PRELOSS AND BEREAVEMENT CARE IN PEDIATRICS

THE PARENTS' AND HEALTHCARE PROFESSIONALS' EXPERIENCES DURING THE CHILD'S END OF LIFE

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Eline Maria Kochen

Preloss and bereavement care in pediatrics The parents' and healthcare professionals' experiences during the child's end of life

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Preloss and bereavement care in pediatrics

The parents' and healthcare professionals' experiences during the child's end of life

Zorg voor verlies en rouw in de kindergeneeskunde
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van een kind
(met een samenvatting in het Nederlands)

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General Introduction

Losing a child is considered the most devastating loss any parent can experience. Throughout their child's palliative trajectory, parents are already confronted with incremental losses resulting in grief and distress. Healthcare professionals (HCPs) acknowledge the losses and feelings of grief that parents experience and want to support them to the best of their abilities. Yet how feelings of grief are experienced by parents during their child's end-of-life (EOL) phase and how to align the support to their needs, still remains unclear. This chapter provides an introduction on pediatric palliative care, bereavement care, experiences of parental losses and grief, and HCPs' perceptions on preloss and bereavement care. Lastly, the objectives, research questions and methods of this thesis will be presented.

PEDIATRIC PALLIATIVE CARE

Incidence

The survival of children with life-threatening or life-limiting diseases, conditions that cause a premature death, has increased due to medical advances.[1,2] Currently around 5000 to 7000 children in the Netherlands require pediatric palliative care.[3] Although care for seriously ill children has improved, children still die due to pre-term birth, trauma, or critical illness. Over the past decades, childhood death (between the ages of 0-20 years old) in the Netherlands, has decreased from 1.926 deaths in 1995 towards 1.063 deaths in 2020.[4] Approximately half of these deaths occur in young infants, and neonates, within their first year of life due to preterm birth, conditions originating in the prenatal period, and congenital anomalies. Another peak in childhood death is seen during adolescence due to accidents and suicides. Throughout childhood, mortality is caused by, among others, oncological, metabolic, cardiac and pulmonic diseases. This thesis focuses on preloss and bereavement care for parents of children of all ages who received care from a HCP in pediatrics during the EOL phase.

Pediatric palliative care

In 1998 the World Health Organization (WHO) defined pediatric palliative care as the active total care of the child's body, mind and spirit and also involves giving support to the family.[5] Palliative care is aimed at optimizing quality of life, and when the moment comes, a dignified death. For the patient and their family, it is important that care is aligned to their values, goals, preferences, and needs in four dimensions of care: physical, psychological, social and existential.[6] Pediatric palliative care starts with the diagnosis of a life-limiting or life-threatening illness. The pediatric palliative care trajectory can be further divided into four consecutive phases: the diagnosis, a relatively stable period in which often a 'new normal' is established, the decline in which symptoms start to accumulate, and the dying phase.[7,8] The latter two phases compose the EOL phase which is referred to, and focused on, in this thesis.

In the commonly used continuum of palliative care (figure 1)[9] it is shown that disease oriented care, which includes treating the disease, and symptom oriented care, which is aimed towards providing comfort care, may be provided simultaneously. Over time, the balance between disease oriented and symptom oriented care will shift more and more towards symptomatic treatment until in the dying phase, palliative care is completely focused on comfort. Yet pediatric palliative care is characterized by an erratic illness course; the disease trajectory is often not linear and the EOL phase is difficult to predict. Lastly, as presented in the continuum, follow-up care is provided to the bereaved family after the child's death.

In 2013, a national guideline on pediatric palliative care in the Netherlands was developed. In the guideline, the importance is stated of incorporating bereavement care during the palliative trajectory,[10] and not solely after the child's death, as presented in the model of palliative care.[9] Indeed, parents face multiple losses throughout the palliative trajectory, which accumulate during the EOL due to their child's decline and having to cope with the knowledge that they will have to live through the loss of their child.[7] However, what preloss care (e.g. care aimed at supporting parental grief during the EOL) would entail remains unclear, as guidance on this topic has not been developed yet.

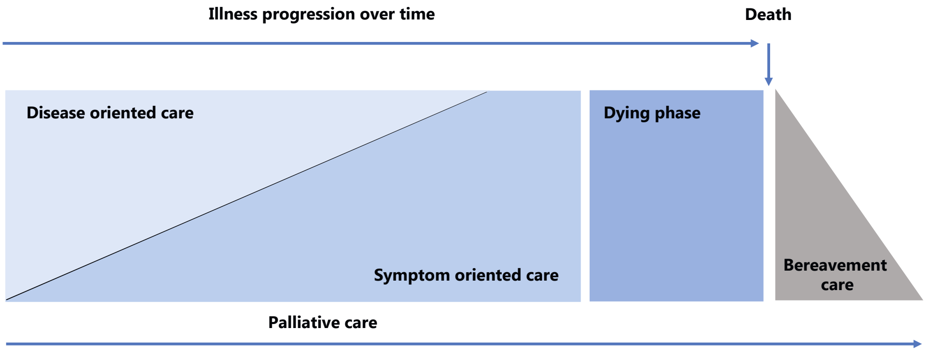

Figure 1. Continuum of palliative care, based on the model of Lynn and Adamson (2003) & guideline general principles of palliative care, Platform PAZORI (2017).[9,11]

Organization of pediatric palliative care in the Netherlands

Medical and technical advances have increased the life expectancy of many children with a life-limiting or life-threatening disease.[1,2] These children often rely on complex (long term) care provided by their parents and a variety of disciplines in first, second and third line care settings. It is widely accepted that the needs of ill children can best be met at home and an increasing number of children also die at home.[12,13] In the Netherlands, pediatric palliative care is primarily provided by regular HCPs (generalists in pediatric care), who are experts in their discipline and who are supported by specialists in pediatric palliative care. Due to the often complex medical care these children require, the treating physician of children who receive palliative care is mostly associated with one of the designated children's hospitals. All children's hospitals host their own pediatric palliative care team (in Dutch: 'KinderComfortTeam'); a multidisciplinary team that consists of, among others, pediatricians, nurses, child life specialists, psychologists, and chaplains.[14] Currently, there are eight of these teams, whose goal is to improve continuity, coordination, and quality of pediatric palliative care in the transition from hospital to home based care.[14,15] Furthermore, these teams are available for consultation to HCPs who provide palliative care and would require guidance or assistance, since generalist HCPs are usually not trained in providing such care. Although many teams aim to support parents and HCPs from the moment a child is in need of palliative care, throughout the end of life and in follow-up care after the child's death, the current focus is mostly on EOL and terminal care.

GRIEF AND BEREAVEMENT

The impact of grief

Grief is a natural emotional response following loss and bereavement, and encompasses a range of emotions such as feelings of anxiety, depression, sadness and despair.[16] What is considered a loss differs per person, but is defined as losing something or someone meaningful.[17] Early integration of care aimed at parental grief is necessary, not at the least because bereaved parents are at risk to develop adverse mental and physical health effects. Parents may develop symptoms of anxiety, depression, post-traumatic stress disorder, cardiac diseases, and even death.[18–21] These symptoms may be present until years after the loss of a loved one. Furthermore, 10 to 25% of parents are at risk to develop prolonged grief disorder, which is characterized as prolonged and persistent feelings of grief and difficulty in adjusting to the bereavement for which specialized aid is required.[22–24]

Theories on loss, grief and bereavement

Grief prior to the death of someone may be categorized in anticipatory grief, which is oriented at the future loss, and illness-related grief, which is oriented at the present and the (re)current losses.[25] Anticipatory grief encompasses the grief that is experienced in the time leading up till death,[17,26] characterized by separation-distress and anxiety about a future in which the loved person is no longer physically present. Chronic sorrow describes sadness, grief and related emotions in response to a significant loss, this grief is characterized by its period recurrence.[27] Chronic sorrow is thus the ongoing grief that is experienced by losses that have occurred and will occur in the future. However, the losses that parents experience during their child's EOL, how they experience and cope with grief, is less understood.

For a considerable time, the experience of grief and bereavement have been described as a linear process that had a start and an ending, in which several tasks or phases needed to be worked through sequentially. Theories came forth from different perspectives such as attachment theory, emotional tasks and the continuation of bonds.[28–31] Some examples that are still used in education and common believes nowadays are the phases of grief by Kubler Ross, explaining that people have to go through five stages of grief: denial, anger, bargaining, depression and acceptance,[30] and Worden's four tasks model: accepting the reality of the loss, processing the pain of the loss, adjusting to an environment where the deceased is missing, and finding a new emotional relation with the deceased to continue one's life.[31]

Since then, the paradigm on bereavement has shifted towards more fluent models that focus on the adjustments that parents have to make towards a new reality in which their child is no longer physically present.[32–37] This readjustment might take months to years to complete while the grief itself may never be resolved. Bereavement is no longer seen as stages that are sequentially experienced, but as a more fluent process of coping with the loss of someone with whom a meaningful relation exists. The loss needs to be integrated in parents' new reality and views on both the world and themselves. To accomplish the integration of the loss in one's life story or autobiographical memory, internal plans need to be adjusted which causes significant distress to parents.[32,33] Parents cope with these stressors by employing several coping strategies. Stroebe and Schut have developed the "dual-process model" which is currently widely used in explaining coping with grief after a loss.[34] Their model explains the non-linear nature of grief and the oscillating process of multiple coping strategies that are used in an alternating fashion. Coping oscillates between loss-oriented coping strategies such as grief work, intrusions and denial; and restoration-oriented coping strategies such as attending to life changes, doing new things and distracting from grief.

Summarizing, just like the presented model of palliative care which places bereavement care after the death, most studies on bereavement have focused on coping with loss after death and less is known about coping with grief prior to the death of a loved one. The grief that parents experience during their child's EOL is not yet understood. Losses do occur yet how parents experience those losses and their coping in the face of their child's death remains unclear.

