated to them-be it a separate adolescent ward, or the grouping of adolescents on children's and/or adult wards.
Education for staff, staff support practices, work-related stress	
Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomised trial	The intervention was effective in manipulating perspective type. The groups did not significantly differ on parent-clinician agreement. Concentrating on personal feelings (imagine-self strategy) did predict lower agreement when controlling for trait empathy. Clinician distress was higher in the imagine-self group.This research could potentially improve communication training and burnout prevention.
Preventing work-related stress among staff working in children's cancer Principal Treatment Centres in the UK: a brief survey of staff support systems and practices	Health professionals' abilities to cope with or manage work related stress have been shown to be associated with patient outcomes and experiences. Debriefs following a patient death was the most frequently reported staff support practice. Support groups were infrequently mentioned. There was wide variability between PTCs, and between professional groups, regarding the number and type of interventions available. Doctors appear to be least likely to have access to support. A few centres routinely addressed work-related stress in wider staff management strategies. Two Centres had developed a bespoke intervention.
Educational Needs of Health Professionals Caring for Adolescents and Young Adults with Cancer	The most prominent educational needs in 2013 were palliative care and biomedical topics such as understanding AYA growth and development as well as specific AYA cancers and treatment. The second survey identified that palliative care education remained important; however, there was a shift toward health professionals request for more psychosocial and practical education on topics including fertility, sexuality, and managing late effects.

Summery of evidence - Research question 2

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Understanding Effective Delivery of Patient and Family Education in Pediatric Oncology - A Systematic Review From the Children's Oncology Group														1	only 33 articles related to cancer diagnosis, overall rating of the quality of evidence is low	5	moderate limitations	⊕ ⊕	major	4	new finding
The integration of psychology in pediatric oncology research and practice: collaboration to improve care and outcomes for children and families																7	major limitations	⊕	major	2	
Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps																7	major limitations	⊕	moderate	2	
Hospital environment																					
How Do Adolescents Affected by Cancer Experience a Hospital Environment?	1														small sample, female perspective overestimated	6	major limitations	⊕	major	2	
Education for staff, staff support practices, work-related stress																					
Comparing two types of perspective taking as strategies for detecting distress amongst parents of children with cancer: A randomised trial	1														selection bias (77% nurses; those who participated were probably more interested in empathy)	2	moderate limitations	⊕ ⊕ ⊕	moderate	3	new finding
Preventing work-related stress among staff working in children's cancer Principal Treatment Centres in the UK: a brief survey of staff support systems and practices																4	no limitations	⊕ ⊕ ⊕	major	4	new finding
Educational Needs of Health Professionals Caring for Adolescents and Young Adults with Cancer	1														Queensland has unique healthcare setting -> results my not be generalizable to other settings; low response rate; percentage of participants who participated in educational activities is unclear	4	moderate limitations	⊕ ⊕	major	3	new evidence/citation

research question	title of study	year of publication	first author	study design	remark on study design	sample
2	Work-related stress and reward: an Australian study of multidisciplinary pediatric oncology healthcare providers	2015	Bowden, M. J.	Observational study (cohort, cross/sectional, case-control)	online survey	N=107 pediatric oncology clinicians (medical (N=16), nursing (N=67), allied health staff (N=24) from two Australian pediatric oncology centers)
	Others					
2	Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology."	2016	Ruhe, K.M.	Individual descriptive or qualitative study	semi-structured interviews	N=52 (19 parents, 17 children, 16 pediatric oncologists) - 8 centers of the Swiss pediatric oncology group
2	Perceptions of parents and paediatricians of pain induced by bone marrow aspiration and lumbar puncture among children with acute leukemia: a qualitative study in China	2017	Wang, J.	Individual descriptive or qualitative study	In-depth semi structured interviews with parents of children with acute leukemia and haemato-oncology paediatricians	N= 20 Parents of children with acute leukemia (n= 12) Haemato-oncology paediatricians (n= 11)

title of study	findings
Work-related stress and reward: an Australian study of multidisciplinary pediatric oncology healthcare providers	The most commonly reported sources of both stress and reward are related to patient care and interactions with children. Results indicated that levels of work-related stress and reward were similar between the professional disciplines and between the two hospitals. -> Results suggest more integrated multidisciplinary approaches to staff well-being; evidence based communication skills training; two hospitals have implemented new peer supervision model.
Others	
Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology."	Three main themes were identified: (a) modes of participation that captured the different ways in which children and adolescents were involved in their healthcare; (b) regulating participation, that is, regulatory mechanisms that allowed children, parents, and oncologists to adapt patient involvement in communication and decision-making; and (c) other factors that influenced patient participation. This last theme included aspects that had an overall impact on how children participated. Patient participation in pediatrics is a complex issue and physicians face considerable challenges in facilitating adequate involvement of children and adolescents in this setting. Nonetheless, they occupy a central role in creating room for choice and guiding parents in involving their child. Adequate training of professionals to successfully translate the principle of patient participation into practice is required.
Perceptions of parents and paediatricians of pain induced by bone marrow aspiration and lumbar puncture among children with acute leukemia: a qualitative study in China	3 superordinate and associated subordinate themes could be found in the study: [1] Inadequate state of current paedatric procedural pain management (physical restraintand no local anaesthetic, neglect of procedural pain management in children) [2] Dilemma of the paeditric procedural pain management (anxious for an active role in their child´s pain management but alsopowerless, inadequate knowledge in usagge of analgesia and sedation) [3] Expectations of paeditric procedural pain management (an efficient analgesic for children procedural pain is badly needed,an adequate pain mnagement education is desired). The study describe potential improvement of the paediatric procedural pain management by BMA and LP.

Summery of evidence - Research question 2

title of study	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	strength of recommendation	inclusion in guideline
Work-related stress and reward: an Australian study of multidisciplinary pediatric oncology healthcare providers	1														Estimated response rate 50%, predominance of female Health Care Providers, possible social desirability	4	moderate limitations	⊕ ⊕	major	3	new finding
Others																					
Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology."	1														possible selective bias (purposive sampling)	6	moderate limitations	⊕ ⊕	moderate	2	new evidence/citation
Perceptions of parents and paediatricians of pain induced by bone marrow aspiration and lumbar puncture among children with acute leukemia: a qualitative study in China															The study was conducted inonly one autonomous region of China and did not reflect the whole situation of China´s (or worldwides´) paediatric patients´ BMAs and LPs procedural pain management.	6	major limitations	⊕	moderate	2	

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Grandparents of children with cancer: Quality of life, medication and hospitalisations	2016	Wakefield, C.	Observational study (cohort, cross/sectional, case-control)	4	Grandparents of children with cancer were questioned on their quality of life, changes in relationship with their grandchildren, quality of sleep, medication and hospitalization through questionnaires. The control group was made up of grandparents of healthy children.	N = 89 grandparents of surviving children with cancer(57 families of Austrialian center) < 17; treated for the last 3 years. CG: N = 133 grandparents from 105 families with healthy children from the clinic's catchment area.
3	Effect of Population Socioeconomic and Health System Factors on Medical Care of Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study	2017	Caplin, D.	Observational study (cohort, cross/sectional, case-control)	4		N=7899 Age at diagnosis = 8.2 years diagnosis=missing
3	Parents' romantic attachment predicts family ritual meaning and family cohesion among parants and their children with cancer	2017	Santos, S.	Observational study (cohort, cross/sectional, case-control)	4	Parents and children reported on family ritual meaning and family cohesion at Time 1 (T1) and after 6 months (T2).	N=58 dyads (parents and children) age of children = 8-19 y, age of parents = 31-56 y, gender of children = 50% female, gender of parents = 87.9% female, diagnosis of children = 60.34% leukemia, 17.24% lymphoma, 1.72% Langerhans cell histiocytosis, 15.52% solid tumor, 5.17% CNS tumor; 3 portuguese centers
3	Childhood Cancer in Context: Sociodemographic Factors, Stress, and Psychological Distress Among Mothers and Children	2015	Bemis, H.	Observational study (cohort, cross/sectional, case-control)	4		* Mothers and children of 2 hospitals in USA * Age of children: 5-17 years * new diagnosis of a tumor / recurrence * currently still in treatment * no developmental disorder prior to diagnosis * Leukemia 36%, lymphoma 24.9%, brain tumor 8.8%, other tumor types 29.3%
3	Trajectories of income and social benefits for mothers and fathers of children with cancer: A national cohort study in Sweden	2018	Hiyoshi, A.	Observational study (cohort, cross/sectional, case-control)	4	Swedish Register based matched cohort study	parents of children <18y, with first life time cancer diagnosis 2004-2009; mothers: 1861, fathers: 1745; matched with parents of children without cancer 1:10; from 2 years before cancer diagnosis to 6 years after CD.
3	The Impact of a Mother's Emotional Strains and Disclosure of Cancer on Her Child's Defensiveness and Adjustment to Cancer	2018	Arabiat, D.	Observational study (cohort, cross/sectional, case-control)	4	Children and their mothers of 4 different hospitals in Jordan filled in standarized questionaires about defensiveness, anxiety and depression. The results were correlated with the question if the children were informed about their illness	N = 58 children aged 8-16 years at least 3 months post diagnosis, and 51 mothers. 43% of the children were not informed about their diagnosis

Summery of evidence - Research question 3

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Grandparents of children with cancer: Quality of life, medication and hospitalisations	2 validated tools (WHOQOL-BREF and EuroQol EQ-5D-5L); the changes in the relationship with the grandchildren: free text data; sleep quality:Pittsburgh Sleep Quality Index. Both in the area of general quality of life, as well as in the areas of **physical health, emotional health and environmental conditions,** grandparents of children with cancer showed **significantly lower scores than the control group.** In the areas of **anxiety and depression as well as general health, the values were significantly lower than in the control group.** Grandparents with children with cancer had greater problems getting in and out of bed and taking more prescription drugs than the control group. Only with regard to the question of hospital stays, no differences between the groups were found. Because grandparents play an important role in informal care in the families of children with cancer, the authors therefore propose their own psychosocial interventions for this group.														
Effect of Population Socioeconomic and Health System Factors on Medical Care of Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study	*population disparities, such as higher median income in a community, was associated with medical care and sociodemographic factors of an individual survivor *Still, interventions should focus in particular on the individual-level factors: including insurance, employment, education, and health beliefs *population-level policies should improve insurance coverage, and educational and employment opportunities														
Parents' romantic attachment predicts family ritual meaning and family cohesion among parants and their children with cancer	*family ritual meaning and family cohesion was predicted by parent's avoidant attachment (but not anxious attachment) *interventions should focus on avoidant attachment and family ritual meaning to strengthen family ties														
Childhood Cancer in Context: Sociodemographic Factors, Stress, and Psychological Distress Among Mothers and Children	Socio-demographic data (single parent, low parental education, low income, ethnicity) have both an independent and collective impact on the perceived psychological stress of children with cancer and their mothers														
Trajectories of income and social benefits for mothers and fathers of children with cancer: A national cohort study in Sweden	Around the time of the child's cancer diagnosis, the total income was **on average up to 6% higher among the mothers of children with cancer** compared with reference mothers, but no differences were noted among fathers. Income from work dropped to the lowest level around the time of a cancer diagnosis, with swift recovery noted for fathers but not for mothers. Sickness and childcare-related benefits were up to 6 times larger for the parents of children with cancer than reference parents. **As social benefits diminished after approximately 3 years, the total income of mothers of children with cancer became lower than that of reference mothers, and the gap widened over time.**														
The Impact of a Mother's Emotional Strains and Disclosure of Cancer on Her Child's Defensiveness and Adjustment to Cancer	In Jordan, many children are not informed about their cancer diagnosis. In this study (response rate 90%) 43% of the children did not know about their illness. The authors found that these children showed significant differences in the defensiveness, depression and anxiety scores between children with full disclosure and those who did not know about their cancer. The study also shows that children's adjustment ot cancer is directly related to that of their mothers'.														

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Grandparents of children with cancer: Quality of life, medication and hospitalisations		**4**	no limitations	⊕ ⊕ ⊕	high		**4**	new finding
Effect of Population Socioeconomic and Health System Factors on Medical Care of Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study		4	no limitations	⊕ ⊕ ⊕	high		**4**	new evidence/citation
Parents' romantic attachment predicts family ritual meaning and family cohesion among parants and their children with cancer		4	no limitations	⊕ ⊕ ⊕	high	Rituals are very important for the family cohesion! These should be promoted by psychosocial care.	**4**	new evidence/citation
Childhood Cancer in Context: Sociodemographic Factors, Stress, and Psychological Distress Among Mothers and Children		4	no limitations	⊕ ⊕ ⊕	high		**4**	new evidence/citation
Trajectories of income and social benefits for mothers and fathers of children with cancer: A national cohort study in Sweden		**4**	no limitations	⊕ ⊕ ⊕	high		**4**	new evidence/citation
The Impact of a Mother's Emotional Strains and Disclosure of Cancer on Her Child's Defensiveness and Adjustment to Cancer		4	no limitations	⊕ ⊕ ⊕	moderate	Interesting findings, but study was conducted in Jordan an results can possibly not been transferred to western countries?	**3**	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Anxiety, Pain and Nausea During the Treatment of Standard-Risk Childhood Acute Lymphoblastic Leukemia: A Prospective, Longitudinal Study from the Children's Oncology Group	2016	Dupuis, L. L.	Observational study (cohort, cross/sectional, case-control)	4	Multicenter study involving 31 clinics (out of 181 in the country); inclusion criteria were ages from 2 to 9.99 years and voluntary parental participation; Research period: 2005-2009. Patients randomly assigned to study conditions: normal and intensified chemotherapy Measurements: * Demographic FB, * General Functioning Scale of the Family Assessment Device (FAD-GF), *Pediatric Quality of Life Inventory (Pedsql) 3.0 Cancer Module (proxy version)	N=160 of 194 parents in selection scheme; depending on 3 time points: 1 month, 6 months, 12 months after diagnosis, 137 to 150 questionnaire data were provided; All children: "standard-risk-average ALL" Average age: 4.9 + -2.2; Gender ratio 52% m, 48% w Participants compared with non-participants found more white, non-hispanic parents with older children in the participant sample
3	Impact of pediatric cancer on family relationships	2018	Erker, C.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study with oncology patients and their siblings, using the PROMIS Pediatric Family Relationship short form and the Depressive Symptoms, Anxiety, and Peer Relationships short form	N = 174 patients, aged 8-17 years, and N = 149 siblings. Four cohorts were built: a) 68 patients on-therapy, b) 92 patients off-therapy (completion of therapy more than 6 months ago), c)45 sibllings of patients on-therapy and d) 45 siblings of children off-therapy.
3	Impact of a child's cancer disease on parents' everyday life: a longitudinal study from Sweden	2017	Hoven, E.	Observational study (cohort, cross/sectional, case-control)	4	study part of a project (7 time points); data was collected from T2-T6 via telephone interviews (2 months (T2), 4 months after diagnosis (T3), one week after end of treatment or six months after end of stem cell transplantation (T4), three months after end of treatment or nine months after end of transplantation/child’s death (T5), one year after end of treatment or 18 months after transplantation/child’s death (T6)); Reports of restrictions were evaluated over time, between mothers and fathers, and in relation to parent-reported child symptom burden (The Memorial Symptom Assessment Scale) and partial post-traumatic stress disorder (PTSD) (The PTSD Checklist-Civilian Version) --> 4 swedish pediatric oncology centers	N=246 parents of 133 children over the study period T2-T6 age parents T1: M=38(SD=6.9); education: 52% (n=127) with upper secondary education, 33% (n=81) with post-secondary education, and 14% (n=34) with primary education T2: siblings: 73% (n=180) had 2 or 3 children, 16% (n=40) more than 4 children, 11% (n=26) no siblings to the child diagnosed with cancer. relationship status: 87%, (n=215) were married/cohabiting, 7% (n=18) single, 5% (n=12) in partnership but not cohabiting, and 0.5% (n=1) divorced. child diagnosis: leukaemia/lymphomas (58%, n=77), solid tumors (30%, n=40), and central nervous system tumors (12%, n=16). child age at diagnosis: M=7.9 (SD=5.1), range=0–18
3	Fear of Progression in Parents of Children with Cancer: Results of An Online Expert Survey in Pediatric Oncology	2018	Clever	Observational study (cohort, cross/sectional, case-control)	4	Expert survey - online questionnaire	N = 77 professionals (PSAPOH)
3	White Matter Microstructure and Information Processing at the Completion of Chemotherapy-Only Treatment for Pediatric Acute Lymphoblastic Leukemia	2018	Darling	Observational study (cohort, cross/sectional, case-control)	4	combination imaging und neuropsychology	N=Twenty-one survivors of ALL and 18 controls Alter= 7–16 years

Summery of evidence - Research question 3

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Anxiety, Pain and Nausea During the Treatment of Standard-Risk Childhood Acute Lymphoblastic Leukemia: A Prospective, Longitudinal Study from the Children's Oncology Group	*Treatment-related anxiety and procedure-related anxiety and pain decrease over the course of treatment according to the parent's assessment *Nausea is most strongly reported 6 months after diagnosis *Family backgrounds do not affect these symptoms *younger age at diagnosis was associated with significantly greater procedure-related anxiety *older age at diagnosis and the assignment to intensified chemotherapy was associated with significantly greater nausea -> Control of nausea should be given more attention -> Targeted interventions, especially for younger children, with a focus on anxiety and for older children with a focus on nausea would be useful									1					
Impact of pediatric cancer on family relationships	Family relationships as measured with the PROMIS Instrument. Patients off-therapy did not differ from their siblings ot the patients on-therapy. Family relationships did not differ between the sibling cohorts. Siblings of patients on-therapy had worse family relathionships than patient on -therapy. An actor-partner interdependence model (APIM) found Patient Family relationships were impaired when their own peer relationships decreased and when their own siblings had increased depressive symptoms. Based on these findings, the authors suggest increased psychosocial resources for patients and siblings of children undergoing cancer therapy.														
Impact of a child's cancer disease on parents' everyday life: a longitudinal study from Sweden	2 and 4 months after diagnosis, 35% and 24% reported that their leisure activities were restricted most of the time. Corresponding percentages for restrictions on work/ studies were 75% and 67%. One year after end of treatment, the great majority reported that their leisure activities (91%) and/or work/studies (76%) were never/seldom restricted. During treatment, more mothers than fathers reported restrictions on work/studies all/most of the time. After end of treatment, gender was only related to reports of restrictions among parents not reporting partial PTSD. More parents who reported being restricted all/most of the time also reported partial PTSD and/or a greater symptom burden for the child.														
Fear of Progression in Parents of Children with Cancer: Results of An Online Expert Survey in Pediatric Oncology	Psychosocial employees describe fear of progression –> standardized assessment in order to find appropriate interventions.														
White Matter Microstructure and Information Processing at the Completion of Chemotherapy-Only Treatment for Pediatric Acute Lymphoblastic Leukemia	The authors identified widespread white matter microstructure abnormalities in the early posttreatment phase of pediatric ALL treated with chemotherapy-only. In addition, we identified an atypical brain–behavior relationship between information processing speed and white matter micro- structure, suggesting a compensatory white matter reorganization mechanism to facilitate processing speed in the context of white matter damage.														

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Anxiety, Pain and Nausea During the Treatment of Standard-Risk Childhood Acute Lymphoblastic Leukemia: A Prospective, Longitudinal Study from the Children's Oncology Group	very high study quality, only slight limitations: * only external assessment - no children's perspective; *only leukemia - is not representative of all cancers, *not all who agreed to participate appear numerically in the results, it is not clear why it came to dropouts (which, however, were limited)	4	no limitations	⊕⊕⊕	high		3	new finding
Impact of pediatric cancer on family relationships		4	no limitations	⊕⊕⊕	moderate	Already included in guideline	3	new evidence/citation
Impact of a child's cancer disease on parents' everyday life: a longitudinal study from Sweden		4	no limitations	⊕⊕⊕	moderate		3	new evidence/citation
Fear of Progression in Parents of Children with Cancer: Results of An Online Expert Survey in Pediatric Oncology		4	no limitations	⊕⊕⊕	high	Beratung und Behandlung von Progredienzangst	3	new finding
White Matter Microstructure and Information Processing at the Completion of Chemotherapy-Only Treatment for Pediatric Acute Lymphoblastic Leukemia		4	no limitations	⊕⊕⊕	moderate	Outcomestudie - Fokus liegt auf dem Einsatz von bildgebenden Verfahren.	2	new evidence/citation

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Children with minimal chance of cure: parent proxy of the child's health-related quality of life and the effect on parental physical and mental health during treatment	2016	Mandrell, B. N.	Observational study (cohort, cross/sectional, case-control)	4	5 time-points: baseline (prior to initiation of treatment), weeks 2, 4 and 6 (of radiation), weeks 16 and 24 (both post-radiation) HRQOL instruments were completed by the child (>= 5) and parent-proxy (ages 2-17 years) and the parent completing the SF-36	N=25 patients and their parents; diagnosis: 24 diffuse intrinsic pontine glioma, 1 medullary glioma; age: M=5.8 years (range=2.3-17.2), age 2-4=10; gender: female=52%; mean survival from enrollment: 13.8 months; parents gender: 24 mothers, 1 father; parents age: M=35.2 (range=22.5-45.3); at week 34 8 (32%) of the patients were off treatment due to progressive disease
3	Prevalence and Impact of Financial Hardship among New England Pediatric Stem Cell Transplantation Families	2015	Bona, K.	Observational study (cohort, cross/sectional, case-control)	4	standardized interview; correlation with medical data	N = 45 parents; different cancer types; age of children on average 10 years; study participation on average 132 days after SZT
3	Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study	2016	Bona, K.	Observational study (cohort, cross/sectional, case-control)	**4**	single site (Boston)	48% of children female; median age at diagnosis: 8.9 y, 57% children with hematologic malignancies were overrepresented and 13% brain tumors were underrepresented (13%); 12% had preexisting chronic medical conditions, most commonly Down syndrome; 87% were treated on or as per clinical protocol
3	Mothers and Fathers Coping With Their Children's Cancer: Individual and Interpersonal Processes	2015	Compas, B.	Observational study (cohort, cross/sectional, case-control)	4		N=317 mothers and 166 fathers of 334 children with cancer (151 couples) mean age of children=10.5 years (Range=5–17 years) mean age of mothers=37.5 years; mean age of fathers=39.5 years Families of children with new diagnoses comprised 89% (n = 297), the others had a relapse.
3	Sick leave among parents of children with cancer - a national cohort study.	2017	Hjelmstedt, S.	Observational study (cohort, cross/sectional, case-control)	4		N=3626 parents of 1899 children diagnosed with cancer in Sweden during 2004 and 2009; matched control group (N=34874)
3	Does socioeconomic status impact physical activity and sleep among children with cancer?	2016	Orsey, A.D.	Observational study (cohort, cross/sectional, case-control)	4	Actigraphy and diaries over 7 days to assess physical activity and sleep	N= 50; Age: 31, 62% (child 8-12 years); 19, 38% (adolescents 13-18 years) Gender: 35 (70%) males; 15 (30%) females Diagnosis: 22 lymphoma, 8 brain tumor, 10 other solid tumor Days since diagnosis: 511,8 days; Assurance: 62% private, 38% public
3	Impact of Caregiving for a Child With Cancer on Parental Health Behaviors, Relationship Quality, and Spiritual Faith: Do Lone Parents Fare Worse?	2016	Wiener, L.	Observational study (cohort, cross/sectional, case-control)	4	cross-sectional design, one questionnaire 6 to 18 months following child´s diagnosis	N= 263 Marital status: 170 (64,6%) married; 82 (31,3%) single; 11 (4,2%) unmarried with a partner Lone vs. non-lone parents: 79 (30.0%) lone parents. 55 (67,0%) single parents, 20 (11.8%) married parents, and 4 (36,4%) unmarried parents with a partner reported feeling like a "lone" parent when it came to caring for their child with cancer.

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title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Children with minimal chance of cure: parent proxy of the child's health-related quality of life and the effect on parental physical and mental health during treatment	Patients reported **physical functioning to be low at baseline** with no significant change at week 6 and week 16. **From baseline to week 6** parents reported **significant improvement in cognitive problems, movement and balance, procedural anxiety and total score** (no significant changes from week 6 to 16). The only significant **difference between the child and parent** reported HRQOL was within the **domain of movement and balance** - patients reporting higher function at baseline trough week 6. Changes in brain-tumor specific HRQOL as reported by the parents was associated with changes in parent's overall mental health HRQOL. Specifically **parents reported higher mental health HRQOL if they reported their child as having less cognitive problems**, less procedural anxiety or higher total score brain tumor specific HRQOL. No relationship between parent's age, time to their child's death, or time since diagnosis and the parent's reported HRQOL –> palliative care consultation should be initiated at the time of diagnosis.	1													
Prevalence and Impact of Financial Hardship among New England Pediatric Stem Cell Transplantation Families	Although families of all patients involved in the study were both insured and receiving routine social and psychological support, 40% of families reported low incomes even before the illness, and 39% of these families lost more than 40% of their household income during SCT; in an univariate analysis, 111 (61%) children from low-income families were diagnosed with GVHD in the first 180 days post SZT, but only 2 (7%) of children from richer families. So far, there is no explanatory model for this relationship; due to the low number of cases, this result must be considered with caution. Despite the good psychosocial care, the extent of the financial burden of the SZT is alarming.	1													
Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study	*Low-income & household material hardship (=food, housing, energy insecurity) are prevalent in a significant proportion of newly diagnosed pediatric oncology families *the proportion of families experiencing unmet basic needs increases during chemotherapy to nearly **one in three families.** *Interventions to ameliorate poverty are vital	1													
Mothers and Fathers Coping With Their Children's Cancer: Individual and Interpersonal Processes	*in mothers and fathers lower depressiv symptoms were associated with primary control coping (e.g., problem solving, emotional modulation) and secondary control coping (e.g., acceptance, cognitive reappraisal) *mothers' coping was associated with fathers' depressive symptoms. *especially mothers' secondary control coping may have a positive effect on both, themselves and their husbands.	1													
Sick leave among parents of children with cancer - a national cohort study.	The risk of sick leave was statistically significantly higher up to six years following a child's cancer diagnosis. The increase in number of days with sickness benefit was most pronounced the year after diagnosis. Although mothers' sick leave prevalence was higher, the increase in risk relative to control parents was similar for mothers and fathers. Bereavement was associated with a heightened risk of sick leave, especially on the year of the child's death.			1											
Does socioeconomic status impact physical activity and sleep among children with cancer?	Physical activity (PA) and sleep efficiency were strongly correlated. Children with state insurance had higher average PA than children on private insurance. There were no significant differences in PA or sleep efficiency by block MHI (Median Houshold Income). The 7-day fatigue score was lower among the patients aged 8-12 years in the group with MHI less than $67000, although there was no significant difference among participants aged 13-18 years. There was no difference in mean fatigue scores by insurance status.														
Impact of Caregiving for a Child With Cancer on Parental Health Behaviors, Relationship Quality, and Spiritual Faith: Do Lone Parents Fare Worse?	Parents reported significant worsening of all their own health behaviors, including poorer diet and nutrition, decreased physical activity, and less time spent engaged in enjoyable activities 6 to 18 months following their child´s diagnosis. Half of the sample reported paying less attention to their own Health after their child´s diagnosis. Significantly more lone-parents reported than the quality of their relationship with the ill child´s siblings had gotten worse and that their relationships with friends had gotten worse after their child´s diagnosis. Spiritual faith increased for all parents.														

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title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Children with minimal chance of cure: parent proxy of the child's health-related quality of life and the effect on parental physical and mental health during treatment	small sample, almost entirely mothers	**4**	moderate limitations	⊕ ⊕	high		**4**	new evidence/citation
Prevalence and Impact of Financial Hardship among New England Pediatric Stem Cell Transplantation Families	Because of the small sample size, it is conceivable and possible that the link between poverty and the occurrence of GVHD does not include important patient or donor-related variables.	4	moderate limitations	⊕ ⊕	high	The extent of the financial burden should in any case be thoroughly assessed; the relationship between socioeconomic status and medical outcome variables needs to be explored more thoroughly.	**4**	new finding
Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study	Children with hematologic malignancies were overrepresented (57%) and brain tumors were underrepresented (13%) as compared to expected population distributions.	**4**	moderate limitations	⊕ ⊕	high		**4**	new evidence/citation
Mothers and Fathers Coping With Their Children's Cancer: Individual and Interpersonal Processes	keine Angaben zur Art der Krebserkrankung	4	moderate limitations	⊕ ⊕	high		**4**	new evidence/citation
Sick leave among parents of children with cancer - a national cohort study.	no information on sick leave diagnoses	4	moderate limitations	⊕ ⊕	high		**4**	new finding
Does socioeconomic status impact physical activity and sleep among children with cancer?	Single-center and cross-sectional study. Insurance and MHI (Median Houshold Income) may be simplified surrogates that do not fully represent the complex construct of SES. Nearly 90% succesfull collection of data, approximately 10 % of data were lost or incomplete due to technical challenges with the actigraphy devices.	4	moderate limitations	⊕ ⊕	high	By understanding how SES impacts the PA and fatigue among pediatric oncology patients, we can better help all cancer survivors overcome SES-related barriers to enjoy the promise of long-term health and high quality of life.	**4**	new finding
Impact of Caregiving for a Child With Cancer on Parental Health Behaviors, Relationship Quality, and Spiritual Faith: Do Lone Parents Fare Worse?	Content and construct validity and reliability are not available for the questionnaire. Cross-sectional design instead of longitudinal study. Only parents whose child was 6 to 18 months post their cancer diagnosis. Health behavior was only assessed in self-report, no objective indicators of parental health.	4	moderate limitations	⊕ ⊕	high	Important regarding the psychological and physical health of parents of children with Cancer in relationship to their marital status and if their care alone or not for the ill child.	**4**	new evidence/citation

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Cognitive dysfunction in children with brain tumors at diagnosis	2015	Margelisch, K.	Observational study (cohort, cross/sectional, case-control)	4	comparison of cognitive performance of braintumor patients with children with non-CNS malignancies (control group)	N=20 children with braintumor, N=27 children with non-CNS malignancies (6.1-16.9)
3	Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer	2017	Klosky, J.L.	Observational study (cohort, cross/sectional, case-control)	4	Prospective, single group, observational study design	N= 122 adolescent males/parents dyads Age adolescents: M= 16,2 years; SD= 1,9 years Age parents: M= 44,5 years; SD= 5,6 years Gender parents: 101 (70,1%) females; 21 (29,9%) males Diagnosis: 65 (53,3%) leukemia/lymphoma; 48 (39,3%) solid tumor; 9 (7,4%) brain tumor
3	Fertility as a priority among at-risk adolescent males newly diagnosed with cancer and their parents	2015	Klosky, J.L.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study. Newly diagnosed adolescent males (and parents) at risk for fertility secondary rank-ordered eight life goals.	N= 96 adolescents (and n= 30 fathers, n= 61 mothers) Age adolescents: M= 16,4 years; SD= 2,1 years; range= 13-21,99 years Diagnosis: 51 (53,1%) leukemia/lymphoma; 7 (7,3%) brain tumors; 38 (39,6%) solid tumors Age mothers: M= 44,2 years; SD= 5,6 years; range= 32-53 years Age fathers: M= 46,7 years; SD= 4,9 years; range= 35-55 years
3	Prevalence and Predictors of Sperm Banking in Adolescents Newly Diagnosed With Cancer: Examination of Adolescent, Parent, and Provider Factors Influencing Fertility Preservation Outcomes	2017	Klosky, J.L.	Observational study (cohort, cross/sectional, case-control)	4	Prospective, single-group, observational study to test the contribution of different factors to fertility preservation outcomes	N= 146 adolescent males (and n= 144 parents) Age= 16,49 years; SD= 2,02 years Diagnosis: 82 (56,2%) leukemia/lymphoma; 9 (6,2%) brain tumor; 55 (37,7%) solid tumor Gender parents: 42 (29%) males; 101 (69,7%) females
3	Presence of cerebral microbleeds is associated with worse executive function in pediatric brain tumor survivors	2016	Roddy, E.	Observational study (cohort, cross/sectional, case-control)	4	Multi-institutional cohort study with pediatric brain tumor patients who received cranial radiation therapy (CRT) compared with patients who did not receive CRT.	N= 126 (n= 110 pediatric brain tumor patients who received CRT; n= 16 who did not received CRT); Median follow-up period for patient who received CRT= 3,6 years; interquartile range=1,4-6,8 years; Median follow-up period for patient who did not received CRT= 5,3 years; interquartile range= 1,8-7,3 years; Median age at initiation of CRT= 8,6 years; range= 5,7-12,7 years Diagnosis majority of patients with CRT: medulloblastoma; ependymoma Diagnosis majority of patients without CRT: low-grade glioma; craniopharyngioma From 110 patients who received CRT, 105 were eligible to complete the CogState assessment of neurocognitive function. Of these 67 (64%) completed the optional assessment (66% of patients with CMBs and 56% without). Median age at CogState administration= 14 years; interquartile range= 10-19 years; range= 5-26 years; Median time from CRT to CogState testin= 4,2 years; interquartile range= 2,3-6,9 years; range= 0,5-16 years

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title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Cognitive dysfunction in children with brain tumors at diagnosis	Compared to the control group, patients with BTs performed significantly worse in tests of working memory, verbal memory, and attention (effect sizes between 0.28 and 0.47). In contrast, the areas of perceptual reasoning, processing speed, and verbal comprehension were preserved at the time of measurement. In the event of a brain tumor, connectivity is interrupted and compromised. The need for cognitive interventions early in the treatment process in order to minimize or prevent academic difficulties as patients return to school is highlighted.	1													
Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer	55,7% of adolescents attempted to bank sperm by the time of survey administration, and 83,8% of those attempts were successful. Parental recommendation to bank sperm and perceived self-efficacy to facilitate banking were significantly associated with an increased likelihood of making a collection attempt. Although not statistically significant , there was also a trend for parent communication of fertility risk to their sons.														
Fertility as a priority among at-risk adolescent males newly diagnosed with cancer and their parents	"Having children" was ranked as a "top 3" life goal among 43,8% of adolescents, 36,7% of fathers, and 21,3% of mothers. Fertility ranked third among adolescent, fourth among fathers, and fifth among mothers. Future health was ranked the top priority across groups, and fertility ranked higher than home ownership and wealth for all groups. For adolescents, low/moderate fertility risk perception was significantly associated with higher fertility rankings than no/high resk perceptions.														
Prevalence and Predictors of Sperm Banking in Adolescents Newly Diagnosed With Cancer: Examination of Adolescent, Parent, and Provider Factors Influencing Fertility Preservation Outcomes	Among adolescents 53,4% (78/146) made a collection attempt, with 43,8% (64/146) successfully banking sperm (82,1%of attempters). The reason for not making a collection attempt (68/146 patients) was: patient or family decided against, adolescent believe banking was not necessary, and the adolescent was unsure what sperm banking was. The overall attempt model revealed adolescent consultation with a fertility specialist, parent recommendation to bank, and higher Tanner stage were associated with an increaseed likelihood of a collection attempt. Adolescent history of masturbation, banking self-efficacy, and parent or medical team recommendation were associated with increased likelihood of sperm banking completion.														
Presence of cerebral microbleeds is associated with worse executive function in pediatric brain tumor survivors	50/110 children who were treated with CRT had evidence of cerebral microbleeds (CMBs) on MRIs. None of the 16 comparison patients who had not received CRT had any evidence of CMBs. Children who received CRT developed CMBs wih a cumulative evidence of 10,8% at 1-year post-CRT and 48,8% at 5 years. In the multivariate analysis, presence of CMBs was associated with worse executive function, especially when CMBs were located within the frontal lobes. In assessment of neurocognitive function, including delayed recall, verbal learning, attention, and working memory, patients with CMBs continued to perform worse than patients without CMBs, with a specific effect of the location of CMBs on these different neurocognitive tasks. Patients with CMBs in the occipital lobe took the longest on the detection test of visual selective attention and psychomotor function. On the "one back test" of working memory, patients with CMBs in the frontal lobe made the most mistakes. On the test of verbal learning, patients with CMBs in the temporal lobes performed the worst.														

