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A Dutch clinical practice guideline for paediatric palliative care: a systematic review and recommendations on psychosocial care including preloss and bereavement care

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Abstract

Background Children with life-threatening and life-limiting conditions and their families are confronted with many uncertainties, incremental losses, and difficult decisions. Attentiveness to psychosocial care, including psychological, social, and spiritual concerns, is essential during the child's life until end-of-life and during bereavement and determines quality of life and wellbeing of child and family. However, use and integration of psychosocial care is found to be challenging. In this paper, we provide recommendations that aim to optimise psychosocial care including preloss and bereavement care in paediatric palliative care.

Methods A multidisciplinary guideline development panel of 25 experts in paediatric palliative care and nine parents was established to develop recommendations on psychosocial care including preloss and bereavement care. We performed a systematic literature search to identify evidence focussing on effectivity of interventions described in systematic reviews (SRs) of randomised controlled trials (RCTs) and RCTs. From the search, we also derived evidence from SRs of observational, qualitative, or mixed-method studies on preloss and bereavement care. The GRADE methodology was used for appraising evidence. We used existing guidelines to deal with lack of evidence. Recommendations were formulated based on evidence, existing guidelines, clinical expertise, and patient and family values.

Results We identified a total two SRs of RCTs and six RCTs that reported on the effect of psychological interventions, spiritual support interventions, and bereavement care intervention. The evidence showed that only some of the interventions improve certain psychosocial outcomes in children or parents. We were unable to draw conclusions on which intervention is most effective, due to the high variability in interventions and measured outcomes. The evidence from ten SRs of observational, qualitative, or mixed-method studies was used as a basis for preloss and bereavement care recommendations. In total, we formulated 48 recommendations.

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Discussion With the provided recommendations, we aim to optimise psychosocial care for children with life-threatening and life-limiting conditions and their families. Psychosocial care should be tailored to the child and family. We found a lack of evidence on psychosocial care including preloss and bereavement care. Although very challenging, we propose implementing strategies to improve research and thereby further optimise quality of paediatric palliative care. These strategies include the development of a standard set of outcomes and to conduct well-designed multisite RCTs.

Keywords Evidence-based guideline, Paediatric palliative care, Psychosocial care, Preloss and bereavement

Background

Children with life-threatening and life-limiting conditions often receive high complex care which lasts for months or years [1–5]. During the child's disease trajectory, children and their families are confronted with many uncertainties, incremental losses, and difficult decisions [1, 4]. These children and their families can experience high levels of suffering and are at risk for poor quality of life [6–8]. Paediatric palliative care focuses on relieving physical, psychological, social, and spiritual suffering and ensuring the best quality of life for these children and their families from diagnosis until end-of-life and during bereavement [4, 5, 9].

Multiple studies highlighted a need for improvement of paediatric palliative care such as symptom management to ease distressing symptoms and enhance quality of life in both children and their families [6, 7, 10, 11]. Moreover, it is increasingly recognised that not only symptom alleviation, but also attentiveness to psychological, social, and spiritual concerns is essential in paediatric palliative care [12–15], as this determines quality of life and experienced distress among children and their family members. Furthermore, children and their families experience incremental losses from the moment of diagnosis, throughout the palliative care trajectory, and even new losses after the child's death. Attentiveness to loss, grief, and bereavement is crucial to support children and their families in coping with these losses [16–18].

Psychosocial care, which includes the attentiveness to psychological, social, and spiritual concerns, and preloss and bereavement care, is an essential component of paediatric palliative care and provides a meaningful opportunity to enhance the wellbeing of the child and the whole family [12, 18, 19]. However, the use and integration of psychosocial care including preloss and bereavement care has been found to be challenging [18, 19]. A recent qualitative study among parents in the Netherlands reported that paediatric palliative care still focuses too much on symptom management [20]. The study highlights the importance to see the child as a person and focus on the child and family as a whole, including psychological, social, and spiritual aspects. Additionally, parents experienced a lack of preloss and bereavement care

during the child's palliative disease trajectory and after the death of their child [20].

Psychosocial care including preloss and bereavement care should be ensured for all children with life-threatening and life-limiting conditions and their families. Clinical practice guidelines (CPGs) are found to be powerful tools in which knowledge from scientific literature, clinical expertise and patient experiences are combined to provide recommendations for clinical practice [21–23]. Care delivered in line with these recommendations can decrease variability in provided care, enhance quality of care, and contribute to integration of care services [21–23].

To achieve more optimal psychosocial paediatric palliative care, we aim to provide new evidence-based recommendations focusing on interventions for psychosocial care in which we distinguish psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care. These recommendations have been developed as part of the revised Dutch CPG on paediatric palliative care [24]. In this paper, we present an overview of the evidence, clinical expertise, and recommendations on psychosocial care.

Methods

The full methodology of the Dutch CPG for paediatric palliative care is outlined in another publication [24].

Scope

This guideline aims to improve quality of palliative care for all children aged 0 to 18 years with life-threatening and life-limiting conditions and their caregivers and siblings (hereafter referred to as families), with the ultimate goal to improve quality of life of children and their families. The guideline covers the entire palliative disease trajectory (from the beginning of the palliative disease trajectory till after the child's death continuing in bereavement) [24].

In this paper, we aim to provide recommendations for psychosocial care including psychological interventions,

practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care.

Multidisciplinary guideline development panel

The guideline development panel included 25 paediatric palliative care experts and a group of nine parents of children with life-threatening and life-limiting conditions (Appendix A). These experts, of which some had specialised certified training in paediatric palliative care, represented various disciplines such as paediatricians, psychotherapists, psychologists, spiritual counsellors, child life specialists, and paediatric nurses. To maintain consistency throughout the guideline, a core group of 11 experts was formed within the panel. The remaining 14 experts were assigned to two working groups (WGs), one dedicated to psychosocial care, and the other to preloss and bereavement care. The psychosocial care WG tackled three topics for which sub-WGs were established, namely psychological interventions, practical and social support, and cultural, spiritual, and religious support. All topics and clinical questions addressed by the (sub)WGs were prioritised based on input from experts and parents [24]. Appendices B and C provide an overview of the working structure and guideline development process.

Representation of patients and their families

To ensure representation of patients and their families, various methods were utilised [24]. First, we gave two members of the core group the specific responsibility of maintaining patient and family representation throughout the guideline development process. Another method involved forming a group of nine parents of children with life-threatening or life-limiting conditions. This group reviewed the initial drafts of all guideline texts and recommendations as well as the draft of the complete guideline. To capture a wide range of experiences, we included parents of children with diverse palliative conditions, ages, and stages of disease. Some of the children with life-threatening or life-limiting conditions were actively receiving palliative care, while others had passed away.

Formulation of clinical questions

The psychosocial care WG formulated four clinical questions on the effect of psychological interventions, practical and social support, and cultural, spiritual, and religious support for children with life-threatening and life-limiting conditions and their family members. The WG that focused on preloss and bereavement care formulated four clinical questions on the effect of preloss interventions for children with life-threatening and life-limiting conditions and their family members and the effect of bereavement care interventions for their family members, components of preloss and bereavement

care interventions, experiences and needs of parents and health care providers, and communicative strategies (Appendix D).

Identification of evidence

To answer clinical questions on the effect of psychosocial care interventions including psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care interventions, we updated the systematic literature search conducted for the former CPG (2013) which focused on quantitative studies on paediatric palliative care interventions (last updated January 24, 2020) (Appendix E) [24]. Studies were selected based on specific inclusion criteria related to study population (children aged 0 to 18 with life-threatening or life-limiting conditions as defined by the World Health Organisation [5]); study design (randomised controlled trials (RCTs), controlled clinical trials (CCTs), and systematic reviews (SRs) of RCTs and CCTs; and study subject (paediatric palliative care psychosocial care interventions including psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care). Only studies published in English or Dutch were included (Appendix F) [24]. Included studies were summarised in evidence tables and categorised by outcome measures in summary of findings tables [24]. We formulated conclusions of evidence for each outcome measure and assessed the quality of the total body of evidence using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) method [25]. The conclusions of evidence were used as a basis for our recommendations [24].

Furthermore, to answer clinical questions on components of preloss and bereavement care interventions, experiences and needs of parents and health care providers, and communicative strategies, we derived SRs of observational, qualitative, or mixed-method studies from the systematic literature search on paediatric palliative care interventions and through referencing [24]. We synthesised the findings from these SRs in evidence tables and translated these into conclusions of evidence. Given the variety of study designs included in the SRs, determining both individual study quality and quality of the total body of evidence were not feasible [24]. The conclusions derived from the SRs served as the basis for our recommendations [24].