PARENTAL EXPERIENCES OF LOSS AND GRIEF DURING THE END-OF-LIFE

During their child's EOL, parents are confronted with incremental losses. These losses start the moment that parents worry that something might be wrong with their child's health, accumulate throughout receiving a diagnosis, the loss of function, and they persist beyond their child's death.[7,38–41] Losses may be perceived in multiple domains. Some parents are confronted with their child's decline, their child becoming increasingly dependent, and watch their child being unable to participate in activities they previously enjoyed.[7,42] Other parents may feel alienated from normal life, their friends and family who cannot truly imagine life at the hospital and how life is taking care of their child.[39,40]

At the same time, parents acquire new roles in addition to their former parenting role. When their child gets diagnosed with a life-threatening or life-limiting illness, parents feel an increasing pressure to be a good parent by being present and the uptake of their role as informal carer.[7,43] New roles may include learning new medical skills to take care of their child, trying to make the best decisions for and with their child, and having to make adjustments at home and within their family-life.[40,44–48] Parents require support from their child's HCPs to acquire and sustain these new acquired roles. It is for example important that HCPs become aware of parents' changing goals, or their involvement as a partner in their child's care. Besides, HCPs are next to parents in the hospital during an admission, outpatient clinic visits, or while receiving bad news. Depending on the HCP, they might be able to support parents during these hardships. Also after their child's death, parents require and value ongoing support from their child's HCPs,[49,50] yet they experience that the delivery of such support practices is highly variable and depending on the HCP they encounter.[51] Parents call for continuous emotional support and guidance in preloss and bereavement care, yet the focus or foundations on which this care should rely needs to be further studied.[52]

CARE FOR PARENTAL LOSS AND GRIEF IN PEDIATRICS BY REGULAR HEALTHCARE PROFESSIONALS

HCPs in pediatrics mostly chose their profession because they want to help children and state they are trained to cure. Yet what if that ultimate goal becomes increasingly difficult to obtain? Most HCPs working in pediatrics are at some point confronted with the loss of their patients and have to guide them and their families throughout the palliative trajectory. In this thesis, we focus on the experiences of regular HCPs: HCPs who are not specialized in palliative, preloss, or bereavement care.

HCPs acknowledge that assisting parents and their patients throughout this journey is part of their job.[53] The Canadian Paediatric Society and the RCPSC Paediatric Specialty Committee created the CanMEDS roles.[54] CanMEDS roles are competency profiles in which all HCPs should be educated. The CanMEDS are also leading in the education profile of HCPs in the Netherlands. These roles state a need for HCPs to be trained to provide palliative and bereavement care, and that familiarizing themselves with these core competencies is indeed part of their responsibilities. However, studies conducted among physicians (in training) have shown that these competencies are among the few competencies that HCPs feel less secure in both regarding their knowledge and skills and regarding which they have received the least training.[55–57] HCPs hold back because they fear to do or say the wrong thing. They experience empty-handedness due to the lack of training and guidance which as a consequence increases restraints to deliver such care, although it is part of their professional role.[51,58–60] Despite the lack of guidance or interventions, HCPs do witness the hardship parents experience and in response have developed several support practices. However, these practices are highly varying between the individual HCPs and an insight into what these practices entail is missing.

One relatively well established form of bereavement care has been developed to support parents after the death of their child: follow-up conversations. These conversations are conducted 6 to 8 weeks after the child's death, between parents and the HCPs that took care of the child during the EOL. Studies have shown that parents benefit from at least one organized contact with HCPs after the death of their child.[61,62] These conversations help parents feel cared for, reduce their sense of isolation, make the disengagement from their contact with HCPs less abrupt and reduce a sense of abandonment.[61,63] These conversations are well embedded in Dutch Children's Hospitals, yet the content of these conversations is highly variable. Furthermore, HCPs experience a barrier to conduct follow-up conversations because they feel uncertain on how to conduct these conversations and what to expect.

Preloss and bereavement care should also be an integral part of pediatric palliative care, and HCPs do acknowledge its importance and their responsibilities. Therefore they have developed several support practices, yet a lack of standardization, empirical evidence and confidence leads to a high variability of support for parents. Due to a lack of guidelines, the focus of what entails preloss and bereavement care remains unclear. Yet these regular HCPs are able to support parents in their needs during the EOL, since they are already closely involved in the child's care and know the family's values and wishes. Insight into HCPs' experiences in clinical practice and what they would require to integrate preloss and bereavement care in their practice is needed in order to develop an embedded approach.

AIM, METHODS AND OUTLINE OF THIS THESIS

Objectives and research questions

Both parents as well as health care professionals acknowledge the need for integrated preloss and bereavement care for parents during a child's EOL. However, most research has focused on the phenomenon of grief, bereavement and bereavement care following the death of the child. The manifestation of grief and bereavement during the EOL phase and optimal manners to support parents in loss and coping with grief remain unclear. This thesis aimed to understand parental grief during the child's EOL from the parents' perspective and the HCPs' perspective, and challenges in providing preloss and bereavement care, in order to understand what this care entails to ultimately optimally support parents.

To gain insight into current practice the first objective of this thesis was to identify bereavement practices and interventions that HCPs currently offer to parents of critically ill children and neonates, both during the EOL as well as after the child's death. In addition, we aimed to determine the level to which (components of) the identified interventions are supported by theoretical knowledge. These objectives led to the following research questions:
1.1 Which well described bereavement interventions performed by HCPs are available to support parents in coping with loss and grief, both during the child's EOL as well as after the child's death (Chapter 2)?

1.2 What is the effectiveness of (components of) bereavement interventions and are current practices substantiated by theoretical knowledge on loss and grief (Chapter 2)?

The second objective was to identify the goals, strategies, barriers, facilitators and challenges HCPs experience when providing preloss and bereavement care to parents as part of their regular care activities.
2.1 What are the HCPs' experiences with providing preloss care aimed at supporting parents during the child's EOL (Chapter 3)?
2.2 What challenges do HCPs encounter while providing preloss care aimed at supporting parents during the child's EOL (Chapter 4)?

The third objective of this thesis was to develop a theoretical representation of parental experiences with loss and grief during their child's EOL and their needs regarding preloss and bereavement care.
3.1 How do parents experience and cope with loss and grief during the child's EOL (Chapter 5)?

The fourth and final objective was to identify the content of follow-up conversations and the relevance of separate topics from the perspectives of bereaved parents and HCPs.
4.1 What is the content of follow-up conversations between bereaved parents and regular health care professionals (HCPs) in pediatrics and how do parents and HCPs experience these conversations (Chapter 6)?
4.2 How do parents and HCPs experience follow-up conversations in pediatrics and to what aspects of the conversation do they derive meaning (Chapter 7)?

METHODS

Methodological approach

Besides two systematic reviews, this thesis relies on three empirical qualitative studies. The first study included HCPs involved in EOL care in pediatrics (Chapter 3 & 4). The second study included parents of critically ill children during the EOL and parents of recently deceased children (Chapter 5). Lastly, the third study included a recording of follow-up conversations and consecutive interviews with the involved parents and HCPs (chapter 7). For the exact methodological approach per study we refer to the method section of each chapter. The general methodological approach of these three studies is described in the following paragraph.

Qualitative research is an interpretative approach aimed to understand the phenomenon under study from the inner perspective of the respondents. Interviews provide the researchers with insight into the respondents' experiences, thoughts, attributes, perceptions and meaning giving.[64] Studies 1 and 3 (Chapters 3, 4 & 7) concern exploratory qualitative research, resulting in a thematic description of the data. Study 2 (Chapter 5) concerns explanatory research, resulting in a theoretical model that is rooted in the data.[65]

Study population

A purposive sample of parents (studies 2 & 3) or health care professionals (studies 1 & 3) was included. Using a purposive sample with maximum variation, we aimed to include participants with a variety of characteristics, to be able to describe the phenomenon from multiple perspectives. Although in the practice of pediatric EOL care, maximum variation was sometimes difficult to ensure.

Participants were recruited from four pediatric university hospitals and one child homecare organization. Participants were identified by key persons in their organizations. In the first study health care professionals were included who encountered child death in their regular practice but were not specialized in palliative and/or bereavement care. Maximum variation was sought with respect to their years of experience, specialism and discipline (e.g. physician or nurse).

In the second study parents of critically ill children during the EOL or of recently deceased children were included. For the first group the treating physician assessed whether parents were eligible based on three criteria: (1) children had a life-expectancy of less than three months: “Would I be surprised if this patient died in the next three months”, or (2) the patient went through a life-threatening event with a high chance of reoccurrence within one year. In addition (3) the option that the child might die in short term is discussed as a possible and likely option with parents. Parents of recently deceased children were eligible for inclusion between the follow-up conversations and six months after death.

For the third study, all follow-up conversations in Dutch, and their participants, were eligible.

In total, 22 HCPs participated in the first study (Chapter 3 & 4), 38 parents of 22 children participated in the second study (Chapter 5), and 9 follow-up conversations connected to 9 deceased children, 8 consecutive interviews with 15 parents and 27 HCP-interviews in the third study (Chapter 7).

Data collection

In the first and second empirical study, data were collected through semi-structured interviews and a background questionnaire. In the third empirical study, the data collection consisted of a recording of the follow-up conversations, semi-structured interviews and background questionnaires of the participants. The interview guides were established based on literature and expert knowledge. Semi-structured interviews were chosen because they provided some structure to ensure the main topics were discussed with all respondents, yet enabled the interviewer to be flexible in response to the parents' story in terms of topic order and choice of words.[66] The flexibility was needed since the topic under study is emotionally loaded and participants might find it hard to talk about these topics. Truly gaining insight into the inner perspectives of the participants, especially the parents, required the researcher to build rapport and first allow the participants to share their story. The interviews all started with a broad opening question, enabling the researcher to understand the participants' situation and to later ask the participant to elaborate on the phases and experiences of interest.