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Cognitive dysfunction in children with brain tumors at diagnosis	relatively small number of subjects did not allow analysis of specific variables, but value of control group at this time-point	4	moderate limitations	⊕ ⊕	high		**4**	new finding
Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer	Sperm banking attempt (primary outcome) was based on self-report and not from the medical record. Administration of the study surveys before the initiation of cancer therapy would have been most advantageous to examining the factors truly predictive of making a banking attempt. Although this study focused on parental factors influencing adolescent sperm banking, a variety of factors influence fertility preservation (patient, provider, hospital system, medical, and developmental variables).	4	moderate limitations	⊕ ⊕	high	Regarding the critical influence of parents for sperm banking among adolescent males newly diagnosed with cancer, an effective communication between parents, patients, and health-care teams when discussing preservations options seems very important.	**4**	new finding
Fertility as a priority among at-risk adolescent males newly diagnosed with cancer and their parents	The study don´t make a distinction between the broader construct of parenthood and biological parenthood.	4	moderate limitations	⊕ ⊕	high	Health care providers should communicate fertility risk and preservation options at diagnosis and facilitate timely discussion among families, who may differ in prioritization of future fertility.	**4**	new finding
Prevalence and Predictors of Sperm Banking in Adolescents Newly Diagnosed With Cancer: Examination of Adolescent, Parent, and Provider Factors Influencing Fertility Preservation Outcomes	Self-report of collection attempt and sperm banking, rather than verifying these outcomes in the medical record. Tanner stage was not assessed with a standardized approach. Despite the large data se,t there are power limitations associated with a sample of N= 146 (particularly with binary variables).	4	moderate limitations	⊕ ⊕	high	Although findings suggest that banking is underutilized, modifiable adolescent, parent, and provider factors associated with banking outcomes were identified and should be targeted in future intervention efforts.	**4**	new finding
Presence of cerebral microbleeds is associated with worse executive function in pediatric brain tumor survivors	CMB development was often assessed retrospectively, time to developement was an estimate based on midpoint between the last normal and first abnormal MRI. Additionaly, patients had disparate interval imaging schedules, and there was variation in scanner strength across institutions and across time.	4	moderate limitations	⊕ ⊕	high	The study showed that CMBs may serve as an early marker of neurocognitive decline and help guide targeted interventions.	**4**	new finding

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research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Fertility preservation in the male pediatric population: factors influencing the decision of parents and children	2015	Wyns, C.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study with three diffenrent questionnaires for two age groups of children (<12 and 12-18 years) and parents	N= 120 from 290 sended questionnaires Recovered quationnaire: 35/77 (45,5%) from 12-18 years; 85/213(39,9%) from <12 years; Age at diagnosis for boys <12 years: median= 6,05 years; SD= 3,74 years; range= 0,1-143 months; Age at diagnosis for boys 12-18 years: median= 14,41 years; SD= 1,5 years; range= 144-212 months; Time between diagnosis and survey: M= 3,4 years; SD= 2,3 years
3	Type D personality parents of children with leukemia tend to experience anxiety	2015	Chen, J.	Observational study (cohort, cross/sectional, case-control)	4		Study group: N=164 children with leukemia (acute lymphocytic and nonlymphocytic leukemia) and 231 parents; sign. more jobless parents, families from rural areas compared to control group; Age of parents= 20-49 years (5 hospitals in Southern China) Control group: N=178 children with acute infectious diseases (enteritis, acute upper respiratory infection, bronchitis, bronchopneumonia) and 261 parents Age of parents= 20-49 years
3	Hoping Is Coping: A Guiding Theoretical Framework for Promoting Coping and Adjustment Following Pediatric Cancer Diagnosis	2015	Germann, J.N.	Observational study (cohort, cross/sectional, case-control)	4	Longitudinal study with measures within 4 weeks of cancer diagnosis and every 3 months for 1 year	N= 61 Age: M= 13,5 years; SD= 2,6 years; range= 8-17 years Gender: 35 (57%) males; 26 (43%) females Diagnosis: 25 (41%) solid tumor; 15 (25%) leukemia; 15 (25%) lymphoma; 6 (10%) neurological tumor
3	Profiles of Connectedness: Processes of Resilience and Growth in Children With Cancer	2015	Howard Sharp, K.M.	Observational study (cohort, cross/sectional, case-control)	4	Correlational, cross-sectional and single-site study, with youth with a history of cancer and youth without a history of serious illness. The project was part of a larger longitudinal study of coping and adjustment in children with cancer.	N= 254 (cancer group n= 153; control group n= 101) Age cancer group: M= 13,96 years; SD= 2,97 years; range= 8-19 years Age control group: M= 13,21 years; SD= 3,06 years; range= 8-19 years Gender cancer group: 50,3% male; 49,7% female Gender control group: 53,5% male; 46,5% female Diagnosis: 22,2% acute lymphoblastic leukemia; 7,2% acute myeloid leukemia; 12,4% Hodgkin´s and non-Hodgkin´s lymphoma; 41,8% solid tumor; 16,3% brain tumor Time since diagnosis: 30,7% <18 months; 17,3% 18 months to 3 years; 21,3% 3-6 years; 30,7% >6 years
3	Parents´ FAith and Hope during the Padiatric Palliative Phase and the Association with Long-Term Parental Adjustment	2015	van der Geest, I.M.M.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study	N= 89 parents of 57 deceased children; Gender parents: 63 % mothers; Age fathers: median= 45 years; range= 31-55 y, Age mothers: median= 42 years; range 25-59 y; Time since death of the child: median= 5 years; range= 3-8 y; Gender children: 41 (72%) males; 16 (28%) females; Age children at death: median= 7 years; range=1-17 years; Diagnosis: 21 (37%) hematological malignancy; 20 (35%) brain tumor; 16 (28%) solid tumor

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title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Fertility preservation in the male pediatric population: factors influencing the decision of parents and children	Fertility preservation (FP) acceptance rates were 74% for boys aged <12 years and 78,6% for boys aged 12-18 years. No discrepancy between patient and parent decisions was noted, the decisions were essentially made jointly.The content of information provided to patients and parents had a significant positive impact on the decision to preserve fertility. While the majority of boys aged 12-18 years considered the information to be clear (72%), complete (80%) and understandable (90,9%), only 33,3% of boys aged <12 years were able to comprehend the information (although, 71,4% of children <12 years found it complete, and 57,9% clear). Furthermore 46% of boys aged 12-18 years considered the FP method challenging because of poor general health, lack of experience, taboos or the embarrassing nature. 76% of children considered their health to be more important than the ability to have a family (compared with 48% of adolescents). Pressure from doctors to reduce the delay between diagnosis and cancer treatment increased significantly the number of refusals, while hope for future parenthood favored significantly acceptance.														
Type D personality parents of children with leukemia tend to experience anxiety	*parents with leukemia showed **higher levels of anxiety and prevalence of type D personality** *type D personality (negative affectivity; social inhibition of emotion expression), lower social support and less positive coping style predicted parental anxiety *also demographic and socioeconomic factors such as lower education was associated with parental anxiety *parents with type D personality reported increased anxiety, lower social support and less positive coping style			1											
Hoping Is Coping: A Guiding Theoretical Framework for Promoting Coping and Adjustment Following Pediatric Cancer Diagnosis	Over the year, participants showed high and increasing levels of hope and QoL, as well as low and decreasing levels of depression and anxiety. Those with clinical levels of anxiety and depressive symptomes had significantly lower hope scores than those without clinical levels of anxiety and depressive symptoms. Linear mixed-effects regression analyses revealed changes in depression, anxiety, and hope to be significant predictors of changes in QoL. Changes in hope were found to partially mediate the effects of depression and anxiety in QoL. These findings suggest that hope may serve as a partial mediator of anxiety and/or depression.														
Profiles of Connectedness: Processes of Resilience and Growth in Children With Cancer	Four profiles emerged: [1] High connectedness (45%), characterized by highest level of connectedness across all indicators. [2] Low connectedness (6%), characterized by low level of connectedness in all domains. [3] Connectedness to parents (40%), characterized by higher connectedness to parents. [4] Connectedness to peers (9%), characterized by higher connectedness to friends. Children with and without cancer did not differ on any of the connectedness subscales, stressful life events, or PTSS. However, children with cancer reported higher levels of benefit finding compared with healthy controls. Child-report PTSS differed across SES, the lower the SES the higher PTSS. Correlations suggested that children reporting a greater number of stressful life events tended to report lower connectedness in most domains, as well as higher PTSS. Children highly connected across domains displayed the lowest PTSS and highest benefit-finding. While low connected children had the highest PTSS. And children with a higher connection to parents or friends had moderate PTSS and benefit finding.														
Parents´ FAith and Hope during the Padiatric Palliative Phase and the Association with Long-Term Parental Adjustment	For 19 parents **(21%) faith was very important during the palliative phase,** and 30 parents **(34%) remained hopeful for a cure.** Parents´ faith was **not** associated with less long-term traumatic grief or symptoms of depression, and parents´ **hope for a cure was not related to more long-term traumatic grief or symptoms of depression.**														

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title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Fertility preservation in the male pediatric population: factors influencing the decision of parents and children	Single-center survey. Recall bias due to the time interval between the FP procedure and the survey. Unquantifiable non-response error. Lack of full external validation of the questionnaires, because of the unavailability of validated instruments to this particular topic.	4	moderate limitations	⊕⊕	high	The study enable to understand the factors that may affect the clinical application of FP methods, and the reported expectations and feelings should be considered and used to improve the MCCP (multidisciplinary collaborative care pathways) design.	4	new evidence/citation
Type D personality parents of children with leukemia tend to experience anxiety		4	moderate limitations	⊕⊕	high		4	new evidence/citation
Hoping Is Coping: A Guiding Theoretical Framework for Promoting Coping and Adjustment Following Pediatric Cancer Diagnosis	Those who declined particpation in the study may have been more psychologically symptomatic, resulting in potential bias and overestimation of the psychological adjustment of this population (participation rate: 68%; 92% of participants provided data for at least 2 time points). More sophisticated analyses of second-order effects were not possible because of the insufficient sample size. Paper-and-pencil administration may have been tedious and burdensome to participants, wich may have affected participation rates or participants´ responses. Finally, participants rating was compared with published standardized norms.	4	moderate limitations	⊕⊕	high	While a variety of interventions are efficacious for treating anxiety and depression, hope theory provides a framework for choosing interventions that may more globally promote children´s ability to maintain goog functioning, adjustment, well-being, and QoL following cancer diagnosis.	4	new finding
Profiles of Connectedness: Processes of Resilience and Growth in Children With Cancer	Correlational and single-site study.	4	moderate limitations	⊕⊕	high	The study showed that connectedness ist a possible mechanism facilitating resilience and growth, and could be a domain that is amenale to intervention.	4	new evidence/citation
Parents´ FAith and Hope during the Padiatric Palliative Phase and the Association with Long-Term Parental Adjustment	Only a small number of parents of different religious affiliations participated in the study. Recall bias? Faith was defined for the purpose of the study as part of religion, although, faith can be considered as a much broader concept. Response rate of 35%	4	moderate limitations	⊕⊕	moderate	The study show that faith was not associated with less long-term traumatic grief or symptoms of depression.	3	new evidence/citation

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Predictors of health-related quality of life over time among pediatric hematopoietic stem cell transplant recipients	2016	Loiselle, K. A.	Observational study (cohort, cross/sectional, case-control)	4	Caregivers of a child who received HSCT for oncologic, immunologic, andmetabolic conditions 5 timepoints: T1= within 4 weeks of discharge from hospital (2 w prior to 2 w after), T2=within 1 month after discharge, T3=within 3 mo after discharge, T4=within 6 mo, T5=within 9 m; Baseline: demographics, PAT2 and PedsQL, T2-T5: PedsQL	N=90 caregivers; gender: 90% mothers, 6.7% fathers, 3.3% guardian; age: M=35.14 (SD=7.99); childs gender: male=57 (63.3%); childs age: M=6.42 (SD=4.88); medical condition: oncologic=31(34.4%), hematologic=19(21.1%), immunologic=40(44.4%)
3	The family of the child with cancer: socioeconomic needs	2017	Marques, G.	Observational study (cohort, cross/sectional, case-control)	4		N=128 families of children with cancer Age of children = 1-18 years old Diagnosis=lymphomas, leukemia, sarcomas, osteosarcomas, neuroblastomas, carcinoma of testicle, wilms tumor
3	Assessing the Experience of Medically Ill Youth Participating in Psychological Research: Benefit, Burden, or Both?	2015	Wiener, L.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study in an outpatient research setting.	N=271 Age: M= 14,5 years; range= 7-21years Gender= 143 (52,8%) males; 128 (47,2%) females Children undergoing treatment for cancer, NF1, sickle cell, HIV, Primary immune deficiencies, and Li Fraumeni was included in the study, but there are not any Information in the study about the statistical distribution of the different disease.
3	Support for school reentry and relationships between children with cancer, peers, and teachers	2015	Soejima, T.	Observational study (cohort, cross/sectional, case-control)	4	mixed-methds: 39 dyads (children-guardian) completed questionnaires, 3 guardians underwent semi-structures interviews multi-center: Children with cancer aged 9–18 years who were an outpatient at three hospitals in Japan and their guardians, were eligible for the study	N=39 children-guardian dyads (62 dyads were given the questionnaires, 39 returened [response rate 62.9%], 2 dyads were missing SESS data) age: M=13.3(SD=2.1), range: 9-19 years gender: female=15 (50%) diagnosis: Leukemia=15 (42%), Lymphoma=14 (39%), Osteosarcoma=4 (11%), other=3 (8%) school absence in past month (days): M=1.8 (SD=5.5)
3	Socioeconomic and psychological impact of treatment for unilateral intraocular retinoblastoma	2015	Soliman, S.E.	Observational study (cohort, cross/sectional, case-control)	4	Retrospectiv review of the impact of two different treatment groups for unilateral intraocular retinoblastoma: enucleation vs. salvage treatment	N= 60 (IIRC group C, D, or E) Age at Diagnosis: Enucleation group: median= 26 months; range=14-41 months Salvage treatment group: median= 21 months; range= 12-28 months Gender: Enucleation group: 14 (50%) males; 14 (50%) females Salvage treatment group: 10 (31%) males; 22 (69%) females

Summery of evidence - Research question 3

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Predictors of health-related quality of life over time among pediatric hematopoietic stem cell transplant recipients	There was a significant change in **overall HRQOL in 3 months postdischarge** (there was no statistically significant change from 3 to 9 months), with the greatest **improvement in physical functioning.** The longitudinal course of HRQOL was not predicted by age, gender, family income, initial diagnosis or transplant type. **Caregiver social support at baseline predicted improvements in patient emotional HRQOL** in the 3- to 9-month period (not in overall or physical HRQOL). **Increased caregiver stress** at baseline **predicted declines** in patient overall and physical HRQOL from 3 to 9 months only (not in emotional HRQOL). Greater child behavioral problems predicted decreases in physical functioning from baseline to 3-months posttransplant. However, more child behavioral/emotional problems at baseline predicted improvements in overall, physical, and emotional HRQOL from 3 to 9 months.									1					
The family of the child with cancer: socioeconomic needs	*increased economic spending due to the disease *this is aggravated by the loss of income by one of the parents , who stops working (typically mother) *greater economic impact by families with greater support needs and lower social support			1											
Assessing the Experience of Medically Ill Youth Participating in Psychological Research: Benefit, Burden, or Both?	The majority of patients (83%) and their caregivers (93%) did not find participating burdensome, the majority of patients (85%) and caregivers (95%) found at least some benefit to participation. The most commonly reported factors that caused burden included "Questions being confusing or difficult to answer", too many questions/took to long", "questions were to personal" and "interfered with other activities". Patient reasons for finding benefit in participation included feeling good about helping others or contributing to Society, providing a task to help patients pass the time/keep their mind busy, and finding it helpful/relief to be asked About issues that affect their life. Patient between 18-21 years were significantly more likely to find the study beneficial than the patients under the age of 18.														
Support for school reentry and relationships between children with cancer, peers, and teachers	According to partial correlation analysis, home visit by peers during temporary discharge was significantly related to social support from peers (r=0.384). Peer understanding of hospital experiences (r=0.376) and how to interact with children (r=0.471) were positively significantly associated with social support from peers. Teachers’ understanding of physical appearance (r=0.453); academic performance (r=0.466); hospital experience (r=0.422); and how to interact with children (r=0.417) was related to social support from peers. Furthermore, teachers’ understanding of diagnosis/treatment (r=0.386); academic performance (r=0.439); and their own status as liaisons between hospitals and schools (r=0.422) were related to social support from teachers. The interview survey found that it was important to make children with cancer recognize that they were members of the local school while staying in contact with peers and teachers and that it was important that peers and teachers understood the long-term recovery process of children with cancer while providing them with information. The guardians also reported in the interviews that providing the information made children with cancer aware of their own fight with the disease.	1								1					
Socioeconomic and psychological impact of treatment for unilateral intraocular retinoblastoma	The enucleation group had a median overall socioeconomic score significantly lower than the salvage treatment group. Attempted eye salvage failed in 25 (from 32) children, due to uncontrolled tumor (44%) and socioeconomic impact of cumulative therapies (56%). Treatment duration and socioeconomic score were significantly higher for the 5 children in the salvage treatment group who developed metastatic disease compared to to those without metastasis.														

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Predictors of health-related quality of life over time among pediatric hematopoietic stem cell transplant recipients	only caregiver/proxy report	**4**	moderate limitations	⊕⊕	high		**3**	new evidence/citation
The family of the child with cancer: socioeconomic needs	Kreuztabellen < 5 Fälle	4	moderate limitations	⊕⊕	high		**3**	new evidence/citation
Assessing the Experience of Medically Ill Youth Participating in Psychological Research: Benefit, Burden, or Both?	The statistical distribution of the different disease was not mentioned. Burden and benefit associated with participating in psychosocial Research might differ with longitudinal studies, where measures are repeated over time. The study only incude self-report measures, and no interviews.	4	moderate limitations	⊕⊕	moderate		**3**	new finding
Support for school reentry and relationships between children with cancer, peers, and teachers	small sample, partly no validated questionnaires used; no information regarting guardian characteristcs authors note that the present findings can be applied only to children with cancer who establish supportive relationships	4	moderate limitations	⊕⊕	high		**3**	new evidence/citation
Socioeconomic and psychological impact of treatment for unilateral intraocular retinoblastoma	The study was only applied in a single community and wasnot widely generalizable. Demographic factors and their impact on the studied variables were not considered.	4	moderate limitations	⊕⊕	high	The study demonstrated that the socioeconomic and psychological impact of attempted ocular salvage for unilateral intraocular retinoblastoma was more severe than of primary enucleation.	**3**	new finding

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	The perceived influence of childhood cancer on the parents´ relationship	2017	Wiener, L.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study via a semistructured self-administered questionnaire	N= 192 Age parent: M= 45,4 years; SD= 8,1 years; range= 19-62 years Relationship to child: 122 (63,5%) biological/step/foster mother; 70 (36,4%) biological/step/foster father; 1 (0,5%) other Relationship status: 184 (95,9%) married/partnered; 6 (3,2%) separated/divorced; 2 (1,0%) widowed/other Relationship lenght: M= 17,4 years; SD= 8,8 years; range= 0-40 years Age child with cancer: M= 11,6 years; SD= 6,3 years; range= 1-25 years Gender child: 108 (56,3%) males; 84 (43,8%) females Child diagnosis: 86 (44,8%) blood/hematological cancer; 43 (22,4%) sarcomas; 32 (16,7%) brain cancer; 18 (9,4%) MTC/MEN2B; 13 (6,8%) other
3	Understanding psychological distress among pediatric cancer caregivers	2016	Nam, G. E.	Observational study (cohort, cross/sectional, case-control)	4	single center study (Utah), no control group	N=366; age range 0-26 (4 categories 0-4,5-9,10-14,15-26); ALL, AML, brain tumor, solid tumor
3	Profiles of Adjustment in Pediatric Cancer Survivors and Their Prediction by Earlier Psychosocial Factors	2018	Okado, Y.	Observational study (cohort, cross/sectional, case-control)	4	longitudinal study (baseline, 1 a follow up, 3 a follow up)	N=209; age: 8-17a m=12.48a (SD=2.86); ALL, AML, Lymphoma, Solid Tumor, Brain Tumor
3	Predicting the neurobehavioral side effects of dexamethasone in pediatric acute lymphoblastic leukemia	2016	Warris, L.T.	Observational study (cohort, cross/sectional, case-control)	4		N= 48 Age= 3-6 years Gender= 25 (52%) females; 23 (48%) males Diagnosis: 44 (92%) Pre B-ALL; 4 (8%) T-ALL
3	Predictors of Adaptive Functioning and Psychosocial Adjustment in Children With Pediatric Brain Tumor: A Report From the Brain Radiation Investigative Study Consortium	2015	Robinson, K.E.	Observational study (cohort, cross/sectional, case-control)	4	Cross-sectional study	N= 56 Age: M= 10,72 years; SD= 4,02 years; range= 4,08-17,31 years Gender: 39 males; 17 females Diagnosis: pediatric brain tumor Time since diagnosis: M= 19,30 days; SD= 34,28 days; range= 0-135 days Caregiver: 49 mothers; 7 fathers Tumor type: medulloblastoma/PNET (n=11); anaplastic astrocytoma (n=9); low-grade astrocytoma (n=6); craniopharyngioma (n=3); germ cell tumor (n=3); Ependymoma (n=3); choroid plexus tumor (n=2); ganglioglioma (n=2); pineal tumor (n=1); other (n=16)
3	Brain morphology and information processing at the completion of chemotherapy-only treatment for pediatric acute lymphoblastic leukemia	2018	Darling	Observational study (cohort, cross/sectional, case-control)	4		N=39 Erkrankung=Participants with ALL were approached at the end of treatment, with assessments scheduled 3–4 months post-treat- ment completion Alter=aged ≥ 4 and ≤ 16 years were targeted for the larger study; however, only children ≥ 7 years of age were provided with the option of participating in the imaging component

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
The perceived influence of childhood cancer on the parents´ relationship	Over half of the participants reported their relationships as challenged following the diagnosis of childhood cancer, with close to 40% feeling their relationship had worsened since diagnosis, and a third scoring low on dyadic adjustment. Diagnosis and relapse of disease were cited as the most individually stressful time point, with hospitalizations and relapse being most stressful on the relationship. Participants felt most emotionally connected at diagnosis and least emotionally connected at the start and end of treatment.														
Understanding psychological distress among pediatric cancer caregivers	**60.5% of caregivers of pediatric cancer patients reported clin. sig. levels of distress; lower annual income, lower education levels had significant association with caregivers distress;** Infrequently or never attending religious services, younger child age, and a diagnosis of AML were associated with higher intrusion (all p < 0.05). Caregivers with a child currently receiving therapy reported higher overall IES (impact of event scale) and intrusion scores compared to those off therapy.	1			1										
Profiles of Adjustment in Pediatric Cancer Survivors and Their Prediction by Earlier Psychosocial Factors	3 class model: **1.65% long term resilience**, 2. **23% "Self report at-risk group":** internalizing and attention problems, 3.**12% Parent-report-at-risk-group":** parent-reported externalizing, internalizing problems + self- and parent-reported attention problems. Several psychosocial predictors, including child posttraumatic stress, affectivity, and connectedness to school, as well as parental distress and overprotection, differentiated the Resilient group from the other groups, in expected directions.				1										
Predicting the neurobehavioral side effects of dexamethasone in pediatric acute lymphoblastic leukemia	Patients with glucocorticoid hypersensitivity experienced more dexamethasone-induced conduct problems and sleeping sroblems/somnolence. The positive predictive values of the DST (Dexamethasone Suppression Test) for psychosocial problems was 50% and for sleeping problems 30%. Dexamethasone levels were not associated with neurobehavioral side effects.														
Predictors of Adaptive Functioning and Psychosocial Adjustment in Children With Pediatric Brain Tumor: A Report From the Brain Radiation Investigative Study Consortium	Rates of impairment in overall behavioral symptoms, internalizing, and externalizing were similar to expected rates in the general population (BASC-2). Rates of impairment in global adaptive functioning exceeded expectations; impairment in social and conceptual skills was within expectation, whereas impairment in practical skills exceeded expectation (ABAS-II). A combination of familial/demographic and diagnostic variables were associated with acute functioning. On the ABAS-II, lower overall adaptive functioning was associated with lower family income, lower parent education, and larger tumor size. On the BASC-2 behavioral symptoms were significantly associated with lower family income, lower parent education, a parent history of psychiatric problems, and supratentorial tumor location. In multiple regressions, tumor size best predicted adaptive functioning after initial diagnosis (ABAS-II), whereas tumor location best predicted variance in behavioral symptoms (BASC-2).														
Brain morphology and information processing at the completion of chemotherapy-only treatment for pediatric acute lymphoblastic leukemia	In summary, survivors of pediatric ALL recently off che- motherapy-only treatment displayed relative deficits in the capacity demands of information processing, while differences in speed of processing and brain morphology did not reach statistical significance in this small sample. Further investiga- tions using imaging outcomes sensitive to white-matter micro- structure and information processing capacity may be more useful to explore related neuropathology. Future research should focus on the end of treatment as a critical time point for cognitive assessment and potential intervention.	1													

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
The perceived influence of childhood cancer on the parents´ relationship	Underrepresentation of ethnic minorities. Overrepresentation of mothers. The data were dependent on recall and perception of the relationship prior to their child´s cancer diagnosis.	4	moderate limitations	⊕ ⊕	high	The study show the impact that childhood cancer can have on both healty and dysfunctional parental relationships and the importance of assessing relationship quality as part routine psychosocial care throughout the illness trajectory.	**3**	new evidence/citation
Understanding psychological distress among pediatric cancer caregivers	exploratory study, no in-dept exploration of psychological distress, heterogen diseases, age records only categorial,	**4**	moderate limitations	⊕ ⊕	high	interventions to minimize financial burden are recommended	**3**	new evidence/citation
Profiles of Adjustment in Pediatric Cancer Survivors and Their Prediction by Earlier Psychosocial Factors	only 60.4% of the sample participated in T2 (delay in the approval of a study amendment)	**4**	moderate limitations	⊕ ⊕	high	importance of targeted prevention strategies for the minority of survivors who are at risk for maladjustment.	**3**	new evidence/citation
Predicting the neurobehavioral side effects of dexamethasone in pediatric acute lymphoblastic leukemia		4	moderate limitations	⊕ ⊕	high		**3**	new evidence/citation
Predictors of Adaptive Functioning and Psychosocial Adjustment in Children With Pediatric Brain Tumor: A Report From the Brain Radiation Investigative Study Consortium	The lack of a healthy control group alowed statistical comparison only to normative samples. Solely parent-reported behavioral and adaptive functioning was measured. The study participation was limited to children between 4 and 17 years of age , and children who had undergone surgical intervention.	4	moderate limitations	⊕ ⊕	high	The study showed that on the basis of familial, sociodemographic, and diagnostic variables (screening), those most at risk of impairment could be identify.	**3**	new evidence/citation
Brain morphology and information processing at the completion of chemotherapy-only treatment for pediatric acute lymphoblastic leukemia	Unvollständige Daten	4	moderate limitations	⊕ ⊕	high	Neuropsychologische Diagnostik und in Folge Intervention bei ALL mit nur Chemotherapie	**3**	new finding

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Neurocognitive functioning in pediatric craniopharyngioma: performance before treatment with proton therapy	2017	Fournier-Goodnight, A.S.	Observational study (cohort, cross/sectional, case-control)	4	Investigation of the impact of patient-, disease-, and treatment-related variables upon neurocognitive outcomes in pediatric patients with craniopharyngioma prior to treatment with proton therapy or observation after radical resection.	N= 104 Age: M= 9,84 years; SD= 4,74 years; range= 0-21 years Gender: 50 (48,08%) males; 54 (51,92%) females Time since diagnosis: M= 0,85 years; SD= 1,33 years; range= 0.03-9,77 years
3	Satisfaction with support versus size of network: differential effects of social support on psychological distress in parents of pediatric cancer patients	2016	Harper, F.W.K.	Observational study (cohort, cross/sectional, case-control)	4	Longitudinal study, with a baseline, and a 3- and 9-months follow-up assessments regarding trait anxiety, depression, and social support network (satisfaction with support and size of support network).	N= 102 families; Age parents: M= 34,71 years; SD= 7,19 y,Age children: M= 6,44 y; SD= 3,13 y, Gender parents: 85 (83%) female; Gender children: 59 (58%) females
3	Emotion Socialization in the Context of Childhood Cancer: Perceptions of Parental Support Promotes Posttraumatic Growth	2017	Howard Sharp, K. M.	Observational study (cohort, cross/sectional, case-control)	4	data were part of a larger longitutinal study (data for this project werwe collected at time point 3, approx. 36 months after initial recruitment; overall attrition rate of 12.5%). recruited from outpatent clinics at children's oncology hostpital Patients completed the emotion socialization measure in reference to the caregiver (primarily mothers) who participated in the study with them.	N=201 (cancer related event n=100 (49.8%), non-cancer related event n=101(50.2%) age: cancer related: M=15.32 (SD=3.18, range=8-21), non-cancer related: M=15.14 (SD=3.5, range=8-21) gender: cancer related: male=50; non-cancer related: male=50.5 child reporting on mother (vs. father): cancer related: mother=87%; non-cancer related: mother=82.2 diagnosis: cancer related: ALL=21, AML=7, Hodgkin's and non-Hodgkin's lymphoma=13, solid tumor=44, brain tumor=15; non-cancer related: ALL=33.7, AML=5, Hodgkin's and non-Hodgkin's lymphoma=13.9, solid tumor=37.6, brain tumor=9.9 time since diagnosis at time 3: cancer related: M=5.91 (SD=3.26), non-cancer related: M=8.27 (SD=4.72)
3	Predictors of psychological functioning in children with cancer: disposition and cumulative life stressors	2015	Howard Sharp, K. M.	Observational study (cohort, cross/sectional, case-control)	4	psychological functioning in children with a history of cancer and a matched sample of healthy peers, while exploring the roles of disposition and stressful life events; Children completed measures of depression, anxiety, and posttraumatic stress symptoms, history of stressful life events, and dispositional factors (incl. optimism and a five-factor personality measure)	N=225 children with cancer, N=101 healthy children from schools in community age: PG: M=12.7 (SD=2.9), CG: M=12.1 (SD=2.9); range=8-17 gender: PG: male=51.8%, CG: male=56.4% diagnosis: PG: ALL=23.9%, AML=7.1%, hodgkin's and non-hodgkin's lymphoma= 13.3%, solid tumor=38.4%, brain tumor=17.3% Children in the two groups did not differ based on age, gender, or ethnicity but significantly differed in socioeconomic status.

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Neurocognitive functioning in pediatric craniopharyngioma: performance before treatment with proton therapy	Participants showed poorer performance in comparison to the normative group across neurocognitive domains including executive functions, learning and memory, and fine-motor coordination. Poor performance across areas was predicted by presurgical hypothalamic involvement, extent of surgery, and vision status. The study demonstrated that patients wit craniopharyngioma show weaker neurocognitive performance in comparison to the normative population resulting from tumor, events leading to diagnosis, and early surgical intervention.														
Satisfaction with support versus size of network: differential effects of social support on psychological distress in parents of pediatric cancer patients	Parents´ satisfaction with support had a direct effect on longer-term psychological distress; **satisfaction with support was negatively associated with distress at both follow-ups**. In contrast, s**ize of support network moderated the impact of trait anxiety and depression on later distress.** Parents with **smaller support networks and higher levels of trait anxiety and depression at baseline had higher levels of psychological distress at both follow**-ups; for parents with larger support networks, there was no relationship.														
Emotion Socialization in the Context of Childhood Cancer: Perceptions of Parental Support Promotes Posttraumatic Growth	Youth with longer elapsed time since diagnosis and with “moderate” treatment severity were more likely to identify a non-cancer event, youth who experienced more intense treatment more likely to identify a cancer-related event. Participants are perceiving their caregivers as primarily reacting with support. Youth who identified a cancer-related event perceived their parents as reacting with more support and reassurance/distraction than those who identified a non-cancer event. Participants who self-identified their cancer as their most stressful life event endorsed significantly higher PTG (post traumatic growth). Perceptions of parental support, reassurance/distraction, and magnification of youth distress were associated with more PTG, with event type (cancer vs. non-cancer) indirectly predicting PTG through perceptions of parental support. Event type also influenced PTG independent of its effect on perceived parental support, indicating a significant direct effect on PTG --> Youth perceive their parents as reacting differently to cancer versus noncancer distress, which is in turn predictive of their perceptions of growth. --> Parental support and reassurance/distraction are possible mechanisms facilitating resilience and growth in children with cancer									1					
Predictors of psychological functioning in children with cancer: disposition and cumulative life stressors	On average, children in both groups were reporting symptoms of depression, anxiety, and PTSS within the normative range, suggesting a well-adjusted sample. Children with cancer did not differ from peers with regard to depression and PTSS, but reported significantly lower anxiety. In hierarchical regressions, children’s depression, anxiety, and PTSS scores were largely predicted by dispositional variables (accounting for 48% of variance in prediction of depression, 28% for anxienty and 26% for PTSS) and, to a lesser extent, stressful life events (accounting for 9-12% of variance), after controlling for demographics and health status. Demographic variables accounted for significant variance in predicting anxiety and PTSS (girls and younger children were significantly more likely to report anxiety symptoms). Health status was a significant predictor of anxiety (approx. 2% of the variance). --> Children with cancer are generally resilient, with factors predictive of their adjustment difficulties mirroring those of children without history of serious illness									1					

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Neurocognitive functioning in pediatric craniopharyngioma: performance before treatment with proton therapy	Changes across neurocognitive domains following treatment wit proton therapy was not investigate. A comparison of the performance of patients treated with proton therapy to a well-matched cohort treated with techniques like photon radiation therapy is missed. Investigation of the impact of additional clinical factors such as sleep and aerobic fitness and psychological factors like income and parent education level on neurocognitive outcomes will be useful in informing treatment for this population.	4	moderate limitations	⊕⊕	high	The study showed that poorer performance is predicted by clinical variables, wich can be used to inform treatment and intervention planning. Accurate characterization of the neurocognitive functioning of this population at baseline sets the stage for more precisely comparing different methods of radiation therapy for potential preservation of neurocognitive functions.	**3**	new finding
Satisfaction with support versus size of network: differential effects of social support on psychological distress in parents of pediatric cancer patients	Social support was assessed only at study entry. Parents provided self-reports of their negative affect, social support, and global distress, thus introducing possible bias due to common method variance.	**4**	moderate limitations	⊕⊕	high	The study showed that whereas interventions that focus on increasing satisfaction with the social support may benefit all parents, at-risk parents will likely benefit from interventions that ensure they have an adequate number of support resources.	**3**	new evidence/citation
Emotion Socialization in the Context of Childhood Cancer: Perceptions of Parental Support Promotes Posttraumatic Growth	only perceptions of youths, retrospective	4	moderate limitations	⊕⊕	high		**3**	new evidence/citation
Predictors of psychological functioning in children with cancer: disposition and cumulative life stressors		4	moderate limitations	⊕⊕	high		**3**	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Metacognitive aspects influence subjective well-being in parents of children with cancer	2015	Toffalini, E.	Observational study (cohort, cross/sectional, case-control)	4	Parents of children being treated for cancer (study group) were compared with parents of children being treated for acute, non life-threatening illnesses (hospitalized control group) and with parents of healthy children (healthy control group).	**Study Group:** N = 30; Gender:20 mothers; Age range= 30-50 years; Active treatment (chemotherapy): at least 1 month and up to 1 year; Time since first diagnosis: 2 month to a few years (in cases of relapses) N (**hospitalized control group)**= 36; Gender=22 mothers; Age range= 24-47 years; Diagnosis hospitalized control group: mostly acute diseases and allergies; N (**healthy control group)**= 30; Gender= 20 mothers; Age: range= 29-54 years Healthy children attending nursery or school
3	Benefit Finding in Maternal Caregivers of Pediatric Cancer Survivors: A Mixed Methods Approach	2016	Willard, V.W.	Observational study (cohort, cross/sectional, case-control)	4	Mix method study, with qualitative and quantitave measures	N= 40 Age mothers: M= 40,1 years; SD= 5,84 years, range= 28-48 years 37 (92,5%) maternal caregivers as the child´s primary caregiver; 3 (7,5%) mothers shared responsibility with child´s father Gender children: 25 (62,5%) males; 15 (37,5%) females Age children: M= 10,6 years; SD= 3,7 years Age at diagnosis: M= 4,0 years; SD= 3,17 years Time off-treatment: M= 57,5 months; SD= 40,48 months Diagnosis: 18 (50,0 %) brain tumor; 18 (50,0%) other
3	Stress, Psychosocial Mediators, and Cognitive Mediators in Parents of Child Cancer Patients and Cancer Survivors: Attention and Working Memory Pathways Perspectives	2015	van der Haegen, M.	Systematic review of descriptive or qualitative studies	5	Experimental studies, meta-analyses, and qualitative studies published between 2000 and 2013	N= 92 studies
3	Teenage and young adult cancer-related fatigue is prevalent, distressing, and neglected: It is time to intervene. A systematic literature review and narrative synthesis	2015	Spathis, A.	Systematic review of descriptive or qualitative studies	5	Search: MEDLINE, EMBASE, PsycINFO, and CINAHL; any aspect of fatigue in patients aged 13–24 at cancer diagnosis or treatment; only englisch language; exclusion criteria: absence of original empirical data, phase I/II clinical trials, trials involving fewer than 10 patients, case reports, and retrospective case note reviews.	N=60 (of 2388)
3	The lived experience of fatigue in children and adolescents with cancer: a systematic review.	2016	Tomlinson, D.	Systematic review of descriptive or qualitative studies	5	searches of Ovid Medline, EMBASE, PsycInfo, Science Citation, Social Science Citation (Web of Science), and CINAHL. Studies in which the experience of fatigue was described by the child/adolescent; restricted to publications in English	N=11 studies in 18 publications (age: 6-19y)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Metacognitive aspects influence subjective well-being in parents of children with cancer	Parents in the study group and the hospitalized control group experienced significantly **lower subjective well-being (SWB)** compared with the healthy control group. However the study group and the hospitalized control group did not differ from each other in terms of the SWB. The study group presented a significantly lower need to control thoughts. Metacognitive aspects explained up to 77% of the variance in SBW in parents of children with cancer, as opposed to only 23% in hospitalized control group and 33% in the healthy control group.														
Benefit Finding in Maternal Caregivers of Pediatric Cancer Survivors: A Mixed Methods Approach	No significant associations between number of benefits and parenting stress (PSI and BSI), but strong associations between qualitative measures and illness-related adjustment (PECI). Fewer benefits was associated with more guilt and worry, unresolved sorrow and anger, and long-term uncertainty, and fewer emotional ressources. 3 Themes (82,5%, n=33 mothers reported some type of benefit): [1] Social support ("cancer community" of hospital and other patients, strengthening of marital bond, human kindness and goodness of makind, family closer together, greater social support network, charity from others) [2] Personal growth (strengthening personal faith and spirituality, greater appreciation for life, inspiring to help others, more compassionate to others, advocate for the child and family, adjusting the relative importance of priorities in life, sense of inner strength and empowerment, healthier lifestyle, less preoccupied with trivial worries, more maturity and understanding) [3] Child-specific (strengthening the parent-child relationship, growth or maturation in the child, being inspired by the child)														
Stress, Psychosocial Mediators, and Cognitive Mediators in Parents of Child Cancer Patients and Cancer Survivors: Attention and Working Memory Pathways Perspectives	The review investigate 3 core issues: [1] The consequences of stress on attention and working memory patterns. Experimental studies demonstrated a negative effect of laboratory stressors on cognitive performances, and researchers emphasized significant attentional deficits and core difficulties in the process of access and retrieval of the working memory. [2] Understanding wich stress symptoms have been observed in parents of child cancer patients and parents of child cancer survivors. During treatment, a host of predictors can lead to a greater risk of depression, anxiety and PTSS, wich are: female gender, innate traits of anxiety and anger, and a low SES. Two main mediators, the psychosocial factor (i.e., social support and family functioning) and the coping appraisal factor (i.e., coping strategies and adjustment) seems to counteract some psychological issues such as depression, anxiety, and PTSS/PTSD. PTSS is frequently observed in families of childhood cancer survivors. These symptoms persist long after treatment completion for parents. Recent studies shows that parents of survivors of pediatric cancer who continued to accompany their child to appointments to hospital, reported identical levels of anxiety and distress to parents of children on active treatment. [3] Investigate the long-term consequences on the quality of the cognitive operations of parents of child cancer survivors. Few studies focused on this topic, but all studies in the field have pointed to a robust link between stress and its effectson memory and attentional performance outcomes.														
Teenage and young adult cancer-related fatigue is prevalent, distressing, and neglected: It is time to intervene. A systematic literature review and narrative synthesis	Cancer-related fatigue was consistently one of the most prevalent, severe, and distressing symptoms, and it persisted long-term in survivors. It was associated with a number of factors, including poor sleep, depression, and chemotherapy. There was little evidence for the effectiveness of any intervention, although exercise appears to be the most promising. Importantly, fatigue was itself a significant barrier to physical and social activities.														
The lived experience of fatigue in children and adolescents with cancer: a systematic review.	Terms used to describe fatigue included: tiredness, weary, loss of strength, dizziness, feeling drained, feeling drowsy, lacking motivation, exhaustion, and feeling emotional. Impact of fatigue related to not being able to participate in regular activities; needing to sleep or rest more; and impact on psychosocial health. Perceived alleviators of fatigue included exercise, distraction, rest, eating, and drinking.														