Identification of additional literature

As we expected that evidence would be limited or of low quality, we conducted a search for existing evidence-based paediatric palliative care guidelines that had performed systematic literature searches on this topic. We

found one evidence-based guideline, ‘End of life care for infants, children and young people with life-limiting conditions (2016)’ of the National Institute for Health and Care Excellence (NICE) [26]. We used the conclusions of evidence, considerations, and recommendations of the NICE-guideline to inform and support our own recommendations [24].

Translating evidence into recommendations

Multiple factors were considered in translating the evidence into recommendations. First, the WG members considered the quality of the evidence when formulating recommendations, in which a higher quality of evidence was likely to support stronger recommendations. If the evidence focused on one specific group of children (e.g. children with cancer), the WG carefully assessed if evidence could be extrapolated to children with other life-threatening and life-limiting conditions before formulating recommendations. Other factors that were considered to formulate recommendations were, additional literature including existing evidence-based guidelines, values and needs of patients and their family, clinical expertise, acceptability (legal and ethical aspects), feasibility (available time, knowledge and manpower), and benefits versus harms of the interventions [24]. The WG members outlined the relevant considerations for each clinical question, and decisions were made through group consensus [24].

The strength of each recommendation was graded using established evidence-based methods [25, 27] (Appendix G). Recommendations were classified as strong to do (green), moderate to do (yellow), or strong not to do (red) [24].

Results

Identification of evidence

The systematic search for quantitative studies on paediatric palliative care interventions resulted in 5078 citations of which 168 citations were subjected to full-text screening [24]. Ultimately, eight studies (two SRs of RCTs and six RCTs) on interventions related to psychosocial care including preloss and bereavement care were included [28–35] (Appendix H). Additionally, ten SRs of observational, qualitative, or mixed-method studies on preloss and bereavement care interventions components, and communicative strategies were included [36–45] (Appendix H).

Appendices J and K present the evidence tables and summary of findings tables. Tables 1, 2, and 3 provide the conclusions of evidence. Figure 1 offers an overview of the identified evidence and recommendations for each WG.

Evidence on effect of psychological interventions

Three studies, two RCTs and one SR of RCTs, reported on psychological interventions that were targeted at improving a variety of psychosocial outcomes in children and adolescents with life-threatening or life-limiting conditions [28, 29, 31]. Two RCTs reported on the effects of the Promoting Resilience In Stress Management (PRISM) intervention which aimed to strengthen four resources of resilience including stress-management, goal-setting, cognitive reframing, and meaning-making in four 30–50 min sessions amongst children and adolescents with cancer [28, 29]. The studies showed that hope-finding was significantly increased in children and adolescents with cancer who received the PRISM intervention as compared to the children and adolescents who received usual psychosocial care provided by a social worker (very low quality evidence) [28]. However, we found no significant effect of benefit-finding (very low quality evidence) [28]. Additionally, no significant difference in percentage of positive health-related quality of life (HR-QoL) trajectories was found between children and adolescents with cancer who participated in the PRISM intervention and those who received usual care (very low quality evidence) [29]. When looking more closely at cancer-specific subdomains of HR-QoL, the percentage of positive trajectories in HR-QoL was only significantly increased in the intervention group in two out of eight cancer-specific subdomains, namely worry and nausea (very low quality evidence) [29]. One SR of RCTs reported on the effects of an educational problem-solving and social skills intervention for children with cystic fibrosis [31]. This intervention showed no significant difference in psychosocial outcomes including perceived loneliness and social support at three, six, and nine month follow-up in children that received the interventions as compared to usual care (moderate quality evidence) [31].

Three studies, one RCT and two SRs of RCTs, reported on psychological interventions that were targeted at improving several psychosocial outcomes in parents of children with life-threatening or life-limiting conditions [30–32]. One RCT investigated the effects of an adapted version of the PRISM intervention directed at parents (PRISM-P) comprising of four 30 to 60 min sessions. The PRISM-P intervention increased resilience and benefit-finding at six month follow-up among parents who received one on one sessions as compared to usual psychosocial care provided by a social worker (very low quality evidence) [30]. No significant effect was found on other outcomes including hope-finding, perceived social support, HR-QoL, perceived stress and psychological distress (very low quality evidence) [30]. When the PRISM-P intervention was delivered in group sessions of two to five parents, no significant effect was found in

Table 1 Conclusions of evidence on paediatric palliative psychosocial care interventions including preloss and bereavement care interventions

Effect of psychosocial care interventions including preloss and bereavement care interventions in palliative care for children aged 0 to 18 years with life-threatening and life-limiting conditions, and their family	
Psychosocial care	Quality of evidence
Psychological interventions	
Promoting resilience in stress management (PRISM) vs. usual care in children and adolescents with cancer	⊕⊕⊕⊕ VERY LOW (1 RCT) (26)
↑ <i>hope-finding</i> at 6-month follow-up	
No significant effect on <i>benefit-finding</i> at 6-month follow-up	⊕⊕⊕⊕ VERY LOW (1 RCT) (27)
No significant effect on <i>the percentage of positive health-related quality of life trajectories</i> at 6-month follow-up	
↑ <i>percentage of positive cancer specific quality of life trajectories regarding the subdomains nausea and worry</i> at 6-month follow-up	
No significant effect on <i>the percentage of cancer specific quality of life trajectories regarding the subdomains, treatment anxiety, procedural anxiety, cognitive, physical appearance, communication, and pain</i> at 6-month follow-up	
Educational problem-solving and social skills interventions vs. usual care in children Cystic Fibrosis	⊕⊕⊕⊕ MODERATE (1 RCT) (29)
No significant effect on <i>loneliness</i> and <i>perceived social support of peers and classmates</i> at 3-, 6- and 9-month follow-up	
Promoting resilience in stress management, parent-directed (PRISM-P) one on one sessions vs. usual care in parents of children with cancer	⊕⊕⊕⊕ VERY LOW (1 RCT) (28)
↑ <i>resilience</i> and <i>benefit-finding</i> at 6-month follow-up	
No significant effect on <i>hope, perceived social support, health-related quality of life, perceived stress, and psychological distress</i> at 6-month follow-up	
Promoting resilience in stress management, parent-directed (PRISM-P) group sessions vs. usual care in parents of children with cancer	⊕⊕⊕⊕ VERY LOW (1 RCT) (28)
No significant effect on <i>resilience, benefit-finding, hope, perceived social support, health-related quality of life, perceived stress, and psychological distress</i> at 6-month follow-up	
Community-based support programme vs. control (contact with a telephone number) in mothers of children with cystic fibrosis	⊕⊕⊕⊕ VERY LOW (1 RCT) (29)
No significant effect on <i>anxiety</i> at 12 month follow-up	
Psychological interventions (cognitive behavioural therapy, family therapy, problem-solving therapy, or multi-systemic therapy) vs. treatment as usual, active control or wait-list control in parents of children with cancer	⊕⊕⊕⊕ LOW (5 RCTs) (30)
↑ <i>parenting behaviour</i> post-treatment, No significant effect on <i>parent behaviour</i> at follow-up (2 to 12 months)	
No significant effect on <i>parent mental health</i> post-treatment	⊕⊕⊕⊕ VERY LOW (9 RCTs) (30)
↑ <i>parent mental health</i> at follow-up (2 to 12 months) intervention	⊕⊕⊕⊕ VERY LOW (6 RCTs) (30)
Practical and social support	
Unknown effect of practical and social support	No studies
Cultural, spiritual, and religious support	
Spiritual training package for parents vs. wait-list control in mothers of children with cancer	⊕⊕⊕⊕ VERY LOW (1 RCT) (31)
↓ <i>stress</i> post-treatment after intervention and at 3-month follow-up (no significant difference as compared to control group), <i>anxiety</i> post-treatment and at 3 month follow-up, and <i>depression</i> after intervention and at 3-month follow-up (no significant difference as compared to control group)	
Educational spiritual intervention vs. control in parents of children with cancer	⊕⊕⊕⊕ VERY LOW (1 RCT) (32)
↓ <i>burnout scores</i> post-treatment and at 1 month follow-up	
Preloss and bereavement care	
Quality of evidence	
Bereavement intervention comprising of a support package, peer supporter's contact and health care personnel's contact vs. usual care in mothers of children who died at age three or younger	⊕⊕⊕⊕ VERY LOW (1 RCT) (33)
No significant effect on <i>grief reactions including despair, panic behaviour, personal growth, blame and anger, detachment, and disorganisation</i> at 6-month follow-up	

any of the assessed outcomes (very low quality evidence) [30]. Additionally, one SR of RCTs reported on the effect of a community-based support programme for mothers of children with cystic fibrosis in comparison to a control intervention consisting of contact with a telephone number. No significant difference in anxiety at 12 month follow-up was found among mothers who received the

intervention and those who were in the control group (very low quality evidence) [31]. Finally, one SR of RCTs reported on the effect of different psychological interventions for parents of children with cancer including cognitive behavioural therapy, family therapy, problem-solving therapy and multi-systemic therapy in comparison to different control interventions including treatment as usual,