Participants could choose their preferred location for the interview: at their home, in the hospital, or via video-conference. The latter was chosen more frequently when the study progressed due to Covid-19 restrictions. Although it was feared that building rapport or interpreting emotions would be more difficult via video-conference, reflections with the participants at the end of the interviews indicated that parents did not perceive boundaries in sharing their story. Moreover they felt heard and understood. The content of face-to-face or digital interviews did not notably differ.

Data analysis

In the first and third studies, the data were thematically analyzed, in the second study the data were analyzed using grounded theory.[65,66] During the thematic analysis, data analysis was performed in two main steps: (1) becoming familiar with the data and reducing the data into meaningful segments by open coding, and (2) categorizing the segments into themes by axial coding using NVivo 12.[67] In addition, several aspects were added by following the grounded theory approach for the analysis of the second study. In this analysis, there was an additional focus on the alternation of data collection and analysis, a focus on constant comparison within and between cases, and after the initial purposive sampling, theoretical sampling was performed.

Some of the main strategies to ensure validity and reliability that were used during the analysis of all studies that enhanced the rigor of the study were: audio recording and verbatim transcription of the interviews, coding using supportive software, alternating data collection and analysis, analysis in a multidisciplinary research team (researcher triangulation), and continuous peer review by the project team with HCPs from different specialties and disciplines.

Alternating data collection and analysis

According to the grounded theory approach, data collection and data analysis alternated in studies 1 and 2. Alternating enabled the researchers to explore newly developed themes and patterns from the analysis more in-depth in the consecutive interviews, thereby deepening our understanding of the phenomenon and being able to explore other relevant perspectives that emerged from the analysis. The interviewers' sensitivity regarding interesting cues and themes is enlarged by the analysis of the data and gaining understanding in the participants' experiences. Furthermore, alternating allowed the researchers to invite participants that might provide a new or different perspective. Data collection continued until saturation on the main themes was reached, meaning that new interviews did not result in chances of the analytical outcomes.[68]

Taking perspective in a multidisciplinary approach

The researchers tried to take the perspective of the parent during the analysis, which was stimulated during the open coding by using verbs in the initial codes. To minimize subjectivity or 'going native', data analysis was performed in a multi-disciplinary team ensuring researcher triangulation. The multidisciplinary team consisted of pediatricians, a neonatologist, nurses, an expert parent, a psychologist, and medical students. By analyzing the data in this multi-disciplinary team, the researchers were forced to take different perspectives regarding the data and these different professionals might notice different relevant themes. Intersubjective agreement on the interpretation of the themes was reached within the research team.

OUTLINE OF THIS THESIS

This thesis starts in chapter 2 with a systematic review of well-defined bereavement interventions for parents during their child's EOL and after their child's death. Furthermore, this chapter presents a synthesis of theories on loss and grief to facilitate the evaluation of the interventions.

In chapter 3, a qualitative study is presented on the goals, strategies, barriers and facilitators that HCPs experience while providing preloss care to parents of children during the EOL.

Chapter 4 provides insight into the lived experience of HCPs. Three dimensions are presented in which HCPs experience tension regarding providing preloss care aimed at parental feelings of grief to parents of children during the EOL.

Chapter 5 explains the parents' experiences with loss and grief during their child's EOL and provides insight into the dynamics of grief during the EOL.

A second systematic review in chapter 6 presents an overview of what is known about the content of follow-up conversations after the death of the child and how these conversations are experienced by both parents and HCPs.

In Chapter 7, the meaning that parents and HCPs derive from the content of follow-up conversations is explored.

This thesis concludes with chapter 8: a general discussion on the findings presented in this thesis. Societal implications, methodological considerations, strengths & limitations, and suggestions for future research are discussed.

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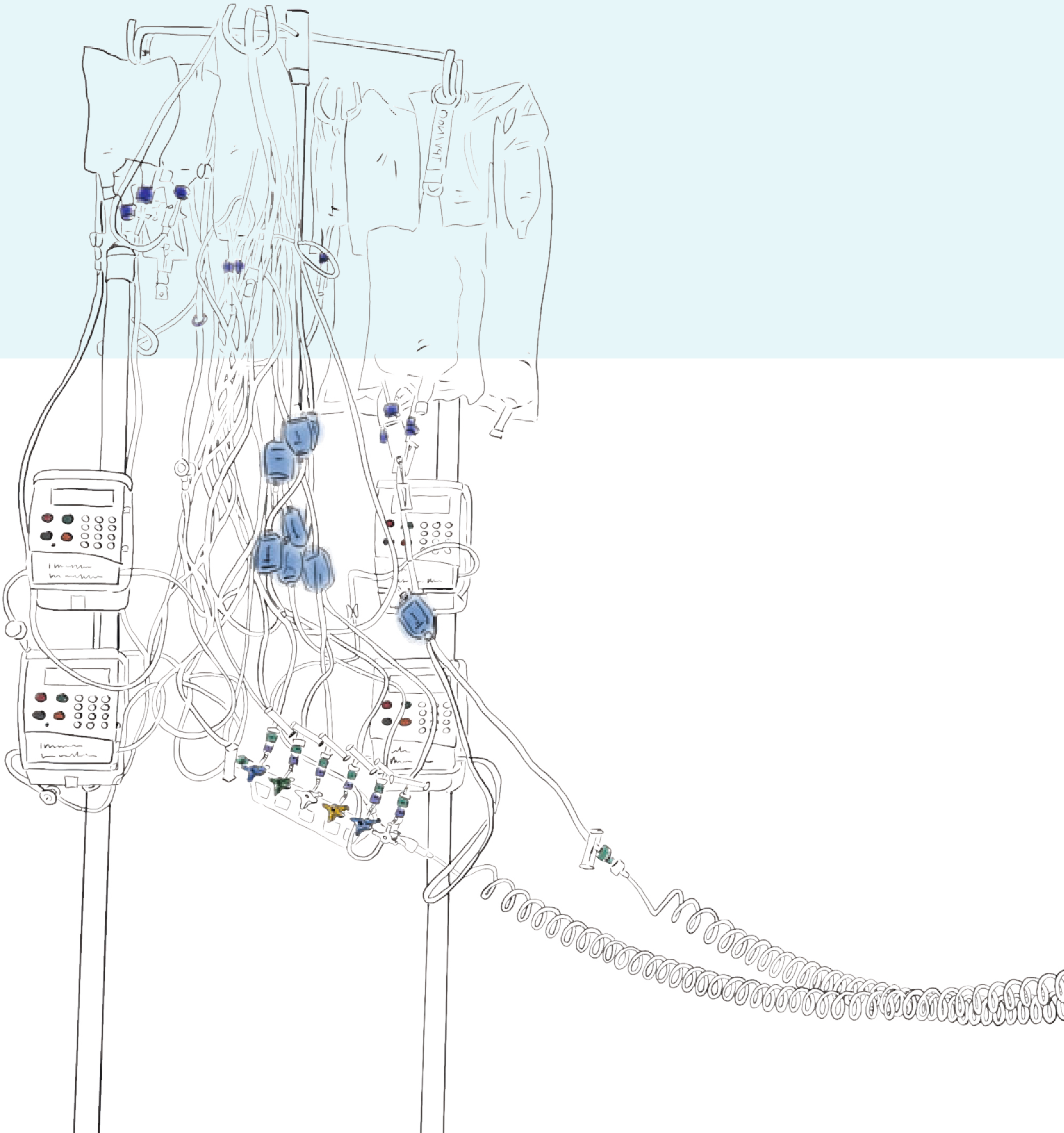

2

When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories

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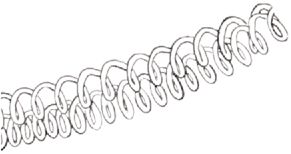

ABSTRACT

Background

The availability of interventions for bereaved parents have increased. However, most are practice based. To enhance the implementation of bereavement care for parents, an overview of interventions which are replicable and evidence-based are needed. The aim of this review is to provide an overview of well-defined bereavement interventions, focused on the parents, and delivered by regular health care professionals. Also, we explore the alignment between the interventions identified and the concepts contained in theories on grief in order to determine their theoretical evidence base.

Method

A systematic review was conducted using the methods PALETTE and PRISMA. The search was conducted in MEDLINE, Embase, and CINAHL. We included articles containing well-defined, replicable, paediatric bereavement interventions, focused on the parent, and performed by regular health care professionals. We excluded interventions on pathological grief, or interventions performed by healthcare professionals specialised in bereavement care. Quality appraisal was evaluated using the risk of bias, adapted risk of bias, or COREQ. In order to facilitate the evaluation of any theoretical foundation, a synthesis of ten theories about grief and loss was developed showing five key concepts: anticipatory grief, working models or plans, appraisal processes, coping, and continuing bonds.

Results

Twenty-one articles were included, describing fifteen interventions. Five overarching components of intervention were identified covering the content of all interventions. These were: the acknowledgement of parenthood and the child's life; establishing keepsakes; follow-up contact; education and information, and; remembrance activities. The studies reported mainly on how to conduct, and experiences with, the interventions, but not on their effectiveness. Since most interventions lacked empirical evidence, they were evaluated against the key theoretical concepts which showed that all the components of intervention had a theoretical base.

Conclusions

In the absence of empirical evidence supporting the effectiveness of most interventions, their alignment with theoretical components shows support for most interventions on a conceptual level. Parents should be presented with a range

of interventions, covered by a variety of theoretical components, and aimed at supporting different needs. Bereavement interventions should focus more on the continuous process of the transition parents experience in readjusting to a new reality.