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Metacognitive aspects influence subjective well-being in parents of children with cancer	Small sample size and heterogneneity of conditions (e.g., different types of tumor and time elapsed after diagnosis). The specific role of each metacognitive aspect should be analyzed more in depth, especially in the case of cognitive confidence, wich seems to partially overlap with the concept of well-being.	4	moderate limitations	⊕ ⊕	high	Metacognitive aspects could be used as a quick screening and for psychological support.	3	new finding
Benefit Finding in Maternal Caregivers of Pediatric Cancer Survivors: A Mixed Methods Approach	Relatively small sample size. Mothers reported on beneffit finding retrospectively. The phrasing of the questionnaire may have resulted in limiting the number of beneefits being reported by some mothers and the relative importance of each benefit wasn´t captured (2 highly salient benefits was ranked below 4 less impactfull benefits).	4	moderate limitations	⊕ ⊕	high	The study highlights the role that benefit finding plays in the adjustment process and the coping with a cancer diagnosis.	3	new finding
Stress, Psychosocial Mediators, and Cognitive Mediators in Parents of Child Cancer Patients and Cancer Survivors: Attention and Working Memory Pathways Perspectives		5	no limitations	⊕ ⊕	high	The review summarize important results concerning stress symptoms in parents of child cancer patients and parents of child cancer survivors.	4	new evidence/citation
Teenage and young adult cancer-related fatigue is prevalent, distressing, and neglected: It is time to intervene. A systematic literature review and narrative synthesis	studies included were heterogeneous and relatively low in quality; grey literature may have been missed; only english-language articles;	5	no limitations	⊕ ⊕	high		4	new finding
The lived experience of fatigue in children and adolescents with cancer: a systematic review.	Majority of studies in review used semi-structured interviews	5	no limitations	⊕ ⊕	high		4	new finding

Summery of evidence - Research question 3

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
3	Patterns of Respons in Parents of Children With Cancer: An Integrated Rieview	2016	Cerqueira, C.	Systematic review of descriptive or qualitative studies	5	Review of 18 studies dealing with the topic of parental role change after diagnosis	18 studies; partly quantitative, partly qualitative.
3	A Systematic Review of the Experiences of Siblings of Children With Cancer	2016	Yang, H.C.	Systematic review of descriptive or qualitative studies	5	10 qualitatives studies published between 1960 and 2013 was appraised with the Joanna Briggs Institute Qualitative Assessment and Review Instrument	The review included studies where the participants were aged from 6 to 20 years and are siblings of a brother or sister with childhood cancer
3	A systematic review of sleep in hospitalized pediatric cancer patients	2017	Lee, S.	Systematic review of descriptive or qualitative studies	5	studies in english, participants 19 or younger, active treatment and hospitalized no book chapters, case studies, dissertaions and purely qualitative studies	N=7 articles included (from 108 found) N=165 participants, range=15-49 age: 1-18 years gender: male=79(47.9%) various cancer diagnoses
3	Factors Related to Healthy Siblings´ Psychosocial Adjustment to Children With Cancer: An Integrative Review	2016	Zegaczewski, T.	Systematic review of descriptive or qualitative studies	5	Review of 7 nonexperimental and 5 quasi-experimental studies; only studies with a minimum sample size of 30 was retain	Not applicable
3	Fertility Preservation in Pediatric and Adolescent Oncology Patients: The Decision-Making Process of Parents	2016	Li, N.	Systematic review of descriptive or qualitative studies	5	Review on 35 articles discussing fertility preservation decision-making (24 in adult population, and 11 in the pediatric and adolescent population)	Not applicable
3	Symptoms and Self-Management Strategies Identified by School-Age Children with Cancer Using Draw-and-Tell Interviews	2018	Linder, L.A.	Individual qualitative study	6	Cross-sectional, exploratory, descriptive study. Draw-and-tell interviews (Driessnack, 2006) with children depicting days that they felt well and days that they felt sick.	N= 27 children Age: M= 9,16 years; SD= 1,9 years; range= 6,33-12,83 years Age group: 14 (52%) younger children 6-8 years; 13 (48%) older children 9-12 years Gender: 14 (52%) male; 13 (48%) female Time since diagnosis: median= 9 months; range= 1-93 months Diagnosis 15 (57%) acute lymphoblastic leukemia; 1 (4%) other acute leukemia; 1 (4%) Hodgkin lymphoma; 1 (4%) non-Hodgkin lymphoma; 2 (7%) brain tumor; 5 (19%) sarcoma; 2 (7%) other solid Disease stage: 26 (96%) primary disease; 1 (4%) recurrent disease

Summery of evidence - Research question 3

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Patterns of Respons in Parents of Children With Cancer: An Integrated Rieview	The authors evaluated studies that deal with changing the respective roles of parent couples through their child's cancer diagnosis. The studies use different methods; The authors have tried to classify the respective reactions of mothers and fathers to four different topics: caring for the child with cancer, becoming a partner in caring for the child, caring for the family and living with a child with cancer. Parents feel the need to have control over their child's illness and develop responses that can give them a sense of control. The focus is always on the possibility of losing the child and the unpredictability of events. Further research is needed to predict which factors may favor successful changes in parental role models.														
A Systematic Review of the Experiences of Siblings of Children With Cancer	Siblings of children with cancer were found to have experienced 4 themes (9 categories): [1] the desintegration of life (living with a chaotic family life, learning about the suffering of the sibling through being with him/her, changes in peer interaction and academic learning difficulties) [2] marginalization within their family relationships (insecurity and loss of original family life and family intimacy, loss of family concerns and development of emotional swings) [3] self-transcendence during the normalization of family relationships (acquiring the power of growth though experiencing illness initiates vitality, reestablishement of roles and intimacy within family) [4] maintenance of family normality (reconstruction of the protective roles and relationships within the family, living together and maintaining family normality).														
A systematic review of sleep in hospitalized pediatric cancer patients	Across all studies, child sleep appeared to be disrupted in the hospital when compared to previously established age-related norms. These results were consistent across wrist actigraphy, self-reports, and parent-reports (patients slept fewer total hours a night, for some children this may signify a clinically significant decrease in total sleep time). Noise, light levels, and staff room interruptions were associated with decreased total sleep minutes and increased nighttime awakenings. --> create a more supportive sleep environment and more effective screening tools for patients who may be at greater risk for sleep difficulties. This may help to minimize the role that hospitalization plays in precipitating and perpetuating chronic sleep disturbances in pediatric cancer patients.														
Factors Related to Healthy Siblings´ Psychosocial Adjustment to Children With Cancer: An Integrative Review	3 Factors that correlate with HSCC´s psychosocial adjustment: characteristics (age, gender), social support, and contextual factors (role overload, family adaptability). Social support from family and HSCC summer camps shows profound effects (less symptoms of depression, significant improvements in HSCC´s post-traumatic stress symptoms, anxiety, total quality of life and self-worth/confidence). Female HSCC exhibit more behavioral problems, anxiety and disturbed quality of life than male. Younger HSCC shows disturbances in play activities while older children tend to internalize and become withdrawn, suffer from feelings of loneliness and/or anxiety, or have difficulties with academic competencies. However, one study shows contrary effects. HSCC need to be assess at individual and familial levels. HSCC perceived contextual threat, family adaption, role-overload, outlook of illness, self-efficacy and self-control also affect HSCC psychosocial adjustment.														
Fertility Preservation in Pediatric and Adolescent Oncology Patients: The Decision-Making Process of Parents	The following key themes could be found in the articles: - Factors considered in fertility preservation decision-making - Decision-making in established procedures and experimental procedures - Decisional conflict and regret - Perceived importance of information - Adolescent involvment in decision-making -Ethical considerations in the pediatric population														
Symptoms and Self-Management Strategies Identified by School-Age Children with Cancer Using Draw-and-Tell Interviews	Children´s drawings related both symptoms and the strategies children use to self-manage their symptoms. Nausea, fatigue, pain, and sadness were the most frequently reported symptoms. Strategies to manage symptoms most often included physical care strategies (efforts to manage their energy balance n=15, personal comfort strategies n= 15, lying down and rest n=11), psychosocial care strategies (use of distractions n=7, effort to personalize and normalize their situation n=7), and medication related strategies (taking a given medication to help relieve a symptom n=4, children´s specific strategies for taking their medications n=2).														

Summery of evidence - Research question 3

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Patterns of Respons in Parents of Children With Cancer: An Integrated Rieview		5	no limitations	⊕ ⊕	high		**3**	new evidence/citation
A Systematic Review of the Experiences of Siblings of Children With Cancer	The study focuses only on the connection between individuals whose family life experiences include a brother or sister diagnosed with cancer.	5	no limitations	⊕ ⊕	moderate	The study show the impact of the childhood cancer on siblings, and that siblings are important participants that affect the ill child´s and family´s well-being.	**3**	new evidence/citation
A systematic review of sleep in hospitalized pediatric cancer patients		5	no limitations	⊕ ⊕	moderate		**3**	new evidence/citation
Factors Related to Healthy Siblings´ Psychosocial Adjustment to Children With Cancer: An Integrative Review	More than the half of the studies (7 from 12) are descriptive correlational design	5	no limitations	⊕ ⊕	moderate		**3**	new evidence/citation
Fertility Preservation in Pediatric and Adolescent Oncology Patients: The Decision-Making Process of Parents		5	no limitations	⊕ ⊕	moderate	Considering that the decision to pursue fertility preservation is known to be difficult in the adult population, decisional conflict and regret may be greater for parents who are making the decision for their child.	**3**	new evidence/citation
Symptoms and Self-Management Strategies Identified by School-Age Children with Cancer Using Draw-and-Tell Interviews	Small cross-sectional, heterogenous sample from a single institution. The self-management strategies were not associated with specific symptoms, and the study did not assess children´s symptoms at a given point in time, but to recall ofdays when they were feeling well and days when they were feeling sick.	6	moderate limitations	⊕ ⊕	high	Healthcare team members should integrate arts-based approaches to symptom assessment and to support children in implementing their preferred strategies to alleviate symptoms.	**4**	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Effect on motivation on academic fluency in survivors of pediatric medulloblastoma	2015	Holland, A.A.	randomised controlled study	2	stratified randomization procedure: incentive condition (money) and non-incentive condition; brief neuropsychological screening evaluation, monetary incentive offered during 5 minute break in study protocol to half of participants	N=36 (of 47) patients (24 male), 2 sites in Texas; Mean age: 14.07y (7-18); 66.7% upper middle or high socioeconomic status; Mean age since diagnosis: 8.55 (1.33-17.42)
4	Screening for Family Psychosocial Risk in Pediatric Cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3.	2018	Kazak, A.E.	observational study (cohort, cross/sectional, case-control)	4	validation	English-speaking caregivers of N=394 patients newly diagnosed (data from one parent per family was used in the report); N=353 female caregivers; age of patient: 0-17y; gender of patient: 51.3 male; diagnosis: leukemias: 36.5%, solid tumors: 30.7%, lymphomas: 17%; brain tumors: 13.7%, others: 2.1%.
4	Screening for psychological distress in very long-term adult survivors of childhood cancer	2016	de Laage, A.	observational study (cohort, cross/sectional, case-control)	4	large cohort study in France (BSI 18, IES, IWS, Mini international neuropsychiatric interview)	N=348 (out of 422) seen at late effect clinic (Inst. Gustave-Roussy and Inst. Curie), 1/2012-3/2013. female=164, male=184. Mean age=38.5y (18.1-65.8y), mean time since diagnosis=31.5 (8.8-56.1). Diagnosis: CNS, Hodgin, Sarcoma, Nephroblastoma, Neuroblastoma, LNH)
4	Development and preliminary validation of a short form of the Beck Depression Inventory for Youth (BDI-Y) in a sample of adolescent cancer survivors	2015	Blackmon, J.E.	observational study (cohort, cross/sectional, case-control)	4	cohort of survivors; development of short form	2 survivors clinics (1 Neuro-Oncology, 1 all other childhood cancer survivors; Boston); N=202 (out of REACH Project); age=12-18 (Mean: 15.4y), male 52%, CNS: 49.3%; age of first diagnosis=birth to 16.4y; mean time since D=9.1y (2.1-17.8)
4	Validity of the Brief Symptom Inventory-18 (BSI-18) for identifying depression and anxiety in young adult cancer survivors: Comparison with a Structured Clinical Diagnostic Interview.	2017	Recklitis, C.J.	observational study (cohort, cross/sectional, case-control)	4	cohort study (young adult cancer survivors), assessment of accuracy of BSI-18 by comparing to SCID (DSM-IV)	N=250 YACS (18-40), single center (Boston), age at first diagnosis: birth to 37y (mean: 20.51y)
4	Psychometric properties of the Fear of Progression Questionnaire for parents of children with cancer (FoP-Q-SF/PR)	2017	Clever, K.	observational study (cohort, cross/sectional, case-control)	4		N=181 parents (119 mothers, 62 fathers); of N=128 children; response rate: 54.3%

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Effect on motivation on academic fluency in survivors of pediatric medulloblastoma	Provision of a performance-based incentive resulted in statistically significant improvement, but not normalization of function, in performance on measures of academic fluency. No demographic, treatment-related, academic, neuropsychological, or self-perception variables predicted response to incentive. Findings suggest that academic performance of survivors may significantly improve under highly motivating conditions. In addition to implications for educational services, this finding raises the novel possibility that decreased motivation represents an inherent neuropsychological deficit in this population and provides a rationale for further investigation of factors affecting individual differences in motivational processes.														
Screening for Family Psychosocial Risk in Pediatric Cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3.	Original structure of the PAT, with seven subscales (Family Structure, Social Support, Child Problems, Sibling Problems, Family Problems, Stress Reactions, and Family Beliefs) was supported using a confirmatory factor analysis. Internal consistency for the total score (Kuder-Richardson 20 coefficient [KR20] = 0.81) and the subscales (KR20 = 0.59-0.85) was moderate to strong. Moderate to strong correlations with the criteria measures provided validation for the total and subscale scores. The validation measures varied significantly, as expected, across the three levels of the PPPHM. Receiver operating characteristic (ROC) analyses showed that the PAT total and subscale scores can discriminate families above and below clinical thresholds.														
Screening for psychological distress in very long-term adult survivors of childhood cancer	Multiple regression analyses of the data collected from self-administered questionnaires (BSI-18, IES, IWS) confirmed that being female, living alone, and self-reported late effects were associated with the high scores for all scales. Negative remembrances and being accompanied to the clinic were associated with higher IWS scores. Unlike the initial hypothesis, the MINI showed that, compared with controls, survivors experienced a higher prevalence of anxiety and mood disorders even after a very long time since the diagnosis. These findings show that a substantial subset of survivors experiment a high prevalence of PD, higher than the general population, and should be screened for PD whatever the time since the diagnosis.														
Development and preliminary validation of a short form of the Beck Depression Inventory for Youth (BDI-Y) in a sample of adolescent cancer survivors	Each of the three short forms had high correlations with the total BDI-Y scale (r > 0.95), good internal consistency (alpha > 0.80), and good overall discrimination compared to a standard BDI-Y cutoff score (AUC > 0.90). The eight-item short form demonstrated notable consistency across the derivation and replication samples, with high sensitivity and specificity using a cutoff score of >/=5, making it a promising tool for clinical screening.														
Validity of the Brief Symptom Inventory-18 (BSI-18) for identifying depression and anxiety in young adult cancer survivors: Comparison with a Structured Clinical Diagnostic Interview.	44 participants (17.7%) met criteria for >/=1 SCID diagnoses, and an additional 20 (8.0%) met criteria for clinically significant SCID symptoms without a diagnosis. The BSI-18 shows good overall concordance with a psychiatric interview, but recommended cut-off scores fail to identify a majority of YACS with psychiatric diagnosis. Clinicians should not rely on the BSI-18 alone as a screening measure for YACS.														
Psychometric properties of the Fear of Progression Questionnaire for parents of children with cancer (FoP-Q-SF/PR)	The FoP-Q-SF/PR demonstrated good reliability and validity for parents of children with cancer. The FoP-Q-SF/PR is a feasible screening instrument, which is suitable for the assessment of parental FoP in pediatric oncology.	1													

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Effect on motivation on academic fluency in survivors of pediatric medulloblastoma		2	no limitations	⊕ ⊕ ⊕ ⊕	high		4	new finding
Screening for Family Psychosocial Risk in Pediatric Cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3.		4	no limitations	⊕ ⊕ ⊕	high		4	new finding
Screening for psychological distress in very long-term adult survivors of childhood cancer	possible selective bias (only survivors attending late effect clinic)	4	no limitations	⊕ ⊕ ⊕	high		4	new finding
Development and preliminary validation of a short form of the Beck Depression Inventory for Youth (BDI-Y) in a sample of adolescent cancer survivors		4	no limitations	⊕ ⊕ ⊕	high		4	new finding
Validity of the Brief Symptom Inventory-18 (BSI-18) for identifying depression and anxiety in young adult cancer survivors: Comparison with a Structured Clinical Diagnostic Interview.		4	no limitations	⊕ ⊕ ⊕	high		4	new finding
Psychometric properties of the Fear of Progression Questionnaire for parents of children with cancer (FoP-Q-SF/PR)	Recruitment of participants via psychosocial professionals may lead to non-representative sample (selection bias towards parents with more stable psychological condition)	4	moderate limitations	⊕ ⊕	high		4	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Pretreatment Cognition in Patients Diagnosed With Pediatric Brain Tumors.	2018	Irestorm, E.	observational study (cohort, cross/sectional, case-control)	4		population based sample: N=101 participants diagnosed with brain tumor the first time between 2006 and 2015 (out of N=161; no assessment in N=29, N=31 NF or tuberous sclerosis); Mean age=9.4, male=54.5%
4	Screening young adult cancer survivors for distress with the Distress Thermometer: Comparisons with a structured clinical diagnostic interview	2015	Recklitis, C.J.	observational study (cohort, cross/sectional, case-control)	4	Survivors completed the DT and SCID. Based on the SCID, participants were classified as having: 1) >/= 1 SCID diagnoses; 2) significant symptoms, but no SCID diagnosis; or 3) no significant SCID symptoms.	N=247 survivors (18 to 40 y)
4	Psychometric properties of the fatigue questionnaire EORTC QLQ-FA12 and proposal of a cut-off value for young adults with cancer	2018	Friedrich, M.	observational study (cohort, cross/sectional, case-control)	4	assessment of reliability and validity	N=577 young adults with cancer (18-39y., diagnosed after the age of 18!, 16 acute care hospitals, 4 rehabilitations clinics, 2 state tumor registries in Germany)
4	The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults.	2015	Klassen, A.F.	observational study (cohort, cross/sectional, case-control)	4	Development of scale (qualitative interviews), field-testing and psychometric evaluation (Rasch-Analysis and traditional psychometric tests of measurement performance)	N=250 survivors (15-26y) from 3 sites (Canada, 7/2011-1/2012)
4	Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment	2017	Pierce, L.	observational study (cohort, cross/sectional, case-control)	4	Parents of children with cancer completed the Psychosocial Assessment Tool (family risk), Distress Thermometer (caregiver distress), Posttraumatic Stress Disorder Checklist-Civilian 6 (caregiver traumatic stress), PedsQL 4.0 (parent-proxy report of patient HRQL) and four acceptability questions via a tablet (iPad).	N=67 parents (of 79 approached from 9-12/2014 [during outpatient clinic or while inpatient, on treatment, fluent in English, child <18y, no endl-of-life care] at single center; 2 parents: incomplete data, 10: did not agree to participate); patients (Mean age = 9.5 SD = 5.5 years) were equally distributed across major pediatric cancer diagnoses.

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Pretreatment Cognition in Patients Diagnosed With Pediatric Brain Tumors.	Overall, cognitive performance was relatively intact, with results close to norm means, but impairments were found in memory and cognitive processing speed. Male gender, older age, epilepsy, increased intracranial pressure, and larger tumors were all associated with lower cognitive function at the time of brain tumor diagnosis; whereas tumor location was not. CONCLUSIONS: Pretreatment neuropsychologic assessments, with some adjustments, can be carried out with children and adolescents with brain tumors. Cognitive impairments before treatment may partly explain the longer-term deficits that commonly occur in pediatric brain tumor survivors. HCP should make sure sufficient resources are available before treatment. Information from these tests may prove critical for future treatment planning.			1											
Screening young adult cancer survivors for distress with the Distress Thermometer: Comparisons with a structured clinical diagnostic interview	The recommended DT cutoff score of >/=5 failed to identify 31.81% of survivors with a SCID diagnosis (sensitivity of 68.18% and specificity of 78.33%), and 32.81% of survivors with either significant SCID symptoms or a SCID diagnosis. No alternative DT cutoff score met the criteria for acceptable sensitivity (>/=85%) and specificity (>/=75%). CONCLUSIONS: The DT does not reliably identify young adult cancer survivors with psychiatric problems identified by a "gold standard" structured psychiatric interview. Therefore, the DT should not be used as a stand-alone psychological screen in this population.														
Psychometric properties of the fatigue questionnaire EORTC QLQ-FA12 and proposal of a cut-off value for young adults with cancer	The new instrument EORTC QLQ-FA12 is able to distinguish between physical, emotional, and cognitive fatigue in young adult patients. It enables us to study different concepts of general fatigue without the need for additional items, and can be used as a screening instrument for young adults.									1					
The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults.	RMT led to the refinement of a 6-item Cancer Worry scale (focused on worry about cancer-related issues such as late effects), a 15-item Self-Management Skills scale (focused on skills an adolescent needs to acquire to manage their own health care), and a 12-item Expectations scale (about the nature of adult LTFU care). Our study provides preliminary evidence about the reliability and validity of these new scales (e.g. Person Separation Index >/= 0.81; Cronbach's alpha >/= 0.81; test-retest reliability >/= 0.85). CONCLUSION: There is limited knowledge about the transition experience of childhood cancer survivors. These scales can be used to investigate barriers survivors face in the process of transition from paediatric to adult care.														
Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment	Majority of parents endorsed electronic screening as acceptable (70%-97%). Patient gender, diagnosis, intensity of treatment and time since diagnosis were not significantly correlated with family risk, caregiver distress, traumatic stress, or patient HRQL. The full regression model predicting total HRQL was significant (R(2) = .42, F(4,64) = 10.7, p = .000). Age (older) was a significant covariate, family risk and caregiver distress were significant independent predictors of poorer total HRQL.-> Screening is acceptable for families and important for identifying risk factors associated with poorer patient HRQL during childhood cancer treatment.														

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Pretreatment Cognition in Patients Diagnosed With Pediatric Brain Tumors.	working memory and processing speed measured with age appropriate Wechsler scale	4	moderate limitations	⊕ ⊕	high		4	new finding
Screening young adult cancer survivors for distress with the Distress Thermometer: Comparisons with a structured clinical diagnostic interview		4	moderate limitations	⊕ ⊕	high		4	new finding
Psychometric properties of the fatigue questionnaire EORTC QLQ-FA12 and proposal of a cut-off value for young adults with cancer	possible bias due to self-report; possible bias due to statistical procedure, but on the other hand very sophisticated methodology	4	moderate limitations	⊕ ⊕	high	for AYAs	4	new finding
The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults.		4	moderate limitations	⊕ ⊕	high		4	new finding
Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment		4	moderate limitations	⊕ ⊕	high		4	new evidence

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Effect of Sensorineural Hearing Loss on Neurocognitive Functioning in Pediatric Brain Tumor Survivors.	2016	Orgel, E.	observational study (cohort, cross/sectional, case-control)	4	retrospective cohort study of audiograms and neurocognitive testing	N=58; age at diagnosis: 6.7+/- 0.6; age at hearing assessment: 9.2 +/- 0.7; age at neurocognitive testing: 11.3+/-0.7; 62.1% male; 67.2% Medulloblastoma; 55% significant hearing loss; 47% prescribed hearing aids
4	DIVERGT screening procedure predicts general cognitive functioning in adult long-term survivors of pediatric acute lymphoblastic leukemia: A PETALE study.	2018	Boulet-Craig, A.	observational study (cohort, cross/sectional, case-control)	4	All survivors completed DIVERGT, N=49 (selected regarding low, average or high scores) aswell as controls completed more comprehensive neuropsychological evaluation. DIVERGT screening = digit span, verbal fluency, grooved pegboard, TmT	N=247 ALL survivors: Mean time after remission: 13.4 y. -> DIVERGT N=49 of these survivors (equally selected amongst those with low, average, and high DIVERGT scores) and N=29 controls -> comprehensive neuropsychological evaluation (within a 3-year period from DIVERGT administration).
4	Characterizing neurocognitive late effects in childhood leukemia survivors using a combination of neuropsychological and cognitive neuroscience measures.	2018	van der Plas, E.	observational study (cohort, cross/sectional, case-control)	4	Neuroscience paradigms: n-back tasks (working memory), stop-signal-task (response inhibition); standardized measures of intelligence (WISC-IV), motor skills (Grooved Pegboard), math abilities (WIAT-III), and executive functions (Delis-Kaplan Executive Function System). Parents: executive function (BRIEF) and attention (Conners-3).	N=130 ALL Survivors (from potentially eligible N=353 treated at 1 site (Toronto) between 1999 and 2010), continuous remission >=2 y; age at diagnosis: Mean: 4.1y (11.6 months-11.2y); Mean time since diagnosis: 9y; N=78 males; controls: N=158, N=88 males;
4	Preoperative neurocognitive evaluation as a predictor of brain tumor grading in pediatric patients with supratentorial hemispheric tumors	2016	Chieffo, D.	observational study (cohort, cross/sectional, case-control)	4		N=90 (64 boys; mean age 9.2 years (24 months-18years), 68=cortical tumor; 22=thalamic tumor) at Ped. Neurosurgery unit Rome, 1/2008-1/2014; Exclusion criteria: severe neurological deficits, seizures, metastatic disease
4	Feasibility of baseline neurocognitive assessment using Cogstate during the first month of therapy for childhood leukemia	2017	Sands, S.A.	observational study (cohort, cross/sectional, case-control)	4	neurocognitive functioning was measured at 6 time-points during and after 2 years of leukemia treatment	N=34 completed Cogstate baseline testing (4 sites)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Effect of Sensorineural Hearing Loss on Neurocognitive Functioning in Pediatric Brain Tumor Survivors.	In a cohort of PBTS (n = 58) treated with platinum therapy, significant SNHL was identified in more than half (55%, n = 32/58), of which the majority required hearing aids (72%, 23/32). RT exposure was approximately evenly divided between those with and without SNHL. PBTS were 6.7 +/- 0.6 and 11.3 +/- 0.7 years old at diagnosis and neurocognitive testing, respectively. In multivariate analyses adjusted for RT dose, SNHL was independently associated with deficits in intelligence, executive function, and verbal reasoning skills. Subtests revealed PBTS with SNHL to have poor learning efficiency but intact memory and information acquisition. CONCLUSIONS: SNHL in PBTS increases the risk for severe therapy-related intellectual and neurocognitive deficits. Additional prospective investigation in malignant brain tumors is necessary to validate these findings through integration of audiology and neurocognitive assessments and to identify appropriate strategies for neurocognitive screening and rehabilitation specific to PBTS with and without SNHL.			1											
DIVERGT screening procedure predicts general cognitive functioning in adult long-term survivors of pediatric acute lymphoblastic leukemia: A PETALE study.	The DIVERGT accurately predicted General Ability Index (GAI) (P < 0.0001), mathematics (P < 0.0001) and verbal memory (P = 0.045). Moreover, the low-performance group consistently had poorer performance than the high performance and control groups on the neuropsychological tests. CONCLUSION: The DIVERGT is a useful, time-effective screening battery for broader neurocognitive impairments identification in long-term adult ALL survivors. It could be implemented as routine examination in cancer follow-up clinics.														
Characterizing neurocognitive late effects in childhood leukemia survivors using a combination of neuropsychological and cognitive neuroscience measures.	ALL survivors exhibited deficiencies in working memory and response inhibition compared with controls. ALL survivors also exhibited deficits on WISC-IV working memory and processing speed, Grooved Pegboard, WIAT-III addition and subtraction fluency, and numerical operations, as well as DKEFS number-letter switching. Parent reports suggested more attention deficits (Conners-3) and behavioral difficulties (BRIEF) in ALL survivors compared with referenced norms. Low correspondence between standardized and experimental measures of working memory and response inhibition was noted. The use of cognitive neuroscience paradigms complements our understanding of the cognitive deficits evident after treatment of ALL.	1	1												
Preoperative neurocognitive evaluation as a predictor of brain tumor grading in pediatric patients with supratentorial hemispheric tumors	Global cognitive functions as well as selective neurocognitive and behavioral profiles were found to be significantly worse in children with low-grade tumors, compared with those affected by higher-grades histotypes. Frontal locations for cortical tumors and thalamic lesions were significantly related with worse results, with a clear contribution of dominant vs. nondominant hemisphere involvement and an age higher than 5 years. Preoperative global and selective neurocognitive evaluation might contribute to the prediction of the tumor aggressiveness. Due to a longer clinical history, more benign tumors more frequently arrive to the diagnosis with a neurocognitive compromise in spite of an apparently mild presence of neurological symptoms and signs.														
Feasibility of baseline neurocognitive assessment using Cogstate during the first month of therapy for childhood leukemia	Testing of patients receiving ALL treatment is feasible with high participations rate among those approached and 100% completion by those enrolled. Baseline data collected during the first 3 weeks of induction chemotherapy indicate reliable data as all subjects (N = 34) completed Cogstate baseline testing, while completion and performance checks indicate that 100 % of subjects completed testing and complied with test requirements. The majority (85 %) exhibited normal function compared with age peers.	1													

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Effect of Sensorineural Hearing Loss on Neurocognitive Functioning in Pediatric Brain Tumor Survivors.	range of survivors ages and abilities in study cohort necessitated combination of results from different measures ("real world" approach)	4	moderate limitations	⊕ ⊕	high		4	new finding
DIVERGT screening procedure predicts general cognitive functioning in adult long-term survivors of pediatric acute lymphoblastic leukemia: A PETALE study.		4	moderate limitations	⊕ ⊕	high		4	new finding
Characterizing neurocognitive late effects in childhood leukemia survivors using a combination of neuropsychological and cognitive neuroscience measures.	possible selection bias for control group; no neuropsychological measures for EF and EF parent-rated behavior for controls; limited information on socioeconomic status of participants	4	moderate limitations	⊕ ⊕	high		4	new finding
Preoperative neurocognitive evaluation as a predictor of brain tumor grading in pediatric patients with supratentorial hemispheric tumors		4	no limitations	⊕ ⊕ ⊕	high		3	new finding
Feasibility of baseline neurocognitive assessment using Cogstate during the first month of therapy for childhood leukemia	article focuses on feasibility	4	moderate limitations	⊕ ⊕	high		3	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Screening for Psychosocial Risk in Dutch Families of a Child With Cancer: Reliability, Validity, and Usability of the Psychosocial Assessment Tool.	2016	Sint Nicolaas, S.M.	observational study (cohort, cross/sectional, case-control)	4	assessment of reliability, validity, usability in European Country	N=117 families (response rate 59%), one parent per family
4	Match of psychosocial risk and psychosocial care in families of a child with cancer	2017	Sint Nicolaas, S.M.	observational study (cohort, cross/sectional, case-control)	4		N=83 families of children with cancer, 4 sites (59% response rate, no difference between responders and non-responders found with respect to age, gender and diagnosis)
4	Healthcare Professionals' Knowledge of Family Psychosocial Problems in Pediatric Cancer: A Pilot Study.	2016	Barrera, M.	observational study (cohort, cross/sectional, case-control)	4	explore psychometric properties of Psychosocial Care Checklist PCCL	N=37 healthcare professionals caring for a child with cancer (15 oncologists, 14 nurses, 8 social workers), 4 sites in Canada
4	Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics	2015	Wiener, L.	observational study (cohort, cross/sectional, case-control)	4	study assesses validity, reliability, sensitivity/specificity, acceptability and feasibility of administration	N=181 patient-provider-parent triads, 2 hospital outpatient clinics, patients diagnosed with cancer (47.1%) or other life-threatening diseases, 7-21y,
4	Importance ratings on patient-reported outcome items for survivorship care: comparison between pediatric cancer survivors, parents, and clinicians	2018	Jones, C.M.	observational study (cohort, cross/sectional, case-control)	4	cohort study; participants were asked to select 8 items that they deemed useful for clinical decision making from 4 item banks (pain, fatigue, psychological distress and positive affect)	N=101 cancer survivors (solids: 46%, leukemia: 30%, CNS:16%, Lymphoma: 9%), N=101 parents; N=36 clinicians (36% Oncologists, 39% Physician assistant, 22% Psychologist, 3% Nurse) from St. Jude Children's Research Clinic; mean age survivors: 13.9y, female: 51%; parents: 85% female;
4	Do we still need IQ-scores? Misleading interpretations of neurocognitive outcome in pediatric patients with medulloblastoma: a retrospective study.	2017	Wegenschimmel, B.	observational study (cohort, cross/sectional, case-control)	4	retrospective analysis of data 1994-2008	N=62 consecutive patients diagnosed with MB, single institution (Vienna) -> N=25 excluded (death, changing residency, poor health condition) -> N=37 patients information for more than 1 timepoint was available; male:70.3%, age: M=9.8y (3.1-21.6), time since diagnosis (0-3y),

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Screening for Psychosocial Risk in Dutch Families of a Child With Cancer: Reliability, Validity, and Usability of the Psychosocial Assessment Tool.	Acceptable reliability was obtained for the PAT total score (alpha = .72) and majority of subscales (0.50-0.82). Two subscales showed inadequate internal consistency (Social Support alpha = .19; Family Beliefs alpha = .20). Validity and usability were adequate. Of the families, 66% scored low (Universal), 29% medium (Targeted), and 5% high (Clinical) risk. CONCLUSIONS: This study confirms the cross-cultural applicability, reliability, and validity of the PAT total score. Reliability left room for improvement on subscale level.	1													
Match of psychosocial risk and psychosocial care in families of a child with cancer	According to the PAT, 65% of families were defined as having low (universal), 30% medium (targeted), and 5% high (clinical) risk for developing psychosocial problems. Thirty percent of patients from universal group got basic psychosocial care, 63% got specialized care, and 7% did not get any care. Fourteen percent of the families at risk got basic care, 86% got specialized care. Team risk estimations and PAT risk scores matched with 58% of the families. CONCLUSIONS: This study showed that families at risk, based on standardized risk assessment with the PAT, received more specialized care than families without risk. However, still 14% of the families with high risks only received basic care, and 63% of the families with standard risk got specialized care. Standardized risk assessment can be used as part of comprehensive care delivery, complementing the team.	1													
Healthcare Professionals' Knowledge of Family Psychosocial Problems in Pediatric Cancer: A Pilot Study.	PCCL had strong test-retest reliability for all domains (alpha > .60) and strong internal consistency for the total PCCL (alpha = .91). Interrater reliability was moderate for the oncologist-nurse dyad with regard to sibling knowledge (r = 0.56) and total psychosocial knowledge (r = 0.65). Social workers were significantly more knowledgeable than both nurses and oncologists about total family problems (P = .01) and sibling problems (P = .03). -> PCCL has adequate test-retest reliability and validity and is useful in differentiating the degree to which HCPs are aware of psychosocial problems within the family, with social workers being the most knowledgeable.	1													
Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics	DT was sign. correlated with both caregiver and patient reports of depression, anxiety, pain, and fatigue, exhibiting concurrent validity. Parent, child, and caregiver report demonstrated significant, moderate inter-rater reliability, with lower concordance between raters in the youngest age group. The DT is a sensitive instrument for screening of psychosocial distress when compared with the selected gold standard (Brief Symptom Inventory 18 depression subscale and the Children's Depression Inventory). The DT is not highly specific but quickly identifies those in need of further psychosocial assessment. DISCUSSION: Screening, using an adapted pediatric DT, is valid, feasible, and acceptable to patients, caregivers, and medical providers across chronic medical illnesses.	1													
Importance ratings on patient-reported outcome items for survivorship care: comparison between pediatric cancer survivors, parents, and clinicians	Compared to survivors, clinicians rated more items across four domains that were statistically different than did parents (23 vs. 13 items). Clinicians rated five items in pain interference domain (ORs 2.33-6.01; p's < 0.05) and three items in fatigue domain (ORs 2.22-3.80; p's < .05) as more important but rated three items in psychological stress domain (ORs 0.14-0.42; p's < .05) and six items in positive affect domain (ORs 0.17-0.35; p's < .05) as less important than did survivors. In contrast, parents rated seven items in positive affect domain (ORs 0.25-0.47; p's < .05) as less important than did survivors. -> These perspectives should be used to assist the development of PROs tools.														
Do we still need IQ-scores? Misleading interpretations of neurocognitive outcome in pediatric patients with medulloblastoma: a retrospective study.	Findings indicate that FIQ was considerably impacted by processing speed and visuomotor coordination, which leaded to an underestimation of the general cognitive performance of many patients. One year after diagnosis, when patients showed the largest norm-deviation, this effect seemed to be at its peak. As already recommended in international guidelines, a comprehensive neuropsychological test battery is necessary to fully understand cognitive outcome. If IQ-tests are used, a detailed subtest analysis with respect to the impact of processing speed seems essential. Otherwise patients may be at risk for wrong decision making, especially in educational guidance.														