Table 2 Conclusions of evidence on preloss and bereavement care intervention components

Preloss and bereavement care intervention components, specific actions, and experiences and needs of parents and health care providers*		
Main category	Specific actions per component	Experiences/needs regarding the intervention component as expressed or experienced by parents and health care providers (HCPs)
Acknowledging the child's life and identity	• Providing the child with a certificate of life (34) • Providing the child with a blessing ceremony (34) • Acknowledging child's identity (35) • Acknowledging birthdays/holidays/ anniversaries (36, 37)	• Not reported • Not reported • Learn the infant's individual needs and routines (35) • Not reported
Acknowledging and enabling parenthood	• Maintaining relationship between parent and child (38) • Washing, holding, or dressing the child both during the end of life and after death (34,35, 39, 40) • Giving parents privacy and input surrounding the death of the child (34, 35, 39)	• During the end of the child's life, parents desired to maintain their relationship with their child (38) • See, touch, and hold the newborn during after life can enable parents to form important bonds and to create memories that are helpful after their newborns' death. Holding their child as he/she died, was valued by and helpful for most parents, but also emotionally difficult. Support and reassurance from hospital staff can be needed. Parents' failure to spend time with, or contribute care for their newborn was associated with regrets (40) • Providing care for their newborns may help individuals develop their identities as parents. Being involved and participating in bedside care was identified as helpful. Parents experienced frustration when staff did not welcome their participation and felt regret when their involvement in care was limited (40) • Parents wanted to be actively involved in the child's care and talk openly with the dying child (41) • Acknowledge the wishes of the parents, even when these wishes conflict with the recommendations of the healthcare team (35) • Parents preferred to be given control over the how and where the child died (39, 41). Some parents preferred to stay home (41) • Parents expressed the need to be with the child at the time of death. Parents preferred to be provided with intimacy and privacy at the time of death, for example by being offered a private room with as little disturbances as possible (41). Parents who were not given the opportunity for a private peaceful place and sufficient time to say goodbye found a negative effect on grieving, accepting and coping (35)
Establishing keepsakes	• Safeguarding a lock of hair (34,40) • Hand, foot, or face print (34, 40) • Basket/memory box: (items that belonged to the child such as toys, a blanket, ornaments, a memory stone, clothes, a baby ring or bracelet, memory books, poems, or other belongings) (34-36, 40) • Pictures (34,36,40)	• Many parents appreciated the opportunity to create mementos with and of their dying child, which was described as meaningful and an important need. Parents expressed a need to be actively supported and guided through all aspects of memory making (38, 40, 42) • Photographs can help parents by confirming the newborn's existence and may legitimize the parents' loss. The images can provide the basis for a continuing relationship between parents and child. Finally, they are important cues for memory to help parents process their losses. Parents wanted health providers to offer education and encouragement to ensure that photographs were taken. Although, parents often feel a range of barriers to bereavement photography, most parents who did not receive photographs wished they had (40)
Establishing follow-up contact with HCPs	• Follow-up contact (calls, cards, visits, flowers, condolence letters) (34, 36, 37, 39, 43)	• Need for a continuity of care after the child's death by the hospital staff that cared for their child. It was important that the same members of the care team were involved from diagnoses throughout bereavement. The basis of care quality was built on communication, honesty, respect and anticipation of needs (38) • Parents experienced a strong bond with the hospital staff and felt abandoned if the bond was broken (36, 37, 42) • Follow-up contact was experienced as supportive and appreciated (37-39, 42). Follow-up contact could provide parents with closure, improved coping and facilitated personal growth (35, 36). Some parents felt unable to return to the hospital or that the follow-up meeting left them with unanswered questions (39)
Providing peer support	• Facilitating contact with peers/support groups (34, 36, 37, 39, 43) • Mindfulness based intervention, cognitive behavioural therapy based and group retreat (43)	• Parents value peer support and expressed a desire to have contact with other families that lost a child (36, 42). Peer support reduced a sense of isolation, resulted in development of healing friendships, improved coping and allowed for personal growth (36) • peer support did not result in a significant change in psychosocial functioning and grief reactions (36) • Mindfulness: showed no significant effect (43) • Cognitive behavioural therapy group: significant reduction in overall grief symptoms in the intervention group (43). • Group retreat: Participating parents showed a significant decrease in depressive symptoms, significant improvement in perceived quality of life and no change in perceived social support (43)
Providing education and information	• Information(sessions), videos folders and booklets (34, 36, 37, 43) • Financial advice (34, 36) • Educational support meetings for peers and relatives (34) • Seminars or workshops on coping and grief (34) • Being involved in developing training sessions and research (37)	• Parents appreciated being involved in the development and administrating of bereavement education programs and interventions (37) • Parents expressed a need for more preparation for death and bereavement (42)
Providing remembrance activities	• Memorial ceremonies or services (34, 36, 37) • HCPs attending the funeral (34, 37)	• Having HCPs attend the funeral may enhance parents' feelings of support from the hospital (35)
Offering therapies	• Therapeutic intentional touch (43) • Expressive art therapy (43) • Referral for individual counselling (36)	• Parents expressed a need for bereavement mental health support in addition to follow-up (37)

active control, or wait-list control [32]. The psychological interventions showed significant improvement in parenting behaviour post-treatment, this effect did not sustain at follow-up (low quality evidence) [32]. Additionally, psychological interventions did improve parent mental health at follow-up, this effect was not seen directly after treatment (very low quality evidence) [32].

Evidence on effect of cultural, spiritual, and religious support

Two RCTs described interventions directed at providing spiritual support [33, 34]. Iranian mothers of children with cancer received a spiritual training package comprising of seven 90-min group sessions and reported less stress, anxiety, and depression post-treatment in comparison to the wait-list control group (very low quality

evidence) [33]. All outcomes remained decreased at three month follow-up, but the effect was only found to remain significant for anxiety (very low quality evidence) [33]. Additionally, an educational spiritual intervention consisting of six 45-min educational sessions on cancer disease, diagnosis, treatment, side effects, diet, spirituality, and meaning-making, decreased burn-out scores among parents of children with cancer (very low quality evidence) [34].

Evidence on preloss and bereavement care interventions

One RCT reported on a preloss and bereavement care intervention comprising of three components including a support package with information, peer supporter's contact via telephone, and contact with a health care

Table 3 Conclusions of evidence on communicative strategies during the child's end-of-life and after death

Communicative strategies for parents and family during the child's end-of-life and after death [#]		
Strategy	Positively labeled	Negative labeled
Provision of communication/information	- Honest and straightforward communication (38, 42) - Provision of complete information (38) - Provision of information in understandable language (35, 39) - Timely provision of information (35, 39) - Facilitating privacy (38)	- Parents receiving inadequate and incomplete information about the child (including autopsy results) (38) - Parents receiving conflicting information (39, 41) due to involvement of a number of HCP (39) - Parents receiving emotional information in a public area (38)
Provision of emotional support	- Support, expression of emotions, kindness and compassion by HCPs who care for the child (35, 39, 42) - Showing dignity and respect (42) - Comforting the parents with a hug, smile or beverage (35) - Delivering difficult news in a sensitive and caring manner (42)	- Lack of sensitivity and empathy (38) - Lack of physical bereavement care (38) - Lack of emotional support and compassion: parents reported that nurses had difficulties supporting them emotionally when care shifted from curing to palliative care (38)
Provision of hope	- Maintenance of hope while accepting their child's prognosis (41, 42) - Not give up hope until it is clear that there is no other course (35)	Not reported
Provision of knowledge/expertise	HCPs have experience and show confidence in caring for the child (35)	Increased parental stress due to incompetence of HCPs, including HCPs not being able to understand the diagnosis, treatment or complications and to deal with equipment required to care for the child (35)
Provision of consistency and continuity of care (personnel)	- Access to medical staff day/night (39, 41) - Coordination and continuity of care (41) - Establishing the relationship between HCP and child facilitated death conversations (41)	- Inconsistency in HCPs near end of life (41) - Sense of being abandoned by HCPs (41)
Provision of sense of control	Personal control and authority over the child's death and life, helped parents with keeping fear and uncertainty within limits of tolerability (41). Provision of informational, emotional and instrumental support enhanced sense of control (41). Control was seen as a mediating factor in the oscillating passage from "preservation" towards becoming prepared to "let their child go" and a precondition for fulfilling parental tasks (41)	- Feeling unprepared for child's death (41) - Loss of control (39, 41)