BACKGROUND

After the death of an infant, or child, parents are left with an intense and overwhelming sense of grief.[1–3] Parents experience an accumulation of feelings of loss from the child's initial diagnosis, through the progressive deterioration in the child's condition, and eventually, to the death of the child.[4] In addition to their own feelings of grief, parents also experience the burden of grief from the dying child and their siblings.[3] Grief is a normal reaction to the loss of a child. For most parents, moderate support from regular health care professionals (HCPs), and relatives, is sufficient in helping to cope with feelings of grief.[5] However, around 10 to 25% of parents experience a serious disruption in emotional stability, which may result in poor psychosocial outcomes and adverse mental and physical health effects.[6,7]

A growing body of literature demonstrates that HCPs recognise parents' need for support in handling feelings of loss and grief.[8–10] This has resulted in an increasing number of interventions in practice aimed at all bereaved parents and provided by regular HCPs.[10] Although care standards state that providing bereavement care to parents is an important aspect of end-of-life care, such care is not yet routinely implemented in most hospitals.[7,11] This might be due to the fact that HCPs often feel ill equipped to provide bereavement care.[12] Another explanation might be that bereavement interventions based in practice do not contain clear guidelines or protocols, making them difficult to standardise.[13] The assumption is that clear protocols and guidelines make interventions replicable for other HCPs. An overview of, clear, replicable interventions, containing guidelines and instructions, could lead to improved implementation and appropriate care delivery to all bereaved parents. This is because the availability of evidence-based practice guidelines could enable HCPs to feel more equipped.[12] However, such an overview is currently missing.

Another characteristic of this practice-based nature of the interventions is that theoretical and empirical support are often unclear or not provided at all.[10,14,15] Theoretical understanding is an essential ingredient in developing, evaluating, and implementing behavioural interventions and best clinical practices.[16] A social theory can be seen as a set of statements that explain aspects of social life, and which demonstrate how people conduct and find meaning in daily life.[17] However, the theoretical field of loss and grief is still evolving. Nevertheless, several theories have been put forward to provide a supporting structure to the theoretical understanding of the process of grief.[18–30] Understanding how different elements of interventions might relate to, or rely on, such theories, could improve our understanding of the underlying mechanisms of these interventions and provide an indication of their effectiveness.

This review will provide an overview of well-defined bereavement interventions performed by regular HCPs, and aimed at supporting parents in coping with loss, during both the end of their child's life and after their child's death. Furthermore, we will provide an overview of their effectiveness and whether the bereavement interventions practiced currently are substantiated by theory about loss and grief, and, as such, provide a theoretical basis for the effective elements of bereavement interventions.

METHODS

Design

The field of paediatric palliative care is relatively young and so clear terminology is yet to be established. Therefore, we used an iterative method for constructing a search strategy: Palliative cAre Literature rEview iTeraTive mEthod (PALETTE).[31] In addition, our method complied with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[32] This systematic review was registered in Prospero (registration number: CRD42019119241).

Databases and searches

The first articles were identified through a preliminary search in PubMed and via expert advice from senior researchers in the field of paediatric palliative care and bereavement. From these articles, different synonyms were gathered and terminology became clearer, a process known as 'pearl growing'. As a result, articles were identified which were referred to as golden bullets because they met all inclusion criteria and thus should be included in the review. These processes resulted in additional searches. The process of pearl growing, identifying such new articles and adjusting the search string conducted in collaboration with an information specialist, was repeated until the search was validated.[31] That is, when all golden bullets were identified in the results of the search. Subsequently the information specialist involved conducted the final structured literature search in the following databases: MEDLINE, Embase, and CINAHL. See additional file 1 for the full search strings.

Study selection

The studies that were published in peer reviewed English language journals between January 1, 1998 and November 15, 2018, were included when they contained a well-defined bereavement intervention, offered by regular HCPs, to parents of deceased children or children with a life limiting condition at the end-of-life phase. This period of time was chosen because palliative care was formalised in a definition by the World Health Organization (WHO) in 1998, providing a consensus around the term ‘palliative care’. Interventions were defined as an intentional act performed for, with, or on behalf of, a parent or parents. An intervention must consist of well-defined, concrete proceedings. This means it can be replicated by other HCPs and is supported by instructions, a manual, training, a program or other supporting documents. We defined regular HCPs as professionals working in neonatal, or paediatric, care, where in their daily tasks, they are confronted with palliative care and care for loss and bereavement, without having necessarily received specialist training in these domains. Furthermore, interventions aimed at complex grief were excluded, since most parents do not require specialised services and such interventions are mostly performed by specialists on bereavement care. Full inclusion, and exclusion, criteria are listed in Table 1. When the full text was not available online, or when it was unclear whether the practices described were supported by a protocol or supporting documents, the first author of the article was contacted by email and requested to send additional information or a copy of the article. Both the title and abstract, and full text screenings, were performed by two researchers independently (EK, FJ), supported by the web-based screening program Rayyan (https://rayyan.qcri.org/welcome). Disagreements were resolved in dialogue with the research team. All the articles included were reference checked for additional relevant studies.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria:

- Articles containing well-defined bereavement interventions offered by regular HCPs to parents of children who have died or those children in the phase of receiving palliative care.
  - Interventions aimed at consoling intense feelings of grief during the end-of-life phase or after the loss of a child. Bereavement care may also occur before the death of the child, for example from the moment the condition of the child is deteriorating and death is imminent.
  - Studies must address interventions defined as: Intentional acts performed for, with, or on behalf of, a parent or parents. An intervention must consist of well-defined, concrete proceedings. This means it can be replicated by other HCPs and is supported by instructions, a manual, training, a program or other supporting documents. Our definition is based upon the definition of interventions handled by the World Health Organization.[33]
  - Studies must address regular HCPs defined as: All types of health care professionals who primarily provide care and/or treatment and, therefore, do not specialise in bereavement care.
- Research in the field of paediatrics and neonatology.
- Articles published in a peer reviewed journal.
- Studies published in English.

Exclusion criteria:

- Review articles.
- Articles published before 1998.
- Articles containing interventions that focus on complex grief and complex bereavement care.
- Articles which solely include prenatal death and stillbirth, defined as: No signs of life at or after 28 weeks' gestation. No occurrence of circulation outside of the uterus.

Data extraction and quality assessment

Data on baseline characteristics, participants, interventions, and outcomes were extracted by three researchers (EK, KG, FJ) using a predesigned form based on Schulz's intervention taxonomy.[34]

The quality assessment was performed by two researchers independently. The trials were assessed using the Cochrane risk of bias tool (KG, AvdH),[35] observational studies with an adapted risk of bias tool based on the Cochrane risk of bias assessment tool (KG, AvdH),[36] and qualitative studies were assessed with the COnsolidated criteria for REporting Qualitative research (COREQ) (FJ, EK),[37] recommended by Cochrane Netherlands. The total scores ranged from 0 to 7 in the trials and observational studies, and from 0 to 32 in the qualitative studies. The quality appraisals did not affect inclusion in the review due to the explorative nature of this systematic review, and also due to the fact that articles containing low appraisal scores could still contain valuable interventions and thus be relevant for the study aim.[38]

Synthesis of grief theories

The interventions were compared with a theoretical synthesis, in order to compensate for the expected lack of evidence for most interventions, and to evaluate the possible effectiveness. Since there is not a singular dominant theory on grief,[16] leading theoretical models have been identified using a pragmatic approach. At first, experts in the field of bereavement (PB, MK, EK) and palliative care (MK) were consulted, preliminary searches were conducted in Google scholar and Medline, and; a compendium on bereavement was consulted.[39] Secondly, a pragmatic search was conducted in Medline using keywords such as grief, loss, bereavement, theory and equivalents (EK). Thirdly, the theories identified were validated by experts (PB, MK). They aimed for articles that showed the variation in bereavement theories and were a reflection of the most accepted theories from several different domains.[18–30] By doing so an overview of the leading theoretical concepts available was developed, which were extracted from the theoretical articles, clustered into communal theoretical concepts, and labelled accordingly. Most theories on grief emphasise that bereaved families need to adjust from the 'old world' to the 'new reality',[18–21,23,26–30] where the deceased is no longer physically present. This readjustment can be seen as a continuous process that takes months to years to complete, while the grief, itself, may never be resolved. The theories propose different approaches to how this adjustment is achieved. However, when comparing the leading theories we found that most theories have several key concepts at their core. This offered the opportunity to synthesize the theories on a conceptual level and, as such, capture the core mechanisms of most theories. These core mechanisms create the 'how' in which the theories explain the process of readjustment to the new reality. The synthesis of theories resulted in five concepts: anticipatory grief; an attachment to working models and plans; appraisal processes; coping behaviours, and; continuing bonds. These five concepts will be discussed in the following section. Importantly, these concepts do not represent elements of a sequential process, but rather elements of adjustment that may be re-addressed over time. The additional file 2 displays how the theoretical concepts are formed, based on different theoretical articles.

Anticipatory grief refers to feelings of loss and grief before an imminent loss.[30] It involves forms of coping and reorganisation prior to loss and death, managing conflicting demands, facilitating a 'good' death, and preparedness. Preparedness comprises several different dimensions such as medical, psychosocial, spiritual, and practical dimensions.[25] Preparedness may help informal caregivers in coping with grief at a later stage.