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Screening for Psychosocial Risk in Dutch Families of a Child With Cancer: Reliability, Validity, and Usability of the Psychosocial Assessment Tool.	possible selection bias and therefore underestimation of families with high levels of distress	4	moderate limitations	⊕ ⊕	high		3	new finding
Match of psychosocial risk and psychosocial care in families of a child with cancer	small sample, possible selection bias	4	moderate limitations	⊕ ⊕	high		3	new evidence
Healthcare Professionals' Knowledge of Family Psychosocial Problems in Pediatric Cancer: A Pilot Study.	small sample	4	moderate limitations	⊕ ⊕	high		3	new finding
Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics	caregivers largely represented by mothers	4	moderate limitations	⊕ ⊕	high		3	new finding
Importance ratings on patient-reported outcome items for survivorship care: comparison between pediatric cancer survivors, parents, and clinicians		4	moderate limitations	⊕ ⊕	high		3	new finding
Do we still need IQ-scores? Misleading interpretations of neurocognitive outcome in pediatric patients with medulloblastoma: a retrospective study.	single institution	4	moderate limitations	⊕ ⊕	high		3	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Parents'relationsship to pain during children's cancer treatment - a preliminary validation of the Pain Flexibility Scale for Parents	2017	Thorsell Cederberg, J.	observational study (cohort, cross/sectional, case-control)	4	cohort study: 485 children being treated for cancer in Sweden at the time of study (from Swedish Childhood Cancer Registry; 6 pediatric oncology centers) -> 243 parents included in analysis; 2 measurements	243 parents included in analysis (60.5% female) from 158 children (44.3% female; Leukemias N=81, CNS=20, Solids=57);
4	Using Colors to Assess Pain in Toddlers: Validation of "The Rainbow Pain Scale"—A Proof-of-Principle Study	2015	Mahon, P.	observational study (cohort, cross/sectional, case-control)	4	Assessment of the concurrent validity of the RPS in children aged 5 to 10 years as proof of principle. Participants suffering from pain related to cancer and cancer treatment were recruited to complete both scales at 3 time points, during both inpatient and outpatient clinic visits.	N=52 children admitted to a tertiary-level hospital for either inpatient or outpatient hematological /oncological treatments (recruited1/2013 - 3/2014) -> N=49 participated (Age: M=7.2, 5.1-10y)
4	Psychometric Analysis of the Three-Factor Eating Questionnaire-R18V2 in Adolescent and Young Adult-Aged Central Nervous System Tumor Survivors.	2016	Swartz, M.C.	observational study (cohort, cross/sectional, case-control)	4	Investigation of factor structure and reliability of TFEQ-R18v2 in AYA CNS tumor survivors, web-based questionnaires	Childhood and AYA CNS tumor survivors N=114 (AYA aged 15-39y) at 2 sites in Texas (via mail, phone or personal) and through flyers or online postings at other hospitals (=60% response rate); female=57%; 41.2% overweight/obese
4	Validation of the German version of the late adolescence and young adulthood survivorship-related quality of life measure (LAYA-SRQL)	2018	Richter, D.	observational study (cohort, cross/sectional, case-control)	4	validation of German version of LAYA-SRQL (30 item questionnaire covering 10 dimensions)	N=234 AYAs (16-39y; Median 30y); from oncological and pediatric oncological wards of Leipzig Univ. Hospital, 5-12/2016 and 2 other hospitals; 70% single; children: 20.5%; high school degree: 73.9%, off treatment: 79.9%; time since diagnosis: median 34 months;
4	Anxiety and worry when coping with cancer treatment: agreement between patient and proxy responses	2015	Hermont, A.P.	observational study (cohort, cross/sectional, case-control)	4	cross-sectional study: agreement between proxy respondents and children/adolescents, with respect to anxiety and worry issues (PedsQL).	N=83 children (age 5-18y, 3 age groups, 50.6% leukemia, 75.9% inpatients; their parents (mean age=37y, female: 74.7%, level of schooling <8 years: 66.3%)
4	The extension of the Leipzig Questionnaire of Motives to have a Child (LKM) for use in oncology-Test construction and psychometric review.	2015	Geue, K.	observational study (cohort, cross/sectional, case-control)	4	extension of questionnaire (-> 20 items) and psychometric review	N= 175 (10/2011-4/2013) diagnosed with cancer in the last 5 y; recruitment at 5 sites in Germany; Mean Age: 30.7y (18-39)

Summery of evidence - Research question 4

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Parents'relationsship to pain during children's cancer treatment - a preliminary validation of the Pain Flexibility Scale for Parents	PFS-P shows good psychometric properties but needs further evaluation. It enables evaluations of acceptance in the context of acute pain in children.														
Using Colors to Assess Pain in Toddlers: Validation of “The Rainbow Pain Scale”—A Proof-of-Principle Study	The association between RPS and the FPS-R was greater than .7 at all 3 visits; r = .96 between the scales at the first clinic visit, .97 at the second visit, and .93 at the third visit. Cohen's kappa between scales was 1.0 at the first clinic visit, .95 at the second visit, and .87 at the third visit. The RPS shows excellent concurrent validity with the FPS-R in school-aged children. The next step will be to examine the psychometric properties of the RPS in preschool-aged children.	1													
Psychometric Analysis of the Three-Factor Eating Questionnaire-R18V2 in Adolescent and Young Adult-Aged Central Nervous System Tumor Survivors.	Confirmatory factor analysis was used to examine the fit of the three-factor structure (uncontrollable eating, cognitive restraint, and emotional eating [EE]) and reliability (internal consistency of the TFEQ-R18v2). The theorized three-factor structure was supported in our population (RMSEA = 0.056 and CFI = 0.98) and demonstrated good reliability (alpha of 0.81-0.93). EE (beta = 0.07, 95% CI 0.02-0.13) was positively associated with BMI, whereas the other two subscale scores were not. CONCLUSION: The TFEQ-R18v2 instrument holds promise for research and clinical use among AYA-aged CNS tumor survivors.									1					
Validation of the German version of the late adolescence and young adulthood survivorship-related quality of life measure (LAYA-SRQL)	The 10-factor structure of the LAYA-SRQL was confirmed in the German sample, and the model shows high values of fit indicators: chi(2) = 723.32 (df = 360, p < 0.001), CFI = 0.92, TLI = 0.90, SRMR = 0.074, RMSEA = 0.066). Subscales showed acceptable to excellent internal consistencies with Cronbach's alpha > 0.70 and total Cronbach's alpha of 0.93. Convergent validity was demonstrated by high positive correlations between the LAYA-SRQL and the physical (r = 0.45) and mental component (r = 0.65) of the SF-12v2. CONCLUSIONS: The German version of the LAYA-SRQL showed good psychometric properties. The instrument proved to be a highly reliable and valid instrument that can be recommended for use in the follow-up care of AYAs and for clinical research.									1					
Anxiety and worry when coping with cancer treatment: agreement between patient and proxy responses	Proxy respondents underestimated the feelings of worry among children (8-12 years) (p < 0.001; effect size 0.71) and overestimated adolescents' (13-18 years) treatment anxiety (p < 0.05; effect size 0.57). The comparison between the three age groups (5-7, 8-12, 13-18 years) showed a tendency for children/adolescents to report increasing feelings of worry as they got older. In the 'treatment anxiety' subscale, there was a tendency for proxy respondents to present higher mean scores, revealing that proxy respondents believed the children's/adolescents' treatment anxiety decreased as they aged. CONCLUSIONS: Discrepancies between the reports of children/adolescents and their proxy respondents were observed. Children's/adolescents' reports should not be ignored nor replaced by proxy reports; both reports should be analyzed together.														
The extension of the Leipzig Questionnaire of Motives to have a Child (LKM) for use in oncology-Test construction and psychometric review.	Based on previous findings and a qualitative questioning (patients, professionals) items for specific motivations were developed and pre-tested. The revised version (20 items) was tested on a sample of 175 young cancer patients. Good to adequate item discrimination parameter and reliability (α = 0.86) were shown. The factor analysis revealed the 2 scales “PRO– motivations for having children after cancer“ and “CON – motivations against having children after cancer“. These additional scales of specific motivations allow for a reliable and economical measure of motivations to have a child in young cancer patients.	1													

Summery of evidence - Research question 4

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Parents'relationsship to pain during children's cancer treatment - a preliminary validation of the Pain Flexibility Scale for Parents		4	moderate limitations	⊕ ⊕	high	Swedish Version has been developed and evaluated; Versions in other languages need to be validated.	3	new finding
Using Colors to Assess Pain in Toddlers: Validation of "The Rainbow Pain Scale"—A Proof-of-Principle Study	singe site	4	moderate limitations	⊕ ⊕	high		3	new finding
Psychometric Analysis of the Three-Factor Eating Questionnaire-R18V2 in Adolescent and Young Adult-Aged Central Nervous System Tumor Survivors.	limited ability to review medical self-report	4	moderate limitations	⊕ ⊕	high		3	new finding
Validation of the German version of the late adolescence and young adulthood survivorship-related quality of life measure (LAYA-SRQL)	non-responder analysis not possible - possible selection bias; no test-retest reliability possible;	4	moderate limitations	⊕ ⊕	high		3	new finding
Anxiety and worry when coping with cancer treatment: agreement between patient and proxy responses		4	moderate limitations	⊕ ⊕	high		3	new finding
The extension of the Leipzig Questionnaire of Motives to have a Child (LKM) for use in oncology-Test construction and psychometric review.	sample not representative with regard to cancer diagnosis and gender	4	moderate limitations	⊕ ⊕	high		3	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	2016	Kunin-Batson, A. S.	Observational study (cohort, cross/sectional, case-controll)	4	prospective longitudinal study, 4 time points: 1 month, 6 months and 12 months after diagnosis, 3 months after completion of chemotherapy (at T4 approx. 60% of the initial participants completed measurements); Parents completed standardized rating scales of their children's emotional-behavioral functioning and measures of coping and family functioning (Emotional-behavioral outcomes were collected as part of an ancillary study at 31 Children's Oncology Group sites that included community-based and tertiary care centers)	N=160 parents of children with standard-risk ALL gender: female=76 (47.8%) age: preschool (2-4y)=86 (54.1%), school age (5-9y)=73 (45.9%) diagnosis: ALL
4	Objective assessment of sleep status and ist correlation in hospitalized children with cancer	2016	Setoyama, A.	Observational study (cohort, cross/sectional, case-controll)	4	actigraph, sleep diary, PedsQl	N=11 hospitalized children, Age: 2-12 with cancer
4	Measurement of neurodevelopmental changes in children treated with radiation for brain tumors: what is a true 'baseline	2016	Ris, M.D.	systematic review of descriptive or qualitative data	5	medline, PubMed, Psychinfo; 1993-2013;	N=44 studies
4	Development and Content Validation of the Transition Readiness Inventory Item Pool for Adolescent and Young Adult Survivors of Childhood Cancer	2017	Schwartz, L.A.	systematic review of descriptive or qualitative data	5	development of item pool; mixed methods: cognitive interviews, literature review	N=21 survivors and N=23 parents for cognitive interviews
4	A systematic review of instruments assessing dimensions of distress among caregivers of adult and pediatric cancer patients.	2017	Tanco, K.	systematic review of descriptive or qualitative data	5	Medline, Embase, Cinahl, Scopus, PubMed ePubs (-2013);	N=135 (out of 5541) articles -> 59 instruments
4	Feasibility of clinical psychosocial screening in pediatric oncology: Implementing the PAT2.0	2016	McCarthy, M.C.	individual qualitative study	6		N= 104 parents of children (0–18 y, Blood 52.94%, Brain 11.76%, Solids 29.41%, Other 5.88%), 3 Australian oncology centers; N=26 HCPs in 58 individual interviews; N=32 staff in seven focus groups.

Summery of evidence - Research question 4

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	A significant percentage of children experience emotional distress during and after therapy for ALL. These data provide a compelling rationale for targeted early screening and psychosocial interventions to support family functioning and coping skills.									1					
Objective assessment of sleep status and ist correlation in hospitalized children with cancer	sleep status was altered on hospitalization; also at home, compared with healthy children	1	1												
Measurement of neurodevelopmental changes in children treated with radiation for brain tumors: what is a true 'baseline	Multiple approaches (to operationalizing baseline levels of ability and to assess change from baseline) varied widely with a trend over time toward reliance on statistical modeling. Researchers were often insufficiently explicit about the reasons for adopting a particular approach. The common use of standardized scores requires caution as they obscure critical inferential limitations about change and magnitude of change. Some viable approaches were infrequently used, such as actuarial prediction formulas. Multiple simultaneous methods akin to theory testing and formal methods of construct validation could enhance scientific yield since all approaches are fallible. ->Estimating baseline neuropsychological functioning is very challenging, particularly when it concerns children in the preschool years.														
Development and Content Validation of the Transition Readiness Inventory Item Pool for Adolescent and Young Adult Survivors of Childhood Cancer	Each stage informed development and refinement of the item pool. Content validity ratings and cognitive interviews resulted in 81 content valid items for the patient version and 85 items for the parent version. -> TRI represents the first multi-informant, rigorously developed transition readiness item pool that comprehensively measures the social-ecological components of transition readiness.														
A systematic review of instruments assessing dimensions of distress among caregivers of adult and pediatric cancer patients.	59 instruments were identified: burden (n = 26, 44%); satisfaction with healthcare delivery (n = 5, 8.5%); needs (n = 14, 23.7%); quality of life (n = 9, 15.3%); and other issues (n = 5, 8.5%). The median number of items was 29 (4-125): 20/59 instruments (33.9%) had </=20 items; 13 (22%) had </=20 items and were psychometrically sound, with 12 of these 13 (92.3%) being self-report questionnaires. There were 44 instruments (74.6%) that measured caregiver distress for adult cancer patients and 15 (25.4%) for caregivers of pediatric patients.													1	
Feasibility of clinical psychosocial screening in pediatric oncology: Implementing the PAT2.0	Parents reported that the PAT2.0 was brief and easy to complete. HCPs' perspectives on the utility of the PAT2.0 were mixed and varied according to clinical roles. A major perceived benefit was the PAT2.0 as a communication tool. Barriers included timing and an increased workload for social workers.									1					

Summery of evidence - Research question 4

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	only parent-proxy reports	4	moderate limitations limitations	⊕ ⊕	high		3	new evidence/citation
Objective assessment of sleep status and ist correlation in hospitalized children with cancer	small sample, different cancer types	4	moderate limitations	⊕ ⊕	high		**3**	new finding
Measurement of neurodevelopmental changes in children treated with radiation for brain tumors: what is a true 'baseline		5	no limitations	⊕ ⊕	high		4	new finding
Development and Content Validation of the Transition Readiness Inventory Item Pool for Adolescent and Young Adult Survivors of Childhood Cancer		5	no limitations	⊕ ⊕	high		4	new finding
A systematic review of instruments assessing dimensions of distress among caregivers of adult and pediatric cancer patients.	only instruments <= 20 items	5	moderate limitations	⊕ ⊕	high		4	new finding
Feasibility of clinical psychosocial screening in pediatric oncology: Implementing the PAT2.0	PAT 2.0 was administered in sites, which had universal referral and access to social work services	6	no limitations	⊕ ⊕	high		4	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
4	Assessing Suicidal Ideation and Behaviors Among Survivors of Childhood Brain Tumors and Their Mothers During Sociobehavioral Research	2015	Lucas, M.S.	individual qualitative study	6	Protocol development - feasibility of the C-SSRS; implementation in a research study: during telephone- and home-based interviews, the interviewer assessed the participant using the Columbia-Suicide Severity Rating Scale (C-SSRS).	Of 86 mother caregivers and 134 adolescent or young adult survivors of childhood brain tumors the protocol was implemented for 5 caregivers and 11 survivors (= 5% of sample).
4	Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer	2015	Taylor, R.M.	individual qualitative study	6	Development of experience survey meaningful and relevant for AYAs to be used in longitudinal cohort study (Brightlight), development with young people for young people: literature search/focus groups/cognitive interviews	N=11 young people, 3 parents, 2 siblings for focus groups; N=23 for cognitive interviews
4	Development of a Psychosocial Risk Screener for Siblings of Children With Cancer: Incorporating the Perspectives of Parents	2018	Long, K. A.	individual qualitative study	6	study evaluated acceptability and utility of PAT siblings items and developed new PAT siblings modules; interviews, thematic analysis,	N=29 families (25 mothers), children <18y, purposive sampling procedure; single institution
4	Evaluation of the electronic self-report Symptom Screening in Pediatrics Tool (SSPedi)	2016	O'Sullivan, C.	individual qualitative study	6	evaluation and refinement of the electronic mobile application of SSPedi using opinion of children (ease of completion, app features, understandability)	N=20 (purposive sampling; 8-17y, Mean age: 11y, 55% boys, 90% active cancer treatment; single site
4	Implementing guidelines: Proposed definitions of neuropsychology services in pediatric oncology.	2016	Baum, K.T.	expert opinion	7	authors air pediatric neuropsychologists of 8 hematology/oncology programs across North America	not applicable
4	Applying the International Classification of Functioning-Children and Youth Version to Pediatric Neuro-oncology	2016	Pletschko, T.	expert opinion	7		not applicable

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Assessing Suicidal Ideation and Behaviors Among Survivors of Childhood Brain Tumors and Their Mothers During Sociobehavioral Research	Implementation of the C-SSRS by nonpsychiatric subspecialty staff members was feasible and valid. Interviewers' conclusions based on this instrument matched those of the mental health professional who followed up with participants. Data collection in potentially vulnerable populations can include a suicide risk safety protocol to provide assistance when needed.	1													
Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer	Stage 1: Two-hundred and thirty eight questions were developed from qualitative reports of young people's cancer and treatment-related experience. Stage 2: The focus groups identified three core themes: (i) issues directly affecting young people, e.g. impact of treatment-related fatigue on ability to complete survey; (ii) issues relevant to the actual survey, e.g. ability to answer questions anonymously; (iii) administration issues, e.g. confusing format in some supporting documents. Stage 3: Cognitive interviews indicated high levels of comprehension requiring minor survey amendments. CONCLUSION: Collaborating with young people with cancer has enabled a survey of to be developed that is both meaningful to young people but also examines patient experience and outcomes associated with specialist cancer care. Engagement of young people throughout the survey development has ensured the content appropriately reflects their experience and is easily understood.														
Development of a Psychosocial Risk Screener for Siblings of Children With Cancer: Incorporating the Perspectives of Parents	Two sibling modules were developed to assess siblings' psychosocial risk at diagnosis (preexisting risk factors) and several months thereafter (reactions to cancer). Most prior PAT items were retained; however, parents recommended changes to improve screening format (separately assessing each sibling within the family and expanding response options to include "sometimes"), developmental sensitivity (developing or revising items for ages 0-2, 3-4, 5-9, and 10+ years), and content (adding items related to sibling-specific social support, global assessments of sibling risk, emotional/behavioral reactions to cancer, and social ecological factors such as family and school).	1													
Evaluation of the electronic self-report Symptom Screening in Pediatrics Tool (SSPedi)	20 children evaluated electronic SSPedi. None found electronic SSPedi difficult to complete or understand. All children understood the app features and each of the 4 more difficult to understand concepts after using the help menu. 19 of 20 children thought the app was a good way to communicate with doctors and nurses. SSPedi is easy to use and understand with features specifically designed to facilitate child self-report.	1													
Implementing guidelines: Proposed definitions of neuropsychology services in pediatric oncology.	Several organizations have published guidelines for the neuropsychological care of survivors of childhood cancer. However, there is limited consensus in how these guidelines are applied. The model of neuropsychology service delivery is further complicated by the variable terminology used to describe recommended services. In an important first step to translate published guidelines into clinical practice, this paper proposes definitions for specific neuropsychological processes and services, with the goal of facilitating consistency across sites to foster future clinical program development and to clarify clinical practice guidelines.														
Applying the International Classification of Functioning-Children and Youth Version to Pediatric Neuro-oncology	This article introduces the International Classification of Functioning-Children and Youth version (ICF-CY) as a conceptual framework for quantifying functional limitations and informing long-term care in pediatric neuro-oncology. A standardized self-report and proxy-report questionnaire for measuring participation is briefly discussed and specific recommendations based on so-called core sets for clinical practice in pediatric neuro-oncology are provided.														

Summery of evidence - Research question 4

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Assessing Suicidal Ideation and Behaviors Among Survivors of Childhood Brain Tumors and Their Mothers During Sociobehavioral Research		6	moderate limitations	⊕ ⊕	high		3	new finding
Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer	development of survey	6	moderate limitations	⊕ ⊕	high		3	new finding
Development of a Psychosocial Risk Screener for Siblings of Children With Cancer: Incorporating the Perspectives of Parents	selective bias	6	moderate limitations	⊕ ⊕	moderate		3	new evidence
Evaluation of the electronic self-report Symptom Screening in Pediatrics Tool (SSPedi)	small sample	6	moderate limitations	⊕ ⊕	high		3	new finding
Implementing guidelines: Proposed definitions of neuropsychology services in pediatric oncology.		7		⊕	high		4	new finding
Applying the International Classification of Functioning-Children and Youth Version to Pediatric Neuro-oncology		7		⊕	high		3	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	Distress/PTSD Parent						
5	Parental Distress Caused by Child's Cancer Diagnosis (Belastungserleben von Eltern krebskranker Kinder)	2016	Dietrich, K.	Observational study (cohort, cross/sectional, case-controll)	4	Multi-center study, parent questionnaires: BDI, STAI, IES-R, SCL-90, OCI-R (September 2013 to September 2014 in 6 pediatric oncology centers in Germany). The examination of parental distress was based on five burdens ("depression", "anxiety", "somatization", "posttraumatic stress disorder (PTSD)" and "obsessive-compulsive").	N = 213 parents of children with cancer (129 mothers, 84 fathers) Diseases: leukemias, lymphomas, soft tissue sarcomas, bone sarcomas, germ cell tumors, kidney tumors, brain tumors Average age children: 8.8 + -6.13 Average age of parents: 42.08 + -7.74 Control group was not collected (comparison with standard values from the questionnaire manuals)
5	Self-distancing Buffers High Trait Anxious Pediatric Cancer Caregivers against Short- and Longer-term Distress	2016	Penner, L.A.	Observational study (cohort, cross/sectional, case-controll)	4	Longitudinal study to test caregivers´ tendencies to self-distance when reflecting on their feelings surrounding their child´s treatments. Caregivers´ self-distancing and trait anxiety was measured at baseline, anticipatory anxietx during their child´s treatment procedures, and psychological distress and avoidance three months later.	N= 99 caregivers (97% parents; 3% grandparents) Gender: 82% mothers Age: M= 33,98 years; SD= 6,96 years Gender children: 60% male; 40 % female Age children: M= 6,59 years; SD= 3,11 years Diagnosis: 79% acute lymphocytic leukemia
5	Post Traumatic Stress Disorder in Parents of Children With Cancer in Jordan	2017	Masa'deh, R.	Observational study (cohort, cross/sectional, case-controll)	4	cross-sectional, convenience sample; demographic checklist and PTSD Checklist Civilian multi-center	N=416 biological parents (fully completed and returned questionnaires, response rate=85.7%); gender: mothers=207 (49.8%), fathers=209 (50.2%) age: M=27.07 (SD=6.8), range=19-56; education: no formal education=3 (0.7%), elementary school=35(8.4%), high school=148(35.6%), college=216(51.9%), graduate and above=14(3.4%) **children:** age: M=6.23 (SD=3.85); gender: male=241(57.9%), female=175(42.1%) diagnosis: Leukemia=141(33.9%), Brain/CNS=83(20%), lymphoma=38(9.1%), bone=20(4.8%), kidney=20(4.8%), eye=29(7%), connective tissue=6(1.4%), nasopharynx=6(1.4%), liver=8(1.9%), adrenal gland=6(1.4%), testis=2(0.5%), others=57(13.7%)
5	Group-Based Tajectory Modeling of distress and Well-Being Among Caregivers of Children Undergoing Hematopoetic Stem Cell Transplant	2017	Sands, S.A.	Observational study (cohort, cross/sectional, case-controll)	4	Longitudinal study with caregivers measures of distress, coping, and social support at baseline, 1 month, 6 months, and 1 year post HSCT of their child.	N= 108 caregivers Age caregiver: M= 37,8 years; SD= 8,5 years; range= 18-62 years Relationship to patient: 96 (88,9%) mothers; 7 (6,5%) fathers; 5 (4,6%) other Age children: M= 8,1 years; SD= 5,3 years; range= <1-19 years Gender children: 61 (56,5%) males; 47 (43,5%) females Diagnosis: 22 (20,4%) ALL; 26 (24,1%) AML; 5 (4,6%) Hodgkin´s disease/non-Hodgkin´s lymphoma; 17 (15,7%) solid tumor; 38 (35,2%) non-malignancy
5	A Longitudinal Study of Hardiness as a Buffer for Posttraumatic Stress Symptoms in Mothers of Children with Cancer	2017	Stoppelbein, L.	Observational study (cohort, cross/sectional, case-controll)	4	prosprective study, longitudinal, 3 time-points: time of diagnosis, 6 + 12 months post-diagnosis; 1 US center instruments: live event checklist, post-traumatic disorder checklist-civilian version, hardiness scale	N=27 mothers: age: M=30.13(SD=5.74), range=22-43y relationship status: married to child's father=48%, separates/divorced=26%, never married=17%, remarried=9%; education: M=13.61 (SD=2.33) children: age at diagnosis: M=7.5(SD=5.9); diagnosis: acute lymphoblastic leukemia=56%; lymphomas=25%, neuroblastoma=10%, other (osteosarcoma, rhabdomyosarcoma, or lung cancer)=3 children
5	Experiential Avoidance and Rumination in Parents of Children on Cancer Treatment: Relationships with Posttraumatic Stress Symptoms and Symptoms of Depression	2016	Cernvall, M.	Observational study (cohort, cross/sectional, case-controll)	4	Data collected from parents of children with cancer while screening for of a RCT Methods used: PTSD Checklist Civilian Version (1993), BDI-2 (1996), Beck Anxiety Inventory (1988), Acceptance and Action Questionnaire-2 (2011), Rumination Subscale of the Responses to Intrusions Questionnaire (2007)	Data from 79 parents (55 mothers) of 79 children with a median of three months since their cancer diagnosis were included in cross-sectional analyses.

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Distress/PTSD Parent															
Parental Distress Caused by Child's Cancer Diagnosis (Belastungserleben von Eltern krebskranker Kinder)	Above-average levels of stress in the areas: depression (42% of parents), anxiety (56.7% of parents),coercion (30.6% of parents), somatization (25.9% of parents), PTSD (17.4% of parents) –> Parents of children with cancer are at risk for the development of psychological stress, even if 7-14% (according to the study percentage of mentally handicapped persons in the general population) are subtracted from the above values.														
Self-distancing Buffers High Trait Anxious Pediatric Cancer Caregivers against Short- and Longer-term Distress	Self-distancing buffered high (but not low) trait anxious caregivers against short- and long-term distress without promoting avoidance. Results identify a coping process that buffers vulnerable caregivers against a chronic life stressor.														
Post Traumatic Stress Disorder in Parents of Children With Cancer in Jordan	Unemployed parents had significantly higer PTSD levels. Mothers reported significantly higher PTSD levels than fathers (the mean difference between scores was 6.92). Significant negative correlation between parental PTSD levels with parental age and time since the child was diagnosed.									1					
Group-Based Tajectory Modeling of distress and Well-Being Among Caregivers of Children Undergoing Hematopoetic Stem Cell Transplant	The majority reported moderate or low anxiety, depression, or distress that decreased over time, but a small group demonstrated high anxiety, depression, or distress that persited or increased over time. Maladaptive coping was highest among caregivers in the high-persistent distress subgroup compared with the moderate-decreasing and low stable groups. Adaptive coping was minimally associated with trajectory subgroups.														
A Longitudinal Study of Hardiness as a Buffer for Posttraumatic Stress Symptoms in Mothers of Children with Cancer	Mothers who scored high on hardiness were less likely to experience PTSS after controlling for the effect of time. Mothers who scored high on hardiness experienced fewer avoidance/numbing symptoms at the time of their child's diagnosis of cancer and across 12 months; The present findings support examining hardiness further as a buffer against specific PTSS clusters and exploring options for identifying and treating mothers of children with cancer that may be at risk for PTSS. PTSS was found to be significantly negatively related to hardiness at the time of the child's medical diagnosis and at the 6- and 12-month follow up.	1								1					
Experiential Avoidance and Rumination in Parents of Children on Cancer Treatment: Relationships with Posttraumatic Stress Symptoms and Symptoms of Depression	EA and rumination were positively correlated with PTSS and symptoms of depression. -> Rumination and EA are important constructs in the understanding of PTSS and symptoms of depression in parents of children on cancer treatment.	1	1												

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Distress/PTSD Parent								
Parental Distress Caused by Child's Cancer Diagnosis (Belastungserleben von Eltern krebskranker Kinder)	no control group	4	moderate limitations	⊕⊕	high		4	new finding
Self-distancing Buffers High Trait Anxious Pediatric Cancer Caregivers against Short- and Longer-term Distress	Only self-report measures of the constructs of interest.	4	moderate limitations	⊕⊕	high		3	new finding
Post Traumatic Stress Disorder in Parents of Children With Cancer in Jordan		4	moderate limitations	⊕⊕	high		3	new evidence/citation
Group-Based Tajectory Modeling of distress and Well-Being Among Caregivers of Children Undergoing Hematopoetic Stem Cell Transplant	secondary analysis of a clinical trial; small sample size for trajectory analyses, and accordingly, the small number of parents who demonstrated high and persistent negative emotional responses. Only one type of maladaptive coping was assessed (self-blame).	4	moderate limitations	⊕⊕	high	Screening HSCT caregivers for distress and maladaptive coping may be useful in identifying caregvers likely to experience persistently high distress who may benefit from psychological intervention.	3	new evidence/citation
A Longitudinal Study of Hardiness as a Buffer for Posttraumatic Stress Symptoms in Mothers of Children with Cancer	small sample, lack of information regarding children, no fathers data	4	moderate limitations	⊕⊕	high		3	new evidence/citation
Experiential Avoidance and Rumination in Parents of Children on Cancer Treatment: Relationships with Posttraumatic Stress Symptoms and Symptoms of Depression	no CG, comparison with standard values; relatively low respron rate -> risk of self-selection	4	moderate limitations	⊕⊕	moderate		3	new finding

Summary of evidence - Research question 5

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Chronic Sorrow in Mothers of Children With Cancer	2015	Nikfarid, L.	Observational study (cohort, cross/sectional, case-controll)	4	Descriptive, cross-sectional study in 3 pediatric teaching hospitals in Tehran, with administration of the Kendall Chronic Sorrow Questionnaire (Persian Version).	N= 264 mothers of children with cancer Age: 18-25 years --> 10,6%; 26-35 years --> 58,7%; 36-45 years --> 27,3%; 46+ years --> 3,4% Diagnosis: leukemia --> 70,8%; brain tumor --> 1,1 %; lymphoma --> 6,8%; Rhabdomyosarcoma --> 3,8%; Wilms tumor --> 3,8 %; other --> 13,6% Duration of the disease: <1 year --> 31,1%; 1-3 years --> 48,1%; 4-6 years --> 12,1%; >6 years --> 8,7%
5	Depression and distress in caregivers of children with brain tumors undergoing treatment: psychosocial factors as moderators	2016	Choi, E. K.	Observational study (cohort, cross/sectional, case-controll)	4	Single center, recruited from 2007 to 2014; questionnaire study (all instruments based on self-assessment); Methods used: Burden of a primary caregiver (BPC) scale; Symptom Checklist-90-Revised (SCL-90-R; Korean version of the Parenting Sense of Competence (K-PSOC) scale; DUKE University of North Carolina Functional Social Support Questionnaire (DUKE-UNC FSSQ); Korean version of the Family Environment Scale-Revised (K-FES-R); Parents were subclassified by the SCL: depressed / non-depressed	N = 82 primary caregivers of children with brain tumors in treatment, including 77 mothers. Age (caregiver) on average 41.72; children on average 10,98. Children: 51 boys, 31 girls. Diagnoses: medulloblastoma (10), germinoma (15), mixed GCT (18), low grade glioma (7), high grade glioma (2), brain stem glioma (3), ependymoma (8), chordoma (8), others (5); recurrence (6)
5	Prevalence and predictors of posttraumatic stress symptoms in parents of children with ongoing treatment for cancer in South China: a multi-centered cross-sectional study	2017	Shi, L.	Observational study (cohort, cross/sectional, case-controll)	4	Examine the predictors of PTSS, and explore the correlation of depression, resilience, and family functions with severe PTSS among parents of cancer children in 4 general hospitals in South China.	N= 279; Gender parents: 192 (68,8%) mothers; Age mothers: M= 34,16 y; SD= 5,28 y; Age fathers: M= 36,56 y; SD= 7 y; Gender children: 182 (65,2%) males; Age children: M= 6,69 years; SD= 4 y; Diagnosis: 102 (36,3%) ALL; 54 (19,4%) other leukemia; 46 (16,5%) lymphomas; 8 (2,9%) CNS tumors; 17 (6,1%) sympathetic nervous system tumors; 17 (6,1%) milignant bone tumors; 18 (6,5%) soft-tissue sarcomas; 23 (8,2%) other solid tumors
5	Posttraumatic Stress in Parents of Children Diagnosed with Cancer: Hyperarousal and Avoidance as Mediators of the Relationship between Re-Experiencing and Dysphoria	2016	Hoven, E.	Observational study (cohort, cross/sectional, case-controll)	4	study part of a larger project (seven assessments (T1-T7) from one week after the child's diagnosis up to five years after the end of the child's treatment or the child's death) data for this study (collected trough telephone): 3 time points: T1= one week, T2= two months, T3=four months after diagnosis of their child 4 swedish pediatric oncology centers 259 participating parents, 243 provided data at T2, 214 provided data at T3 (16 participants who only provided data at T1 were excluded) --> PTSS assessed with the Swedish version ofthe PTSD Checklist Civilian Version (PCL-C);	**N=243 parents** (at T1 and T2, of 132 children) gender: mothers=122, fathers=121; marital status: mothers: spouses/couples=112 (91.8%), single=10 (8.2%); fathers: spouses/couples=113 (93.4%), single=8 (6.6%) age: mothers: <30=19(15.6%), 30-39=63(51.6%), >= 40=40 (32.8%); fathers: <30=10(8.3%), 30-39=62(51.2%), >= 40=49 (40.5%); Parent of daughter/son: mothers: daughter=55(45.1%), son=67 (54.9%); fathers: daughter=55(45.5%), son=66(54.5%) **children:** age: 0-3=37(28%), 4-7=35(26.5%), 8-12=34(25.8%), 13-18=26(19.7%) diagnosis: Leukemia/lymphoma=52 (39.4%), CNS tumor=16 (12.1%), other solid tumor=64 (48.5%)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Chronic Sorrow in Mothers of Children With Cancer	The mean score on the Kendall Chronic Sorrow Questionnaire was 76.39 +/- 15.81. **Chronic sorrow was likely present or present in 97.7% of the mothers (n = 252).** The mean scores on the Disparity, Sadness, and Getting Along subscales were 30.26 +/- 104.209, and 33.38 +/- 42.777, respectively, and the mean score for coping was 12.75 +/- 11.922. The relationships between most demographic characteristics and scores on the Kendall Chronic Sorrow Questionnaire were not significant. Chronic sorrow is a concept experienced by families of children with cancer.														
Depression and distress in caregivers of children with brain tumors undergoing treatment: psychosocial factors as moderators	Younger patient age, lower family income, and caregivers' greater number of years of education significantly predicted caregiver distress. Caregivers with depression experienced significantly more distress than those without depression. High parental efficacy and social support were protective factors against distress in caregivers without depression. CONCLUSIONS: A multi-dimensional assessment of the psychosocial factors that may affect caregivers of children with brain tumors should precede interventions for distress management. Interventions tailored to individuals' psychosocial factors are needed.		1							1					
Prevalence and predictors of posttraumatic stress symptoms in parents of children with ongoing treatment for cancer in South China: a multi-centered cross-sectional study	**Severe PTSS (PCL-C score ≥ 50) were reported in 32,97%** (n= 92) of the total participants, 26,44% (23/87) in the fathers and 35,94% (69/192) in the mothers. The level of PTSS was positively correlated with depression (r=0,782), and a poor general family function (r=0,325) and negatively correlated with resilience (r=-0,236). Multivariate analyses indicated that **depression, general family function, gender and education level were significant predictive factors of severe PTSS in the overall parents, accounting for 64,2% of the variance in the prediction of PTSS.** For the mothers, depression and family function accounted for 66,5% of the variance in the prediction of PTSS; for the fathers, depression and educational level accounted for 58,5% of the variance in the prediction of PTSS.														
Posttraumatic Stress in Parents of Children Diagnosed with Cancer: Hyperarousal and Avoidance as Mediators of the Relationship between Re-Experiencing and Dysphoria	For fathers, none of the hypothesized mediators were significant. For **mothers, hyperarousal mediated the relationship between re-experiencing and dysphoria,** but avoidance did not. CONCLUSIONS: Results suggest that hyperarousal is important for the development of dysphoria in mothers, supporting use of interventions targeting such symptoms in the early and ongoing period following the child's diagnosis.									1					