[#] This table provides the conclusions of evidence described in the ten SRs of observational, mixed-method, or qualitative studies

Working groups	Sub working groups and clinical questions	Identified evidence	Recommendations
Psychosocial care	Psychological interventions - What is the effect of psychological interventions for children with life-threatening and life-limiting conditions? - What is the effect of psychological interventions for family members?	Psychological interventions 2 RCTs, 1 SR of RCTs 1 RCT, 2 SRs of RCTs	 Recommendations on psychological interventions N = 8
	Practical and social support What forms of practical and social support are effective for children with life-threatening and life-limiting conditions and their family members?	Practical and social support No studies	 Recommendations on practical and social support N = 8
	Cultural, spiritual, and religious support What forms of cultural, spiritual, and religious support are effective for children with life-threatening and life-limiting conditions and their family members?	Cultural, spiritual, and religious support 2 RCTs	 Recommendations on cultural, spiritual, and religious support N = 11
Preloss & bereavement care	What is the effect of preloss interventions for children with life-threatening and life-limiting conditions and their family members and bereavement care interventions for family members?	1 RCT	 Recommendations on preloss and bereavement care for parents N = 13
	- Which components are used in preloss and bereavement care interventions? - What are the experiences and needs of parents and health care providers with regards to components of preloss and bereavement care interventions? - Which communicative strategies can support parents and family members during the end of life and after the death of the child?	10 SRs of observational, mixed-method, or qualitative studies	 Recommendations on preloss and bereavement care for children N = 8

 Strong recommendations to do

Fig. 1 Identified evidence and recommendations per working group and clinical question

provider two to six weeks after death of the child [35]. The preloss and bereavement care intervention had no significant effect on grief reactions among mothers whose children died at age three or younger.

Evidence on components of preloss and bereavement care interventions, and communicative strategies

We included ten SRs of observational, qualitative, or mixed-method studies that reported on preloss and bereavement care intervention components for parents during the child's end-of-life and after the child's death [36–45]. We identified eight preloss and bereavement care intervention components including 1) acknowledging the child's life and identity 2) acknowledging and enabling parenthood, 3) establishing keepsakes, 4) establishing follow-up contact with health care providers, 5) providing peer support, 6) providing education and information, 7) providing remembrance activities, and 8) offering therapies. For each component, we described the reported corresponding actions that could be taken. For example, studies described the following actions to acknowledge the child's life and identity: providing the child with a certificate of life, providing the child with a blessing ceremony, acknowledging the child's identity by learning individual needs and routines, and acknowledging birthdays, holidays, and anniversaries. Furthermore, we identified experiences and needs related to these components that were expressed by parents and health care providers. Generally, parents and health care providers experienced the identified preloss and bereavement care intervention components as desirable or helpful during the end-of-life and after the child's death. For example, with regard to the component 'acknowledging and enabling parenthood', parents reported they desired to maintain a relationship with their child during the end-of-life and wished to be actively involved in the child's care during this time. Moreover, most parents expressed that washing, holding, or dressing the child during the end-of-life and after the child's death is helpful and valuable, but also emotionally difficult. They expressed that support and reassurance from health care providers to spend time with their child during the end-of-life and after the child's death is needed. Table 2 summarises the preloss and bereavement care intervention components, specific actions, and corresponding experiences and needs reported by parents and health care providers.

Furthermore, the studies reported on a number of communicative strategies that provided support to parents during the child's end-of-life and after the child's death. We identified following strategies including provision of 1) communication, 2) emotional support, 3) hope, 4) knowledge, 5) consistency and continuity of care, and 6) sense of control. For each strategy we summarised

positively and negatively labelled aspects that were reported in the SRs. For example, with regards to provision of communication, honest and straightforward communication was positively labelled, while the communication of inadequate and incomplete information about the child was labelled as negative. In Table 3, we provide an overview of these strategies and the reported positive and negative aspects.

Translating evidence into recommendations

The guideline development panel formulated 27 recommendations on psychosocial care including psychological interventions ($n = 8$), practical and social support ($n = 8$), and cultural, religious, and spiritual support ($n = 11$). Furthermore, a total of 21 recommendations were formulated on preloss and bereavement care. Recommendations were based upon evidence, existing guidelines, clinical expertise, and patient and family values. Table 4 provides an overview of all formulated recommendations. We indicated for each recommendation whether it was supported by evidence.

Recommendations on psychological interventions

The evidence showed that some psychological interventions can improve certain psychosocial outcomes in both children with life-threatening and life-limiting conditions and their parents [28–32]. In the identified evidence, we found a large variability in intervention characteristics and measured outcomes [28–32]. Additionally, the quality of evidence was often rated as very low. Therefore, the guideline development panel was unable to recommend specific psychological interventions. Nevertheless, the panel recognised that psychological support could facilitate children with life-threatening and life-limiting conditions and their families in processing their experiences, concerns, and thoughts and formulated recommendations based on clinical expertise and patient values, considering the principles of good clinical practice. To facilitate appropriate psychological support, the panel stated that the health care provider who has the ultimate responsibility for the patients care (primary health care provider), should be responsible for timely initiation of psychosocial care in consultation with the family (recommendation 1, 9, 28). Moreover, the panel emphasised that psychological support should be tailored to the individual needs and preferences of child and family. The panel recognised that in order to tailor psychological support appropriately, attentiveness to the child's age, developmental stage, and changes in the child's condition is crucial. Furthermore, the panel highlighted the importance of providing clear information on emotional and psychological consequences of the child's disease trajectory and monitoring the wellbeing of siblings and other

Table 4 Recommendations on paediatric palliative psychosocial care interventions including preloss and bereavement care interventions

Recommendations on psychosocial care interventions, including preloss and bereavement care interventions for children aged 0 to 18 years with life-threatening and life-limiting conditions, their families, and health care providers (n=48)	
Psychosocial care	
Psychological interventions	
Do	1 The primary health care provider is responsible for initiating psychosocial care, but other health care provider can also identify and draw attention to the need for psychosocial care. The interpretation of psychosocial care takes place in consultation with the child, family, and multidisciplinary team.
	2 Provide clear information to child and family (including siblings) about the emotional consequences that may be appropriate for the child's condition.
	3 Be alert that child and family (including siblings) may have problems in the areas of: • Social emotional development. • Cognitive development. • Mental health.
	4 Be aware that it is important for children to have the space and opportunities in activities and conversations to be able to express themselves appropriate to their developmental stage about the experience of their illness and impending death. Note that there may be developmental differences in emotional responses, experiences and understanding of death.
	5 If emotional burden persists, refer child and family to expert psychosocial care services to help with the processing of profound experiences and stress, and assist with coping and building resilience. Consider a child life specialist, medical social worker, or a psychologist. To provide support for religious and spiritual suffering and answer questions on meaning, a spiritual counsellor may be consulted. ^{a, b}
	6 Actively monitor the wellbeing of siblings and provide appropriate support including practical and social support, educational, psychological, or cultural, spiritual, and religious support.
	7 Keep in mind that other family members (e.g. grandparents) and loved ones (e.g. friends, boyfriends, or girlfriends) who are important to the child and family may need support including practical and social support, educational, psychological, or cultural, spiritual, and religious support. Be aware that emotions of other family members and loved ones may also have a significant effect on child and family.
	8 Respond promptly to rapid changes in the child's condition, as children may need rapid access to psychosocial support including practical and social support, educational, psychological, or cultural, spiritual, and religious support.
Practical and social support	
Do	9 The primary health care provider is responsible for initiating psychosocial care, but other health care providers can also identify and draw attention to the need for psychosocial care. The interpretation of psychosocial care is made in consultation with the child, family, and multidisciplinary team.
	10 Strive for as much continuity in care providers as possible. Keep in mind that this is important for confidence in the care and provides peace of mind for children and their parents or health care providers.
	11 When having conversations with child and parents, such as when changes in the course of illness occur, it is important to: • Allow time and space for emotions. • Provide honest and open information appropriate for the child and family. Also provide space for those who do not want to know • Establish what the parents and child already know.
	12 With changes in the course of illness, give parents the opportunity and space to reflect with health care providers on how they will communicate with the child and siblings. Help parents by creating this space.
	13 Inform parents about potentially confrontational questions that child or siblings may ask. Explain that parents do not have to have ready answers and can use the questions to find out more about what is on the child's or sibling's mind. Explain that parents do not have to hide their emotions from their child(ren). Children are usually perceptive to the feelings of their loved ones so hiding emotions can be confusing for a child. Explain to parents that they can explain to their children that they can grief and remain available to them.
	14 Be alert that children and parents have different needs regarding practical and social support and that these needs may change during the course of the illness. This may include the following: • Social support including attention to parenting, relationship with spouse or partner or sibling support. If necessary, involve a (medical) social worker, a child life specialist, psychologist, or spiritual counsellor. Also refer to peer to peer contact groups if necessary. • Material support including housing, home modifications, aids for medication administration or mobility and transportation. • Practical support such as access to respite care, attention to the work situation of parents or attention to the wishes of the child, family and loved ones. If necessary, engage wish foundations such as Make a Wish, Make a Memory, Living Memories Foundation. • Educational support including attention to educational facilities at home and in the hospital • Financial support including attention to financial and organisational issues.
	15 Be alert that health care providers may also need practical, social, and spiritual support
	16 Discuss necessary practical arrangements with parents or health care providers after their child's death and provide them with written information. Emphasise that things may feel different after death and that arrangements can always be adjusted. These may include arrangements regarding: • care of the body.