Concepts concerning attachment working models and plans enhance multiple types of plans, namely: internal plans such as personal plans which may help a person understand their environment;[27,28] relational plans such as how the self relates to others,[26,28,30] and; attachment plans such as those created in early childhood and which guide a person in forming attachment bonds with others.[19,23] Such plans make the world understandable, recognisable, and predictable. However, sometimes they do not match reality, for example when a child dies. This causes a severe stress reaction. This new reality must be incorporated into the existing plans to establish a new stable situation.[18,20]

Appraisal systems are set up when a new situation needs to be evaluated. In the situation of the loss of a child, the appraisal systems conclude the fact that the reality does not match the existing plans.[19,20,23,24,26] Appraisal systems will then be active until new plans are developed,[26] or the old plans are revised.[26,30] The loss is then incorporated into the autobiographical memory and a revision of self-identity can take place.[18,27]

Stressful situations are managed by employing helpful coping behaviours.[18,20] Different coping styles exist, such as those focusing on the problem or the emotion.[24] Some coping styles may be orientated towards loss or restoration,[21,30] while some strategies may seek to make meaning out of the experience.[28] The reaction and coping behaviours differ between individuals and depend upon several factors including context and personality.[26] Effective coping includes the ability to shift, flexibly, between different coping strategies.[20,21,27]

Finally, the concept of continuing bonds refers to an ongoing relationship between the individual and the deceased.[21,22,26]

RESULTS

The search yielded 5,144 unique articles, of which nineteen met the inclusion criteria[40–58] and two were added following an additional reference check (Figure 1).[59,60] Twelve articles represented empirical data drawn from the interventions of bereavement care programmes. Of these, four represented quantitative studies,[40–43] six represented qualitative studies,[44–49] and two represented studies which included both quantitative and qualitative outcomes.[50,51] Nine articles were descriptive in nature.[52–60] These articles contained well-defined bereavement interventions, yet the interventions were not tested empirically and, therefore, the outcomes could not be provided. An overview of all the articles included is provided in Table 2. Quality appraisals ranged between 2 and 5 for trials and observational studies, and between 8 and 21 for qualitative studies. Quality scores on all studies can be found in Table 2. Qualitative studies received higher appraisal scores.

The twenty-one articles included fifteen unique bereavement interventions, identified with the letters of the alphabet A through to O. Two interventions were described in multiple articles (A and G). The intervention characteristics are summarised in Table 3.

The characteristics of bereavement care interventions

The bereavement care programmes were predominantly initiated by hospital staff (A-N). They took place in the field of neonatology (n=5) (F,H,I,M,O), paediatrics (n=9) (B,C,D,E,G,J,K,L,N), or both neonatology and paediatrics (n=1) (A). Some interventions were aimed at children with a certain diagnosis: Sudden Infant Death Syndrome (SIDS) (n=1) (O), and cancer (n=4) (B,E,G,N). Three studies presented a bereavement care programme, while focussing on the impact on HCPs of losing a patient (A,G,J).

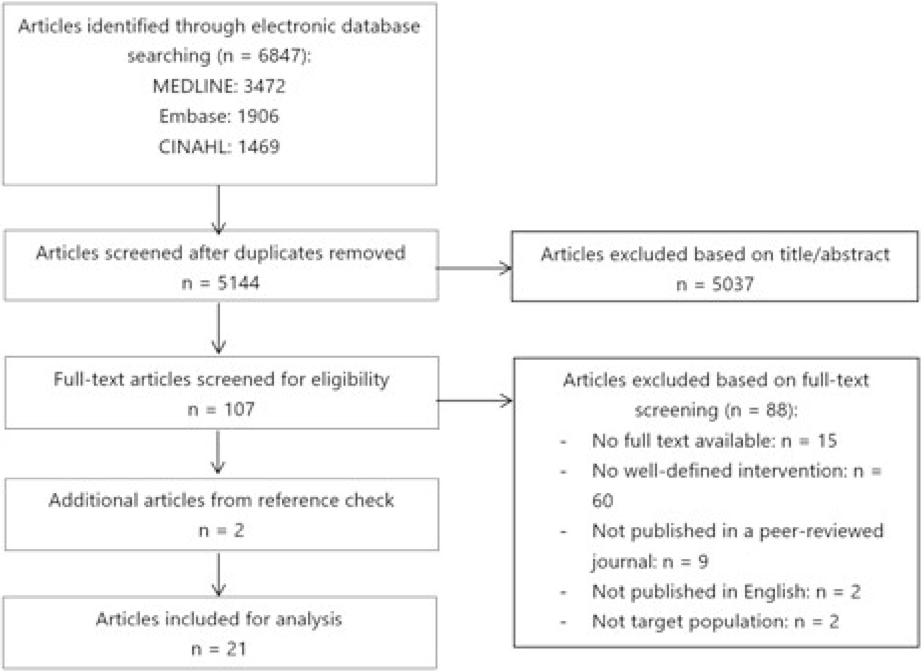

Figure 1. Study flow.

With regard to the timing, we found that eleven interventions started after the child's death (A,B,C,D,E,G,I,K,L,M,O), one intervention started during the end-of-life phase (J), and three interventions covered both before, and after, death (F,H,N).

In most interventions, the person intervening was either a nurse, appointed as the primary carer and operating individually or as part of a team (A,C,E,H,I,K,M), or a physician (A,C,D,G,I). Other people intervening included clinical social workers (B,H,K), chaplains (A,L) or peer supporters - parents who have previously lost a child too - (A), photographers (J), trained counsellors (D), public health nurses (O), team members who had the most contact with parents or experienced the lightest workload (F) or, bereavement care team members not otherwise specified (N).

Table 2. Baseline characteristics.

Quantitative studies							
Author/ year/ country	**Study type**	**Aim of the study**	**Setting**	**Sample**	**Method of data collection**	**Outcomes measures**	**Quality**
Aho et al. (2011),[40] Finland	RCT Follow-up program vs. usual care	To evaluate a bereavement follow-up intervention for fathers, by comparing grief reactions and to explore their experiences with the program	Intensive care unit, maternity ward, and emergency room in five university medical centres	Fathers of children who died at age ≤3 years	1. Hogan Grief Reactions Checklist 2. Questionnaire measuring social support provided by HCPs and peer supporters 3. Questionnaire measuring fathers experience with the follow-up program	1.Despair, panic behaviour, personal growth, blame and anger, detachment, disorganisation. 2. Affect, affirmation, aid from HCPs and peer supporters 3**.** The implementation of the program	2 out of 7
Meert et al. (2014),[41] USA	Observational study	To evaluate the feasibility and perceived benefits of conducting physician-parent follow-up meetings	Seven children's hospitals, oncology units	Critical care physicians, bereaved parents of children who have died in the PICU, relevant others	Survey (items on Likert scale and open-ended questions)	1. Physician adherence to the framework 2. Experiences with follow-up meeting	4 out of 7
Nikkola et al. (2013),[42] Finland	Observational study	To describe mothers' experiences with the bereavement follow-up program	Intensive care unit, maternity ward, and emergency room in five university medical centres	Mothers of children who died at age ≤3 years	1. Questionnaire measuring social support provided by HCPs and peer supporters 2. Questionnaire measuring mothers experience with the follow-up program	1. Affect, affirmation, aid. 2. The implementation of the program	5 out of 7
Raitio et al. (2015),[43] Finland	RCT Follow-up program vs. usual care	To explore the effects of a bereavement follow-up intervention on mothers' grief	Five university medical centres	Mothers of children who died at age ≤3 years	1. Hogan Grief Reactions Checklist	1. Despair, panic behaviour, personal growth, blame and anger, detachment, disorganisation.	2 out of 7

Table 2. Baseline characteristics. (continued)

Author/ year/ country	Study type	Aim of the study	Setting	Sample	Method of data collection	Outcomes measures	Quality
Qualitative studies							
Aho et al. (2011),[44] Finland	Generic qualitative study	To evaluate the experiences and suggestions for further improvement of a bereavement follow-up program intervention	Perinatal and neonatal units	HCPs who were appointed to care for a child who died at age ≤3 years	Open-ended questionnaire and individual telephone interviews	1. Experiences with the bereavement follow-up program 2. Ideas to improve the bereavement follow-up program	14,5 out of 32
Berrett-Abebe et al. (2017),[45] USA	Generic qualitative study	To understand parents' experiences with participation in a hospital-based bereavement support program following the loss of a child to cancer	Tertiary care centre, Department of paediatric haematology/ oncology	Parents of children who have died of cancer	Focus group	1. Experiences with medical team during child's illness 2. Experiences with bereavement follow-up program after child's death 3. Experiences of other bereavement support	19,5 out of 32
Brink et al. (2016),[46] Denmark	Generic qualitative study	To explore parents' experience of a follow-up meeting	University hospital, Paediatric Intensive Care Unit	Parents of children (aged 0-16) who have died in the PICU	Individual face-to-face interview	1. Experiences around a follow-up meeting	19 out of 32
Darbyshire et al. (2012),[47] Australia	Generic qualitative study	To explore the experiences of parents who participated in a nurse-led telephone follow-up support program in paediatric oncology.	Regional women's & children's hospital, paediatric oncology unit	Parents of children who have died from an oncology-related condition	Individual face-to-face interview	1. Experiences with a follow-up support program	21 out of 32
Eggly et al. (2011),[48] USA	Generic qualitative study	To describe a framework to assist PICU physicians in conducting follow-up meetings	Seven children's hospitals, oncology units	Critical care physicians and bereaved parents whose children died in the PICU	Individual interviews by telephone	1. Experiences with follow-up meetings	8 out of 32

Table 2. Baseline characteristics. (continued)

Author/ year/ country	Study type	Aim of the study	Setting	Sample	Method of data collection	Outcomes measures	Quality
Meert et al. (2011),[49] USA	Generic qualitative study	To investigate physicians' experiences and perspectives regarding follow-up meetings	Seven children's hospitals, oncology units.	Critical care physicians	Individual interviews by telephone	1. Experiences with follow-up meetings 2. Ideas for future follow-up meetings	17 out of 32
Mixed method study							
Michelson et al. (2013),[50] USA	Mixed method study	To describe implementation of, reflections on, and address barriers for a PICU bereavement photography program, according to HCPs	Children's hospital, PICU	HCPs who cared for children at PICU who met one of following criteria: impending death, planned withdrawal of life-sustaining therapies with an expectation of a sudden death, examination consistent with brain death	Questionnaires (closed and open-ended questions)	1. Experiences with a bereavement photography program 2. Ideas to improve the program	4 out of 7 15,5 out of 32
Oliver et al. (2001),[51] USA	Mixed method study	To explore experiences with a bereavement support program	Regional children's hospital, paediatric trauma centre	Families of children who have died in the paediatric trauma centre and parental supporters	Survey and individual interview	1. Experiences with a bereavement support program	4 out of 7 10 out of 32