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Chronic Sorrow in Mothers of Children With Cancer		4	moderate limitations	⊕ ⊕	moderate	The health care provider´s knowledge about this concept and its components can facilitate the development of better support and treatment program and lead to improved quality of life for children and their families.	3	new evidence/citation
Depression and distress in caregivers of children with brain tumors undergoing treatment: psychosocial factors as moderators	no control group;	4	moderate limitations	⊕ ⊕	moderate		3	new evidence/citation
Prevalence and predictors of posttraumatic stress symptoms in parents of children with ongoing treatment for cancer in South China: a multi-centered cross-sectional study	Assessment of PTSS only through self-report questionnaires. No matching control group. Only parents who reported domestic violence or sexual abuse or had ongoing treatment for depression were excluded, wich may potentially introduce compounding factors in the analysis.	4	moderate limitations	⊕ ⊕	moderate	Parents, especially the mothers, of children with ongoing treatment for cancer are at risk of developing PTSS. Gender specific interventions of PTSS in the parents during their children´s treatment may help prevent long-term psychological issues in the parents and promote the family functioning to provide optimal support for the children during cancer treatment.	3	new evidence/citation
Posttraumatic Stress in Parents of Children Diagnosed with Cancer: Hyperarousal and Avoidance as Mediators of the Relationship between Re-Experiencing and Dysphoria	internal and external avoidance was measured with just one item each	4	moderate limitations	⊕ ⊕	moderate		3	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Illness Uncertainty, Global Psychological Distress, and Posttraumatic Stress in Pediatric Cancer: A Preliminary Examination Using a Path Analysis Approach	2016	Tackett, A. P.	Observational study (cohort, cross/sectional, case-controll)	4	caregivers of children with newly diagnosed cancer completed measures of IU (illness uncertainty), PTSS, and GPD (global psychological distress) as part of a larger study investigating family adaptation to the cancer. instruments: Parent Perception of Uncertainty Scale, Impact of Event Scale—Revised, Brief Symptom Inventory	N=105 parents (entrollment rate=85%) gender: mothers=91.4% age: M=36.9 (SD=8.6) children: gender: male=52.4% age: M=8.6 years (SD=5.0) time since diagnosis: M=2.6 months (SD=1.6 months) diagnosis: solid tumor=44(41.9%), lymphoma=15(14.2%), leukemia=46(43.8%)
5	Post-traumatic stress disorder in mothers of children who have undergone cancer surgery	2017	Karadeniz Cerit, K.	Observational study (cohort, cross/sectional, case-controll)	4	cross-sectional, multi-center (2?) in Turkey, at least 1 month after surgery of child; interview, Hospital Anxiety and Depression Scale, Clinician-administered PTSD Scale (CAPS)	N=60 mothers, age: M=36.45 (SD=7.15), marital status: married=54 (90%), not married=6 (10%), support of souse: satisfactory=44 (73.3%), not satisfactory=14 (23.3%) chidren: age: Median=7y (range=1-17), gender: female=44 (73.3%), time since operation: Median=6 months (range=1-28), diagnosis: neuroblastoma, n = 18; Wilms tumor, n = 14; lymphoma, n = 7; rhabdomyosarcoma, n = 5; Ewing’s sarcoma, n = 5; hepatoblastoma, n = 4; germ cell tumor, n = 4; and osteosarcoma, n = 3
5	Factors Influencing Posttraumatic Growth in Mothers of Children With Cancer	2017	Kim, M.Y.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study to determine the factors that influence posttraumatic growth in mothers of children with cancer; single center	N= 222 mothers (All the subjects were Korean and married) Age: M= 39,3 years; SD= 5,97 years Age children: M= 5,3 years; SD= 4,6 years Diagnosis: 86 (38,7%) leukemia; 36 (16,2%) brain tumor; 24 (10,8%) neuroblastoma; 20 (9%) malignant lymphoma; 13 (5,9%) retinoblatoma; 43 (19,4%) others Duration of illness: M= 2,7 years; SD= 2,8 years Current treatment: 140 (63,1%) on tratment; 82 (36,9%) treatment terminated
5	Infancy and pediatric cancer: an exploratory study of parent psychological distress	2017	Vernon, L.	Observational study (cohort, cross/sectional, case-controll)	4	cross-sectional; mothers and fathersof infants under 2 years who either had a cancer diagnosis or was an infant sibling of an older child with cancer recruited from a single oncology center (Australia; 21 couple dyads) instruments: Depression Anxiety Stress Scales short form and the Posttraumatic Stress Disorder Checklist.	N= 41 mothers, 25 fathers (of infant patients (IP) n=37; infant sibling (IS) n=29) parent age: IP: mothers: M=33.82(SD=4.94), fathers: M=38.99 (SD=7.28); IS: mothers: M=36.0(SD=3.68), fathers: M=38.70 (SD=3.23) marital status: IP: married=15(65.22%), IS: married=15(78.9%) child's diagnosis: IP: leukemia=3(13.04%), solid tumors=17(73.91%), Brain/CNS tumor=1(4.35%), non-hodgkin's lymphoma=0, Ewing's sarcoma=1(4.35%), Neuroblastoma=7 (30.43%), Rhabdomyosarcoma=0, Wilm's tumor=2(8.7%), other solid=6(26.09%), other=3(13.04%), IS: leukemia=15(78.95%), solid tumors=4(21.05%), Brain/CNS tumor=1(5.26%), non-hodgkin's lymphoma=1 (5.26), Ewing's sarcoma=0, Neuroblastoma=1 (5.26%), Rhabdomyosarcoma=1(5.26), Wilm's tumor=0, other solid=0, other=0 infant age: IP: M=18.39 months (SD=6.59); IS: M=17.95 months (SD=8.26) infant age at diagnosis: IP: M=9.78 months (SD=5.74), IS: M=10.74 (9.01)
5	Post-traumatic Stress Symptoms among Iranian Parents of Children during Cancer Treatment	2015	Iranmanesh, S.	Observational study (cohort, cross/sectional, case-controll)	4	200 parents in 2 iranian hospitals; Impact of Event Scale-revised (translation via formward-backward procedure, assessement of content validity and reliability), convenience sample (data collection at least 1 month after diagnosis)	N=200 (100 mothers, 100 fathers) age: mothers: M=34.12 (SD=7.42); fathers: M=37.07 (SD=7.24) religion: muslim; education: illiterate=12 (6%), non-academic=120 (60%), academic=68(34%); marrital status: 97% married age childern: M=7.75(SD=4.6), gender children: male=131 (65.5%),diagnosis: ALL=146 (73%), Wilm's tumor=24 (12%), brain tumor=14 (7%), other=16 (8%)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Illness Uncertainty, Global Psychological Distress, and Posttraumatic Stress in Pediatric Cancer: A Preliminary Examination Using a Path Analysis Approach	51 of the 105 (48.57%) caregivers of children newly diagnosed with cancer reported a total PTSS score in the severe (n=16) or clinically significant range (n=35). SEM: For the direct pathways, a positive relationship between GPD and PTSS was observed, as well as a positive relationship between ambiguity and GPD. Ambiguity did not have a direct effect on PTSS. However, ambiguity appeared to indirectly affect PTSS through GPD. The final model accounted for 47.3% of the variance in PTSS and 17.1% in GPD. Lack of clarity and unpredictability were not significant predictors. --> Ambiguity experienced by parents may be salient in the development of PTSS.									1					
Post-traumatic stress disorder in mothers of children who have undergone cancer surgery	Of all participants, 13 (21.7%) were diagnosed with PTSD (CAPS Scores). These mothers had shorter duration of marriage, longer duration of hospital stay after surgery, and higher HADS scores (both: anxiety and drepression scores), compared with the others without PTSD. Thoughts of guilt such as "I am being punished or tested" were more frequent in mothers with PTSD. Insomnia, irritability, concentration problems, and psychological reactivity were the most common symptoms. --> PTSD may worsen the daily functioning of mothers and may also have an unfavorable effect on child. It is therefore of utmost importance for clinicians to recognize PTSD and the associated risk factors in order to guide these parents	1													
Factors Influencing Posttraumatic Growth in Mothers of Children With Cancer	The variables of optimism, disruption of core beliefs, social support, and deliberate rumination accounted for 41,4% of the variance in the mothers´ PTG (Of the 7 paths in the modified model, the following 6 were statistically significant: optimism to disruption of core beliefs [DCB], DCB to social support, DCB to deliberate rumination, DCB to PTG, deliberate rumination to PTG, and social support to PTG; only the path between social support and deliberate rumination was not statistically significant). Social support and deliberate rumination are important factors directly affecting PTG in mothers of children with cancer.														
Infancy and pediatric cancer: an exploratory study of parent psychological distress	**Mothers (47.5%) and fathers (37.5%) reported elevated, cancer-related posttraumatic stress symptoms.** Additional **17.5% of mothers and 12.5% of fathers met the criteria for 'partial' cancer-related PTSD** (2 of the 3 PTSD symptom clusters). Rates of depression (12.2% of mothers and 12.0% of fathers) and anxiety symptoms (17.1% of mothers and 8.0% of fathers) were lower. Parental gender was not significantly associated with rates of cancer-related PTSS, depression, or anxiety symptoms. The parents of infant siblings reported higher rates of depressive symptoms than the parents of infant patients (and trends toward higher rates of posttraumatic stress symptoms and anxiety symptoms). Parent anxiety was higher with increased time post diagnosis. No demographic or illness-related variables were associated with psychological distress, with the exception of the number of children in the family.	1								1					
Post-traumatic Stress Symptoms among Iranian Parents of Children during Cancer Treatment	The total mean score of post-traumatic stress symptoms was 41.70. Among all categories of the Impact of Event Scale – Revised, the **highest mean belonged to the category of 'intrusion' 16.03** (SD = 6.24) and the lowest one belonged to the category of 'hyperarousal' 10.68 (SD = 4.58). Based on the results, **mothers had higher post-traumatic stress symptoms** (more intrusion and more hyperarousal) compared with fathers ($p < 0.05$). Based on the cut-off value ≥33, **more than 75.5% of parents had PTSS** (42% of mothers and 33.5% of fathers).									1					

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Illness Uncertainty, Global Psychological Distress, and Posttraumatic Stress in Pediatric Cancer: A Preliminary Examination Using a Path Analysis Approach		4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Post-traumatic stress disorder in mothers of children who have undergone cancer surgery	relatively small sample	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Factors Influencing Posttraumatic Growth in Mothers of Children With Cancer	The pretrauma characteristics of the subjects could not be accurately assessed because they were investigated retrospectively.	4	moderate limitations	⊕⊕	moderate	Importance of early intervention strategies, Furthermore, the mothers´personal strength and intrinsic resources must be conserved and nurtured so that they are not overpowered by the trauma.	3	new evidence/citation
Infancy and pediatric cancer: an exploratory study of parent psychological distress	small sample	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Post-traumatic Stress Symptoms among Iranian Parents of Children during Cancer Treatment	cultural bias?	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Posttraumatic Stress and Attentional Bias towards Cancer-Related Stimuli in Parents of Children Recently Diagnosed with Cancer	2016	Cernvall, M.	Observational study (cohort, cross/sectional, case-controll)	4	Sample taken as part of the screening phase of an RCT for internet-based self-help groups for parents of children with cancer. No CG. Methods used (internet survey): PCL-C, Emotional Stroop Task - Use of neutral words, cancer-woken words and cardiovascular disease words (call font color); Measurement of latency to solve the task; self-assessment questionnaire: PTSD checklist Civilian version; BDI-2; Beck Anxiety Inventory;	N = 62 parents of children with cancer (2 equal groups: one with high values in the PTSD questionnaire, one with low values). 36 of the 62 were mothers, mean age 40.2, average age of the child 8.2, on average 3 months since the diagnosis. Diagnoses of children: Leukemias (28), sarcomas (11), lymphomas (6), CNS tumors (9), others (13)
5	Racial/Ethnic Disparities in the Risk of Posttraumatic Stress Disorder Symptoms Among Mothers of Children Diagnosed with Cancer and Type 1 Diabetes Mellitus	2017	Greening, L.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study; measures: PCL-C, BDI-II, STAI, Life Event Checklist, Cortisol	N= 91 mothers of children diagnosed with a life-threatening illness (cancer n= 56, or typ 1 diabetes n= 35) at southeastern university medical center (USA) Age mothers cancer: M= 36 years; SD= 8,69 years Age mother typ 1 diabetes: M= 40,29 years; SD= 7,29 years Race/Ethnicity cancer: 31 (56%) african american; 25 (44%) caucasians Race/Ethnicity Typ1 diabetes: 14 (41%) african americans; 21 (59%) caucasians
5	Quality of Life' of Parents of Children Suffering from Pediatric Malignancies in a Low Income Setting	2018	Bafna, Vibha Sanjay	Observational study (cohort, cross/sectional, case-controll)	4	Sample in the clinical setting and healthy control sample of parents, who came with their children for vaccination. Methods used: World Health Organization quality of life (WHOQOL-BREF); Depression Anxiety Stress Score (DASS)	N = 70 (VG): parents of children with cancer in India; no information on the age of the parents or the children. Cancers that were present: 71.4% hematologic disorders, remaining tumors. N = 50 (CG); In both groups mainly questionnaires answered by men (approx. 60% each)
5	Spiritual and religious coping and depression among family caregivers of pediatric cancer patients in Latin America	2018	Vitorino, L. M.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study with random sample, without CG. Methodology: Self-Assessment Questionnaire: BDI, sociodemograph. data incl. assessment of own health, SRC scale (spiritual / religious coping with 49 items)	N = 77 primary caregivers (minimum age 18); Response rate: 98.7% Mean age 37.3; 88.3% women; 81.8% employed/in employment. 53.2% reported financial problems in the family; nearly half of the primary caregivers reported having chronic disease, 5.2% taking medication daily. Almost all of them are religious (71), and faith is helping them (76).
5	Prevalence and Levels of Depression Among Parents of Children with Cancer in Basrah, Iraq	2016	Al-Maliki, Shukrya	Observational study (cohort, cross/sectional, case-controll)	4	no control-group; Face-to-face Interviews (CES-D)	Inclusion Criteria: Parents of children <16 with any cancer diagnosis within the last year, but at least 2 months before the interview; N = 336 (384 requested, response rate 87.5%); 224 mothers (mean age 31.9 + -5.3 y), 112 fathers (mean age 37.1 + -5.9 y); Mothers predominantly housewives (90.5%), fathers predominantly employed (91.1%); mean age of children: 7.7 + -2.6 y; Diagnosis: ALL (150, 44.6%), lymphoma (109, 32.4%), neuroblastoma (28, 8.3%), others (49, 14.6%); Gender of the children: 232 female (69%)
5	Predictors of anxiety and depression among parents of children with cancer in Jordan	2017	Al Qadire, M.	Observational study (cohort, cross/sectional, case-controll)	4	Descriptive study, methods used: HADS	N = 222 parents of children with cancer (Inclusion criteria: cancer patient < 18 with cancer diagnosis within the last 6 months): 46 fathers, 176 mothers with average age 37.3; related children: 122 boys, 102 girls, average age 8.5; 135 of them with leukemia and lymphoma; 87 with 'solid tumors'; Types of treatment: OP (135), Chemotherapy (43), Other (44)

Summary of evidence - Research question 5

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Posttraumatic Stress and Attentional Bias towards Cancer-Related Stimuli in Parents of Children Recently Diagnosed with Cancer	(1) The group with high rates of post-traumatic symptoms had significantly longer latency in the Stroop task with cancer-related words (this was not observable in the other groups of words) -> authors conclude that PTSD symptoms in parents go along with attentional bias. (2) Strong connections between PTSD and depression symptoms. (3) Longer latencies for the cancer-related words for mothers, unemployed and persons in care of the child		1		1										
Racial/Ethnic Disparities in the Risk of Posttraumatic Stress Disorder Symptoms Among Mothers of Children Diagnosed with Cancer and Type 1 Diabetes Mellitus	A full factorial MANCOVA revealed that mothers diagnosed with typ 1 diabetes had higher cortisol levels than mothers of children with cancer. There was no racial/ethnic disparity in the risk of PTSS among the mothers.														
Quality of Life' of Parents of Children Suffering from Pediatric Malignancies in a Low Income Setting	Statistically significant differences in all areas of quality of life between VG and CG (VG -> lower QoL); QoL was influenced by quality of sleep (physical component), depression (psychic component), interpersonal relationships (social component) and missing information (environmental component); statistically significant difference in depression, anxiety and stress -> VG shows sig more of all 3 symptom groups; QoL was also dependent on the socioeconomic status: the higher, the higher the LQ (significant)	1			1	1		1							
Spiritual and religious coping and depression among family caregivers of pediatric cancer patients in Latin America	75% of primary caregivers did not report depressive symptoms based on BDI cutoff (cutoff is 10; average was 8.5); overall, the use of positive coping strategies was significantly higher than the use of negative ones; the higher the BDI value, the more pronounced were negative coping strategies; negative religious coping strategies came along with depression (sign.), not positive strategies. Authors interpret this as a religious struggle in response to the situation.	1													
Prevalence and Levels of Depression Among Parents of Children with Cancer in Basrah, Iraq	High prevalence of depression in parents was found (70.5%). Mothers had significantly higher depression rates than fathers:77.2% vs. 57.1%. Higher education of mothers was predictor for lower depression. Major depression was significantly more common among lower income parents.			1						1					
Predictors of anxiety and depression among parents of children with cancer in Jordan	Parents of children with cancer in Jordan have high levels of anxiety and depressive symptoms. Parents who report depression and have children with cancer that suffer from nausea tend to have symptoms of anxiety. Parents with younger children, problems with work, chronic illness and higher levels of anxiety symptoms were also more likely to have depressive symptoms -> The authors need screenings for anxiety and depression and psychological support when needed.			1						1					

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Posttraumatic Stress and Attentional Bias towards Cancer-Related Stimuli in Parents of Children Recently Diagnosed with Cancer	no control-group; assessment via internet, no control of surrounding	4	moderate limitations	⊕ ⊕	moderate		3	
Racial/Ethnic Disparities in the Risk of Posttraumatic Stress Disorder Symptoms Among Mothers of Children Diagnosed with Cancer and Type 1 Diabetes Mellitus	Mothers of children with cancer: different types of cancer -> different stressors; all off treatment -> no generalizability for mothers with children on treatment	4	moderate limitations	⊕ ⊕	low		2	
Quality of Life' of Parents of Children Suffering from Pediatric Malignancies in a Low Income Setting	Article leaves questions unanswered; statistical analysis problematic, cultural bias; Little information on the recruitment of the sample, the response rate is not specified.	4	major limitations	⊕	moderate		2	
Spiritual and religious coping and depression among family caregivers of pediatric cancer patients in Latin America	Article leaves questions unanswered (no information on diagnosis of children etc.); sample in group with depressive symptoms small for analysis; cultural bias	4	major limitations	⊕	moderate		2	
Prevalence and Levels of Depression Among Parents of Children with Cancer in Basrah, Iraq	no control-group; cultural bias; questionnaire CES-D (1977) translated to arabic by study team; questionnaire as interview	4	major limitations	⊕	moderate		1	
Predictors of anxiety and depression among parents of children with cancer in Jordan	Methodology does not seem sufficient (Only 14-item HADS items); cultural bias	4	major limitations	⊕	moderate		1	

Summary of evidence - Research question 5

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Coping with the diagnosis and hospitalization of a child with childhood cancer	2015	de Cerqueira Nóia, T.	Indivudual qualitative study	6	Descriptive-exploratory design study with qualitative data analyses	N= 10 member of the families of children with cancer Gender: 9 mothers; 1 father Age: M= 39,9 years; range= 20-52 years Time of treatment of the children or adolescents: range= 2 months-8 years Diagnosis: 4 leukemia; 1 adenocarcinoma, 1 soft tissue sarcoma; 1 hepatoblastoma; 1 peritoneal tumor Age children: range= 1;11-14 years
	Distress/PTSD child-parent-family						
5	Maternal Coping and Depressive Symptoms as Predictors of Mother-Child Communication About a Child´s Cancer	2016	Rodriguez, E.M.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study, 2 US pediatric oncology centers	N= 100 mother-child dyads Age mothers: M= 37,83 years; SD= 7,82 years Age children: M= 10,19 years; SD= 3,86 years; range= 5-17 years Gender children: 48% female; 52% male Diagnosis: 40 leukemia; 19 lymphoma; 6 brain tumor; 35 other solid tumor Time since diagnosis: M= 1,9 months
5	The interdependence of posttraumatic stress symptoms in parental dyads during and after their child's treatment for cancer.	2017	Wikman, A.	Observational study (cohort, cross/sectional, case-controll)	4	Data on PTSS from six assessments: (1-3) during treatment; (4-6): after end of treatment. Actor-partner interdependence models were estimated using a structural equation modeling approach to explore the dyadic relationship of PTSS.	N= 150 parents (75 dyads) of 75 children diagnosed with cancer in Sweden during 2002-2004, with follow-up until one year after end of treatment.
5	Effects of Time since Diagnosis on the Association between Parent and Child Distress in Families with Pediatric Cancer	2016	Okado, Y.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study about how the amount of time elapsed since the child´s diagnosis moderates the associations between self-reported parent and child symptoms of depression, anxiety, and post-traumatic stress.	N= 255 parent-child dyads (247 after exclusion of 8 participants due to concerns about the validity of their responses); Gender parents: 83,1% mothers; 12,2% fathers; 4,7% other adult figur; Age children: M= 12,61 y; SD= 2,88 y; range= 8-17 y; Time since diagnosis: 1-6 months (n= 64, 25,1%); 6 months-2 y (n=63, 24,7%); 2-5 y (n=65, 25,5%); 5+ y (n=63, 24,7%); Age at diagnosis: M= 9,39 y; SD= 4,74 y; range= 3 months-17,42 y; Diagnosis: ALL (23,1%); AML (7,3%); lymphoma (13%); solid tumors (39,3%);brain tumors (17,4%); Treatment status: 118 (46,3%) on treatment; 137 (53,7%) off treatment
5	Child´s symptom burden and depressive symptoms among caregivers of children with cancers: an argument for early integration of pediatric palliative care	2016	Olagunju, A.T.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study; Measures: Memorial Symptom Assessment Scale (MSAS 7-12) and Center for Epidemiologic Studies Depression Scale-Revised (CES-DR).	N= 72 caregivers and children with cancers undergoing treatment in tertiary hospitals in Nigeria; Gender caregivers: 83,7% mothers; 16,3% fathers; caregivers: M= 39 years, SD= 2 years; Gender children: 42 (53,3%) males; Age: M=10 years; SD= 2 years; Diagnosis: 30 (41,6%) lymphoma; 20 (27,8%) leukemia; 3 (4,1%) retinoblastoma; 3 (4,1%) Wilms; 5 (6,9%) CNS tumors; 11 (15,5%) others Duration of cancer illness: M= 10,48 months; SD= 8,20 months; range= 1-48 months
5	The Relationship Between Parent Trait Anxiety and Parent-reported Pain, Solicitous Behaviors, and Quality of Life Impairment in Children With Cancer	2016	Link, C. J.	Observational study (cohort, cross/sectional, case-controll)	4	parents of children treated for cancer completed measures of anxiety, behavioral responses to children's pain, and of their child's quality of life and pain. Children (8 to 18) completed measures of their own quality of life and pain. single center	N=353 parents, 137 children child age: M=10.6(SD=4.9) child gender: male=210(54.4%) diagnosis: leukemia=148(45.4%), CNS tumor=59(18.1%), Lymphoma=43(13.2%), other=39(12%), sarcoma=37(11.3%) parents age: M=39.1(SD=7.2) parents gender: mother=314(83.3%), father=53(14.1%), other=10(2.7%) marital status: married=266(77.6%) education years: M=13.8(SD=3.6)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Coping with the diagnosis and hospitalization of a child with childhood cancer	Two categories emerged from the data: [1] How families coped with the diagnosis (Cancer is still a term surrounded by several taboos, most participants, don´t use the term "cancer". Reactions of shock, despair, crying, denial and fear were highlighted along with the emotions at the time of the interviews.) [2] How families coped with hospitalization (Some families had to experience seeking treatment in different cities, in these cases it becomes necessary to build another life routine, as well re-evaluate the roles and tasks of the family members.)														
Distress/PTSD child-parent-family															
Maternal Coping and Depressive Symptoms as Predictors of Mother-Child Communication About a Child´s Cancer	**Higher primary and secondary control coping, and lower depressive symptoms,** were generally correlated **with more positive, and less harsh and withdrawn communication.** In regression models, higher primary control coping (i.e., coping efforts to change the stressor or one´s emotional reaction to the stressor) independently predicted less withdrawn communication, and depressive symptoms mediated relations between coping and harsh communication.														
The interdependence of posttraumatic stress symptoms in parental dyads during and after their child's treatment for cancer.	Results show both actor and partner effects during the child's treatment. The association between mothers' and fathers' PTSS did not remain after end of treatment. -> Parents appear to react as an interdependent emotional system during the child's treatment but this effect disappears after end of treatment. Results suggest psychological interventions for parents during the child's cancer treatment should also be sensitive to and address the influence that distress in one partner may have on the other.	1													
Effects of Time since Diagnosis on the Association between Parent and Child Distress in Families with Pediatric Cancer	Time since diagnosis moderated the associations between parental symptoms and child-reported anxiety and post-traumatic stress. Dyads farther out from diagnosis exhibited stronger associations between parental and child symptoms.									1					
Child´s symptom burden and depressive symptoms among caregivers of children with cancers: an argument for early integration of pediatric palliative care	More than one-third of caregivers (38,2%) screened positive for significant depressive symptoms. The global symptom burden (r=0,58) and individual symptoms (nausea r=0,68; lack of energy r=0,65; sleep difficulty r=0,62; pain=0,61) correlated positively with depressive symptoms in caregivers.														
The Relationship Between Parent Trait Anxiety and Parent-reported Pain, Solicitous Behaviors, and Quality of Life Impairment in Children With Cancer	Parent anxiety was significantly associated with parent ratings of children’s pain severity (P=0.004) and frequency (P=0.008), as well as parent solicitous responses (P=0.041) and parent-reported child quality of life (not with child-reported QoL). Parents with high anxiety reported greater frequency of children’s pain episodes. Regression analysis revealed that parent anxiety significantly predicted solicitous behaviors (P=0.006), pain frequency (P=0.043), and parent-reported child quality of life (P=0.004, but not child-reported QoL). --> These findings suggest parent anxiety plays a significant role in parent perception of children’s pain and quality of life in pediatric cancer patients.									1					

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Coping with the diagnosis and hospitalization of a child with childhood cancer	Coping strategies used by the families were not described well in the study.	6	major limitations	⊕	low		1	
Distress/PTSD child-parent-family								
Maternal Coping and Depressive Symptoms as Predictors of Mother-Child Communication About a Child´s Cancer	Although the study was prospective, there were only two time points to assess three key variables; a meditational model of coping´s impact on commnication as mediated by depressive symptoms would have required at least three time points.	4	moderate limitations	⊕⊕	high	These findings suggested that promoting primary control coping skills and intervening to reduce or prevent depressive symptoms following a child´s diagnosis may help mothers communicate more effectively with their children.	4	new finding
The interdependence of posttraumatic stress symptoms in parental dyads during and after their child's treatment for cancer.	cohort included large sample of parents, relative to study population in Sweden, but small for analyses carried out	4	moderate limitations	⊕⊕	high		3	new finding
Effects of Time since Diagnosis on the Association between Parent and Child Distress in Families with Pediatric Cancer	Missing demographics (age parents and gender children). Single-center study. Because of the cross-sectional design it is not possible to conclude that the association between parent and child symptoms would decline over time in the same families followed longitudinally and prospectively.	4	moderate limitations	⊕⊕	moderate	Findings suggest the importance of monitoring the psychological adjustment of parents and children over time.	3	new evidence/citation
Child´s symptom burden and depressive symptoms among caregivers of children with cancers: an argument for early integration of pediatric palliative care	single center	4	moderate limitations	⊕⊕	moderate	The study showed that children wth cancer and their caregivers need both to be supported by health care providers.	3	new evidence/citation
The Relationship Between Parent Trait Anxiety and Parent-reported Pain, Solicitous Behaviors, and Quality of Life Impairment in Children With Cancer	not all instruments were validated, cross-sectional design (no causal conclusions possible)	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Parent illness appraisals, parent adjustment, and parent-reported child quality of life in pediatric cancer	2016	Mullins, L. L.	Observational study (cohort, cross/sectional, case-controll)	4	Parents completed measures of demographic and medical information, illness uncertainty, attitude toward illness, parenting stress, posttraumatic stress symptoms, general distress, and both parent-reported general and cancer-specific child QOL. single center	N=138 caregivers (85% response rate) **Children:** gender: male=53%, diagnosis: leukemia/lymphoma=41.0%, non-central nervous system (CNS) solid tumors=26.6%, brain tumors=13.7%, other cancers=18.7%, Age: less than 7 years of age=53%; M= 8.01 (SD = 5.22) **Caregiver:** caregiver status: mother=77%, father=15.8%, custodial caregiver=5.0%, missing=2.2%; martial status: married=66.2%, never married=11.5%, divorced=10.8%, cohabiting/living with partner=5.8%, other=4.3%, missing=1.4%
5	Longitudinal associations among maternal communication and adolescent posttraumatic stress symptoms after cancer diagnosis	2016	Murphy, L. K.	Observational study (cohort, cross/sectional, case-controll)	4	multi-method, 3 time-points: T1: 2 months after cancer diagnosis (selfreported PTSS, adolescents and mothers), T2: 3 months after T1 (mother–adolescent dyads were videotaped discussing cancer, and maternal communication was coded with macro (harsh and withdrawn) and micro (solicits and validations) systems - Iowa familiy interaction scale), T3: 1-year follow-up (selfreported PTSS, adolescents and mothers) 2 pediatric oncology centers/US	N=41 adolescents, 41 mothers **adolescents:** age: M=13.27(SD=2.33); gender: female=54%; diagnosis: leukemia=36.6%, lymphoma=22.0%, other solid tumors (e.g. sarcomas=41.5%), no brain tumors at T3 20 (49%) were still receiving treatment **mothers:** age: M=41.8(SD=7.82); educational background: high school - graduate school (M=3 years of college or trade school)
5	Parental Post-Traumatic Stress Symptoms as Predictors of Psychosocial Problems in Children Treated for Cancer	2016	Nakajima-Yamaguchi, R.	Observational study (cohort, cross/sectional, case-controll)	4	cross-sectional study; instruments: Impact of Event Scale-Revised (IES-R), the Parent Experience of Child Illness (PECI), and the Child Behavior Checklist (CBCL), Parent-child communication rated on a scale (0=did not inform the child of the disease at all, 1= informed the child that he/she had a disease not using the word “cancer”, 2=fully informed the child including diagnosis and prognosis), Information about the children’s illnesses: medical records. one hospital in Japan	**N=37 parents** participated (34 included, 3 excluded because of missing data) gender: 36 mothers, 1 father; age: M=37.9(SD=6.4), range=22-52y education: high school or less=18(52.9%), more than high school=15(44.1%), no answer=1(2.9%) **children:** gender: 17 girls (50%); age at enrollment: M=10.5 (SD=3.9), range=4-17y age at diagnosis: M=6.4(SD=4.3), range=0-16y; diagnosis: acute leukemia=19 (55.9%); lymphoma=6 (17.6%); brain tumor=4 (11.8%); other solid tumor=5 (14.7%)
5	Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-threatening chronic disease: A pilot study	2015	Graziano, S.	Observational study (cohort, cross/sectional, case-controll)	4	Aim of study: To compare the (post-traumatic) stress levels of mothers of children with life-threatening and non-life-threatening diseases. Measures: CBCL 1.5-5 and 6-18, depending on the age of the children; Adult self-report (ASR); Parenting stress index form; Trauma symptom inventory (TSI-A); STAI	N=15 children (2-12y)+ mothers with malignant solid tumor at least 2-6 months before, on chemotherapy; 2 control groups (juvenile rheumatoid arthritis; healthy)

Summary of evidence - Research question 5

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Parent illness appraisals, parent adjustment, and parent-reported child quality of life in pediatric cancer	Exploratory analyses indicated that parent illness uncertainty and illness attitudes conferred indirect effects on parent-reported general and cancer-related quality of life through parenting stress. Negative parent illness appraisals appear to have adverse impacts on parents' psychosocial functioning and have implications for the well-being of their child with cancer.			1											
Longitudinal associations among maternal communication and adolescent posttraumatic stress symptoms after cancer diagnosis	Adolescent PTSS at T1 was associated with adolescent PTSS at T3. Greater maternal PTSS at T1 predicted greater harsh maternal communication at T2. There was an indirect effect of maternal PTSS at T1 on adolescent PTSS at T3 through maternal validations at T2. --> Findings underscore the importance of maternal PTSS, maternal communication, and subsequent adolescent PTSS over the course of treatment of childhood cancer.	1													
Parental Post-Traumatic Stress Symptoms as Predictors of Psychosocial Problems in Children Treated for Cancer	--> Psychosocial problems of children with cancer were associated with parental post-traumatic stress symptoms (PTSS) --> Provision of early, adequate support to parents who are vulnerable to PTSS will help not only the parents, but also their children with cancer.	1													
Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-threatening chronic disease: A pilot study	Findings show that there are differences in the psychological functioning in children with respect to age. The 6- to-12-year-old children with cancer had more significant internalizing problems and attention problems with respect to healthy children but not to JRA children. Conversely, the two- to -five-year old children with cancer did not show any significant problems compared to children with JRA and healthy children. Regarding the mother's results, we found that mothers of children with cancer had higher levels of both PTSS and parental distress than mothers of children with JRA and mothers of healthy children.	1								1					

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Parent illness appraisals, parent adjustment, and parent-reported child quality of life in pediatric cancer	only self-reports (and proxy-report) from 1 informant	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Longitudinal associations among maternal communication and adolescent posttraumatic stress symptoms after cancer diagnosis	smaller sample	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Parental Post-Traumatic Stress Symptoms as Predictors of Psychosocial Problems in Children Treated for Cancer	small sample	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-threatening chronic disease: A pilot study	small sample, wide age range; only perspective of mother - bias?	4	moderate limitations	⊕⊕	moderate		2	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	Distress/PTSD child/adolescent						
5	Life stress vs. traumatic stress: The impact of life events on psychological functioning in children with and without serious illness	2016	Willard, V.W.	Observational study (cohort, cross/sectional, case-controll)	4	Children with cancer and age-, sex-, and race/ethnicity-matched controls were compared; Stressful life events included those that may meet Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV; American Psychiatric Association, 2000) A1 criteria (PTEs; 9 events) and others that would likely not (other events; 21 events).	N= 254 children with cancer, N=142 CG (children without a history of a chronic or life threatening illness), Age patient: M= 13,09 y; SD= 2,89 y; range= 8-17 y; control: M= 12,68 y; SD= 2,89 y (range= 8-17); Gender: patient: 132 (52%) males; control: 74 (52,1%) males; Diagnosis: 61 (24%) ALL; 18 (7,1%) AML or APL; 34 (13,4%) lymphoma; 99 (39%) solid tumor; 42 (16,5%) brain tumor; Age at diagnosis: M= 9,29 y; SD 4,74 y; Time since diagnosis: M= 45,06 months; SD= 51,57 mo; Treatment status: 147 (57,9%) on therapy; 107 (42,1%) off therapy
5	Pediatric Cancer Patients' Treatment-Related Distress and Longer-Term Anxiety: An Individual Differences Perspective	2016	Trentacosta, C. J.	Observational study (cohort, cross/sectional, case-controll)	4	Objective: To find out if individual differences in temperament and personality play a role in how children react to treatment procedures. At baseline, parents reported on children's effortful control and ego-resilience. Multiple raters assessed children's distress during multiple cancer-related procedures. Treatment-related anxiety was measured 3 months and 9 months after the last assessed treatment procedure.	Inclusion criteria: Child between 3 and 12 years; diagnosed with cancer 1 to 18 months before enrollment; English good enough to fill in questionnaire -> N = 147 parents with their children (response rate 87%), 2 sites Parents: 85% female, average age 34; Children: 60% male, average age 6.5; Diagnoses: ALL (79.6%), Wilm's tumors (4.8%), non-Hodgkin's lymphoma (3.4%), other lymphomas (2.8%), astrocytomas (2%), other cancers (7, 4%)
5	Symptom Trajectories in Children Receiving Treatment for Leukemia: A Latent Class Growth Analysis With Multitrajectory Modeling	2017	Hockenberry, M.J.	Observational study (cohort, cross/sectional, case-controll)	4	Repeated-measures research design, symptom trajectories were explored over 4 periods: initiation of post-induction therapy, 4, 8, and 12 months post-induction therapy; symptom measures on: fatigue, sleep disturbances, depression, nausea and pain	N= 236 children with leukemia; Age: 113 (47,9%) young children 3-6years; 77 (32,6%) children 7-12 years; 46 (19,5%) adolescents 13-18 years Gender: 107 (45,3%) females; Leukemia risk: 26 (11%) low; 83 (35,2%) average/standard; 48 (20,3%) high; 79 (33,5%) very high; 4 US cancer treatment centers
5	Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study	2015	Wolfe, J.	Observational study (cohort, cross/sectional, case-controll)	4	Longizudinal study, symptom distress in chilldren with advanced cancer during 9 months of follow-up, 3 large pediatric cancer centers; Measure: PediQUEST Memorial Symptom Assessment Scale (PQ-MSAS): administered 920 times: 459 times in teens (99% self-report), 249 times in children ages 7 to 12 years (96% child/parent report), and 212 times in those ages 2 to 6 years (parent reports).	N= 104 children (full cohort) Age: 54 (51,9%) ≤12 years; 50 (48,1%) ≥13 years; range= 2-18 y; Gender: 51 (49%) females; Diagnosis: 58 (55,8%) solid tumor; 36 (34,6%) hematologic malignancy; 10 (9,6%) brain tumor; time from diagnosis to enrollment: median= 27 months; IQR= 17-51 months; N= 25 children (subgroup with End-of-Life PQ-Surveys) Age: 12 (48%) ≤12 years; 13 (52%) ≥13 years; range= 2-18 y; Gender: 12 (48%) females; Diagnosis: 13 (52%) solid tumor; 11(44%) hematologic malignancy; 1 (4%) brain tumor; Time from diagnosis to enrollment: median= 29 months; IQR= 21-35 months
5	Quality of Life Among Pediatric Patients With Cancer: Contributions of Time Since Diagnosis and Parental Chronic Stress	2015	Hamner, T.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study, 1 southern US center	N= 43 pediatric patients undergoing oncological treatment Age: M= 10,2 years; SD= 3,6 years; range= 5-18 years Gender: 33 (76,7%) males; 10 (23,3%) females Diagnosis: 17 (39,5%) ALL; 26 (60,5%) other Relation to child: 34 (79,1%) mothers; 3 (7%) fathers; 6 (14%) other (e.g., guardian)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Distress/PTSD child/adolescent															
Life stress vs. traumatic stress: The impact of life events on psychological functioning in children with and without serious illness	Children with cancer endorsed significantly more poatientially traumatic events (PTEs) than control children (cancer spontaneously identified in 52%). There were no differences between groups in number of other events experienced. Hierarchical regression analyses revealed that number of other events accounted for significant variance in psychological functioning, above and beyong group status, demographic factors (age and SES) and number of PTEs. Therefore the study confirmed some prior research, that non-PTEs are more impactful with regard to psychological functioning. There was a significant difference in SES, such that there were more participants in the cancer group in the low SES category.														
Pediatric Cancer Patients' Treatment-Related Distress and Longer-Term Anxiety: An Individual Differences Perspective	Attention control was linked to ego-resilience and lower levels of distress, and these variables, in turn, accounted for indirect associations between attention control and treatment-related anxiety. Associations involving ego-resilience were stronger for boys than girls. CONCLUSION: Attention control plays an important role in children's immediate and longer-term responses to cancer-related medical procedures. Medical staff should consider individual differences in child temperament and personality when considering the nature and extent of support to provide to pediatric cancer patients and their families.	1													
Symptom Trajectories in Children Receiving Treatment for Leukemia: A Latent Class Growth Analysis With Multitrajectory Modeling	Three latent classes of symptom trajectories were identified and classified into **mild (36.6%), moderate (52.2%), and severe (11.1%) symptom trajectories.** The only demographic characteristic with a significant relationship to membership in the latent class symptom trajectories was **race/ethnicity.** All other demographic characteristics including leukemia risk levels showed no significant relationships. CONCLUSION: This study is unique in that groups of patients with similar symptoms were identified rather than groups of symptoms.														
Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study	Common symptoms included pain (48%), fatigue (46%), drowsiness (39%), irritability (37%), and sleep disturbances (29%). Among the 73 PQ-MSAS administered in the last 12 weeks of life, pain was highly prevalent (62%), drowsiness (50%) and fatigue also (49%); other physical symptoms like nausea, anorexia, diarrhea, dry mouth, and irritability were particularly prevalent at the end of life. **Being female, having a brain tumor, experiencing recent disease progression, and receiving moderate- or high-intensity cancer directed therapy in the prior 10 days were associated with worse PQ-MSAS scores.** In the final 12 weeks of life, receiving mild cancer directed therapy was associated with improved psychological PQ-MSAS scores.														
Quality of Life Among Pediatric Patients With Cancer: Contributions of Time Since Diagnosis and Parental Chronic Stress	Parental chronic stress is associated with reduced levels of emotional, physical, and social functioning among pediatric patients.														