Table 4 (continued)

	• funeral preparations. • postmortem examination. • relevant legal considerations, including: ○ the involvement of a 'child death overview panel'. ○ mandatory notification of the coroner after death. ○ determination of the death
Cultural, spiritual, and religious support	
Do	17 In discussions with children and their parents, investigate whether there are aspects of their religious or philosophical beliefs that should be considered in care, especially in decision-making about treatment options. ^a
	18 Ask about the uniqueness and specialness of the child and the specific meaning-making of parents, especially with regard to their child's quality of life and his or her place in the family.
	19 Explore whether children and their parents would like to talk to someone about their beliefs and values (e.g., cultural, spiritual, and religious). Refer to a spiritual counsellor for this purpose, if necessary.
	20 Consider and enquire about what rituals are performed and what needs the children and parents may have, especially in the terminal phase.
	21 Be open to spiritual experiences that may play a role in children and families without being linked to religion or a philosophical framework. Ask what is meaningful, and important to them at this time.
	22 Be alert to the influence of culture and, if parents wish, include their family or other people in their network in communication around decision making, as they may otherwise exert an unseen influence on the decision-making process.
	23 Be open to the fact that parents have the right to "consciously not want to know". Also provide space when parents want to know more.
	24 Be aware that certain terminology can create misunderstandings. For example, "We are going to discontinue treatment" suggests that treatment is available but is being withheld from this child.
	25 Be aware that in many cultures the child's spiritual well-being takes precedence over the importance of hearing the truth and that for religious reasons it may be difficult for parents to agree to discontinue treatment.
	26 Keep in mind that if parents hold out hope for a good outcome until the end it does not mean that they have not heard or understood the bad news.
	27 Engage a spiritual counsellor when uncertain about the appropriate approach to people of a different culture or religion or for information about performing rituals.
Preloss and bereavement care	
Preloss and bereavement care for parents	
Do	28 The primary care provider is responsible for initiating preloss and bereavement care conversations. In consultation with child, family and multidisciplinary team including primary care providers, it is ensured that the desired preloss and bereavement care conversations take place.
	29 Loss is what parents experience as loss; this can vary from person to person. Be alert to loss experiences from the time the child is suspected of a serious condition until well after the child's death.
	30 Be alert to parents' experiences of loss, even some interventions may feel like a step backwards to parents and thus a loss. Provide support if parents need it.
	31 During the end of life of their child and in crisis situations, parents usually try to remain strong to support their child and to cope with the situation. During this period, parents may deeply suppress their own emotions. Assist and support parents to cope at this time.
	32 Explain to parents what normal grief reactions to expect from themselves and other people. Grief reactions are normal reactions in an abnormal situation. ^c
	33 Offer parents emotional peace of mind during the palliative phase. Designate one or two health care providers who will talk with parents about their feelings of loss and grief if the parents have the capacity to do so. Be sensitive to what the parents need, for example, is their coping more loss-oriented or recovery-oriented. Other health care providers can keep the atmosphere lighter and less serious unless parents initiate a deeper conversation.
	34 Be quick to recognise signals from parents, such as questions or comments, that parents want to talk about loss or deeper concerns.
	35 Whenever possible, discuss parents' wishes, the child's prognosis, and loss at arranged times. This ensures that parents know when to prepare emotionally for such a conversation and when parents should not expect it. ^c
	36 Make parents feel safe and secure in their child's palliative journey by: seeing and acknowledging the child, approaching parents as equal partners, not making decisions apart from parents, and keeping parents fully informed. ^c
	37 Actively offer initiatives or information to parents about possible support in terms of choices that can be made, making memories, loss and grief, and support options for parent and family. ^c
	38 Discuss how parents want to say goodbye to their child. Consider cultural differences. Discuss whether there are religious aspects that are important in dealing with loss and mourning and what health care providers can do/contribute to that regard.
	39 Prepare parents for winding down and stopping support from regular health care providers and transferring care. Ensure that parents continue to feel supported immediately after the death and the ensuing bereavement period, and that parents know how they can access additional support. ^c

Table 4 (continued)

	40 Provide space for parents to have multiple preloss and bereavement care conversations with health care providers who were involved in their child's care before, during and after death. Because children receive care and treatment in different settings, this may require multiple conversations with different health care providers. Ensure the presence of familiar health care providers who can reflect on the child's life and identity, answer questions, and go through the illness and death process and the process of decision-making. ^c
Preloss and bereavement care for children	
Do	41 Explore with parents whether or not and how they want to talk to their children about the approaching end-of-life and death. ^c
	42 Explain to children in developmentally appropriate ways what is going on and what will happen.
	43 Give the child the opportunity to express their emotions and feelings to a trusted adult outside the family.
	44 Involve siblings at the time of death by giving them a meaningful task appropriate to their developmental age and level of responsibility.
	45 Help children regulate and normalise emotions by assigning words to behavioural expressions of emotions.
	46 Help siblings find a way to adequately express their emotions.
	47 Children grieve intermittently. At times they experience the loss and at other times the loss does not exist for a while. Support children in this and also accept that children quickly turn their attention to other activities.
	48 Children's conceptualisation of death changes and develops as they mature. As a result, after several months or years, a child may have to process new aspects of their grief and new questions may arise.

^a For this recommendation, very low to low quality evidence was identified

^b For this recommendation, moderate quality evidence was identified

^c For this recommendation, evidence from systematic reviews of observational, qualitative, or mixed-method studies was identified

family members actively (recommendation 2–7, 11, 12). The panel realised that the considerations used are not only essential in provision of psychological support but are the basis for provision of practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care as well.

Recommendations on practical and social support

We found no evidence on the effects of practical and social support for children with life-threatening and life-limiting conditions and their family. Therefore, the guideline development panel formulated recommendations based on the NICE-guideline, clinical expertise, and patient and family values. With regards to practical and social support, low to moderate quality evidence from the NICE guideline showed that support for accessing care, and support from family members and local communities is helpful, as reported by parents. The panel acknowledged this and recommended that tailored practical and social support should be offered to the child and family. Additionally, the panel strongly recommended that when having conversations with child and family, health care providers should establish carefully what child and family already know, allow space, and time for emotions, and prepare parents on difficult questions children might ask (recommendation 11, 13). Furthermore, very low to moderate quality evidence from the NICE-guideline showed that parents and other family members greatly benefited from respite care but had difficulties to access it. Both parents and health care providers indicated that awareness and understanding of the benefits of respite care is

important. The panel recognised that child and family do not always know what forms of practical support exist. They recommended that the child and family should be informed about existing and available practical support, such as respite care, financial support, and support at work (recommendation 14). Also, moderate quality evidence from the NICE-guideline showed that parents appreciated support that was provided before and after their child's death. Moreover, they appreciated continuity in care and staff during the end-of-life and after their child's death. Therefore, the panel recommended to discuss arrangements that can be made prior to and after the child's death (recommendation 16). Moreover, they highlighted the importance of providing continuity in health care providers as much as possible to create trust and peace of mind (recommendation 10). Finally, the panel emphasised that not only child and family but also health care providers might need practical and social support (recommendation 15).