Table 2. Baseline characteristics. (continued)

Author/ year/ country	Study type	Aim of the study	Setting	Target population	Method of data collection	Outcomes	Quality
Descriptive articles							
Aho et al. (2010),[52] Finland	Descriptive article	To describe the development and implementation of a bereavement follow-up intervention for grieving fathers	Five university medical centres, perinatal and neonatal unit	Fathers of children who died at age 3 or younger	N.A.	N.A.	N.A.
Cook et al (2002),[53] UK	Descriptive article	To review local bereavements support practices over the last 5 years	Regional hospital, PICU	Parents of children who have died unexpectedly in the PICU	N.A.	N.A.	N.A.
Edi-Osagie et al (2005),[59] UK	Descriptive article	To describe a template for a bereavement service	Tertiary care centre, NICU	Parents of children who have died in the NICU	N.A.	N.A.	N.A.
Gibson et al. (2011),[60] USA	Descriptive article	To describe the development of a NICU bereavement program	University hospital, NICU	Parents of children who have died in the NICU	N.A.	N.A.	N.A.
Levick et al. (2017),[54] USA	Descriptive article	To summarize and evaluate a comprehensive approach of bereavement services to NICU families and education/support to NICU staff	Regional children´s hospital, NICU	Parents of children who have died in the NICU	N.A.	N.A.	N.A.

Table 2. Baseline characteristics. (continued)

Author/ year/ country	Study type	Aim of the study	Setting	Target population	Method of data collection	Outcomes	Quality
Morris et al. (2016),[55] USA	Descriptive article	To discuss the goals of bereavement care and the need to standardize bereavement care in the paediatric setting, and describe their hospital wide bereavement model	Hospital, paediatric setting	Families of children who have died in a paediatric setting	N.A.	N.A.	N.A.
Reilly-Smorawski et al. (2010),[56] USA	Descriptive article	To evaluate experiences of both individuals and couples with a bereavement support group	Tertiary Centre , NICU	Parents of new-borns or infants who have died in the NICU.	N.A.	N.A.	N.A.
Snaman et al. (2017),[57] USA	Descriptive article	To review the three primary pillars of a parent-inspired and parent-derived bereavement program	University children's hospital, oncology and palliative care unit	Parents of children who have died of cancer	N.A.	N.A.	N.A.
Stastny et al. (2016),[58] USA	Descriptive article	To provide a practical guideline for public health nurses (PHN) in performing home visits to bereaved parents	Home visits	Parents of children who have died of sudden infant death syndrome	N.A.	N.A.	N.A.

Table 3. Intervention characteristics.

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	**Components**				
A. Aho et al. (2010), Aho et al. (2011a), Aho et al. (2011b), Nikkola et al. (2013), Raitio et al.(2015), Finland	Peer supporters and HCPs	- Support package at discharge after the child's death - Peer support one week after the child's death - Follow-up contact by HCP after 2-6 weeks	- Support package - Peer contact - HCP contact	Outcomes fathers (Aho et al. 2011a): -Experienced most affect and emotional support, more from peer supporters than from HCPs. -Most fathers responded that the follow up contact helped them in coping, timing of contact was appreciated -Lower values in all dimensions of grief except for personal growth in the intervention group Outcomes mothers: -No significant differences in grief reactions between intervention- and control group (Raitio et al. 2015) -Mothers received most affect, moderate affirmation, and little aid from HCPs and peer supporters (Nikkola et al. 2013) - Follow-up contact helped mothers in coping (Nikkola et al. 2013). Outcomes HCPs (Aho et al. 2011b) -Follow-up contact important element of care, but also stressful and difficult -Implementation possible due to positive attitude HCPs, resources inadequate -Intervention increased cooperation between HCPs and peer supporters	- Baseline study on current bereavement support systems - Systematic review - Expert panel -Clinical experience and patient perspective	- Training for implementers - Training to use the intervention was provided for peer supporters and HCP	Not mentioned
B. Berrett-Abebe et al. (2017), USA	Social worker (program coordinator) and clinician	Two years bereavement program: - Comfort basket 3-4 weeks after death - Phone call/note: 2 weeks, 1 month and 2 months after child's death, annually on birthday and anniversary - Letters: at 3,6,10,12,18,24 months after death	- Comfort basket - Phone calls - Letters - Info sheets - (Anniversary-)cards	Identified themes: (1) Lived experience of grief; grief is intense, long-lasting, varies day by day, different for everyone. Relationships could become strained or a comforting source of support. (2) Relationships HCPs: Being treated like family, human connectedness and compassion (3) Hospital-based bereavement support: Feeling of not being forgotten by HCPs, parents appreciated talking to HCPs who were not afraid of talking about their traumatic experiences. Parents valued the content of the letter, comfort basket and materials. (4) Preferences extended bereavement care: ongoing, flexible, annual informal gathering, formalizes peers support contact	- Development by multidisciplinary working group in oncology - Based on social support theory, input from parents, and clinical knowledge	Not mentioned	Stress and coping social support theory: social support helps individuals manage stressful situations by improving coping responses