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Distress/PTSD child/adolescent								
Life stress vs. traumatic stress: The impact of life events on psychological functioning in children with and without serious illness	Lack of method variance, as all measures were self-report in nature. The measures of psychological distress focused exclusively on internalizing concerns and not externalizing behaviors. Information about how often each event occured was not collected.	4	moderate limitations	⊕⊕	high	The authors suggested that it would be prudent for clinicians to assess a wide range of negative life events.	3	new finding
Pediatric Cancer Patients' Treatment-Related Distress and Longer-Term Anxiety: An Individual Differences Perspective		4	moderate limitations	⊕⊕	high	study offers important content (not necessarily just about the symptoms, but also for risk and protective factors). It focuses on clinically meaningful points and their results provide clues that are valuable and workable in terms of treatment (the ideas with attention control, distraction during treatment...)	3	new finding
Symptom Trajectories in Children Receiving Treatment for Leukemia: A Latent Class Growth Analysis With Multitrajectory Modeling	Heterogene population (the largest race/ethnic group in this study was Hispanic, wich was indicative of the population at two of the study sites).	4	moderate limitations	⊕⊕	high		3	new finding
Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study	The study does not permit conclusions regarding specific age subgroups or non-English speaking families. In addition, because of sample heterogeneity and the pragmatic approach used to collect patient-reported outcomes (PROs), wich resulted in an unbalanced design, longitudinal patterns of symptoms, if they exist, may have been veiled.	4	moderate limitations	⊕⊕	high	Strategies to promote intensive symptom management are indicated, especially with disease progression or administration of intensive treatments.	3	new evidence/citation
Quality of Life Among Pediatric Patients With Cancer: Contributions of Time Since Diagnosis and Parental Chronic Stress	Due to the small sample size, no exploration of interaction effects possible. Causal conclusions are not possible due to the cross-sectional and correlational nature of the data. All measures were reported by parents. Due to confidential nature of the study, the authors were unable to confirm parent report of time since diagnosis against patient medical records.	4	moderate limitations	⊕⊕	moderate	The findings indicate that consideration of family-factors, such as chronic stress, are important to consider in treatment and care practices from diagnosis and treatment through remission.	3	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	2016	Kunin-Batson, A. S.	Observational study (cohort, cross/sectional, case-controll)	4	prospective longitudinal study, 4 time points: 1 month, 6 months and 12 months after diagnosis, 3 months after completion of chemotherapy (at T4 approx. 60% of the initial participants completed measurements); Parents completed standardized rating scales of their children’s emotional-behavioral functioning and measures of coping and family functioning (Emotional-behavioral outcomes were collected as part of an ancillary study at 31 Children’s Oncology Group sites that included community-based and tertiary care centers)	N=160 parents of children with standard-risk ALL gender: female=76 (47.8%) age: preschool (2-4y)=86 (54.1%), school age (5-9y)=73 (45.9%) diagnosis: ALL
5	Predicting trajectories of behavioral adjustment in children diagnosed with acute lymphoblastic leukemia	2016	Sint Nicolaas, S. M.	Observational study (cohort, cross/sectional, case-controll)	4	multicenter (6 of 7 dutch pediatric oncology centers) longitudinal study; 3 timepoints: during induction treatment (T0), after induction/consolidation treatment (T1), and after end oftreatment (T2) instruments: CBCL, Profile of Mood states (POMS), Illness Cognistions Questionnaire(ICQ), Utrecht Coping List (UCL), parental Stress Index-short form(PSI), Inventory for social reliance (ISR), Child Health Questionnaire (CHQ), PedsQL cancer-module latent class growth modeling (LCGM) analyses	N=108 included in analysis (complete data at 2 out of 3 asessments) children: age: M=6.3(SD=4.2), range=1-17; gender: female=57(53%); diagnosis: ALL parents: age: M=38.2(SD=5.6), range=25-52; gender: female=90(86%); education level: low=13(12%), medium=51(47%), high=44(41%); single-parent household=11(10%) No differences were found between participants (N = 108) and drop-outs (N = 23) with respect to age (p = .52) and treatment protocol (p = .10). Drop-outs were more often boys (p = .00)
5	Longitudinal Analysis of Quality-of-Life Outcomes in Children During Treatment for Acute Lymphoblastic Leukemia: A Report From the Children´s Oncology Group AALL0932 Trial	2018	Zheng, D.J.	Observational study (cohort, cross/sectional, case-controll)	4	Longitudinal study with measures of the Padiatric Quality of Life Inventory Generic Core Scales Version 4.0 (PedsQL4.0) at approximatly 2 months, 8 months, 17 months, 26 months, and 38 months after diagnosis. Prospective cohort study of a subset of children enrolled in the COG interventional clinical trial AALL0932 at 157 COG member institutions.	N= 594 children with average-risk acute lymphoblastic leukemia (AR-ALL) Age at diagnosis: M= 6 years; SD= 1,6 years Gender: 317 (53,4%) males; 277 (46,6%) females
5	Profiles of Resilience and Growth in Youth With Cancer and Healthy Comparisons	2016	Tillery, R.	Observational study (cohort, cross/sectional, case-controll)	4	Children completed measures of PTS, PTG, and a life-events checklist. Parents reported on their own PTS and PTG. instruments: youth: UCLA PTSD Reaction Index for DSM-IV, Benefit Finding/Burden Scale for Children, Life Events Scale; caregiver: Impact of Events Scale, Revised, The Benefit Finding Scale; Latent profile analysis (LPA); 1 center St. Jude	N=435 children and adolescents (patient group(PG)=253, healthy controls(CG)=182) and 1 primary caregiver for each child/adolescent caregiver's gender: mother=85%; father=12%; other adult participant=3% youths age: range=8-17; PG: M=12.61(SD=2.88), CG: M=12.14(SD=2.94) gender: PG: female=48.6%, CG=51.1% diagnosis: Acute lymphoblastic leukemia=24.1%, Other leukemia= 6.3%, Hodgkin’s and non-Hodgkin’s lymphoma=13.4%, Solid tumor=38.7%, Brain tumor=17.5%

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	A significant percentage of children experience emotional distress during and after therapy for ALL. These data provide a compelling rationale for targeted early screening and psychosocial interventions to support family functioning and coping skills.									1					
Predicting trajectories of behavioral adjustment in children diagnosed with acute lymphoblastic leukemia	For internalizing behavior, a three-trajectory model was found: a group that experienced no problems (resilience trajectory, 60 %), a group that experienced only initial sub-clinical problems (recovery trajectory, 30 %), and a group that experienced chronic problems (10 %). For externalizing behavior, a three-trajectory model was also found: a group that experienced no problems (resilience, 83 %), a group that experienced chronic problems (12 %), and a group that experienced increasing problems (5 %). Only parenting stress and baseline QoL (cancer related) were found to contribute uniquely to adjustment trajectories. --> Screening for risk factors for developing problems might be helpful in early identification of these children									1					
Longitudinal Analysis of Quality-of-Life Outcomes in Children During Treatment for Acute Lymphoblastic Leukemia: A Report From the Children´s Oncology Group AALL0932 Trial	At 2 months, a substantial proportion of participants had impaired scores for physical (36.5%) and emotional (26.2%) functioning compared with population norms of 2.3%. These elevations persisted at 26 months. Emotional impairment at 2 months was found to significantly predict emotional impairment at 26 months. In repeated measures analysis with multivariate modeling, unhealthy family functioning significantly predicted emotional impairment controlling for age and sex. QOL outcomes were similar between sexes at the end of therapy (26 months for girls and 38 months for boys). **Younger age at the time of diagnosis was a significant risk factor for impairment in both emotional and social functioning**. Girls were more likely to have emotional impairment at 2 months after diagnosis, while boys were more likely to have physical impairment at 17 months after diagnosis. Otherwise, there were no differences between boys and girls.														
Profiles of Resilience and Growth in Youth With Cancer and Healthy Comparisons	LPA revealed three profiles. The majority of youth (83%) fell into two resilient groups differing by levels of PTG --> PTS and PTG appear to be relatively independent constructs, and their relation is dependent on contextual factors. The majority of youth appear to be resilient, and even those who experience significant distress were able to find benefit.									1					

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study	only parent-proxy reports	4	moderate limitations	⊕ ⊕	high		3	new evidence/citation
Predicting trajectories of behavioral adjustment in children diagnosed with acute lymphoblastic leukemia	only proxy report	4	moderate limitations	⊕ ⊕	high		3	new evidence/citation
Longitudinal Analysis of Quality-of-Life Outcomes in Children During Treatment for Acute Lymphoblastic Leukemia: A Report From the Children´s Oncology Group AALL0932 Trial	Response rates dropped by the end of therapy (girls and those with better physical functioning at 2 months were more likely to complete the final evaluation); it is possible that the current study underestimated the actual prevalence of QOL impairment at the end of therapy. All outcomes were based on parent report, wich may inaccurately estimate a child´s QOL.	4	moderate limitations	⊕ ⊕	high	Many children with AR-ALL experience physical and emotional functioning impairment that begins early in treatment and persists. Early screening may identify high-risk patients who might benefit from family-based interventions.	3	new evidence/citation
Profiles of Resilience and Growth in Youth With Cancer and Healthy Comparisons	lack of information regarding caregiver	4	moderate limitations	⊕ ⊕	moderate		3	new finding

Summary of evidence - Research question 5

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Anxiety and depression: A Cross-sectional Survey among Parents of Children with Cancer	2018	Rahmani, A.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study to assess anxiety and depression of parents of Iranian children with cancer	N= 148 parents of children with cancer (single center) Gender parents: 31 (29,9%) males; Age parents: M= 36,08 y; SD= 2,08 y (range= 21-49 y); Gender children: 65 (43,9%) males; Age children: M= 10,18 y; SD= 2,56 y; range= 6-15 y; Time since diagnosis: M= 13,62 months; SD= 12,73 months; range= 3-72 months
5	Attention Deficit Hyperactivity Disorder and Anxiety in Children With Malignancy	2016	Yousefi Chaijan, P.	Observational study (cohort, cross/sectional, case-controll)	4	100 children with malignancy and 100 healthy children without malignancy or any chronic disease were compared.	N= 100 children with malignancy N=100 healthy children Age patient: M= 6,67 years; SD= 3,04 years; range= 3-15 years Age control: M= 6,69 years; SD= 2,92 years; range= 5-16 years Gender patient: 57 (57%) males; 43 (43%) females Gender control: 53 (53%) males; 47 (47%) females
5	Factors Associated with Emotional Distress in Children and Adolescents during Early Treatment for Cancer	2017	Sohn, I. J.	Observational study (cohort, cross/sectional, case-controll)	4	A retrospective chart review on patients newly diagnosed with cancer at a single center in Korea from 2014 to 2016 intruments (at initial psychiatric evaluation): The Korean-Child Behavior Checklist (K-CBCL, completed by mothers), children 7 and 12: Children's Depression Inventory (CDI), State-Trait Anxiety Inventory for Children (STATIC); children 13 and 17: Beck Depression Inventory-II (BDI-II), State-Trait Anxiety Inventory (STAI)	N=85 patients and their mothers age: M=7.6(SD=5.7) gender: male=50(58.8%) relapsed=8(9.4%) diagnosis: Acute leukemia=30(35.3%), Brain tumor=17(20%), Non-Hodgkins lymphoma=10(11.8%), Bone sarcoma=8(9.4%), Soft tissue sarcoma=5(5.9%), Neuroblastoma=4(4.7%), Willms' tumor=3(3.5%), Hepatoblastoma=2(2.4%), Retinoblastoma=2(2.4%), Langerhans cell histiocytosis=2(2.4%), Hemophagocytic lymphohistiocytosis=1(1.2%), Sacrococcygeal germ cell tumor=1(1.2%)
5	Examining the perceived social support and psychological symptoms among adolescents with leukemia	2015	Cavasoglu, H.	Observational study (cohort, cross/sectional, case-controll)	4	multicentre study (no psychologists or psychosocial employees in any of the 3 participating hospitals); used instruments: demographic data; BSI (self-assessment questionnaire, symptom checklist); MPSSS (Social Support Scale); the questionnaires in the form of an interview	N = 70 adolescents (13 and 19 y) with leukemia, but excluding high-risk, leukemia diagnosed before at least 1 year; 18 female, 52 male participants; Diagnosis: ALL (49 pers.), AML (21 pers.); N=57 treated with chemotherapy, 13 with chemo- and radiotherapy
5	Positive schemas, psychopathology, and quality of life in children with pediatric cancer: A pilot study	2017	McArthur, B.A.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study with a new comprehensive measure of positive schemas to better understand the relationship between positive schemas, quality of life, and psychopathology, for children on active treatment for cancer.	N= 22, Age: M= 12,64 y; SD= 3 y; range= 8-18 y Gender: 11 females; 11 males Age at initial diagnosis: M= 11,6 y (100% of proxy-reports were completed by mothers)

Summary of evidence - Research question 5

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Anxiety and depression: A Cross-sectional Survey among Parents of Children with Cancer	Nearly 41,2% (n=61) and 32,4% (n=48) of participants had clinical symptoms of anxiety and depression, respectively.														
Attention Deficit Hyperactivity Disorder and Anxiety in Children With Malignancy	ADHD and anxiety are more common in children with malignancy as compared with children without malignancy and anxiety is also more common in their parents. Therefore, implementing interventions and psychiatric counseling are recommended for these children and their parents.														
Factors Associated with Emotional Distress in Children and Adolescents during Early Treatment for Cancer	The maternal Beck Depression Inventory-II (BDI-II) score was positively correlated with total problem scores and externalizing scores in patients aged 1-6 years. In patients aged 7–12 years, there was no significant association between the patient's emotional distress and other variables. in 13-17 year olds patient BDI-II score was associated with maternal BDI-II, maternal trait anxiety and maternal state anxiety scores. Patient trait anxiety score was associated with maternal BDI-II and maternal trait anxiety scores. Patient state anxiety was associated with maternal state anxiety. Maternal BDI-II score was the strongest factor associated with patient depression in adolescents. --> develop early psychiatric interventions for patients and their parents at the initial psychological crisi									1					
Examining the perceived social support and psychological symptoms among adolescents with leukemia	Patients showed significantly higher levels of mental symptoms than the control group from previous study (especially anxiety, depression, somatization, negative self-concept); Adolescents reported greater social support from family than from friends or special persons (such as partners), and social support when relapse occured was particularly pronounced; Greater perceived social support overall and by friends correlated with better self-image, less depression and anxiety, and generally less pronounced mental symptoms	1	1												
Positive schemas, psychopathology, and quality of life in children with pediatric cancer: A pilot study	Child-reported positive schemas were significantly related to child-reported child quality of life. Overall total PSQ (Positive Schema Questionnaire) was significantly and positively related to the child report of social functioning, higher levels of positive schemas come along with higher level of social quality of life. Similarly, children who scored higher on the PSQ Interpersonal trust subscale reported a higher level of social functioning and emotional functioning.														

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Anxiety and depression: A Cross-sectional Survey among Parents of Children with Cancer	Parents´ psychological responses might have been influenced by quality of care received by this cancer center. Single-center study.	4	moderate limitations	⊕⊕	moderate	Effective interventions are essential to improve the mental health of parents of children with cancer. These interventions may include mental health screening, psychological counseling, and training programs to cope with the problems caused by the child´s disease.	3	new evidence/citation
Attention Deficit Hyperactivity Disorder and Anxiety in Children With Malignancy	Single-center study	4	moderate limitations	⊕⊕	moderate	The authors recommended the implementation of interventions and psychiatric counseling for children with malignancy and their parents.	3	new evidence/citation
Factors Associated with Emotional Distress in Children and Adolescents during Early Treatment for Cancer	no information regarding mothers, retrospective, number of patients 7-12 years was small compared to other groups	4	moderate limitations	⊕⊕	moderate		3	new evidence/citation
Examining the perceived social support and psychological symptoms among adolescents with leukemia	Control group was taken from 2 other studies (from 2002 and 2011)	4	moderate limitations	⊕⊕	moderate	The study was conducted in Turkey, where, as described in the article, psychosocial support is not standard practice. Therefore, it is questionable to what extent the results are transferable to circumstances of guideline.	2	
Positive schemas, psychopathology, and quality of life in children with pediatric cancer: A pilot study	Small and heterogene sample. Only one variable (positive schemas) that may be related to quality of life and treatment intensity was examined, although there are a number of variables that may contribute to these outcomes. Use of self-report methods to measure key study variables. Reporting bias due to subjective reporting (social desirability, defensiveness, etc.). Only parent report of child psychopathology was measured.	4	major limitations	⊕	moderate		2	

Summary of evidence - Research question 5

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Prevalence of Psychiatric Symptoms in ALL Patients during Maintenance Therapy	2015	Farhangi, M.	Observational study (cohort, cross/sectional, case-controll)	4	no control-group; measures: - Revised Children's Manifest Anxiety Scale (RCMAS) - Selbstbeurteilung; Children Depression Inventory (CDI) - Selbstbeurteilung, SDQ (parents)	N=42 patients (7-17y, Mean age: 9,83; N=29 male)
5	Neuropsychiatric presentations and outcomes in children and adolescents with primary brain tumours: Systematic review	2015	Zyrianova, Y.	Systematic review of descriptive or qualitative studies	5	31 papers were chosen for discussion in this review	Not applicable
5	The Age Conundrum: A Scoping Review of Younger Age or Adolescent and Young Adult as a Risk Factor for Clinical Distress, Depression, or Anxiety in Cancer	2015	Lang, M.J.	Systematic review of descriptive or qualitative studies	5		N=34 studies
5	Inflammatory cytokines and depression in children with cancer: A review of the literature	2018	Narendran, G.	Expert opinion	7		Not applicable
5	Improving care in pediatric neuro-oncology patients: an overview of the unique needs of children with brain tumors	2016	Fischer, Ch.	Expert opinion	7		Expert opinion with cases
	Posttraumatic growth						
5	Factors associated with posttraumatic growth among parents of children with cancer	2016	Nakayama, N.	Observational study (cohort, cross/sectional, case-controll)	4	cross-sectional, single-center questionnaire survey in Tokyo, instruments: PTG Inventory, Center for Epidemiologic Studies Depression Scale, State-Trait Anxiety Inventory, and Impact of Event Scale-Revised	N=119 parents (of 83 children), final response rate=44.1% gender: 48(40.3%) fathers, 71(59.7%) mothers age: M=41.4y (SD=6); education: university graduate or higher=44(37%), junior college or lower=75(63%) children: age: M=9.4y (SD=4.8) gender: female=64(53.8%) diagnosis: hematologic malignancies=79(66.4%), solid tumors=40(33.6%) treatment status: on treatment=39(32.8%), less or equal to 12 months off treatment=16(13.4%), greater than 12 months off treatment=64(53.8%)
5	Posttraumatic Grwoth and Its Dimensions in the Mothers of Children with Cancer	2018	Behzadi, M.	Observational study (cohort, cross/sectional, case-controll)	4	Posttraumatic Growth Inventory (PTGI) and demographic data; Multi-center design, 3 clinics involved.	N = 180 mothers: mean age: 34 y, 83% housewives. Children: 1 to 18 years, 42% between 3 and 6, 80 girls, 100 boys; Diagnosis: Leukemia (47%), glioma (2%), neuroblastoma (11%), lymphoma (16%), osteosarcoma (4%), nephroblastoma (1%), other (20%) - percentages rounded.

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Prevalence of Psychiatric Symptoms in ALL Patients during Maintenance Therapy	The authors conclude that there is a high prevalence rate among children and adolescents with cancer. The complete sample shows depressive symptoms, 60% anxiety symptoms, 26% behavioral problems.			1	1	1		1	1						
Neuropsychiatric presentations and outcomes in children and adolescents with primary brain tumours: Systematic review	Neuropsychiatric presentations are common in children with CNS tumours - with the presence of **behavioural and psychological symptoms in up to 57% of cases,** their frequency varies according to **age of onset and is strongly associated with time since diagnosis.** A particularly high rate of depression and adjustment disorders at over 30% has been reported in children treated for **medulloblastoma.** Survivors of paediatric brain tumours are at risk for long-term psychiatric morbidities and social maladjustment and appear to be in danger experiencing suicidal ideation.														
The Age Conundrum: A Scoping Review of Younger Age or Adolescent and Young Adult as a Risk Factor for Clinical Distress, Depression, or Anxiety in Cancer	All 34 studies found a significant association between at least one DDA construct and the younger age group relative to the older age groups at some point along the cancer trajectory. However, age as an independent risk factor for DDA is still unclear, as the relationship could be confounded by other age-related factors. Despite the wide range of definitions and effect sizes in the studies included in this review, one thing is clear: adolescents and young adults, however defined, **are a distinct group within the cancer population with an elevated risk of DDA.**														1
Inflammatory cytokines and depression in children with cancer: A review of the literature	Pediatric cancer patients experience unique inflammatory changes secondary to their disease and accompanying treatments. It has been reported that inflammatory changes in the context of illness are related to cytokine dysregulation which in turn may influence the expression of depressive symptoms.														
Improving care in pediatric neuro-oncology patients: an overview of the unique needs of children with brain tumors	Pediatric brain tumor patients have unique needs during treatment, as cancer survivors and at end of life. Knowledge of the unique aspects of care for children with brain tumors, and the appropriate interventions required, allows for improved QoL.														
Posttraumatic growth															
Factors associated with posttraumatic growth among parents of children with cancer	Higher PTG Inventory scores were associated with parents' lower trait anxiety (P = .028), parents' sex (female; P = .004), treatment status (within 12 months from treatment end compared with on-treatment; P = .048), surgery (P = .007), and late effects (P = .01). CONCLUSIONS: Parents' PTG was associated with children's clinical characteristics, parents' sex, and parents' anxiety levels. When dealing with PTG, the parents' psychological characteristics and children's clinical characteristics should be considered. Particularly for parents with high trait anxiety, it is important to reduce anxiety first before addressing PTG.									1					
Posttraumatic Grwoth and Its Dimensions in the Mothers of Children with Cancer	Mothers reported average PTG of 62.4 (scale of 0-104); highest prevalence in the areas of: spiritual change, appreciation of life, relationships with others, personal strength, new opportunities; The higher the level of education of the mother, the greater the "value of life" values; Mothers of male children had higher "personal strength" values - the authors attribute this to cultural specifics; authors conclude that the experience of having a child with cancer can lead to PTG.	1	1						1						

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Prevalence of Psychiatric Symptoms in ALL Patients during Maintenance Therapy	The article is very short and leaves questions unanswered (statistical analysis, charts...). Methodology is outdated (year data for the questionnaire between 1981 and 1997). It is questionable whether the questionnaire for the relatively broad age range (7-17) is so generic used.	4	major limitations	⊕	low		1	
Neuropsychiatric presentations and outcomes in children and adolescents with primary brain tumours: Systematic review	The search strategy might not have identified all relevant papers and unpublished and non-English articles. A large portion of included studies were descriptive in nature. There was variation in the data detail between studies, with some studies providing a detailed account and others being concise. Most studies were under-powered and only a small percentage of multi-center studies were found.	5	moderate limitations	⊕ ⊕	high	These findings highlight the necessity for routine psychological and psychiatric screenings of children with suspected brain tumours and at follow-up of childhood brain tumour survivors.	3	new evidence/citation
The Age Conundrum: A Scoping Review of Younger Age or Adolescent and Young Adult as a Risk Factor for Clinical Distress, Depression, or Anxiety in Cancer	AYA not consistent defined, wide age range	5	moderate limitations	⊕ ⊕	moderate		3	new finding
Inflammatory cytokines and depression in children with cancer: A review of the literature	Exact number of articles incuded in the review was not mentioned - review not systematically	7	moderate limitations	⊕	high		2	
Improving care in pediatric neuro-oncology patients: an overview of the unique needs of children with brain tumors		7	major limitations	⊕	high	for indication - risk group	2	
Posttraumatic growth								
Factors associated with posttraumatic growth among parents of children with cancer		4	moderate limitations	⊕ ⊕	high		3	new finding
Posttraumatic Grwoth and Its Dimensions in the Mothers of Children with Cancer	cultural bias; no normative data of PTG	4	moderate limitations	⊕ ⊕	moderate		3	new finding

Summary of evidence - Research question 5

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
5	Association of Posttraumatic Growth and Illness-Related Burden With Psychosocial Factors of Patient, Family, and Provider in Pediatric Cancer Survivors	2016	Wilson, J.Z.	Observational study (cohort, cross/sectional, case-controll)	4	Cross-sectional study investigating the associations of psychosocial factors of the patient, family, and health care team with posttraumatic growth (PTG) and illness-related burden (IRB) in childhood cancer survivors. Single center	N= 61 children and adolescents; Age: M= 11,59 years; SD= 3,38 years; range= 7-18 years; Gender: 39 (63,9%) males; Time since end of treatment: M= 1,73 years; SD= 1,47 years; Diagnosis: 35 (57,4%) leukemia; 19 (31,1%) solid tumor; 7 (11,5%) lymphoma Age parents: M= 38,18 years; SD= 6,61 years; Gender parents: 51 (83,6%) mothers; 10 (16,4%) fathers
5	Correlates of post-traumatic growth following childhood and adolescent cancer: A systematic review and meta-analysis	2017	Turner, J.	Systematic review of descriptive or qualitative studies	5	inclusion criteria: diagnosed with cancer <21y; examined PTG with appropriate measure; reported participants' mean age or age range at diagnosis and survey; examined at least one relevant demographic variable; reported quantitative data; used cross-sectional or longitudinal design; search: Embase, Medline, PILOTS, PsycINFO, Web of science	N=18 studies (out of 905)
	Medication						
5	Predictors of benzodiazepine use among parents of children with cancer: a cross-sectional study from Lebanon	2016	Fayad, D.	Observational study (cohort, cross/sectional, case-controll)	4	single center study; measures: socio-demographic data; medical data; Hopkins Symptom Checklist 25 for scrrening of anxiety, depression and overall score	N = 100 parents of children suffering from cancer were included in the study. Parents mean age: 37.8y; Children mean age: 6.9y; Cancers: 75% leukemia, 25% other
	Siblings						
5	Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review	2018	Long, K.A.	Systematic review of descriptive or qualitative studies	5	quantitativ+qualitativ+mixed method	N=102 studies (63 quantitative, 35 qualitative, 4 mixed-methods).
5	Experiences of posttraumatic growth in siblings of children with cancer	2016	D'Urso, A.	Indivudual qualitative study	6	semi-structured interviews with siblings of children with cancer	N = 6 siblings of children with cancer: leukemia (4), brain tumor (2); Age of the patients: 11-16

Summary of evidence - Research question 5

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Association of Posttraumatic Growth and Illness-Related Burden With Psychosocial Factors of Patient, Family, and Provider in Pediatric Cancer Survivors	Regression analyses showed that **PTG was positively associated with the patients´ posttraumatic stress symptoms**. It was also positively associated with the parents´ **religious coping, and with measures of stronger family and oncologist relationships.** IRB was positively associated with patient-reported mental distress, lower family SES, and female gender. There was no significant association with parenting style or parent-reported posttraumatic stress symptoms in the child.														
Correlates of post-traumatic growth following childhood and adolescent cancer: A systematic review and meta-analysis	After the removal of outliers, post-traumatic growth shared small, negative associations with time since diagnosis (r = -0.14) and time since treatment completion (r = -0.19), and small, positive associations with age at diagnosis (r = 0.20), age at survey (r = 0.17), post-traumatic stress symptoms (r = 0.11), and social support (r = 0.25). **Post-traumatic growth was positively and moderately associated with optimism (r = 0.31).** CONCLUSIONS: Several findings were consistent with a comparable meta-analysis in adult oncology populations. Targeted social support, clinical intervention, and education may facilitate post-traumatic growth.														
Medication															
Predictors of benzodiazepine use among parents of children with cancer: a cross-sectional study from Lebanon	Many parents showed symptoms of anxiety and /or depression from the Hopkins questionnaire, in the total score 71%. 27% of parents reported self-medication, 17% with benzodiazepines, of which only 23% were prescribed; The mental symptoms (anxiety-depression total score) were more pronounced in: unemployed; younger than 35 years old; female; with inpatient children	1		1											
Siblings															
Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review	Methodological limitations are common. Mean levels of anxiety, depression, and general adjustment are similar across siblings and comparisons, **but symptoms of cancer-related posttraumatic stress are prevalent. School-aged siblings display poorer academic functioning and more absenteeism but similar peer relationships as peers.** Quality of life findings are mixed. **Adult siblings engage in higher levels of risky health behaviors** and may have poorer health outcomes than comparisons. **Risk factors fo**r poor sibling adjustment include lower social support, poorer family functioning, lower income, non-White race, and shorter time since diagnosis, but findings are inconsistent. Qualitative themes include siblings' maturity, compassion, and autonomy, but also strong negative emotions, uncertainty, family disruptions, limited parental support, school problems, altered friendships, and unmet needs.														
Experiences of posttraumatic growth in siblings of children with cancer	All siblings reported changes in their lives through cancer diagnosis. the thematic analysis produced 3 overarching themes for the perception of siblings: (1) difficult emotions: shock, anxiety and uncertainty at diagnosis; guilt, anger, helplessness, jealousy and sadness during or after treatment (2) Strengthened relationships: within and outside the family, and some have also considered peer-to-peer support to be important; In addition, support from school and friends has been described very important (3) personal development: personal maturity, empathy, resilience that is developing	1		1											

Summary of evidence - Research question 5

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Association of Posttraumatic Growth and Illness-Related Burden With Psychosocial Factors of Patient, Family, and Provider in Pediatric Cancer Survivors	As cross-sectional study, cause-and-effect determinations were not possible. The study relied on parent reports (from only one parent) of family functioning, coping, resilience, and mental distress, wich were not assessed in patients. On the otherhand, PTG and IRB was not assessed in parents or other family members. Sample was not representative for leukemia, relative to population prevalences for childhood cancers. Finally, the internal consistency of the measure of Negative Religious Coping was well below standard values.	4	moderate limitations	⊕⊕	moderate	The findings suggested that the young cancer patient´s psychosocial and ressource milieu (e.g., financial) may be instrumental in PTG and IRB. Psychosocial interventions with high-risk families and their health care teams could increase growth and reduce burden.	3	new finding
Correlates of post-traumatic growth following childhood and adolescent cancer: A systematic review and meta-analysis	effect sizes in studies were small; inaccuracy of retrospective report - recall bias	5	moderate limitations	⊕⊕	high		4	new finding
Medication								
Predictors of benzodiazepine use among parents of children with cancer: a cross-sectional study from Lebanon	Leukemia overrepresented; only one questionnaire	4	moderate limitations	⊕⊕	moderate		3	new finding
Siblings								
Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review	The tendency for siblings to be compared with non-matched control groups diminishes internal validity. Non-diverse samples and low response rates raise questions of external validity and generalizability of findings. Lack of longitudinal designs	5	moderate limitations	⊕⊕	high		4	new evidence/citation
Experiences of posttraumatic growth in siblings of children with cancer	small sample	6	major limitations	⊕	moderate		1	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	COMMUNICATION, PSYCHOEDUCATION						
6	Interventions for patients and caregivers to improve knowledge of sickle cell disease and recognition of its related complications (Review)	2016	Asnani MR	Systematic review or meta-analysis of controlled study	1		patients with mit sickle cell disease (SCD) + families
6	Reduction of Secondhand Smoke Exposure in the Cars of Children With Cancer	2015	Peck, K.R.	Randomized controlled trial	2	Parental reports of SHSe were collected over the course of 12 months. Intervention: Parents/guardians in the intervention group were assigned a health counselor who delivered a 3-month, multicomponent SHS reduction program; CG: parents where advised about health risk.	Participants: 71 (45% female, 7% CNS, 62% leukemia, 31% solid tumor, parent mean age: 34.5 SD 8.8); smoking parents or guardians of nonsmoking children (<18 years) being treated for cancer and at least 30 days postdiagnosis. Intervention Group: n=38, 32%female, child diagnosis: 5% CNS, 61%leukemia, 34%solid tumor; 90%white, 63% 2 smokers in home, mean age 9.3 SD 5.5, parent mean age 35.0 SD 8.6; Control Group: n=33, 61%female, child diagnosis: 9% CNS, 64%leukemia, 27%solid tumor; 91%white, 61%; 2 smokers in home, mean age 9.3 SD 5.0, parent mean age 33.8 SD 7.9
6	Pilot Evaluation of a Palliative and Endof-Life Communication Intervention for Parents of Children With a Brain Tumor	2017	Hendricks-Ferguson, V. L.	Non-Randomized controlled trial	3		13 parents of 11 children, Parent characteristics: gender: mothers (85.7%) and fathers (14.3.%); marital status: single parents (38.5%), married couples (30.8%), parent living with a partner (23.1%), and divorced parents (7.7%). Characteristics 11 children: gender: 5 girls (45.5%); age: 0.4 to 14.5 years (mean = 6 years); brain tumor and a poor prognosis=100%

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
COMMUNICATION, PSYCHOEDUCATION															
Interventions for patients and caregivers to improve knowledge of sickle cell disease and recognition of its related complications (Review)	This review identifies important positive effects of educational interventions on improving patient knowledge of sickle cell disease and depression.														
Reduction of Secondhand Smoke Exposure in the Cars of Children With Cancer	Younger children were exposed at baseline more than their older counterparts. The greatest initial declines in car exposure were observed among children ≤5 years old in the intervention group compared with same-aged peers in the control group. After the 3-month time point, the control group showed greater reductions in car exposure in comparison with the intervention group. Interventions that teach parents strategies to manage their smoking while driving in their personal vehicles may produce even greater reductions in child exposure and should be developed.														
Pilot Evaluation of a Palliative and Endof-Life Communication Intervention for Parents of Children With a Brain Tumor	The goals of this study were to determine feasibility, acceptability, and parent responses related to a PC/EOL communication intervention, titled “Communication Plan: Early through End of Life (COMPLETE)” to parents of children with a brain tumor. COMPLETE intervention is feasible and acceptable and produces promising effects on 3 parent outcomes (ie: decision regret, hope, and uncertainty).	1													

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
COMMUNICATION, PSYCHOEDUCATION								
Interventions for patients and caregivers to improve knowledge of sickle cell disease and recognition of its related complications (Review)		1	no limitations	⊕⊕⊕⊕	high		**4**	new finding
Reduction of Secondhand Smoke Exposure in the Cars of Children With Cancer	reliance on parent reports of SHSe. Although the CG did not receive the individualized intervention, repeatedly asking parents to report their child's exposure to vehicular SHS may have artificially reduced car exposure.	2	moderate limitations	⊕⊕⊕	moderate		**3**	new finding
Pilot Evaluation of a Palliative and Endof-Life Communication Intervention for Parents of Children With a Brain Tumor	no control group	3	major limitations	⊕⊕	high		**2**	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	PSYCHOSOCIAL INTERVENTIONS TO IMPROVE QOL						
6	The Effectiveness of Psychosocial Interventions for Psychological Outcomes in Pediatric Oncology: A Systematic Review	2018	Coughtrey, A.	Systematic review or meta-analysis of controlled study	1	according to Cochrane guidelines for systematic reviews on intrervention	N = 12 RCTs (total 1393 participants) Age: mean under 18 years; Diagnosis: 9 studies current cancer diagnosis, 3 studies with survivors; Control groups: standard treatment (n = 4), waiting list (n = 3), alternative intervention (n = 5) Inclusion: studies with participants > 18y (if the mean age <18), current or previous cancer (of any kind), also "survivors"; studies that included parents and siblings as long as the child with cancer was the main target of the intervention; active (other intervention) or passive (waiting list) control group; no restriction regarding publication year
6	Pilot Randomized Trial of Active Music Engagement Intervention Parent Delivery for Young Children With Cancer	2017	Robb, S. L.	Randomized controlled trial	2	pilot study; multi-method (self-report, interviews, video analysis); baseline, post intervention and 30 days post intervention	N=16 (IG=9; CG=7); randomized to a parent-delivered active music engagement (AME-P; 3 sessions, 45 min each, 1 session daily on 3 consecutive days) or attention control (audio story books)
6	Arash: A social robot buddy to support children with cancer in a hospital environment	2018	Meghdari, A.	Randomized controlled trial	2	study to assess acceptability; 2 experiments to evaluate the acceptance of the robot (1. arash as a storyteller (robot/audio), 2. fill in another questionnaire, which evaluates the anthropomorphism, animacy, likability, intelligence, and safety of the robot from the child’s point of view)	N=14, age: range: 5-12 years, M=9.5 (SD=1.2); sex: males n=10 (72%)

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
PSYCHOSOCIAL INTERVENTIONS TO IMPROVE QOL															
The Effectiveness of Psychosocial Interventions for Psychological Outcomes in Pediatric Oncology: A Systematic Review	Interventions: cognitive behavioral therapy (CBT, n = 4), joint CBT and physical exercise therapy (n = 1), family therapy (n = 2), therapeutic music video (n = 2), self-coping strategies (n = 1), wish fulfillment intervention (n = 1), and joint family therapy and CBT (n = 1). - 2 studies have found no improvement in the intervention group - studies that specifically measured anxiety and depressive symptoms showed significant improvements with CBT. (In a study combining family therapy and CBT, there were high results - reduction in PTSD and a complete reduction in arousal in the intervention group). - 8 studies reported physical outcomes: In all but one reported positive physical outcomes (including reduction in pain on treatment and symptom distress). -> A range of psychosocial interventions are effective and can positively affect mental and physical health. -> a lack of RCTs regarding solution-oriented approaches, narrative therapy and psychotherapy despite being used in clinical practice														
Pilot Randomized Trial of Active Music Engagement Intervention Parent Delivery for Young Children With Cancer	Parent delivery was feasible, as they successfully delivered AME activities, but interviews indicated parent delivery was not acceptable to parents. Emotional distress was lower for AME-P children, but parents derived no benefit –> Despite child benefit, findings do not support parent delivery of AME-P.	1	1							1					
Arash: A social robot buddy to support children with cancer in a hospital environment	12 children preferred the robot (85.7%), 2 preferred the Audio book (14.3%). The score of the robot storyteller in emotion, transportation, valance, arousal, and dominance are higher than the Audio storyteller; however, the difference is only significant in the emotion category. The mean score of cognition and imagination for the Audio storyteller is higher; however, the difference is not significant. The children liked the robot and its favored conceptual sketch very much. Also, they perceived the robot and its sketch as an intelligent creature. On the other hand, regarding anthropomorphism, the robot is not completely human-like. The mean score of the safety of the sketch was a bit higher than the robot; which is reasonable since children would feel more secure facing a sketch versus a first-time visit with the robot. However, no significant difference is observed on any item, which insured that the constructed robot is very similar to the children’s favored conceptual sketch.	1								1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
PSYCHOSOCIAL INTERVENTIONS TO IMPROVE QOL								
The Effectiveness of Psychosocial Interventions for Psychological Outcomes in Pediatric Oncology: A Systematic Review		1	no limitations	⊕⊕⊕⊕	high		**4**	new finding
Pilot Randomized Trial of Active Music Engagement Intervention Parent Delivery for Young Children With Cancer	small sample, a lot of qualitative data	2	major limitations	⊕⊕	moderate		**1**	
Arash: A social robot buddy to support children with cancer in a hospital environment	small sample, no information regarding cancer diagnosis (in general little information about participants)	2	major limitations	⊕⊕	moderate	Pilot: no statement on effectiveness possible	**2**	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Digital storytelling: an innovative legacy-making intervention for children with cancer	2015	Akard, T. F.	Non-Randomized controlled trial	3	randomized assignment to experimental and control group, but not really controlled; pre-post design; partly qualitative evaluation of data	intervention group (n = 15), control group (n = 13) mean age: 11 y. (7-17); mixed diagnoses ("diagnosed with any cancer"); N=15 girls; 1 child died
6	The Effect of Painting on Depression in Children with Cancer Undergoing Chemotherapy	2017	Tahmasebi, Z.	Non-Randomized controlled trial	3	pretest, posttest (immediately after intervention); 65 (7-12 year old) children who had obtained scores higher than 12 on Children's Depression Inventory (CDI) were chosen as participants and were randomly assigned to IG or CG	N=65 children (IG=32, CG=33)
6	Pilot Study of Therapy Dog Visits for Inpatient Youth With Cancer	2017	Chubak, J.	Non-Randomized controlled trial	3	no control group	N=19; Inpatients aged 7 to 25 years (inclusive) on the hematology/ oncology unit who were present on at least 1 of the 25 potential therapy dog visit days were eligible for this study; mean age = 12.9 years, 9 females and 10 males, Age 7-13: 11 children, age 13-17: 7, age 18-25: 1; Cancer type: Leukemia/lymphoma 8, Sarcoma 7, Brain 4
6	Yoga for Children and Adolescents After Completing Cancer Treatment	2016	Hooke, M. C.	Non-Randomized controlled trial	3	one group, repeated measures design	N=13 (10-18); 77 % female; 84% Caucasian, 38% Leukemia, 15% solid tumor, 46% CNS tumor; had completed treatment in the past 2 to 24 months