Recommendations on cultural, spiritual, and religious support

We found very low quality evidence that (educational) spiritual trainings can improve psychosocial outcomes [33, 34]. The effectivity of these interventions was studied in populations with cultural, religious, and spiritual backgrounds that were different from the Dutch population [33, 34]. Therefore, the guideline development panel was unable to state whether these same interventions would be effective for child and family in the Netherlands and therefore could not recommend these specific spiritual

interventions. Additionally, very low to moderate quality evidence in the NICE guideline showed that parents reported a wide variety in their attitudes and needs regarding cultural, spiritual, and religious support, and experienced benefits and difficulties with regard to one's beliefs. Moreover, parents reported the use of different aphorisms, rituals, and practices. As a result, the panel could not give recommendations on specific needs and preferences related to cultural, spiritual, and religious support. Instead, the panel emphasised that health care providers should consider and explore child and families' cultural, spiritual, and religious beliefs, needs, values and wishes and that child and family should have access to cultural, spiritual, and religious support (recommendations 19, 21). The panel emphasises this is especially essential during decision-making, communication of bad news and meaning-making (recommendation 17, 18, 22–26). Spiritual counsellors can support child and family, regardless of their background, when existential questions may arise. Therefore, the panel recommended to engage a spiritual counsellor if necessary (recommendation 27).

Recommendations on preloss and bereavement care

We found very low quality evidence from one RCT, that a preloss and bereavement care intervention, comprising of a support package and health care provider or peer contact, had no significant effect on grief reactions among mothers [35]. From the evidence derived from ten SRs, we identified multiple preloss and bereavement care intervention components and communicative strategies that were experienced as helpful or desirable by both parents and health care providers (Tables 2 and 3) [36–45]. Based on these results, the guideline development panel emphasised the importance of offering preloss and bereavement care to children with life-threatening and life-limiting conditions and their family. Furthermore, the panel highlighted the importance of understanding the extent of losses that parents encounter. As parental coping with loss and grief entails both containing feelings of grief and experiencing them, losses may be more intertwined with daily experiences than health care providers may be aware of. Therefore, the panel recommended health care providers to be alert to the losses that parents experience, which vary per person (recommendation 29, 30). Moreover, the panel recognised that health care providers can have a great impact on how parents experience the child's end-of life and can support parents by engaging in conversation with time and attention and seeing the child as a person and family as a whole. It is recommended for health care providers to inform parents on grief reactions, attune their care to the parents' coping, to be sensitive to signals from parents, to discuss child

and family wishes at arranged times, and to be attentive to the impact of culture, spirituality and religion on loss and grief (recommendation 31, 32). Furthermore, health care providers should offer time and space to talk about feelings of loss and grief. However, they should be careful not to disrupt the parents' coping by, for instance, postponing the exploration of grief when parents are in need of containing their grief. Therefore, the panel recommended to appoint a few health care providers that explore the topic of loss and grief with parents so that others may offer them some respite on the topic (recommendation 33). Based on the identified preloss and bereavement care components and communicative strategies that parents and health care providers perceived as desirable, the panel recommended to make parents feel safe and secure by seeing and acknowledging the child, to actively offer information about possible support, and to provide multiple preloss and bereavement care conversations over time (recommendation 34–38). Health care providers play an important role in the continuity of care and support after the child's death. During follow-up conversations, they can support parents to build a narrative around their child's (end-of-) life, by acknowledging the child's identity, discussing the disease trajectory, exploring future needs regarding bereavement care, and facilitating the parents to provide feedback (recommendation 39, 40).

Finally, the panel emphasised the importance of supporting the sick child and sibling during experiences of loss, grief, and bereavement. It is recommended to explore with parents whether or not and how to talk to their children about approaching end-of-life, to explain to children what will happen in a developmentally appropriate way, to give the child the opportunity to express emotions and feelings, to involve siblings at the time of death by giving them a meaningful task, and to help children and siblings regulate emotions by assigning words to expressions or emotions (recommendation 41–46). Furthermore, the panel highlighted that children often grief intermittently and conceptualisation of death may change as children mature and recommend health care providers to consider this when providing support, which may also include prolonging support over a longer period of time as children grieve new losses as they reach new developmental stages (recommendation 47, 48).

Discussion

It is widely recognised that a child's diagnosis with a life-threatening or life-limiting condition impacts the psychosocial functioning of the child and the entire family [8]. This is not only relevant during the child's life, but also after the death of the child [19, 46]. Provision of

psychosocial care including preloss and bereavement care is essential for child and family, enhances quality of life and is often mentioned as being a crucial part of paediatric palliative care [7, 8, 15, 16]. However, studies frequently report a lack of attention to psychosocial care including preloss and bereavement care [8, 20]. In this paper, we present the identified evidence and provide recommendations to optimise psychosocial care including psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care in paediatric palliative care. Below, we discuss the methods used, the identified evidence, and the provided recommendations.

We formulated recommendations through an evidence-based approach using different methods. First, we systematically searched for quantitative evidence on effectivity of paediatric palliative care interventions in SRs of RCTs and CCTs, RCTs, and CCTs. We identified eight studies reporting on effectivity of psychological interventions, spiritual training interventions, and a bereavement care intervention [28–35]. The quality of the total body of evidence was rated as very low to moderate. We also included evidence from ten SRs of observational, qualitative, or mixed-method studies on preloss and bereavement care [36–45]. Unfortunately, our clinical questions could be only partly answered with the identified evidence.

Second, since we identified limited evidence, we used the conclusions of evidence, considerations, and recommendations on paediatric palliative care from the NICE-guideline to refine considerations and inform our recommendations [26]. Finally, we formulated all recommendations in close collaboration with a national multidisciplinary guideline development panel consisting of professionals from multiple disciplines and parents. If no or limited evidence or no existing guidelines were available, the recommendations were based upon clinical expertise and patient and family values only. By using different sources of knowledge, i.e. the identified evidence, existing guidelines, clinical expertise, and patient and family values, we were able to compile a comprehensive set of strong recommendations that provide guidance on psychosocial care including preloss and bereavement care.

The identified studies described the effects of a variety of interventions related to psychosocial care, of which only some interventions were found to significantly improve certain psychosocial outcomes in children with life-threatening and life-limiting conditions or their parents. As a result, we identified multiple gaps of knowledge. First, the majority of the studies reported on effects of psychological, spiritual, and preloss and bereavement care interventions among parents. Only three studies

focused on the effectivity of psychological interventions among children. The majority of conclusions of evidence were rated as very low quality evidence. Additionally, we found no evidence on practical and social support among both children with life-threatening and life-limiting conditions and their family. Finally, we have found no evidence on the effectivity of any psychosocial care interventions among siblings. Both social and practical support including respite care and psychosocial care interventions for siblings have been well documented knowledge gaps but are yet to be addressed [12, 16, 18, 46, 47]. We acknowledge that due to the small numbers of children who need paediatric palliative care, diversity of diseases, vulnerability of the population and ethical issues, conducting studies in this vulnerable patient population is very challenging [48]. Therefore, we urge for international collaboration to conduct well-designed multisite parallel RCTs to address these knowledge gaps.

Moreover, we found a large variability in reported psychosocial outcomes and outcome measurements, which made it difficult to compare the effectivity of interventions. As a result, we could not draw a definitive conclusion on which intervention can best be used. This was in line with the findings of a recent SR that reported significant heterogeneity in used outcomes in paediatric palliative care [49]. In this SR, 136 outcomes in 46 outcome domains were used to measure the effect of specialised paediatric palliative care interventions [49]. In order to improve comparability between interventions, we suggest developing a standard set of outcome indicators for paediatric palliative care with harmonised outcome definitions and measurement tools [50]. To ensure that the standard set of outcome indicators represents the values and needs of patient, family, and health care providers, all stakeholders should be involved in selecting the outcome indicators [50]. Adopting this standard set of outcomes for paediatric palliative care across organisations and countries, could facilitate the identification of best practices and further improve quality of paediatric palliative care worldwide.