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
C. Brink et al. (2016), Denmark	PICU physician and nurses	90-minutes follow-up meeting at the PICU, 4-8 weeks after the loss of the child: 45 minutes to discuss medical topics (physician and nurse) and 45 minutes to discuss care and dealing with everyday life (nurse)	- Follow-up meeting	Identified themes: (1) Turning back: stressful and unpleasant to return to PICU, no prior expectations, valuable to see HCPs affected by the child's admission (2) Framework meeting: ambience calm and oppressive or good and emotional (with focus on parents). Participation of nurses was valued, parents experienced more tenderness when the physician left. (3) Relations HCP: relationship with staff makes return to PICU good experience, eg. being recognized and mentioned by name (4) Closure: meeting was experienced as closure of the course in the PICU.	Not mentioned	Not mentioned	Not mentioned
D. Cook et al (2002), UK	Trained counsellor and doctor	- Information letters for parents - Encouragement of families to seek support - Follow-up meetings 8-12 weeks after child's death	- Follow-up meeting - Personalized information - Encouragement	Not applicable	Trained counsellor is available	Not mentioned	Not mentioned
E. Darbyshire et al. (2012), Australia	Designated nurse	- Information folders, containing contacts, readings and practical advice - Attending the child's funeral - Phone calls until 13 months after death - Cards at special times such as birthday.	- Information folders - Attending the funeral - Follow-up phones calls - Sending cards	- All parents received the follow-up calls and were satisfied with the length of the follow-up program. - All parents were positive about the telephone follow-up program and valued the opportunity to share memories with someone who knew their child - Personalized cards and letters felt as an acknowledged of the important relationship with the hospital.	The intervention was based on a literature search and a focus group.	- Bereavement education and training twice a year. - Bereavement case file is created, including a photo, call plan, and copies of correspondence.	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
F. Edi-Osagie et al (2005), UK	Bereavement Care Team (BCT): team member that had most contact with the parents before death, or the one with the lightest case load.	*Prior to death:* Introducing member of BCT, counsellor, and chaplain. Offer blessing or religious ceremony and access to bereavement suite. *Immediate period following death:* Literature/ information is provided, clothing from bereavement room nursing the baby, provide cold cot. Help planning the funeral and attend, card is sent. Provision of memory box and keepsake bag. Helps explaining the death to the siblings. 24 hour telephone support available. Advice on financial matters and social benefits. *Follow up:* Home visit to all bereaved parents, flowers are sent after 6 weeks. Annual remembrance service.	- Blessing/religious ceremony - Bereavement suite - Memory book - Pictures - Keepsakes - Information letters - Provide cold cot - Help in arranging the funeral - Memory box and keepsake bag - Access to telephone support 24/7 - Financial advice and benefits - Follow-up visit - Flowers sent - Annual remembrance service	Not applicable	Members of bereavement care team have undertaken counselling courses, educational workshops, and workshop on how to train others.	Regular education sessions for HCPs, written guidance.	Not mentioned
G. Eggly et al. (2011), Meert et al. (2011), Meert et al. (2004)	Physicians of the PICU who are trained in conducting follow-up meetings.	Framework follow-up meeting: - Invitation at discharge and after one month - Card/call after one month, evaluating preferences for meeting and planning - Follow-up meeting (1h) - After meeting: thank you note, supportive information - Debriefing for HCPs	- Follow-up meeting - Supportive materials and information - Phone call and card	- Physicians' participation in follow-up meetings: never (33%), 1-5 meetings (31%), > 5 meetings (36%). Attendants participated more often than fellows. - Parents perceived the meeting as helpful for themselves (92%), for others (89%) and in coping with the future (78%) - Physicians stated that they adhere to the framework (75%), consider the framework easy to use (92%), beneficial for parents (92%) and for themselves (89%)	Eggly S (2011): Framework is based on the experience and perspectives of bereaved parents and paediatric intensive care unit physicians.	Physician participants were trained to use the follow-up meeting framework via face-to-face or web-based small group sessions. Training included: education on bereavement processes and the framework, simulated follow-up meetings and interactive discussions	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
H. Gibson et al. (2011), USA	Staff of the NICU (mostly nurses and social workers), all bereavement council members.	*Prior to death:* professional photography, offer baptism, discuss end of life preferences *After death of the child*: Give teddy bear; inform about memory box and follow-up contact; provide folders and reading material. *Follow-up contact:* 6 fixed times, from 1 day through 1 year. Card schedule: 6 cards on special days. Twice a year a memorial service. Parents are invited the first two years after death.	- Washing/holding the child - Baptism/religious ceremony availability of family room - Hand-/footprints and lock of hair - Memory box (includes CD with photos, bracelets, rings, shell from baptism, any bedside belongings) - Follow-up cards (including butterfly ornament) and calls - Family support folder - Casket - Remembrance ceremony	Not applicable	Practice-based and on the personal experiences of one nurse. Several nurses and 2 social workers attended the Resolve Through Sharing (RTS) training by Bereavement Services	- Checklist in medical file - Education new employees and one-a-year education fair - Monthly council meeting	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
I. Levick et al.(2017), USA	Neonatologist and designated staff member (primarily nurse) with support from BCT	*When neonate just died:* inviting loved ones, hold and bathe child, preserving infant's bedside till parents are ready to remove it. Keepsakes even if parents are uncertain. In that case, hospital stores the keepsakes. The ability to let parent help with making keepsakes. Checklist of services that can be provided. *Follow-up program*: call schedule; within days, at 2-3weeks, after three weeks adjusted to wishes parents until 12 months after death. Card schedule: standard within 2 weeks and at 11 months. Other moments adjusted to wishes of parents.	- Hold/bath child - Sympathy cards - Follow-up phone calls - Photos of the child - Hand-/foot-/head prints of the child, could be combined with hand of the parent/sibling - Sibling support program - Bereavement information folder - Certificate of life - Beaded name bracelet - Memory stone - Locket of hair - Seashell used for baptism - Bereavement gown and/or gown crafted from donated wedding dresses - Escort parents/ siblings to the car - Keepsake box for siblings (storybooks, stuffed animals, memory stone, hand-/footprints	Not applicable	- Literature review	- The intervention is coordinated by the NICU Bereavement Care Team (BCT). - Bereavement/ keepsake checklist is used by all personnel. - BCT Nurse reports personal information and dates, and designated nurse appointed in spreadsheet.	Not mentioned
J. Michelson et al. (2013), USA	Photographer who has specific expertise in bereavement photography and training in bereavement support.	Photographer is updated on medical/ family situation of family by HCP. Taking photographs of patient and family without posing. Preparing album in documentary style and deliver album to family.	- Photograph album of patient and family in documentary style	- HCPs thought parents were grateful for photos (85%), and photos made HCPs feel better about their role (70%) and did not take too much time (85%). - Positive: impact program on families and HCPs - Barriers: funding, availability photographers, informed consent parents	Program was based on a bereavement photography program in NICU and adjusted with input from multidisciplinary group.	Education of staff members about the program through presentations at regular meetings, information provided online and individually.	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
K. Morris et al (2016), USA	Program coordinator, social workers and a nurse practitioner	- Newly bereaved families are mailed a bereavement packet (includes a formal condolence letter, a psycho-educational bereavement guide, a flyer outlining upcoming seminars at the hospital, and a list of online programs). - Seminars for parents about coping with grief and 8-week support group each spring. - Availability of support groups, individual counselling, telephone support, and memorial service	- Condolence letter - Memorial events - Educational guide (booklet and on website) - Seminars about coping with grief - Support group - Workshop for parents and siblings - Telephone support - Referral and resource information	Not applicable	The program is developed by parents and staff. The bereavement program was modelled on the bereavement program developed at a near cancer institute where education, guidance and support were identified as the primary constructs.	Quarterly seminars for staff, offered by the bereavement Task Force, about grief, bereaved families, and self-care for clinicians .	The psycho-educational bereavement guide “When Grief is New”, is based on cognitive behaviour theory principles.
L. Oliver et al. (2001), USA	Chaplain	- First meeting at hospital just after child’s death (religious rituals are offered, parents are provided with informational brochures) - Second meeting at funeral or the families’ home after one month - Third meeting: educational dinner with the family and 15 supporters (eg friends/ family), within two months after death	- Information brochure - Information video for surviving children - Attending funeral - Home visit - Educational event with supporters	Parent Survey: - Time in hospital: staff were reported sensitive to the child and parents (90% & 93%), prepared parents for death (81%), and the treatment was understandable (90%). - Chaplain’s first visit: parents wanted a meeting, the meeting was helpful, and answered questions (80%, 90%, 78%). -Meeting with supports: Supporters remembered the child (91%), accepted adjustment time (89%), and called, visited, take out and wrote more (73%) - Supporters survey: The meeting helped supporters understand parents’ journey (95%), prepared to care (82%), made it likely to use advise (82%), supporters took specific actions to remember the child (69%), accepted adjustment time (94%), and called, visited, took out, wrote more (78%). Observations on the support network: 63% took actions to remember the child, 50% accepted adjustment time, 31% called, visited, took out and wrote often, and 77% reported ongoing benefit from dinner meeting.	Not mentioned	Not mentioned	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	**Components**				
M. Reilly-Smorawski et al. (2010)	Two senior NICU staff nurses with backgrounds in psychology and social work	A closed, hospital-based format for couple-based support group(12 weeks): week 1-3: introductory phase week 3-11: open-format design week 11: a qualitative evaluation tool was distributed and collected. week 12: summarizing the support group experience and for final preparation for life after the bereavement group. Leaders planned to offer to reconvene the group at intervals of 3 months for the year following the baby's death	12 weeks couple-based bereavement group; attending weekly Topics for discussion: A the baby's death and related events B personal grief experiences C couple issues including gender-related grieving and communication D the future	Not applicable	Program was based on several observations on bereaved couples. Couple-based bereavement group was part of bereavement care program.	- After each 12-week session themes of the survey were bundled, and adjustments were made where needed to improve the support group functioning. - Education of the facilitators - Attending of bereavement counselling workshops and related conferences	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
N. Snaman et al. (2017), USA	Quality of life team, bereavement program coordinator and bereaved parent mentors	The bereavement program describes three parts: *Part 1:* Clinical and Supportive Interventions: - Child/family meet the QOL team and bereavement coordinator to start supportive relationship. Families receive a booklet, option for peer support. - Memorial event; two day gathering for bereaved parents whose child died 6 months to three years previously. *Part 2:* Parent-Created Materials: - Condolence card, several weeks to child's death. - Bereavement resources guide is mailed within two weeks of a child's death. - Seasons booklet & Remembrance mailings - Additional resources: books for siblings, parents videos. *Part 3:* Bereaved parent could be involved in education for staff and participate in research.	- Sending cards - Peer contact - Memorial day - Booklets and information folders - Video's for parents - Contact by cards/ emails	Not applicable	The program is developed by parents and staff. Bereaved parents and multidisciplinary members of the hospital comprise the Quality of Life (QOL) steering council under the guidance of an expert bereavement coordinator.	Parent mentors receive training on a variety of topics.	Not mentioned

Table 3. Intervention characteristics. (continued)

Author/year/ country	Interventionist	Intervention		Outcomes	Development	Implementation	Theoretical support
		Outline	Components				
O. Stastny et al. (2016), USA	Public health nurse	After public health nurse has received information of coroner's investigator families are contacted by phone/ email to schedule a home visit(s). Friends and family may be invited. During the home visit(s) the main focus is to provide support, education, SIDSs referrals, resources and connect with other SIDS bereaved families	- Phone contact - Home visit (Educate, support, provide resources, connect with peers, referral)	Not applicable	Authors experience (PHN SIDS coordinator)	Not mentioned	Not mentioned

We identified five overarching components of interventions which encompass the variety of practices described in the interventions. These are: (i) the acknowledgement of parenthood and the child's life; (ii) establishing keepsakes; (iii) follow-up contact; (iv) education and information, and; (v) remembrance activities.

i. The acknowledgement of parenthood and the child's life consisted of washing, holding, or dressing the child (H,I), giving parents privacy in the moments surrounding the death of the child, for instance in a family room (H), providing the child with a certificate of life (I), or a blessing ceremony (F,H).
ii. Establishing keepsakes consisted of safeguarding a lock of hair (H,I), hand, foot, or face print (H,I), pictures (F,H,I,J), or items that belonged to the child, such as toys, a blanket (H), ornaments (H), a memory stone (I), clothes (I), a baby ring or bracelet (H,I), memory books (F), poems (A,H), or other belongings (F,H). The created items were often provided to the parents in the form of a comfort basket or memory box (B,H). Keepsakes, especially for siblings, could also be provided (I).
iii. Follow-up contact consisted of follow-up calls (A,B,E,F,G,H,I,K,O), cards (B,E,G,H,I,N), visits (A,F,L,O), flowers (F), condolence letters (K), and appointments (A,C,D,G,M). Follow-up contact also included facilitating contact with peers (A,K,N).
iv. Education and information on coping, grief, and practical information concerning the death of the child, consists of folders and booklets with information (A,B,E,F,G,H,I,K,L,N), financial advice (F), videos containing information (L), educational support meetings for peers and relatives (L), seminars or workshops on coping and grief (K), and information sessions (A,C,D,G,M) during which HCPs provided information about the treatment and autopsy (I), or answered questions (I).
v. Remembrance activities included ceremonies or services (F,H,K,N), and HCPs attending the funeral (E,L).

The empirical basis of the interventions and the outcomes of the studies

Most interventions identified consisted of a description of practices, sometimes based on years of experience, but which did not include an empirical or theoretical basis. Several studies did provide substantiation for their interventions such as a previous, non-specified, literature search (A,E), interviews and focus groups (B,E,G), or expert knowledge and special education (A,B,D,F,J,O). Only two interventions were developed using a clear theoretical basis. One intervention was based on principles of stress and social support theory (B), and the other contained a psycho-educational bereavement guide based on the principles of cognitive behavioural theory (K).