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Digital storytelling: an innovative legacy-making intervention for children with cancer	Feasibility was strong (1 attrition). While differences between the groups in physical, emotional, social or school functioning change was not statistically significant, the **intervention group showed slightly better emotional and school functioning** compared to controls. Parents reported that their child's digital story **provided emotional comfort to them (**n=11, 46%), **facilitated communication between parents and children (**n=9, 38%), and was a **coping strategy for them** (n=4, 17%). Parents reported that the intervention **helped children express their feelings** (n=19, 79%), cope (n=6, 27%), and feel better emotionally (n=5, 23%). All children reported that they liked the digital story telling activity.	1	1			1									
The Effect of Painting on Depression in Children with Cancer Undergoing Chemotherapy	IG: 6 group sessions of open watercolour painting lasting 25 min (after 25 min they explained their paintings to the researchers and other children). CG: same provided care but no painting in groups; –> No significant differences between groups regarding demographic characteristics. In IG depression score after the intervention was significantly lower than before the intervention. In CG depression score after painting was significantly higher than before painting. Before intervention no significant differences in depression scores between groups, after intervention depression score of children in IG was significantly lower than in the CG. Significant difference in the mean changes in depression score between the two groups.									1					
Pilot Study of Therapy Dog Visits for Inpatient Youth With Cancer	Following the therapy dog visit, **patients had lower distress and significant decreases in worry, tiredness, fear, sadness, and pain.** Providers were generally supportive of the intervention. Eight patients developed infections during the 14 days after the dog visit but none could be clearly attributed to the therapy dog visit.	1	1												
Yoga for Children and Adolescents After Completing Cancer Treatment	Recruiting pediatric cancer survivors to a yoga intervention study over a multi-week time period is challenging. Those who did participate were engaged with excellent attendance with their family and friends. Self-report scores for anxiety/sense of wellness decreased, but scores for other symptoms were not affected by the yoga intervention.	1													

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Digital storytelling: an innovative legacy-making intervention for children with cancer		3	moderate limitations	⊕ ⊕	high		**3**	new finding
The Effect of Painting on Depression in Children with Cancer Undergoing Chemotherapy	no effect sizes reported; no information regarding specific cancer diagnoses, mean age, gender; lack of enthusiasm to participate in painting sessions: nurses had to give prizes and encourage the children to attend	3	moderate limitations	⊕ ⊕	high		**3**	new finding
Pilot Study of Therapy Dog Visits for Inpatient Youth With Cancer	small sample, single institution	3	major limitations	⊕ ⊕	high		**2**	
Yoga for Children and Adolescents After Completing Cancer Treatment		3	major limitations	⊕ ⊕	moderate		**2**	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	…to reduce fatigue/improve fitness, sleep						
6	Non-pharmacological interventions to manage fatigue and psychological stress in children and adolescents with cancer: an integrative review	2016	Lopes-Júnior, L.C.	Systematic review or meta-analysis of controlled study	1	papers Jan 2000- Dez 2013; Studies with children between 0-19 years; Evidence leves were analysed according to Melnyk and Fineout-Overholt (2011); Methodological quality Assessment (Law et al. (modified by Machotka et al. (2009))	N = 9 studies
6	Adventure-based training to promote physical activity and reduce fatigue among childhood cancer survivors: A randomized controlled trial	2018	Li, W. H. C.	Randomized controlled trial	2	Intervention group (IG): 4-day adventure-based training programme; Control group (CG): placebo intervention (simulated the time and attention received by the IG) pre-test, repeated post-test (6 and 12 months after the intervention began) between-subject design; single-blind (participants were blinded to group assignment)	N=222 (IG n=117, CG n=105) [completed: IG=103; CG=89] Age at study enrollment: IG: M=12.8(SD=2.6); CG: M=12.4(SD=2.6) (range: 9-16 years) Diagnosis: IG: Leukemia n=41 (39.8%), Lymphoma n=27 (26.2%), Brain tumour n=13 (12.6%), Bone tumour n=14 (13.6%), Neuroblastoma n=8 (7.8%)CG: Leukemia n=40 (44.9%), Lymphoma n=24 (26.9%), Brain tumour n=12 (13.5%), Bone tumour n=7 (7.9%), Neuroblastoma n=6 (6.8%), Sex: IG: male=55 (53.4%); CG: male=47 (52.8%)
6	A Sleep Hygiene and Relaxation Intervention for Children With Acute Lymphoblastic Leukemia: A Pilot Randomized Controlled Trial	2017	Zupanec, S.	Randomized controlled trial	2	pilot study: Child sleep outcomes and fatigue levels were measured across 5 days and nights before randomization; 1 hour intervention, implementation of discussed strategies by parents over next 4 weeks + record children's shool attendance; 4-weeks post intervention sleep and fatique measures repeated for both groups	N=20 participants (IG=11 - 2 lost to follow-up, CG=9) age: IG: M=6.3 (SD=1.8), CG: M=6.2 (SD=2.0) diagnosis: ALL sex: IG: male=10 (91%), CG: male=8 (89%)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
…to reduce fatigue/improve fitness, sleep															
Non-pharmacological interventions to manage fatigue and psychological stress in children and adolescents with cancer: an integrative review	The articles were grouped into five categories: **physical exercise, healing touch, music therapy, therapeutic massage, nursing interventions and health education.** 6 studies showed significant outcomes - the use of the interventions led to a decrease in the symptoms and positive results (regarding fatique and/or stress levels). The most frequent tested intervention using different CRF management methods involved **exercise training programmes or EPA** (enhanced physical activity). It is suggested that these interventions are complementary to conventional treatment and that **their use can indicate an improvement in CRF and psychological stress.**														
Adventure-based training to promote physical activity and reduce fatigue among childhood cancer survivors: A randomized controlled trial	Significant change in participants' physical activity levels, self-efficacy, cancer-related fatique and QoL over time; the change in activity levels, self-efficacy, cancer-related fatique and QoL over time in the IG differed from that in the control group; **participants in the experimental group reported lower levels of cancer-related fatigue, higher levels of physical activity and self-efficacy, and better QoL than those in the control group** during the 12-month follow-up; Significant differences between the experimental and control groups were also evident for cancer-related fatigue and QoL at T3; the effect sizes for the adventure-based training on the levels of physical activity, self-efficacy, cancer-related fatigue and QoL ranged from small to large.														
A Sleep Hygiene and Relaxation Intervention for Children With Acute Lymphoblastic Leukemia: A Pilot Randomized Controlled Trial	Acceptabiliy: most of those approached chose to participate, responded positively to the intervention, and **found the sleep strategies useful;** Feasibility: Parents **reported using many of the sleep strategies, it was feasible to deliver the intervention in the clinical setting during regularly scheduled appointments.** Completion rates for subjective sleep and fatigue and objective sleep data were high (not all parents used the available open text fields on data collection). Poor compliance with completion of the investigator-developed school attendance calendar. - 35-minute difference in nighttime sleep between the sleep intervention and control groups (n.s.) - 44-minute difference in wake time after sleep onset between the sleep intervention and control groups (n.s.) Children in both groups slept significantly less than the recommended number of nighttime sleep hours	1	1												

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
…to reduce fatigue/improve fitness, sleep								
Non-pharmacological interventions to manage fatigue and psychological stress in children and adolescents with cancer: an integrative review		1	moderate limitations	⊕ ⊕ ⊕	high		**4**	new finding
Adventure-based training to promote physical activity and reduce fatigue among childhood cancer survivors: A randomized controlled trial		2	no limitations	⊕ ⊕ ⊕	high		**4**	new finding
A Sleep Hygiene and Relaxation Intervention for Children With Acute Lymphoblastic Leukemia: A Pilot Randomized Controlled Trial	small sample, bite all ALL (authors didn't reach the planned 15 Participants/group), overrepresentation of male participants	2	moderate limitations	⊕ ⊕ ⊕	high	Pilot: no statement on effectiveness possible, but good feasibility results	**3**	new finding

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Sustainability of an Integrated Adventure-Based Training and Health Education Program to Enhance Quality of Life Among Chinese Childhood Cancer Survivors: A Randomized Controlled Trial	2015	Chung, O. K. J.	Randomized controlled trial	2	A follow-up study of an RCT (12 and 18 months). Intervention group (n = 33) participated in a 4-day integrated adventure-based training and health education program. Control group (n = 36) received standard medical care (and 4-day recreational program)	N = 69 survivors (N = 33 in experimental group, N = 36 in control group) [2 excluded from IG -> recurrence; 1 aus CG excluded -> no longer interested; Gender: boys = 52.1%; Girls = 47.9%; Age: M = 12.6 (SD = 2.1) years; Diagnosis: leukemia = 49.3% or lymphoma = 25.4% Treatment: most patients received chemotherapy = 69.1%; 18.3% received more than 1 treatment
6	Changes in fitness are associated with changes in body composition and bone health in children after cancer	2015	Dubnov-Raz	Non-Randomized controlled trial	3	Exercise group vs.waiting CG	Excercices Group (n=10) und CG (n=12 - not matched); ager=7-13; mixed cancer types
6	Effects of a combined physical and psychosocial intervention program for childhood cancer patients on quality of life and psychosocial functioning: results of the QLIM randomized clinical trial	2016	van Dijk-Lokkart, E. M.	Randomized controlled trial	2	patients were max. 12 months off treatment; after baseline measurement participants were randomized to IG or CG (care as usual); stratification on pubertal stage, sex, diagnosis and whether recruitment took place during or shortly after treatment; baseline measures, 4 moths and 12 months after baseline	4 pediatric oncology centers; N=68 (IG=30; CG=38), 4 months: IG=26; CG=33; 12 months: IG=22, CG=31 age: IG: M=13.0 (SD=3.0); CG: M=12.6 (SD=3.1) sex: IG: male=16 (53.3%), CG: male=20 (52.6%) diagnosis: IG: Leukemia/Lymphoma=20 (66.7%), Brain/CNS tumors=2 (6.7%), solid tumors =8 (26.7%); CG: Leukemia/Lymphoma=26 (68.4%), Brain/CNS tumors=5 (13.2%), solid tumors=7 (18.4%)
6	A Fitbit and Facebook mHealth intervention for promoting physical activity among adolescent and young adult childhood cancer survivors: A pilot study	2017	Mendoza, J.A.	Randomized controlled trial	2	two-arm, unblinded, RCT, + interviews	Intervention Group: n=29, Control group n=30, Mean age: 16.6 ± 1.5 years; 59.3% female, 28.8% racial/ethnic minorities, 69.5% parents with bachelor's degree or higher, 71.2% private health insurance. Acute lymphoblastic leukemia (27.1%) and neuroblastoma (18.6%), median duration off-therapy was 10.3 years. Facebook group engagement: 26 of 29 intervention participants (89.7%) joined the intervention's private Facebook group.

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Sustainability of an Integrated Adventure-Based Training and Health Education Program to Enhance Quality of Life Among Chinese Childhood Cancer Survivors: A Randomized Controlled Trial	Survivors of the IG reported significantly higher levels of physical activity, self-efficacy (in terms of physical activity) and QOL (measured after 12 and 18 months) Effect intensity for QOL was small (0.05 -> from 0.01 = small, from 0.06 = moderate); Significant differences between T1 and T2, T1 and T3, and T2 and T3 in terms of QOL									1					
Changes in fitness are associated with changes in body composition and bone health in children after cancer	Exercise programs have an effect on physical fitness. Effects are a tendency to observe.	1	1					1							
Effects of a combined physical and psychosocial intervention program for childhood cancer patients on quality of life and psychosocial functioning: results of the QLIM randomized clinical trial	Intervention: training: 2 sessions/week, 45 min each for 12 weeks; psychosocial training: individualized structured program to reinforce socio-emotional functioning and coping with disease-related effects - 6 child sessions of 60 min once every 2 weeks and two parent sessions (start and end of the program), consisting of psycho-educational and cognitive-behavioral techniques –> largely no effect on HrQoL, behavioral problems, depressive symptoms, and self-perception. **Some small effects on the long-term were seen for HrQoL** (reported only by the parents and not by the patients themselves - at both shortterm and long-term follow-up, parents in the IG reported a greater improvement for their children on the Pain and Hurt scale, compared with parents in CG). No differences between groups in behavioral problems, depressive symptoms, and self-perception: at baseline participants reported only few (internalizing) behavior problems and depressive symptoms, and their self-perception was relatively good - it would be interesting to make this distinction to determine whether specific risk groups could benefit from intervention.									1					
A Fitbit and Facebook mHealth intervention for promoting physical activity among adolescent and young adult childhood cancer survivors: A pilot study	Qualitative data confirmed intervention acceptability. Exploratory analyses found no significant adjusted group differences for change, comparing intervention subjects to controls. Some modest differences were found for select subscales of quality of life and motivation for physical activity (PA).	1													

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Sustainability of an Integrated Adventure-Based Training and Health Education Program to Enhance Quality of Life Among Chinese Childhood Cancer Survivors: A Randomized Controlled Trial	Patient data in this study described inaccurately (maybe in previous study?); Instruments seem partly not standardized, some qualitative data collection -> but QOL with PedsQL collected	2	moderate limitations	⊕ ⊕ ⊕	moderate		**3**	new finding
Changes in fitness are associated with changes in body composition and bone health in children after cancer	Heterogeneous and very small sample	3	major limitations	⊕ ⊕	moderate		**3**	
Effects of a combined physical and psychosocial intervention program for childhood cancer patients on quality of life and psychosocial functioning: results of the QLIM randomized clinical trial	authors state: In the control group, patients could choose whatever support they needed and, because participation in the study, may have had heightened interest in the topic possibly leading to a higher consumption of support from physical therapists and/or psychologists themselves	2	moderate limitations	⊕ ⊕ ⊕	high		**3**	new finding
A Fitbit and Facebook mHealth intervention for promoting physical activity among adolescent and young adult childhood cancer survivors: A pilot study		2	moderate limitations	⊕ ⊕ ⊕	moderate	Pilot study, new media + physical activity: no difference between intervention and control group found	**2**	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Impact of the initial fitness level on the effects of a structured exercise therapy during pediatric stem cell transplantation	2018	Wallek, S.	Randomized controlled trial	2	RCT: intervention group (IG fit and IG unfit) vs. control group (CG fit and CG unfit)	N= 53, Age: M= 10,9 years; SD= 3,5 years; range= 5-17 years Gender: 35 males; 18 females Diagnosis: 30 (57%) leukemia; 5 (9%) MDS; 8 (15%) solid tumor; 5 (9%) malignant lymphoma; 2 (4%) congenital diseases; 2 (4%) fanconi anemia; 1 (2%) others Prior HSCT: 5 yes; 48 no IG unfit: n= 14; IG fit n= 12; CG unfit n= 16; CG fit n= 11
6	The effect of an aerobic exercise program on the quality of life in children with cancer	2017	Khodashenas, E.	Randomized controlled trial	2	IG (standard treatment and intervention: go, run and various games) and CG (standard treatment), pre and post examination 3 units (60 min) per week over 12 weeks	N = 20, 10 in IG; Diagnosis: ALL; Age: M = 8.8 years (CG), M = 10.1 years (IG), 5-12 years, Sex: 8 girls
	...Effect of wish granting						
6	Positive interventions in seriously-ill children: Effects on well-being after granting a wish	2016	Chaves, C.	Randomized controlled trial	2	wish group, waiting list control group	N=78 children; wish group (WG) n=41, wait list control group (CG) n=37 ; Fathers n=38, mothers n=86; mean age: WG: M=11.49(SD=3.25), CG: M=11.89(SD=3.56); diagnoses: WG: Cancer=33%, transplants=6.4%, other diseases=12.8%; CG: Cancer=32% , transplants=9%, other diseases=6.4%; sex: WG: male=58.5%, CG=56.7%; lost to follow-up due to child's health condition: 3 children, 2 fathers, 3 mothers

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Impact of the initial fitness level on the effects of a structured exercise therapy during pediatric stem cell transplantation	Intergroup comparison revealed significant differences between IG unfit and CG unfit. Between baseline and discharge there were no significant changes in 6MWD (6-min walking distance) in the IG unfit (+7,7% [range: -66,1 to +25,7]) and the IG fit (+0,7% [range: -33,3 to +15,2]). In contrast he 6MWD declined significantly in both subgroups of the CG (CG unfit: -14%; CG fit: -16%). At discharge, the IG fit achieved 85,5 % (SD= 10,3%) of healthy reference values.														
The effect of an aerobic exercise program on the quality of life in children with cancer	The results show a significant association in the pain and injury subscale (p=0.002), improving in interventional groups after test compared to the control groups. The reports of parents of the children's quality of life showed significant association in the pain and injury subscale (P=0.002), and cognitive problems subscale at school (P=0.039). The regular exercise and psychosocial program intervention can improve wellbeing and thereby enhance efficacy of the children during treatment. (Intervention: Each patient received three exercise sessions per week during 12 weeks, each of which took 60 minutes, by lower intensity with 60 to 85% of maximum heart rate.)	1	1							1					
…Effect of wish granting															
Positive interventions in seriously-ill children: Effects on well-being after granting a wish	Wish intervention **significantly increased levels of positive emotions, satisfaction with life, personal strengths (gratitude and love), and reduced rates of nausea** compared with the control group. **Mothers in the wish group also perceived positive changes in children's benefit finding and quality of life** (fathers: no significant percieved changes)	1	1	1						1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Impact of the initial fitness level on the effects of a structured exercise therapy during pediatric stem cell transplantation	The cardiorespiratory fitness was not evaluate with a maximal exercise test. Two aerobic intervention was necessary to obtain a higher recruitment, this is why autologous patients, who received a less intensive and shorter therapy, were also included.	**2**	moderate limitations	⊕ ⊕ ⊕	high		**3**	new evidence/citation
The effect of an aerobic exercise program on the quality of life in children with cancer	small sample of children in various stages of disease; sample scarcely described	2	major limitations	⊕ ⊕	moderate		**2**	
...Effect of wish granting								
Positive interventions in seriously-ill children: Effects on well-being after granting a wish	heterogeneous samples for diagnoses; partly unstandardized questionnaires; intervention not described Effect sizes of the intervention are relatively small	2	moderate limitations	⊕ ⊕ ⊕	high		**3**	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomised controlled trial	2016	Shoshani, A.	Randomized controlled trial	2	randomly assigned (block randomization) to the Make a Wish intervention (n = 32) or a wait-list control group (n = 34) after baseline data collection, children were interviewed and made an authentic wish that they wanted to come true; wishes were made possible 5–6 months after baseline (to fuel anticipation and excitement over the wishfulfillment event); post-intervention assessment 5 weeks after wish fulfillment (approx. 7 months after baseline) stratified by diagnosis and gender	N=66 (IG=32; CG=34) age: IG: M=10.13(SD=3.51); CG: M=10.67(SD=4.71) - range: 5-12 years sex: IG: boys=20(62.5%), CG: boys=19(55.9%) diagnosis: IG: Leukemia=9(28%), Hodgkin's lymphoma=4(13%), Ewing's sarcoma=5(15%), Medulloblastoma=4(13%), other solid tumor (e.g. nervous system tumors, retinoblastoma, nephroblastoma)=10(31%); CG: Leukemia=10(29%), Hodgkin's lymphoma=6(18%), Ewing's sarcoma=4(12%), Medulloblastoma=3(9%), other solid tumor (e.g. nervous system tumors, retinoblastoma, nephroblastoma)=11(32%) IG: originally 37 patients - 5 dropped out, analyses based on 32; CG: originally 37 patients - 3 dropped out, analyses based on 34
	...Psychosocial interventions siblings						
6	A randomized controlled trial of a group intervention for siblings of children with cancer: Changes in symptoms of anxiety in siblings and caregivers	2018	Barrera, M.	Randomized controlled trial	2	siblings were assigned to 1 of 2 groups, stratifying by site, balanced by age and gender, and based on families' availability. After enough participants (>3 per group) were enrolled, blocked randomization of the groups to SibCT or CG was conducted centrally by 3 researchers, who were blind to the participant's identity.	N = 75 (siblings), SibCT = 41; CG = 34 (7-16 Years) Mean age: SibCT M=11.05(SD=2.50), CG M=11.40(SD=2.90); Diagnoses of patient sibling: SibCT: Leukemia/Lymphoma=12, Brain Tumour=16, Other (solid Tumour)=13 ; CG: Leukemia/Lymphoma=15, Brain Tumour=10, Other (solid Tumour)=9; Geschlecht: SibCT: female=21 (51.2%) ; CG: female=13 (38.2%)

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomised controlled trial	Children in the intervention group exhibited a significant reduction in general distress (d = 0.54), depression (d = 0.70), and anxiety symptoms (d = 0.41), improved health-related quality of life (d = 0.59), hope (d = 0.71), and positive affect (d = 0.80) compared to decrease in positive affect and no significant changes in their levels of hope, health-related quality of life, or psychological symptomatolog in the control group. There were no statistically significant differences in panic or somatization over time for either of the groups and no significant differences between the intervention and control groups for negative emotions or levels of optimism over time.									1					
…Psychosocial interventions siblings															
A randomized controlled trial of a group intervention for siblings of children with cancer: Changes in symptoms of anxiety in siblings and caregivers	No main effects of group or time were found in sibling scores. A group × gender interaction (P < .05) indicated that in the intervention group female siblings reported less total anxiety symptoms than male siblings, with no significant gender differences in the control group. **Caregivers' total anxiety symptoms declined over time (P < .02).** A group × on/off treatment interaction in physiological/panic subscale (P < .03) indicated that when ill child was on treatment, **caregivers of siblings in SibCT reported less anxiety compared with caregivers of CG.**														

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomised controlled trial	no information on what kind of wishes were fulfilled	2	moderate limitations	⊕⊕⊕	high		**4**	new finding
...Psychosocial interventions siblings								
A randomized controlled trial of a group intervention for siblings of children with cancer: Changes in symptoms of anxiety in siblings and caregivers		2	no limitations	⊕⊕⊕	high		**4**	new evidence/citation

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Outcomes of an enhancement study with additional psychoeducational sessions for healthy siblings of a child with cancer during inpatient family-oriented rehabilitation	2018	Niemitz, M.	Non-Randomized controlled trial	3		healthy sibling of a child or adolescent with any oncological disease participating in the FOR program (Germany): CG: N=111, mean age 8.85 SD 3.27 (4-17), 47.7% female, participating caregivers 50.5% mother; IG: N=73: mean age 9.55 SD 3.14 (4-18), 47.9% female, 49.3% mothers; parents: most >10 years school, fathers: most full time employment, mothers: most not employed/part time
6	Feasibility of Group Intervention for Bereaved Siblings after Pediatric Cancer Death	2016	Greenwald, N.	Non-Randomized controlled trial	3		10 siblings (after pediatric cancer death), Siblings' mean age at enrolment= 11.30 years (SD = 2.39). Siblings ranged in age from 12 to 15 years in one group and from 6 and 14 years in another. Half of siblings had two or more brothers or sisters before the death occurred. Time since the death ranged from 6 to 30 months.

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Outcomes of an enhancement study with additional psychoeducational sessions for healthy siblings of a child with cancer during inpatient family-oriented rehabilitation	The outcomes of n = 73 healthy children who participated in 5 additional psychoeducational sessions, were compared with the outcomes of n = 111 healthy children, who underwent the usual inpatient rehabilitation program. Intention-to-treat analyses showed that **both groups improved significantly from preintervention to postintervention.** Improvements comprised knowledge about cancer (F(1,174) = 11.03, p < 0.001), self-reported emotional symptoms (F(1,135) = 31.68, p < 0.001), and parent-proxy-reported emotional symptoms (F(1,179) = 37.07, p < 0.001). The additional psycho- educational program **did not significantly enhance the outcomes.**Inpatient family-oriented rehabilitation is effective in improving multiple psychosocial outcomes of healthy children in families which have a child with cancer. Additional psycho-educational sessions did not show any substantial additional improvement.														
Feasibility of Group Intervention for Bereaved Siblings after Pediatric Cancer Death	Intervention consisted of eight 2-hour sessions that focused on strategies for coping with grief, relationships, and emotional growth. Positive outcomes were obtained **with respect to acceptability, recruitment, retention rates, and treatment fidelity. Parent pre- and post-intervention outcomes suggested improvements i**n siblings' overall, emotional and social quality of life. Siblings' self-reports reflected no improvements.	1		1											

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Outcomes of an enhancement study with additional psychoeducational sessions for healthy siblings of a child with cancer during inpatient family-oriented rehabilitation		3	moderate limitations	⊕ ⊕	high		**3**	new finding
Feasibility of Group Intervention for Bereaved Siblings after Pediatric Cancer Death		3	moderate limitations	⊕ ⊕	high		**3**	new evidence/citation

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	...Psychosocial interventions parents						
	internet-based, e-mental health						
6	Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade"	2016	Wakefield, C. E.	Randomized controlled trial	2	parents randomized to CASCADE (Cope, Adapt, Survive: Life after Cancer; 3 weekly 129 min **online sessions)** or wait list control; assessment: baseline, 2 weeks and 6 monts after CASCADE (Control group had another assessment following their participation in CASCADE) child had completed cancer treatment within the last 5 years	N= IG: n=23, CG: n=22 age of parents: IG: M=42 (SD=5.76, range: 25-50), CG: M=42.77 (SD=5.21, range: 33-55); sex of parents: IG: female=21 (91.3%), CG: female=18 (81.8%); age of children: IG: M=8.48 (SD=3.83, range: 2-16), CG: M=8.18 (SD=3.84, range: 3-15); sex of cgildren: IG: female=13 (56.5%), CG: female=7 (31.8%); child diagnosis: IG: CNS tumor: 9 (47.4%), Leukemia: 5 (26.3%), Lymphoma: 2 (10.5%), Sarcoma: 2 (10.5%), Wilms tumor: 1 (5.3%); CG: CNS tumor: 4 (21.1%), Leukemia: 7 (36.8%), Lymphoma: 5 (26.3%), Sarcoma: 0, Wilms tumor: 3 (15.8%)
6	FAMily-Oriented Support (FAMOS): development and feasibility of a psychosocial intervention for families of childhood cancer survivors	2017	Salem, H.	Randomized controlled trial	2	Evaluation of feasibility of intervention; + RCT for comparing the intervention with usual care; 4 pediatric oncology departments in Denmark (cover all cases of pediatric cancer) = part of an ongoing nationwide RCT; stratified by cancer type and pediatric oncology department	N=68 families: 68 mothers, 60 fathers, 68 children with cancer and 73 siblings); cancer diagnosis: ALL=30(45%), AML=3(4%), non-Hodgkin lymphoma=3(4%), brain tumor=8(12%), other solid tumor=24(35%); gender of cancer survivor: female=39(57%); age of cancer survivor: 0-5: M=3.85, 6-12=56(82%),13-18=12(18%)

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
…Psychosocial interventions parents															
internet-based, e-mental health															
Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade"	The response rate was 54 %. **96% of parents allocated to Cascade (n = 24/25) remained engaged i**n the intervention, and 80 % completed every questionnaire (representing an attrition rate of 20 %). There was no significant main effect of group (waitlist vs. intervention) or time (baseline vs. post-intervention vs. followup) on quality of life, psychological functioning, and family functioning. There was a significant main effect of **time on the fear of cancer recurrence, such that the fear of cancer recurrence was significantly lower at T2 and T3 for both groups.** **–> Cascade appears to be feasible and highly acceptable, and its efficacy is worthy of further evaluation** –> including additional sessions can increase intervention efficacy; therfore Cascade was modified by adding a fourth group session, and a one-on-one booster														
FAMily-Oriented Support (FAMOS): development and feasibility of a psychosocial intervention for families of childhood cancer survivors	IG: FAMOS: based on principles of family systems therapy and cognitive behavioral therapy, six sessions at home shortly after the end of intensive treatment); CG: usual care; participation rate of 62% of families. Fathers were highly represented (88% of families); also families with single parents (12%) and parents with basic education (7–12 years of primary, secondary, and grammar school education) were represented (12%). The dropout rate was 12% of families (all in the control group), and two families did not complete the intervention because of relapse. Evaluation by parents in the intervention group **showed overall satisfaction with the format, timing, and content of the intervention.** **–> The results indicate that the FAMOS intervention is feasible in terms of recruitment, retention, and acceptability.** The effects of the intervention on post-traumatic stress, depression, anxiety, family functioning, and quality of life will be reported after the nationwide RCT has been completed.	1													

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
…Psychosocial interventions parents								
internet-based, e-mental health								
Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade"		2	no limitations	⊕ ⊕ ⊕	moderate	no intervention effect (yet), but good acceptability	**2**	
FAMily-Oriented Support (FAMOS): development and feasibility of a psychosocial intervention for families of childhood cancer survivors		2	moderate limitations	⊕ ⊕ ⊕	high	no statement on effectiveness possible, but now only on good results feasibility	**3**	new evidence/citation

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Twelve-Month Follow-Up of a Randomized Controlled Trial of Internet-Based Guided Self-Help for Parents of Children on Cancer Treatment	2017	Cernvall, M.	Randomized controlled trial	2	Intervention group and wait-list control, preassessment-postasessment, 12-month follow-up	N=58 parents of 46 children, Intervention group (n=31), wait list (n=27), 18 completed the intervention; edescription of sample see Cernvall (2015)
6	Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial	2015	Cernvall, M.	Randomized controlled trial	2	Intervantion group and wait-list control, preassessment-postasessment	N=58 parents of 46 children, Intervention group (n=31), wait list (n=27), 18 completed the intervention Age parents: Intervention: M=40(SD=7.4), wait list: M=36(SD=6.6); diagnosis of child: Intervention: Leukemia=13(52%), Sarcoma=5(20%), Lymphoma=3(12%), CNS=2(8%), other=2(8%); Wait list: Leukemia=11(52%), Sarcoma=3(14%), Lymphoma=0, CNS=5(24%), other=2(10%) Sex of parents: Intervention: mothers=21(68%), wait list: mothers=18(67%); sex of children: intervention: girl=16(64%), wait list: girl=9(43%); paticipants recruited from 5 of 6 pediatric oncology centers

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Twelve-Month Follow-Up of a Randomized Controlled Trial of Internet-Based Guided Self-Help for Parents of Children on Cancer Treatment	10-week guided self-helf program via the internet bases on principles from cognitive behavior therapy--> Intention-to-treat analyses revealed significant effects **in favor of the intervention on the primary outcome PTSS, w**ith large between-group effect sizes at postassessment (d=0.89; 95% CI 0.35-1.43) and at 12-month follow-up (d=0.78; 95% CI 0.25-1.32). The intervention group exhibited a significant decline that abated over time. The control group showed no change. **Significant effects in favor of the intervention on the secondary outcomes depression and anxiety were also observed**. However, there was no evidence for intervention efficacy on health care consumption or sick leave.									1					
Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial	Intervention: 10-week guided self-helf program via the internet bases on principles from cognitive behavior therapy --> As the attrition rate was high, it might be the case that the intervention with its current content and format was **too demanding or not suitable for many participants.** However, the ITT analyses suggested that the intervention was effective: Intention-to-treat analyses indicated **a significant effect of the intervention on PTSS** with a large between-group effect size at postassessment (Cohen's d= 0.88). The intervention group reported **reductions in PTSS** with a large within-group effect size (d= 1.62) compared with a minimal reduction in the wait-list group (d= 0.09). There was a significant **intervention effect on depression and anxiety** and reductions in the intervention group with large within-group effect sizes (d= 0.85–1.09).									1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Twelve-Month Follow-Up of a Randomized Controlled Trial of Internet-Based Guided Self-Help for Parents of Children on Cancer Treatment	poor enrollment-rate (26% of the approached parents); 58% completion rate: 14 participants in the intervention group (45%) and 7 in the wait list group (26%) did not provide postassessments - 6 did not start the intervention, 7 discontinued before completion; lost to follow-up: intervention (n=1), wait list (n=4)	2	moderate limitations	⊕⊕⊕	high	large effects of intervention remain in 12-months follow-up	**4**	new finding
Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial	poor enrollment-rate (26% of the approached parents); 58% completion rate: 14 participants in the intervention group (45%) and 7 in the wait list group (26%) did not provide postassessments - 6 did not start the intervention, 7 discontinued before completion; unclear, if results persist over time	2	moderate limitations	⊕⊕⊕	high	large effects of intervention	**4**	new finding

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	group intervention						
6	The effectiveness of positive psychology intervention on the well-being, meaning, and life satisfaction of mothers of children with cancer: A brief report	2018	Damreihani, N.	Randomized controlled trial	2	Mothers of children with cancer (leukemia) in an outpatient cancer clinic (convenience sample) were randomly assigned to a trial group and control group. group intervention	N = 50 Age of the mothers: IG: 20-30 = 17%, 30-40 = 66%, 40 and higher = 17%; CG: 20-30 = 14%, 30-40 = 63%, 40 and higher = 23%
6	Addressing behavioral impacts of childhood leukemia: A feasibility pilot randomized controlled trial of a group videoconferencing parenting intervention	2016	Williams, L. K.	Randomized controlled trial	2	pilot study, randomized to IG (Triple P: Positive Parenting Program) or CG (no intervention, wait list); measurements at baseline (2 weeks pre intervention), time 2 (2 weeks post intervention), time 3 (8 weeks post intervention); mixed methods design	N=12 parents with a child aged between 2 and 8 years (IG: n=6, CG: n=6); child age: IG: M=5.62 (SD=1.34; range= 3.47-7.68), CG: M=5.49 (SD=1.76; range= 2.63-8.02); child diagnosis: ALL (maintenence phase treatment); sex: IG: male=5 (83.3%), CG: male=5 (83.3%) parent age: IG: M=36.62 (SD=1.61; range=34.31-39.09), CG: M=33.37 (SD=6.14; range=23.94-38.94); sex: IG: female=6 (100%), CG=6 (100%)
6	Effect of Instructing Care Program Through Group Discussion on the Quality of Life of the Parents of the Children Afflicted With Leukemia	2015	Asadi Noughabi, F.	Non-Randomized controlled trial	3		41 parents of children with leukemia: IG: 21, average age 33.8; CG: 20, average age 35.5; 73.2 % of the participants were mothers of children afflicted with leukemia. Mean time since onset: 2.7 years.