With regard to the translation of evidence into recommendations, a few points should be addressed. First, it should be noted that evidence published from 1970 to 2020 was included in this guideline. As a result, it is possible that we missed some recently published studies. However, given the limited and generally low-quality evidence we found over this large time frame, it is likely that only a small number of studies were missed. We expect that this will not significantly change the recommendations. Nonetheless, there is a possibility that some recommendations might become outdated when new evidence emerges. Guideline development is a time-consuming

process, making it challenging to respond to newly published evidence rapidly. To address this, we propose the development and use of automated tools for identifying and appraising evidence for improving efficiency of future guideline updates, allowing an update of a recommendation as soon as new relevant evidence becomes available [51, 52].

Furthermore, due to the lack of evidence, the majority of the recommendations was based upon clinical expertise and patient and family values only. Often, these recommendations are viewed negatively and are considered less trustworthy [53]. However, the incorporation of clinical expertise and patient and family values in clinical decision-making is one of the core principles of evidence-based medicine [54, 55]. As a result, clinical expertise and patient and family values are essential components for interpreting evidence and formulating recommendations. However, it is important to note that recommendations based upon clinical expertise can be prone to personal bias [56]. Therefore, we ensured that the recommendations were developed through a careful process in which only recommendations on which there was group consensus were approved. Unfortunately, the clinical expertise and patient values were not systematically collected. To further improve transparency of recommendations based on clinical expertise and to limit personal bias, using surveys to systematically and independently identify expert opinions and patient values could be an opportunity [56].

Additionally, when translating evidence into recommendations, it became very clear that psychosocial care including psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care is considered beneficial for all children with life-threatening and life-limiting conditions and their families. Psychosocial care including preloss and bereavement care should not only be offered to every child and family but should also be tailored to the child and family as a whole. We recognise that provision of tailored psychosocial care, requires adequate staffing, time, funding, and education on the importance of psychological, social, and spiritual needs assessment and support [16, 57–59]. We emphasise that addressing these issues is a precondition for application of recommendations in clinical practice [59]. We believe a large proportion of these recommendations will be applicable in other countries and can be used to optimise psychosocial care including preloss and bereavement care. However, we recognise that country and culture specific factors should be carefully considered before applying any recommendations.

Furthermore, it is increasingly recognized that caring for children who are suffering, and their families can lead to

distress and burnout among health care providers [9, 16]. Health care providers who provide paediatric palliative care should receive support to prevent distress, compassion fatigue, and burnout. However, there remains a lack of studies on the effectivity of interventions aiming to prevent distress and burnout among health care providers [9, 16]. We strongly urge for more research on this topic to formulate evidence-based recommendations.

In conclusion, with the provided recommendations, we aim to optimise psychosocial care including preloss and bereavement care for children with life-threatening and life-limiting conditions and their families. We identified that psychosocial care requires a personal approach tailored to the child and family. We urge for more research on effectiveness of psychosocial care, including psychological interventions, practical and social support, cultural, spiritual, and religious support, and preloss and bereavement care interventions among children with life-threatening and life-limiting conditions and parents, but also in siblings. Furthermore, although very challenging, we propose implementing strategies to improve research and thereby further optimise the quality of paediatric palliative care. These strategies include the development of a standard set of outcomes and international collaboration to conduct well-designed multisite RCTs.

Abbreviations

CPG	Clinical Practice Guideline
CCT	Controlled Clinical Trial
GRADE	Grading Recommendation Assessment Development and Evaluation
HR-QoL	Health-Related Quality of Life
NICE	National Institute of Health Care Excellence
PRISM	Promoting Resilience In Stress Management
PRISM-P	Promoting Resilience In Stress Management directed at Parents
RCT	Randomised Controlled Trial
SR	Systematic Review

Supplementary Information

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Supplementary Material 1.

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Author's contributions

KvT, RM, EV, LK, JV, HR, BB, and EM conceived and designed the study. KvT, RM, EK, and EM performed the search, data extractions, risk of bias assessment, and GRADE assessment. KvT, RM, EV, LK, JF, PH, EvdB, MK, EK, and EM interpreted the data. KvT, RM, EV, LK, JF, PH, EvdB, MK, JV, HR, BB, EK, and EM contributed to the formulation of the recommendations. KvT, RM, EV, LK, EK, and EM drafted the manuscript; and all authors (KvT, RM, EV, LK, JF, PH, EvdB,

MK, JV, HR, BB, EK, and EM critically revised the manuscript. All the authors and the collaborators approved the final version of this manuscript.

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Data availability

All data analysed during this study is included in this published article and additional information file 1.

Declarations

Ethics approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations, all participants in the study have given consent to participate. No institutional or other licensing committee's approval is needed for guideline creation, as participants are not subjected to procedures and are not required to follow rules of behaviour. Therefore, in accordance to the Dutch law (Medical Research Involving Human Subjects Act (WMO)), article 1b) ethics approval was deemed unnecessary: <https://english.ccmo.nl/investigat/ors/legal-framework-for-medical-scientific-research/your-research-is-it-subje-ct-to-the-wmo-or-not>.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- Vallianatos S, Huizinga CSM, Schuiling-Otten MA, Schouten-van Meeteren AYN, Kremer LCM, Verhagen AAE. Development of the Dutch Structure for Integrated Children's Palliative Care. *Children* (Basel). 2021;8(9):741.
- Arias-Casais N, Garralda E, Rhee JY, de Lima L, Pons JJ, Clark D, et al. EAPC Atlas of Palliative Care in Europe 2019. Vilvoorde: EAPC; 2019. Available from: <http://hdl.handle.net/10171/56787>. Cited 2021 July, 21.
- Constantinou G, Garcia R, Cook E, Randhawa G. Children's unmet palliative care needs: a scoping review of parents' perspectives. *BMJ Support Palliat Care*. 2019;9(4):439–50.
- Fraser LK, Bluebond-Langner M, Ling J. Advances and Challenges in European Paediatric Palliative Care. *Medical Sciences*. 2020;8(2):20.
- World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers. Geneva: World Health Organization; 2018.
- Marcus KL, Kao PC, Ma C, Wolfe J, DeCoursey DD. Symptoms and Suffering at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage*. 2022;63(1):88–97.
- Wolfe J, Orellana L, Ullrich C, Cook EF, Kang TI, Rosenberg A, et al. Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study. *J Clin Oncol*. 2015;33(17):1928–35.
- Wiener L, Devine KA, Thompson AL. Advances in pediatric psychooncology. *Curr Opin Pediatr*. 2020;32(1):41–7.
- Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet*. 2008;371(9615):852–64.
- Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel EJ, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA*. 2000;284(19):2469–75.
- Balkin EM, Wolfe J, Ziniel SI, Lang P, Thiagarajan R, Dillis S, et al. Physician and parent perceptions of prognosis and end-of-life experience in children with advanced heart disease. *J Palliat Med*. 2015;18(4):318–23.
- Weaver MS, Heinze KE, Kelly KP, Wiener L, Casey RL, Bell CJ, et al. Palliative Care as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. 2015;62 Suppl 5(Suppl 5):S29–33.
- Wolfe J, Hammel JF, Edwards KE, Duncan J, Comeau M, Breyer J, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol*. 2008;26(10):1717–23.
- Jones BL. Companionship, control, and compassion: a social work perspective on the needs of children with cancer and their families at the end of life. *J Palliat Med*. 2006;9(3):774–88.
- Scott HM, Coombes L, Braybrook D, Roach A, Harðardóttir D, Bristowe K, et al. Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliat Med*. 2023;37(6):856–65.
- Koch KD, Jones BL. Supporting Parent Caregivers of Children with Life-Limiting Illness. *Children* (Basel). 2018;5(7):85.
- Shelkowitz E, Vessella SL, O'Reilly P, Tucker R, Lechner BE. Counseling for personal care options at neonatal end of life: a quantitative and qualitative parent survey. *BMC Palliat Care*. 2015;14:70.
- Weaver MS, Heinze KE, Bell CJ, Wiener L, Garee AM, Kelly KP, et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliat Med*. 2016;30(3):212–23.
- DeCoursey DD, Silverman M, Oladunjoye A, Balkin EM, Wolfe J. Patterns of Care at the End of Life for Children and Young Adults with Life-Threatening Complex Chronic Conditions. *J Pediatr*. 2018;193:196–203.e2.
- Brouwer M, Maeckelberghe ELM, van der Heide A, Hein I, Verhagen E. Barriers in care for children with life-threatening conditions: a qualitative interview study in the Netherlands. *BMJ Open*. 2020;10(6):e035863.
- Grimshaw JM, Russell IT. Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations. *The Lancet*. 1993;342(8883):1317–22.
- Lugtenberg M, Burgers JS, Westert GP. Effects of evidence-based clinical practice guidelines on quality of care: a systematic review. *Qual Saf Health Care*. 2009;18(5):385–92.
- Grimshaw JM, Thomas RE, MacLennan G, Fraser C, Ramsay CR, Vale L, et al. Effectiveness and efficiency of guideline dissemination and implementation strategies. *Health Technol Assess*. 2004;8(6):iii–iv, 1–72.
- van Teunenbroek KC, Kremer LCM, Verhagen AAE, Verheijden JMA, Rippen H, Borggreve BCM, et al. Palliative care for children: methodology for the development of a national clinical practice guideline. *BMC Palliat Care*. 2023;22(1):193.
- Atkins D, Best D, Briss PA, Eccles M, Falck-Ytter Y, Flottorp S, et al. Grading quality of evidence and strength of recommendations. *BMJ*. 2004;328(7454):1490.
- National Institute for Health and Care Excellence. End of life care for infants, children and young people with life-limiting conditions: planning and management. London: NICE; 2016 [updated 2019, July 25]. Available from: <https://www.nice.org.uk/guidance/ng61>. Cited 2023, May 8.
- Gibbons RJ, Smith S, Antman E. American College of Cardiology/American Heart Association clinical practice guidelines: Part I: where do they come from? *Circulation*. 2003;107(23):2979–86.