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
group intervention															
The effectiveness of positive psychology intervention on the well-being, meaning, and life satisfaction of mothers of children with cancer: A brief report	In all the dimensions recorded (mental well-being, life satisfaction, meaning of life and hope), only in the IG the mean values increased significantly (both at the time of the intervention and the follow-up compared to the pre-test). The posttest values in theIG were significantly higher than those of theCG in all measured dimensions.									1					
Addressing behavioral impacts of childhood leukemia: A feasibility pilot randomized controlled trial of a group videoconferencing parenting intervention	Preliminary **support for the feasibility** (but study completion by eligible parents was low, 31.6%), acceptability and satisfaction of a parenting intervention. Parents reported mixed preferences with regards to mode of delivery (online). A potential solution would be to provide 'mixed-modal' intervention delivery (online and face-to-face). Results indicate high program satisfaction amongst intervention group participants but could be strengthened by a reduction in the psycho-education component, as well as including both parents in sessions where possible and amending the program to be more cancer-specific. Quantitative results: a trend for improvements in child emotional and peer problems for both groups (IG: trend towards reduction in child conduct problems; CG: trend towards reduction in child hyperactivity). No significant differences in total child emotional and behavioral difficulties between intervention and control group.	1													
Effect of Instructing Care Program Through Group Discussion on the Quality of Life of the Parents of the Children Afflicted With Leukemia	Comparison of the parents' quality of life mean scores, obtained before and two months after training (Intervention-Group: instructional sessions), showed that promotion in 6 domains of bodily pain, general health, emotional health, role limitation due to emotional problems, social functioning, and vitality were occurred. (P <0.05)	1		1											

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
group intervention								
The effectiveness of positive psychology intervention on the well-being, meaning, and life satisfaction of mothers of children with cancer: A brief report	Except for diagnosis (leukemia) no information about the patients; did not describe what the control group had received; did not describe how the randomized allocation took place; no effect sizes calculated.	2	moderate limitations	⊕ ⊕ ⊕	high		3	new finding
Addressing behavioral impacts of childhood leukemia: A feasibility pilot randomized controlled trial of a group videoconferencing parenting intervention	small sample, only mothers included	2	moderate limitations	⊕ ⊕ ⊕	moderate		2	
Effect of Instructing Care Program Through Group Discussion on the Quality of Life of the Parents of the Children Afflicted With Leukemia	Age of children?	3	moderate limitations	⊕ ⊕	high		3	new evidence/citation

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	individual intervention						
6	The effectiveness of solution-focused brief therapy for psychological distress among Chinese parents of children with a cancer diagnosis: a pilot randomized controlled trial	2018	Zhang, A.	Randomized controlled trial	2	pilot study; pretest-posttest randomized controlled trial (baseline, immediately after completion and 2 weeks after completion) parents had to meet the screening/baseline score of Brief Symptom Inventory of the gender-specific cut-off score for distress Intervention (4 individual sessions over a 2-week period) or active control (matched the intervention regarding number and intensity of the sessions and counceling from CBT or client-centered perspectives)	N=44 parents (IG: 22, CG=22) 4 dropped out of IG, 3 dropped out of CG (missing 1 or more sessions respectively) age of parents: M=31.57(SD=5.52) range:24-46 years sex of parents: n=27 (61%) female age of children: M=6.13(SD=6.75) sex of children: n=25 (56.8%) girls Diagnosis: Leukemia: n=18 (40.9%), Lymphoma: n=15 (34.1%), other (bone cancer, brain tumour, hepatoblastoma, neuroblastoma, sarcoma, rhabdoid tumour): n=11(25.0%)
6	Effectiveness of a Brief Psychosocial Intervention on Quality of Life of Primary Caregivers of Iranian Children With Cancer: A Randomized Controlled Trial	2016	Safarabadi-Farahani, A.	Randomized controlled trial	2	rendomization to IG (BPI + usuals service) or CG (usual service) pre-, post and follow-up (30 days after intervention) measurements	N=65 (62 completed entire intervention, 3 parents withdrew after childs death) child age: IG: M=6.42(SD=3.88); CG: M=5.65(SD=4.25) caregivers age: IG: M=33.45(SD=5.41), CG: M=34.00(SD=7.13) caregivers education years: IG: M=11.29(SD=3.35); CG: M=11.54(SD=3.54) caregivers gender: IG: mothers=30(96.77%); CG: mothers=29(93.54%) diagnosis: IG: brain=15 (48.4%), Blood=9 (29%), other=7(22,6%); CG: brain=16(51.06%), blood=8(25.8%), other=7(22.6%)
6	Effects of a brief problem-solving intervention for parents of children with cancer.	2018	Lamanna, J.	Randomized controlled trial	2	Children at least 4 weeks after cancer diagnosis (and have completed a maximum of 75% of the expected treatment protocol); random assignment to IG/CG 2 sessions of intervention (individual intervention); Distance between sessions 2-4 weeks; baseline assessment + follow-up assessments 1 month and 3 months after the intervention	N = 39 parents (IG = 21, GG = 18) Age of the parents: M = 36.5; Age of the children: M = 7.7, SD = 4.9 (range: 2-16 years); Diagnoses: ALL (61.5%), lymphoma (5.1%), neuroblastoma (7.7%), sarcoma (7.7), CNS (7.7), rhabdomyosarcoma (10.3%)

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
individual intervention															
The effectiveness of solution-focused brief therapy for psychological distress among Chinese parents of children with a cancer diagnosis: a pilot randomized controlled trial	Parents receiving SFBT reported a significantly greater reduction in their overall psychological distress compared to parents receiving AC. In addition, parents in the SFBT group reported significantly greater reduction in sub-scores of somatization, depression, and anxiety. Similarly, parents receiving SFBT indicated significantly greater improvement in levels of hope compared to those in the AC group. SFBT showed moderate to large within-group treatment effect sizes. Large between-group treatment effect size for Chinese parents' overall psychological distress, indicating clinically meaningful effects of SFBT for Chinese parents' distress. –> feasible and promising intervention for alleviating psychological distress	1								1					
Effectiveness of a Brief Psychosocial Intervention on Quality of Life of Primary Caregivers of Iranian Children With Cancer: A Randomized Controlled Trial	Intervention: 5 week (once/week) brief psychosocial intervention (BPI; individual counseling sessions conducted by a trained social worker [adressed individual psychosocial concerns, opportunity to aks questions, discuss their concerns, encourage positive coping strategies, homework assignments] and telephone follow-up once a week) –> No differences between IG and CG on study variables at baseline. **The mean score of QOL of the IG was significantly higher than the mean score of QOL in the CG over time.** The mean scores for mental/emotional burden, lifestyle disruption, and positive adaptation of the IG were significantly higher than scores in the CG over time. The results did not show any statistically significant difference in the subscale for financial concerns score between two groups. **–> feasable and "effective" to improve QOL**									1					
Effects of a brief problem-solving intervention for parents of children with cancer.	CG: same amount of time as IG with person who carried out intervention - general support, useful information was given. –> duration of session 1 was sign. higher for IG -> neither the intervention nor the past time had a significant effect on PTSS, caregiving stress and problem-solving ability (all effect sizes were small) -> Parents enjoyed the participation and felt comfortable with the therapist -> Low participation rate (48%) - possible that more burdened parents did not attend -> 2 sessions may be too short -> Future studies should find out how many sessions are good as well as balancing the goals of effectiveness and knowledge transfer	1	1							1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
individual intervention								
The effectiveness of solution-focused brief therapy for psychological distress among Chinese parents of children with a cancer diagnosis: a pilot randomized controlled trial	high refusal rate (46.3%) --> proceeded as pilot study (orgiginally planned to recruit a larger sample) children had brief hospital stays --> follow-up contacts to assess maintanance were not feasable)	2	moderate limitations	⊕ ⊕ ⊕	high	medium to large effects of the intervention	3	new finding
Effectiveness of a Brief Psychosocial Intervention on Quality of Life of Primary Caregivers of Iranian Children With Cancer: A Randomized Controlled Trial	no effect sizes, lack of assessment of confounders	2	moderate limitations	⊕ ⊕ ⊕	high		4	new evidence/citation
Effects of a brief problem-solving intervention for parents of children with cancer.	small sample, heterogeneous diagnoses, low participation	2	moderate limitations	⊕ ⊕ ⊕	moderate	no effect of intervention	2	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Effectiveness of a relaxation intervention (progressive muscle relaxation and guided imagery techniques) to reduce anxiety and improve mood of parents of hospitalized children with malignancies: A randomized controlled trial in Republic of Cyprus and Greece	2017	Tsitsi, T.	Randomized controlled trial	2	non-blinded; two public hospitals; parents were randomly assigned to IG (PMR and GI) or CG (standard psychological support); pre- and post measurements; physiological measurements (blood pressure, heart rate and skin temperature; 5 min prior to intervention, immediatly after it and 5 min later) and self-administered questionnaires	N=54 completed all assessments (IG=29; CG=25) [62 were eligible] age: mothers: IG: mothers: M=39.79 (SD=5.93), fathers: M=37.72 (SD=6.94); CG: mothers: M=40.92 (SD=5.9), fathers: M=43.92 (SD=6.42); diagnosis of child: ALL=23 (43.4%), AML=4 (7.5%), Lymphoma=14(26.4%), Nephroblastoma=1(1.9%), Sarcoma=5(9,4%), Brain tumor=2 (3.8%), Ectodermal tumor=1 (1.9%), other=3 (5.7%), missing=1
6	Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of Caregivers	2016	Borjalilu, S.	Non-Randomized controlled trial	3		42 mothersof children with cancer residing in Tehran province, aged 21 to 52 years old (M=34.1), age of the child (7 - 15 years), 21 in CG (M=31.9 years), 21 in IG (M=36.8 years, group training sessions)
6	The Effect of Spiritual Care on Mental Health in Mothers of Children With Cancer	2016	Nikseresht, F.	Non-Randomized controlled trial	3	one group pretest posttest design (without control group)	N=25 mothers of children with cancer (44% female; Mean age of children 44% 5-10, 66% 11-15; Mothers: 16% 20-30, 64% 31-30, 20% 41-50; 48% below high school diploma, 32% high school diploma, 20% university degree); 48% Leukemia, 16% Osteosarcome, 16% Lymphoma, ...), Religion: 80% Shiite, 20% Sunni

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Effectiveness of a relaxation intervention (progressive muscle relaxation and guided imagery techniques) to reduce anxiety and improve mood of parents of hospitalized children with malignancies: A randomized controlled trial in Republic of Cyprus and Greece	Intervention: 3 weeks (aid of CD), individualized sessions once a weeks for 25 min; additionally each participant applied the relaxation techniques at least once a day (CD was given to the parents to continue applying the relaxation techniques at the hospital or at home) -> A statistically significant difference was observed **in depression dejection** (p=0.071) and in tension (p=0.027) in T0 and T1 intervention measurements in the **intervention group a**nd a statistically **significant difference was observed in fatigue** (p=0.014) in the control group. Additionally, the effect size for depression (0.24), fatigue (0.22) and tension (0.28) in the intervention group was relatively small and fatigue (0.50) in the control group was significant. For a further exploration of the differences in both measurements of the six mood factors of the POMS brief questionnaire, each item of the subscales was analyzed separately. Thus, parents in the **intervention group reported significantly less sadness** (p=0.001), **less weariness (p=0.026), less forgetfulness (p=0.050), less tension (p=0.001) and less anxiety (p=0.031**) at the postintervention measurements. Parents in the control group significantly reported that they were less exhausted (p=0.018), forgetful (p=0.010) and felt less reduction in fatigue (p=0.002) at the postintervention measurements.	1				1			1	1					
Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of Caregivers	There was significant difference between anxiety and spiritual, religious, personalized care and total scores spiritual care between the intervention and control groups at follow-up (P<0.001).There was no statistically significant difference in stress and depression scores between the intervention and the control groups at follow-up. Findings show that spiritual care training program promotes spirituality, personalized care, religiosity and spiritual care as well as decreasing anxiety in mothers of children with cancer and decreases anxiety.	1													
The Effect of Spiritual Care on Mental Health in Mothers of Children With Cancer	The findings show that implementation of spiritual care in mothers of children with cancer can improve their mental health.														

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Effectiveness of a relaxation intervention (progressive muscle relaxation and guided imagery techniques) to reduce anxiety and improve mood of parents of hospitalized children with malignancies: A randomized controlled trial in Republic of Cyprus and Greece	small sample; no information regarding the number of mothers and fathers per group; diagnosis of child not stated separated for IG and CG; no differences between IG and CG calculated; results reported in Abstract couldn't be found in results or tabels	2	major limitations	⊕ ⊕	moderate		**2**	
Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of Caregivers	no information on what type of cancer child suffers from	3	moderate limitations	⊕ ⊕	moderate		**3**	new evidence/citation
The Effect of Spiritual Care on Mental Health in Mothers of Children With Cancer	sample small and was chosen purposefully, no control group; one center in Iran -> reduced generalizability	3	major limitations	⊕ ⊕	moderate		**2**	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	PSYCHOSOCIAL INTERVENTIONS TO REDUCE PROCEDURAL ANXIETY/PAIN						
6	Effectiveness of non pharmacological interventions to reduce procedural anxiety in children and adolescents undergoing treatment for cancer: A systematic review and meta-analysis	2018	Nunns, M.	Systematic review or meta-analysis of controlled study	1	no restrictions on date; only RCTs that involved children and young people (0-25 years) and a non pharmacological intervention; quality appraisal using criteria adapted from Cochrane risk of bias tool	--> 4 studies with control group were included in quantitative analyses
6	Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial	2018	Jibb, L. A.	Randomized controlled trial	2	Pilot study	Overall: n= 40: Intervention Group: n=19, mean age=6.3, 7 female, 12 male, 17 leukemia, 1 lymphoma, 1 other, Time since diagnosis mean 1.1 years; Control Group: n = 21, mean age=6.1, 9 female, 12 male, 17 leukemia, 1 lymphoma, 1 brain tumor, 2 other, Time since diagnosis mean 1.2 years;

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
PSYCHOSOCIAL INTERVENTIONS TO REDUCE PROCEDURAL ANXIETY/PAIN															
Effectiveness of non pharmacological interventions to reduce procedural anxiety in children and adolescents undergoing treatment for cancer: A systematic review and meta-analysis	**Hypnosis and Anxiety**: Hypnosis yielded a significant, large pooled effect size indicating a reduction when compared with Treatment as usual (TAU, d=2.30) and attention controls (d=2.06). Active controls: significant and large pooled effect size indicating a reduction in anxiety (d=0.81) was found. However, the width of the confidence intervals reflects uncertainty about the true magnitude of this effect. **Hypnosis and Pain**: significant and large reduction in pain when compared with TAU (d=2.16) and attention controls (d=2.24). Active controls: lack of evidence for the effect of hypnosis over active controls (d=0.41). **Nonhypnosis**: Only two studies reported data on anxiety outcomes that were suitable for meta-analysis: When compared with TAU, there was a lack of evidence for the effect of nonhypnosis interventions on either anxiety or pain. –> Non-hypnosis interventions provided more equivocal results. Single studies: listening to music (reduction: pain and anxiety), an interactive device (reduction: anxiety) virtual reality or non-virtual reality distraction (reduction: pain) and CBT (reduction: pain and anxiety) –>Evidence suggests promise for hypnosis interventions to reduce procedural anxiety in CYP undergoing cancer treatment.														
Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial	The interactive MEDiPORT robot has been programmed to implement psychological strategies to decrease pain and distress during subcutaneous port needle insertions. Overall, MEDiPORT and the study were acceptable to participants. There was no difference in pain between arms, but distress during the procedure was less pronounced in the active distraction arm.			1											

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
PSYCHOSOCIAL INTERVENTIONS TO REDUCE PROCEDURAL ANXIETY/PAIN								
Effectiveness of non pharmacological interventions to reduce procedural anxiety in children and adolescents undergoing treatment for cancer: A systematic review and meta-analysis	Results largely emerge from one research group, therefore wider research is required. Promising evidence for individual non-hypnosis interventions must be evaluated through rigorously conducted RCTs.	1	no limitations	⊕⊕⊕⊕	high		**4**	new evidence/citation
Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial		2	no limitations	⊕⊕⊕	low	robot not finished	**1**	

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Children's experiences and responses towards an intervention for psychological preparation for radiotherapy.	2018	Engvall, G.	Non-Randomized controlled trial	3	Baseline Group (9/2012 - 1/2014) vs. Intervention Group (2/2104-6/2015) -> Qualitative content analysis of semi-structured interviews + statistical analysis of anxiety ratings; Ratings at 4 times (T1 = study start and decision for RT, T2 = fixation and CT, T3 = start of RT, T4 = end of RT)	N = 57 (baseline: n = 30, intervention: n = 27) Age at the time of examination: Baseline: M = 9 (SD = 4.5); Intervention: M = 10 (SD = 5.1); Diagnoses: baseline: ALL = 1, CNS tumors = 14, sarcom = 6, neuroblastoma = 5, Hodgkin = 3, Wilm's tumor = 1; Intervention: ALL = 0, CNS tumor = 13, sarcom = 6, neuroblastoma = 4, Hodgkin = 1, Wilm's tumor = 3; Gender: baseline girl = 15; Intervention girl = 13
6	Parents' Verbal and Nonverbal Caring Behaviors and Child Distress During Cancer-Related Port Access Procedures: A Time-Window Sequential Analysis	2017	Bai, J.	Non-Randomized controlled trial	3	Very large-scale study design, multi-centered, integrates several issues simultaneously.	N=104 video-recorded port accessing procedures were subjected to this analysis (a) the child's age was 3–12 years, (b) the child had been diagnosed with cancer at least 1 month but no more than 18 months before study entry and was undergoing regular port accessing, and (c) the parent and child were able to speak English and the parent read English.
6	Age-appropriate preparations for children with cancer undergoing radiotherapy: A feasibility study	2017	Gardling, J.	Non-Randomized controlled trial	3	historical control group: 16 children in CG (May 2012-Apri l2014), 17 children in intervention group (May 2014-April 2016)	N = 33 (17 = IG, 16 = CG) Age: CG: median = 7 (range: 3-16); IG: median = 6 (range: 3-17) Gender: CG: boys = 6; IG: boys = 10 Diagnoses: CG: brain tumor = 9, solid tumor / leukemia = 7; IG: brain tumor = 6, solid tumor / leukemia = 11
6	Effects of massage therapy on pain and anxiety arising from intrathecal therapy or bone marrow aspiration in children with cancer	2015	Celebioglu, A.	Non-Randomized controlled trial	3	pre- und posttest	IG: N = 12 (41.7% female); CG: 13 (38.5% female) Age 0-15; Diagnosis = leukemia and others
	PREVENTION/REHABILITATION						

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Children's experiences and responses towards an intervention for psychological preparation for radiotherapy.	Children: no sign. difference at no time between baseline and intervention in terms of anxiety. In both groups the fear was tendentially lower (not significant). Parents: no sign. difference at no time between baseline and intervention in terms of anxiety. **Ratings were lower in the intervention group at T4 sign than at T1; Interviews described that the intervention was most useful for younger children. In addition, intervention has nurtured the interaction in the family system** and with peers about the current situation of the child; Suggestions for improvement: make information more adapted and interactive	1	1												
Parents' Verbal and Nonverbal Caring Behaviors and Child Distress During Cancer-Related Port Access Procedures: A Time-Window Sequential Analysis	**Parental behavior affects the child's stress during procedures such as port piercing.** In particular, nonverbal behaviors. Even if a child is already experiencing stress, **verbal information also has a stress-reducing effect on the child.** -> Implications from everyday clinical practice are derived.			1											
Age-appropriate preparations for children with cancer undergoing radiotherapy: A feasibility study	CG: standard treatment (no standardized information; book on child receiving radiotherapy and mask was available and occasionally used); IG: books explaining the procedure (3-10 years & 11-18 years); book about 2 children who have radiation treatment; models of doll-sized devices; Possibility to visit the actual equipment; Listening to music/stories or watching movies during treatment; Safety thread that connects the children with the parents in the waiting room; IG could choose parts of the intervention –> younger children needed significantly more anesthesia (in both groups); children who received anesthesia showed sign. more negative emotional behavior (observed) before starting treatment in both groups; no sign. difference between IG and CG regarding self-rated anxiety or observed behavior before treatment. -> 3 children of the IG who had anesthesia planned, managed the treatment without anesthesia; Giving children individualized preparation may decrease the need for GA during RT, which gives benefits in terms of fewer risks and restrictions in life for the child and lower costs for health care.	1	1												
Effects of massage therapy on pain and anxiety arising from intrathecal therapy or bone marrow aspiration in children with cancer	Massage has a positive effect on the reduction of anxiety and stress levels during investment treatments.	1	1	1		1									
PREVENTION/REHABILITATION															

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Children's experiences and responses towards an intervention for psychological preparation for radiotherapy.	heterogeneous cancer types	3	moderate limitations	⊕ ⊕	high		3	new evidence/citation
Parents' Verbal and Nonverbal Caring Behaviors and Child Distress During Cancer-Related Port Access Procedures: A Time-Window Sequential Analysis	Good methods chosen for the description of the behavior, questionnaires or other survey methods very old (1988)	3	moderate limitations	⊕ ⊕	high		4	new evidence/citation
Age-appropriate preparations for children with cancer undergoing radiotherapy: A feasibility study	small sample for wide age range	3	moderate limitations	⊕ ⊕	moderate	only feasybility by now, not intervention effects	2	
Effects of massage therapy on pain and anxiety arising from intrathecal therapy or bone marrow aspiration in children with cancer	Small group, very heterogeneous, no consideration of possible other confounding ariables	3	major limitations	⊕ ⊕	moderate		2	
PREVENTION/REHABILITATION								

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
	…School Re-entry						
6	Facilitation of school re-entry and peer acceptance of children with cancer: a review and meta-analysis of intervention studies	2016	Herlms, A. S.	Systematic review or meta-analysis of controlled study	1	Intervention studies involving children with cancer and / or classmates; Programs for re-entry and programs for informing peers (peer-education)	N = 6 studies Reintegration: n = 3, 5-19 years peer education: n = 3, 6-17 years -> different cancer diagnoses
6	Lessons Learned From a Randomized Controlled Trial of a Family-Based Intervention to Promote School Functioning for School-Age Children With Sickle Cell Disease	2015	Daniel, L. C.	Randomized controlled trial	2	Randomized to Intervention Group (Families Taking Control - FTC: 1 full-day workshop for children and their primary caregivers and 3 booster calls), or delayed intervention control. baseline and time 2 assessment - 6 months after baseline (group was concealed from researchers and families at baseline assessment)	N= 83 families were enrolled (IG=43, CG=41), 61 families completed time 2 assessments (IG=24, CG=38) age: IG: M=8.29 (SD=2.12), CG M=8.66 (SD=2.10) Sex: IG: male=21 (50%), CG: male=21 (51.22%)
	…Psychosocial interventions to improve social skills						
6	A randomized control intervention trial to improve social skills and quality of life in pediatric brain tumor survivors	2018	Barrera, M.	Randomized controlled trial	2	Control group also weekly 2-hour meeting, to control group- and attention effects	N = 91, IG=43, CG=48 Mean age: IG: M=11.56 (SD=2.79); CG: M=10.91 (SD=2.74) (8-16 Years; IG: LGG=19(44.2%), Medullo=8(18.6%), Ependymoma=2(4.7%), Craniopharyngioma=4(9.3%), Other=10(23.3); CG: LGG=20 (41.7%), Medullo=11(22.9%), Ependymoma=8(16.7%), Craniopharyngioma=3/6,3%), Other: 6 (12.5%) Geschlecht: IG: male=19 (44.2); CG: male=28 (58.3%)

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
...School Re-entry															
Facilitation of school re-entry and peer acceptance of children with cancer: a review and meta-analysis of intervention studies	**Reintegration:** Meta-analysis - Significant effectiveness of programs in terms of improving academic performance and reducing children's levels of depression. No sign. Results in terms of behavioral problems a nd social skills.**Peer education:** all 3 studies found sign. increase in the knowledge of classmates, 2 studies found sign. increase in interest in interaction with the sick child. Higher knowledge was associated with less fear and a more positive attitude towards the child with cancer.														
Lessons Learned From a Randomized Controlled Trial of a Family-Based Intervention to Promote School Functioning for School-Age Children With Sickle Cell Disease	Baseline: significantly more school absences in CG. IG reported significantly better social problem solving and slightly fewer school concerns. Controlling for Time 1 the groups did not differ at Time 2 regarding number of formal academic and disease-related accommodations, individualized education plan, school absences, schol HRQOL or academic skills.--> **Although families found FTC to be acceptable, there were no intervention effects.**														
...Psychosocial interventions to improve social skills															
A randomized control intervention trial to improve social skills and quality of life in pediatric brain tumor survivors	Compared to controls, PBTS in the intervention group reported significantly better total and empathy SSRS scores, with improvements persisting at follow-up. PBTS in the intervention group who had low scores at baseline reported the greatest improvements. **They showed significant improvement after the intervention and continued to improve their scores at follow-up.** No significant intervention effect was found regarding childrens QoL. Proxy and teacher reports showed no intervention effect. Participating in group social skills intervention can improve self-reported social competence that persisted to follow-up. **PBTS should be given the opportunity to participate in social skills groups to improve social competence.**														

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
…School Re-entry								
Facilitation of school re-entry and peer acceptance of children with cancer: a review and meta-analysis of intervention studies		1	no limitations	⊕⊕⊕⊕	high		**4**	new evidence/citation
Lessons Learned From a Randomized Controlled Trial of a Family-Based Intervention to Promote School Functioning for School-Age Children With Sickle Cell Disease		2	no limitations	⊕⊕⊕	moderate	no intervention effect, but good acceptance	**2**	
…Psychosocial interventions to improve social skills								
A randomized control intervention trial to improve social skills and quality of life in pediatric brain tumor survivors		2	no limitations	⊕⊕⊕	high		**4**	new finding

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Social Competence in Childhood Brain Tumor Survivors: Feasibility and Preliminary Outcomes of a Peer-Mediated Intervention	2016	Devine, K. A.	Non-Randomized controlled trial	3	Schools with a driving distance of max. 90 minutes had been assigned to the IG; schools with a journey> 90 minutes to the CG. T1 = start of the study T2 = at the end of the school year	In the 13 classrooms, 232 of 269 parents (86.2%) gave permission for their child to participate. **Brain tumor survivors:** IG = 8, CG = 4; Age: IG: M = 10.5 (SD = 2.6), CG: M = 9.8 (SD = 2.3); Diagnosis: IG: astrocytoma = 3 (37.5%), germinoma = 3 (37.5%), ependymoma = 1 (12.5%), craniopharyngioma = 1 (12.5%); KG: astrocytoma = 3 (75%), germinoma = 0, ependymoma = 0, craniopharyngioma = 1 (25%); Gender: IG: male = 5 (62.5%); CG: male = 2 (50%) **Classmate:** IG = 136, CG = 81; Age: IG: M = 10.2 (SD = 2.6), CG: M = 9.9 (SD = 2.0); gender: IG: male = 66 (48.5%); CG: male = 41 (50.6%)
	…Psychosocial interventions to reduce cognitive late effects						
6	Computerized Cognitive Training for Amelioration of Cognitive Late Effects Among Childhood Cancer Survivors: A Randomized Controlled Trial	2015	Conklin, H. M.	Randomized controlled trial	2	randomized assignment to intervention group (25 training sessions with weekly telephone coaching) and waiting list group; Blind study (psychological investigators who have performed cognitive testing) Intervention: Cogmed	N = 68 children who received CNS-directed therapy (skull irradiation or intrathecal chemo) for brain tumor or ALL, IG n = 34 (n = 4 did not complete training); CG n = 34 (n = 4 loss to follow-up assessment after approx. 6 months); Age at the time of study: 8-16 years; IG: M = 12.21 (SD = 2.47); CG: M = 11.82 (SD = s.42) Diagnoses: IG: ALL = 23 (68%), brain tumor = 11 (32%) [ependymoma = 1 (9%), glioma = 2 (18%), medullo / PNET = 8 (73%)]; CG: ALL = 24 (71%), brain tumor = 10 (29%) [ependymoma = 3 (30%), glioma = 0, medullo / PNET = 7 (70%)] Sex: IG: girls = 16 (47%); CG: girls = 16 (47%)

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Social Competence in Childhood Brain Tumor Survivors: Feasibility and Preliminary Outcomes of a Peer-Mediated Intervention	The intervention (5–8 sessions over 4–6 weeks) taught peer leaders skills for engaging classmates. –> Social competence of the PBTS: 5 of the 13 PBTS were selected as Leaders. PBTS who were chosen as leaders differed from those who were not elected just by the time since the diagnosis (which was shorter for the leaders). No sign. differences between PBTS and classmates in terms of social literacy to T1. Investigation of the potential effects: no sign. differences betweenIG and CG (social acceptance, rejection, bullying). Classroom-Level Outcomes: **Sign. less rejection and harassment in IG.** No differences in friend nomination or sozailer acceptance. Feedback from Leaders: **qualitative advantage for making friends;** Leaders nominated more classmates than friends at T2. -> **Accepted by PBTS and their parents and feasible in schools.** -> larger, RCTs necessary to investigate effectiveness -> additional modules to handle rejection and harassment should be introduced.	1								1					
…Psychosocial interventions to reduce cognitive late effects															
Computerized Cognitive Training for Amelioration of Cognitive Late Effects Among Childhood Cancer Survivors: A Randomized Controlled Trial	Training improved the short-term measurement (about 10 weeks after T1) of attention, working memory and processing speed. Parents reported a reduction in inattention and executive dysfunction. fMRT: Reduction in prefrontal and parietal activation -> Neuroplasticity through training. Training is effective and workable.									1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Social Competence in Childhood Brain Tumor Survivors: Feasibility and Preliminary Outcomes of a Peer-Mediated Intervention	small sample of survivors, but only preliminary data; no pre-screening of social problems	3	moderate limitations	⊕ ⊕	high	good acceptance; larger study for effectiveness necessary	**3**	new evidence/citation
…Psychosocial interventions to reduce cognitive late effects								
Computerized Cognitive Training for Amelioration of Cognitive Late Effects Among Childhood Cancer Survivors: A Randomized Controlled Trial	no fMRI in CG	2	no limitations	⊕ ⊕ ⊕	high		**4**	new finding

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Long-Term Efficacy of Computerized Cognitive Training Among Survivors of Childhood Cancer: A Single-Blind Randomized Controlled Trial	2017	Conklin, H. M.	Randomized controlled trial	2	randomized assignment to intervention group and waiting list group; 25 training sessions with weekly telephone coaching; Blind study (psychological investigators who have performed cognitive testing) Intervention: Cogmed	N = 68 children who received CNS-directed therapy (skull irradiation or intrathecal chemo) for brain tumor or ALL, IG n = 34 (n = 4 did not complete training); CG n = 34 (n = 4 loss to follow-up assessment after approx. 6 months); description of sample see Conklin 2015
6	Effects of educational versus peer discussion interventions on perceived competence in adolescents with medulloblastoma	2015	Zhu, L.	Randomized controlled trial	2	education-based group (EG) vs.peer discussion-based group (PDG) pre-post test design (baseline, immediately after intervention, 2 weeks after intervention, 6 months after intervention groups: weekly for 8 consecutive weeks Only children between 9-18 years included	N=45 (PDG n=22; EG n=23) age: PDG: M=12.2(SD=2.7), EG: M=12.9 (SD=2.8) sex: PDG: 14 male/8 female, EG: 16 male/7 female diagnosis: medulloblastoma most patients (96%) completed the questionnaires at both assessment points.
6	Neurofeedback ineffective in paediatric brain tumour survivors: Results of a double-blind randomised placebo-controlled trial	2016	de Ruiter, M. A.	Randomized controlled trial	2	5 medical centers in the Netherlands randomized double blind placebo controlled trial; placebo-controlled: placebo feedback (PF); double blind: Participants, parents, coaches and investigators did not know about group allocation; assign participant 1: 1 to NF or PF (after selecting the appropriate NF module based on qEEG -> 3 possible modules); Examination: T0 (pre-training), T1 (post-training), T2 (follow-up after 6 months)	N = 82; 80 were randomly assigned (NF = 40, PF = 40), 71 completed the training (NF = 34, PF = 37), 68 completed the training and completed the 6 month follow-up examination (NF = 33, PF = 35); Age at the time of examination: NF: M = 14.45 (SD = 2.99), PF: M = 13.45 (SD = 3.28) -> range (8-18 years); Tumor grade: NF: HG = 11 (32%), LG = 23 (58%); PF: HG = 14 (46%), LG = 20 (54%); Treatment: NF: surgery = 17 (50%), chemo/radiation = 17 (50%); PF: Operation = 18 (49%), Chemo / Radiation = 19 (51%); location: NF: supratentorial = 20 (59%), Infratentorial = 14 (41%); PF: supratentorial = 20 (59%), Infratentorial = 17 (46%); Gender: NF: Boys = 16 (47%), PF: Boys = 19 (51%); Participants> 2 years after treatment; Parents were given a screening disruptive behavior rating scale -> if the value was 14 or higher and at least 2 problems were reported, the child was considered fit for the study

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Long-Term Efficacy of Computerized Cognitive Training Among Survivors of Childhood Cancer: A Single-Blind Randomized Controlled Trial	Over a period of about 6 months, none of the groups (IG, CG) showed a change in Spatial Span backwards (WISC-IV), which indicates a stable maintenance of performance. -> Working memory and processing speed showed no change in the period "immediately after the intervention" to "approximately 6 months later". -> the improvement in attention did not appear after 6 months. -> **clinical benefit of this intervention**														
Effects of educational versus peer discussion interventions on perceived competence in adolescents with medulloblastoma	**Participants in both groups showed improvement over time.** The EG participants scored themselves **higher on subscales including social acceptance, global self-worth and behavioral conduct at 2 weeks** compared with those in the PDG (P<0.05). However, no significant differences were found between the groups at 6 months. PDG exhibited a more potent effect on **physical appearance** than EG. Moreover, pessimists did not benefit more by attending an EG intervention than they did by attending a PDG intervention. –> **EG intervention seems to enhance shortterm, rather than long-term, perceived competence**														
Neurofeedback ineffective in paediatric brain tumour survivors: Results of a double-blind randomised placebo-controlled trial	Intervention NF: 30 sessions of 30 minutes each, twice a week at home or at school; No effect of NF on neurogognitive functions (attention, processing speed, memory, executive functions, visuomotor integration and "intellectual functioning" found [primary outcome]; Also no effects on secondary outcomes (self, parent, teacher assessment of HRQOL, social-emotional functions, self-esteem, fatique, "behavioral EF", attention in daily life, sleep problems).-> PBTS of both glands show improvements in most outcomes over time (with small to medium effects).									1					

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Long-Term Efficacy of Computerized Cognitive Training Among Survivors of Childhood Cancer: A Single-Blind Randomized Controlled Trial		2	no limitations	⊕ ⊕ ⊕	high		**4**	new finding
Effects of educational versus peer discussion interventions on perceived competence in adolescents with medulloblastoma		2	no limitations	⊕ ⊕ ⊕	high		**4**	new finding
Neurofeedback ineffective in paediatric brain tumour survivors: Results of a double-blind randomised placebo-controlled trial		2	no limitations	⊕ ⊕ ⊕	moderate	no effect of intervention	**1**	

Summery of evidence - Research question 6

research question	title of study	year of publication	first author	study design	level of evidence	remark on study design	sample
6	Exercise training for neural recovery in a restricted sample of pediatric brain tumor survivors: a controlled clinical trial with crossover of training versus no training	2017	Riggs, L.	Non-Randomized controlled trial	3	Clinical trial with crossover of exercise training versus no training in a restricted sample of children treated with radiation for brain tumors. Participants were allocated to the group or combined training setting in a quasi-random manner based on the order in which they were recruited to each training block.	**Combined group/home setting (n=12)** 58.3%male, mean age at diagnosis 6.33y SD 1.56, range 2.92-8.08y, mean age at baseline assessment 12y SD 3; Range: 8.08-16.92y, tumor type: anaplastic astrocytoma 0, ependymoma 1, anaplastic ependymoma 1, Medulloblastoma 8, Pineoblastoma 0, Sarcoma 1, Germ cell 0, Astroblastoma 1. **Group Setting (n=16)** 56.3%male, mean age at diagnosis 5.61 SD 2.61, range 1.92-9.33, mean age at baseline assessment 11.19 SD 2.98 Range: 7.67-16.92, tumor type: anaplastic astrocytoma 1, ependymoma 1, anaplastic ependymoma 3, Medulloblastoma 8, Pineoblastoma 1, Sarcoma 0, Germ cell 2, Astroblastoma 0.

Summery of evidence - Research question 6

title of study	findings	! sample	! if applicable: controls	! methods (materials, procedure etc.)	! data collection	! statistical analysis	! sparse data	! handling of missing data	! transperency of interpretation	! other limitations	! Rev: type of studies included	! Rev: analysis of quality of studies	! Rev: coherent conclusion	! Rev: inclusion of relevant results	! Rev: other limitations
Exercise training for neural recovery in a restricted sample of pediatric brain tumor survivors: a controlled clinical trial with crossover of training versus no training	The group setting consisted of three 90-minute sessions/week for 12 consecutive weeks. The combined setting consisted of two 90-minute group sessions and two 30-minute individual home-based sessions per week. All sessions included aerobic activities designed to increase participants' heart rate**. –> Twenty-eight participants completed training in either a group (n=16) or a combined group/home (n=12) setting**. **Training resulted in increased white matter** FA (Δ=0.05, P<.001). A carryover effect was observed for participants ~12 weeks after training (Δ=0.05, P<.001). **Training effects were observed for hippocampal volume** (Δ=130.98mm3; P=.001) and mean RT (Δ=-457.04ms, P=0.36) but only in the **group setting**. Related carryover effects for hippocampal volume (Δ=222.81mm3, P=.001), and RT (Δ=-814.90ms, P=.005) were also observed. Decreased RT was predicted by increased FA (R=-0.62, P=.01). There were no changes in accuracy. **Exercise training is an effective means for promoting white matter and hippocampal recovery and improving reaction time in children treated with cranial radiation for brain tumors.**	1													

Summery of evidence - Research question 6

title of study	remark on limitation	level of evidence	limitations summary	GRADE* QUALITY OF EVIDENCE	relevance for improvement of psychosocial care	remark on relevance	strength of recommendation	inclusion in guideline
Exercise training for neural recovery in a restricted sample of pediatric brain tumor survivors: a controlled clinical trial with crossover of training versus no training	small sample size, but elaborated design	3	moderate limitations	⊕ ⊕	high		**3**	new finding

Summery of evidence - Research question 7

research question	title of study	year of publication	first author	study design	level of evidence	strength of recommendation
7	Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: Current state of the literature.	2018	Brinkman, T.M.	Systematic review or meta-analysis of controlled studies	**1**	4
7	Neurocognitive outcomes in long-term survivors of childhood acute lymphoblastic leukemia treated on contemporary treatment protocols: A systematic review.	2015	Cheung	Systematic review or meta-analysis of controlled studies	**1**	4
7	Late effects surveillance recommendations among survivors of childhood hematopoietic cell transplantation: A children's oncology group report.	2016	Chow	Systematic review or meta-analysis of controlled studies	**1**	4
7	Mental health of long-term survivors of childhood and young adult cancer: A systematic review.	2018	Friend, A. J.	Systematic review or meta-analysis of controlled studies	**1**	4
7	The relationship between cognitive and neuroimaging outcomes in children treated for acute lymphoblastic leukemia with chemotherapy only: A systematic review.	2017	Hearps	Systematic review or meta-analysis of controlled studies	**1**	4
7	Unemployment following childhood cancer.	2017	Mader, L.	Systematic review or meta-analysis of controlled studies	**1**	4
7	Smoking, binge drinking, and drug use among childhood cancer survivors: A meta-analysis.	2016	Marjerrison, S.	Systematic review or meta-analysis of controlled studies	**1**	4
7	Quality of life in adolescent and young adult cancer patients: a systematic review of the literature.	2015	Quinn, G. P.	Systematic review or meta-analysis of controlled studies	**1**	4
7	Systematic review and meta-analysis of health-related quality of life in pediatric CNS tumor survivors.	2017	Schulte	Systematic review or meta-analysis of controlled studies	**1**	4

Summery of evidence - Research question 7

research question	title of study	year of publication	first author	study design	level of evidence	strength of recommendation
7	Psychosocial interventions for adolescent cancer patients: a systematic review of the literature.	2009	Seitz, D. C.	Systematic review or meta-analysis of controlled studies	**1**	4
7	Long-term psychiatric outcomes in pediatric brain tumor survivors.	2015	Shah	Systematic review or meta-analysis of controlled studies	**1**	4
7	Health-related quality of life of survivors of childhood acute lymphoblastic leukemia: a systematic review.	2018	Vetsch	Systematic review or meta-analysis of controlled studies	**1**	4
7	A randomized controlled pilot trial of a web-based resource to improve cancer knowledge in adolescent and young adult survivors of childhood cancer.	2016	Kunin-Batson, A.	Randomized controlled trial	**2**	4
7	The unmet emotional, care/support, and informational needs of adult survivors of pediatric malignancies.	2016	Cox, C.L.	Observational study (cohort, cross/sectional, case-controll)	**4**	4
7	Burden of Parents of Pediatric Cancer Patients in Pediatric-oncological Rehabilitation]	2017	Inhestern, L.	Observational study (cohort, cross/sectional, case-controll)	**4**	4
7	Psychosocial follow-up in survivorship as a standard of care in pediatric oncology	2015	Lown, E. A.	Systematic review of descriptive or qualitative studies; Anhang D	**5**	4
7	The impact of long-term follow-up care for childhood cancer survivors: A systematic review.	2017	Signorelli, C.	Systematic review of descriptive or qualitative studies	**5**	4
7	Psychosocial late effects in pediatric cancer survivors: A report from the children's oncology group.	2016	Bitsko, M.J.	Systematic review of descriptive or qualitative studies	**5**	4

Summery of evidence - Research question 7

research question	title of study	year of publication	first author	study design	level of evidence	strength of recommendation
7	Neurocognitive dysfunction in hematopoietic cell transplant recipients: expert review from the late effects and Quality of Life Working Committee of the CIBMTR and complications and Quality of Life Working Party of the EBMT.	2018	Buchbinder	Systematic review of descriptive or qualitative studies	**5**	4
7	A systematic review of neuropsychological outcomes following posterior fossa tumor surgery in children.	2015	Hanzlik	Systematic review of descriptive or qualitative studies	**5**	4
7	Review of the behavioral and emotional aspects in pediatric cancer patients.	2017	Lanier	Systematic review of descriptive or qualitative studies	**5**	4
7	Strategies to improve the quality of survival for childhood brain tumour survivors.	2015	Tallen, G.	Systematic review of descriptive or qualitative studies	**5**	4
7	Childhood brain cancer and its psychosocial impact on survivors and their parents: A qualitative thematic synthesis.	2016	Woodgate, R.L.	Systematic review of descriptive or qualitative studies	**5**	4
7	ReCAP: ASCO core curriculum for cancer survivorship education.	2016	Shapiro, C.L.	Narrative review	**7**	4
7	Chemotherapy-induced neurotoxicity in pediatric solid non-CNS tumor patients: An update on current state of research and recommended future directions.	2016	Sleurs	Narrative review	**7**	4

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4	⊕ ⊕
5	⊕ ⊕
6	⊕ ⊕
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10	⊕
11	⊕