28. Rosenberg AR, Bradford MC, Barton KS, Etsekson N, McCauley E, Curtis JR, et al. Hope and benefit finding: Results from the PRISM randomized controlled trial. *Pediatr Blood Cancer*. 2019;66(1): e27485.
29. Steineck A, Bradford MC, Lau N, Scott S, Yi-Frazier JP, Rosenberg AR. A Psychosocial Intervention's Impact on Quality of Life in AYAs with Cancer: A Post Hoc Analysis from the Promoting Resilience in Stress Management (PRISM) Randomized Controlled Trial. *Children (Basel)*. 2019;6(11):124.
30. Rosenberg AR, Bradford MC, Junkins CC, Taylor M, Zhou C, Sherr N, et al. Effect of the Promoting Resilience in Stress Management Intervention for Parents of Children With Cancer (PRISM-P): A Randomized Clinical Trial. *JAMA Netw Open*. 2019;2(9): e1911578.
31. Goldbeck L, Fidika A, Herle M, Quittner AL. Psychological interventions for individuals with cystic fibrosis and their families. *Cochrane Database of Systematic Reviews*. 2014;2014(6):CD003148.
32. Eccleston C, Fisher E, Law E, Bartlett J, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Syst Rev*. 2015;4(4):CD009660.
33. Borjalilu S, Shahidi S, Mazaheri MA, Emami AH. Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of Caregivers. *Asian Pac J Cancer Prev*. 2016;17(2):545–52.
34. Beheshtipour N, Nasirpour P, Yektatalab S, Karimi M, Zare N. The effect of educational-spiritual intervention on the burnout of the parents of school age children with cancer: a randomized controlled clinical trial. *International journal of community based nursing and midwifery*. 2016;4(1):90.
35. Raitio K, Kaunonen M, Aho AL. Evaluating a bereavement follow-up intervention for grieving mothers after the death of a child. *Scand J Caring Sci*. 2015;29(3):510–20.
36. Kochen EM, Jenken F, Boelen PA, Deben LMA, Fahner JC, van den Hoogen A, et al. When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. *BMC Palliat Care*. 2020;19(1):28.
37. Sieg SE, Bradshaw WT, Blake S. The Best Interests of Infants and Families During Palliative Care at the End of Life: A Review of the Literature. *Adv Neonatal Care*. 2019;19(2):E9–14.
38. Donovan LA, Wakefield CE, Russell V, Cohn RJ. Hospital-based bereavement services following the death of a child: a mixed study review. *Palliat Med*. 2015;29(3):193–210.
39. Lichtenthal WG, Sweeney CR, Roberts KE, Corner GW, Donovan LA, Prigerson HG, et al. Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. 2015;62(Suppl 5):S834–69.
40. Aschenbrenner AP, Winters JM, Belknap RA. Integrative review: parent perspectives on care of their child at the end of life. *J Pediatr Nurs*. 2012;27(5):514–22.
41. Longden JV. Parental perceptions of end-of-life care on paediatric intensive care units: a literature review. *Nurs Crit Care*. 2011;16(3):131–9.
42. Thornton R, Nicholson P, Harms L. Scoping Review of Memory Making in Bereavement Care for Parents After the Death of a Newborn. *J Obstet Gynecol Neonatal Nurs*. 2019;48(3):351–60.
43. Chong PH, Walshe C, Hughes S. Perceptions of a Good Death in Children with Life-Shortening Conditions: An Integrative Review. *J Palliat Med*. 2019;22(6):714–23.
44. Stevenson M, Achille M, Lugasi T. Pediatric palliative care in Canada and the United States: a qualitative metasummary of the needs of patients and families. *J Palliat Med*. 2013;16(5):566–77.
45. Dias N, Hendricks-Ferguson VL, Wei H, Boring E, Sewell K, Haase JE. A Systematic Literature Review of the Current State of Knowledge Related to Interventions for Bereaved Parents. *Am J Hosp Palliat Care*. 2019;36(12):1124–33.
46. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SK, Simon TD, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–38.
47. Bousso RS, Misko MD, Mendes-Castillo AMC, Rossato LM. Family Management Style Framework and Its Use With Families Who Have a Child Undergoing Palliative Care at Home. *J Fam Nurs*. 2012;18(1):91–122.
48. Tomlinson D, Bartels U, Hendershot E, Constantin J, Wrathall G, Sung L. Challenges to participation in paediatric palliative care research: a review of the literature. *Palliat Med*. 2007;21(5):435–40.
49. Marcus KL, Santos G, Ciapponi A, Comandé D, Bilodeau M, Wolfe J, et al. Impact of Specialized Pediatric Palliative Care: A Systematic Review. *J Pain Symptom Manage*. 2020;59(2):339–64.e10.
50. van Kalsbeek RJ, Hudson MM, Mulder RL, Ehrhardt M, Green DM, Mulrooney DA, et al. A joint international consensus statement for measuring quality of survival for patients with childhood cancer. *Nat Med*. 2023;29(6):1340–8.
51. Cheyne S, Fraile Navarro D, Hill K, McDonald S, Tunnicliffe D, White H, et al. Methods for living guidelines: early guidance based on practical experience. Paper 1: Introduction. *J Clin Epidemiol*. 2023;155:84–96.
52. Akl EA, Meerpohl JJ, Elliott J, Kahale LA, Schünemann HJ. Living systematic reviews: 4. Living guideline recommendations *J Clin Epidemiol*. 2017;91:47–53.
53. Ponce OJ, Alvarez-Villalobos N, Shah R, Mohammed K, Morgan RL, Sultan S, et al. What does expert opinion in guidelines mean? a meta-epidemiological study. *Evidence Based Medicine*. 2017;22(5):164.
54. Djulbegovic B, Guyatt G. Evidence-Based Medicine and the Theory of Knowledge. In: Guyatt G, Rennie D, Meade MO, Cook DJ, editors. *Users' Guides to the Medical Literature: A Manual for Evidence-Based Clinical Practice*, 3rd ed. New York, NY: McGraw-Hill Education; 2015;3:15–19.
55. Djulbegovic B, Guyatt GH, Ashcroft RE. Epistemologic inquiries in evidence-based medicine. *Cancer Control*. 2009;16(2):158–68.
56. Mustafa RA, Garcia CAC, Bhatt M, Riva JJ, Vesely S, Wiercioch W, et al. GRADE notes: How to use GRADE when there is "no" evidence? A case study of the expert evidence approach. *J Clin Epidemiol*. 2021;137:231–5.
57. Kazak AE, Abrams AN, Banks J, Christofferson J, DiDonato S, Grootenhuis MA, et al. Psychosocial Assessment as a Standard of Care in Pediatric Cancer. *Pediatr Blood Cancer*. 2015;62(Suppl 5):S426–59.
58. Steele AC, Mullins LL, Mullins AJ, Muriel AC. Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. 2015;62(Suppl 5):S585–618.
59. Benini F, Papadatou D, Bernadà M, Craig F, De Zen L, Downing J, et al. International Standards for Pediatric Palliative Care: From IMPaCCT to GOPPACS. *J Pain Symptom Manage*. 2022;63(5):e529–43.

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