The studies that evaluated an intervention, showed that parents reported a positive experience with bereavement photography and follow-up contact (A,B,C,E,G,J,L). Parents were grateful to receive photos of their child, and helped HCPs feel better about their role (J). The outcomes of most of the empirical studies focused on how the parents had experienced the follow-up contact with the HCPs who had taken care of their child. Follow-up contact was generally valued. It helped parents cope with their grief, provided closure, and gave parents a secure feeling of the ongoing bond with the hospital and their child (A,B,C,E,G,L). Parents found follow-up meetings with HCPs and/or peers helpful in learning to tolerate and understand grief better. Moreover, it stimulated further thinking and discussion between the parents about the topics addressed in the meeting and helped parents to express their ideas and feelings concerning grief to each other and to their family and friends (L,M).

The alignment between intervention components and theoretical key concepts

Given the lack of knowledge concerning the effectiveness of the interventions, the potential worth of the components of intervention is evaluated by aligning the five intervention components identified (i-v) to the key theoretical concepts as described in the method section. These are: anticipatory grief; attachment to working models and plans; appraisal processes; coping, and; continuing bonds. Hereafter, all the components will be discussed and hypothesised, considering how they align with the theoretical concepts identified (Table 4).

The acknowledgement of parenthood and the child’s life

This component includes facilitating parents to fulfil their role as a parent, and to acknowledge the identity of their child. Facilitating parents in their parental role is a component HCPs provide before and after death. The main strategy in these interventions is to enable parents to nurture their child and to acknowledge their child’s uniqueness.[54] Parents are facilitated to experience the bond with the child, create memories, have a blessing ceremony, and say their farewells.[59,60] It allows parents to begin to contemplate the idea that their child is dying, while ensuring that their child is as comfortable as possible.[60] These practices support anticipatory grief, since they foster emotional preparedness, allow parents to adjust slowly to the fact that their child is dying, and help to create lasting memories for parents to cherish after death.[54] A certificate of life empowers parents to recognise the identity of their child. In letting parents participate in the last care for their child, this also enables them to adjust, gradually, to the fact that their child is dying, and makes the transition between the internal plans less abrupt.

Table 4. The alignment of theoretical key concepts and intervention components.

	Components concerning anticipatory grief	*Components concerning attachment working models and plans*	*Components concerning the appraisal processes*	*Components concerning coping*	*Components concerning continuing bonds*
Acknowledging parenthood and the child's life	+	+		+	
Keepsakes		+		+	+
Follow-up contact		+	+	+	+
Education and information		+	+	+	
Remembrance activities				+	+

+ : Intervention component supported by key theoretical concept.

Establishing Keepsakes

HCPs take the initiative in creating keepsakes together with, or in accordance with, the parents. These keepsakes provide the parents with a tangible memory of the child. Especially in neonatology, where parents will not have been outside the hospital with their child, keepsakes provide parents with a way to cherish a part of their child, when the child is no longer present. Establishing keepsakes can help parents feel attached and close to their child and to provide comfort.[54] Over time, the keepsakes can help the parents in remembering the child, and help parents with processing, conceptually, the loss, while they revise the autobiographical memories and the memories of the child in order to adjust to the new reality. Over time, when the parents have adjusted to the new reality, the tangible memories of the child serve as a form for expressing the continuation of the bond between the parents and their child.

Follow-up contact

Follow-up contact with the hospital may take various forms. Parents value ongoing contact with the hospital staff, since the hospital staff know the child and many parents developed a bond with them over time.[45–47] When parents feel that the HCPs remember their child, this is felt as an acknowledgement of the child's identity, and a validation that their child has made an impact and mattered.[45,46] This acknowledgement results in positive reappraisal processes and adds positive meaning to the past events. These positive reappraisals could also foster adaptive coping behaviours, for example the sharing of the story of the loss with friends and family. The continuous reappraisal and coping behaviours in turn result in altering the working models and plans because the loss is processed conceptually. This helps parents to find a place for, and to define a new bond with, the deceased child in the new reality.[47] Follow-up contact with HCPs and peer supporters, simply their presence and conversations, help parents to cope with loss.[40,43] During follow-up contacts, HCPs can offer parents an explanation of the course of treatment and the rationale for certain decisions that were made. This is important as parents often describe being in a haze during the end-of-life period of their child.[44,46] Furthermore, autopsy results are often shared in order to clarify the physical illness.[53,54] HCPs also have the opportunity to reassure parents that there is nothing that they could have done differently.[58] This helps parents to make sense of the preceding events and to clarify the memories surrounding the death of their child.[46,53] This clarification, in turn, aids reappraisal of the situation and past events, and provides parents with a form of closure. It also allows parents to readjust their memories of the situation, address doubts about themselves, and treasure memories of their child, which results in readjustment to new memories and thus creates new plans about themselves, their child, and the past events.

Education and information

Information folders, booklets, workshops, and seminars can help parents in regaining some control over the many different challenges they face in a new, unknown, and insecure, situation. It makes parents feel more prepared in practical terms such as with financial aid, funeral arrangements, and in finding extra emotional assistance when needed.[59] An example of practical assistance might be how to provide explanations to, and support for, the siblings, reassuring parents that what they are feeling is normal, actions which can be termed preparation and which offer a sense of validation.[55,59] But practical assistance could also include providing information about when and who to turn to for extra support.[55] These forms of assistance support parents in coping with the new situation because it makes the new demands slightly more manageable. The information provided, and the validation of the emotions they experience, also assist parents in creating new knowledge structures and plans with regard to their grief and the future they face. It helps the appraisal processes and offers new working models.

Remembrance activities

The remembrance activities provide an opportunity to feel close to the child again and to recollect memories about their life.[60] It is also a means of feeling supported by friends, family, hospital staff, and the community, that may help parents to cope with the loss.[51] These remembrance occasions provide a secure environment where parents feel connected to the child and feel the bond that they had, and that still exists. Remembrance activities help parents in finding a way to continue their bond with the child in the new reality. Religious or spiritual aspects of the events can also help parents to make sense of, and find meaning in, the child's death. Such "meaning making" after the death is a helpful coping mechanism for parents, in which they can revise their memories and plans surrounding the death of their child in a positive and helpful manner.

DISCUSSION

This review identified fifteen well-defined bereavement interventions provided by regular HCPs to support parents of seriously ill children both at the end of their child's life and after death. All interventions were clustered into five overarching components of the intervention. These are: the acknowledgement of parenthood and the child's life; establishing keepsakes; follow-up contact; education and information, and; remembrance activities. The majority of interventions started after the death of the child, and were performed by a nurse, assigned as the primary carer, or a physician. Most of the empirical studies included in this review evaluated how to conduct the intervention and experiences with the interventions, but not their effectiveness. To compensate for this lack of evidence, the components of intervention were assessed against a theoretical synthesis on loss and grief, which revealed that all the components from which the interventions were built were covered by theories on a conceptual level. The theoretical synthesis did uncover that bereavement is characterised by the continuous process of adjusting to a new reality.[18–21,23,26–30] Five key theoretical concepts clarify this process: anticipatory grief; attachment working models and plans; the appraisal processes; coping behaviours, and; continuing bonds. The theoretical synthesis shows the need for bereavement interventions to focus on the continuous nature of grief, and thus, starting before the death and guiding parents through the grieving process. Most interventions we identified relied on a combination of multiple components or time points. However, few interventions reviewed here showed such a continuous process in supporting the parents.

In our comparison of the components of intervention, and the theoretical synthesis, we found HCPs pursued several underlying aims for providing bereavement care to parents. The interventions were offered by HCPs to enhance the parents' feeling of preparedness towards the death of their child. These comprise providing parents with information, nurturing the child, and experiencing support from HCPs or their peer supporters. Those designed to enhance their ability to create memories of, and with, their child include nurturing the child, treasuring keepsakes, and recollecting memories at the subsequent remembrance ceremony. Finally, the interventions to provide parents with comfort and reassurance involve making memories and keepsakes, answering questions and providing comfort in follow-up, providing information in general, and remembering and acknowledging the child. These elements are not captured in a single moment, but require support at different moments and in a continuous nature.[61] A difference we noticed is that the importance of supporting parents in their parental role, and acknowledging the identity of the child, may have a different meaning in neonatology compared to paediatrics.[54,62] The time in the hospital is often the only time these parents can make memories with their child and to nurture them. The HCPs are often the only people, apart from the family, to have seen the child alive.

Bereavement theories emphasise that dealing with loss takes form in a transition towards a new reality.[18–21,23,26–30] However, only four interventions included in this review commenced before the death of the child.[50,57,59,60] Yet, conversations between HCPs and parents about the condition of their child, and their preparedness for the death of their child, can contribute positively to the bereavement process after their child has died.[25,63] The possible explanations for this are, firstly, that there is a delicate balance between preserving hope and letting go of the child during the end-of-life phase. Most, but not all, parents are able to make this transition.[4,64] Most parents are intellectually aware that their child's death is imminent, however, emotional awareness usually follows at a later stage, or not until after the death.[65] For the HCPs these phenomena, and the parental diversity, make it difficult to assess when parents are receptive to bereavement support during the end-of-life phase. Furthermore, this diversity tends to provoke insecurity among HCPs. However, HCPs should be able to influence parents' awareness and openness towards bereavement support, for example by informing parents about the finality of curative options by sharing information honestly and considering whether to stop ongoing curative treatment.[65] Secondly, given the diversity both in parental responses to letting go of their child, and in their emotional awareness, it is difficult to create a standardised intervention, including a protocol, for bereavement care for parents during the end-of-life phase. Since our inclusion criteria consisted of interventions that needed to be replicable, and supported by a protocol or documents, these kind of interventions could have been excluded. This could mean that there is, in fact, attention for feelings of loss and grief, prior to the death of the child, by HCPs in their current daily practice. However, these practices are not standardised and thus were not covered in this review.

The comparison of key theoretical concepts and components of intervention showed that interventions all account for small fragmented pieces in the grieving process. But, also, that there are no interventions that emphasise the continuous parental adjustment process as a whole. The regular HCPs who had been involved in the child's care since diagnosis could be a significant factor in this continuous care. Studies have shown that parents require at least one meaningful follow-up contact with the HCPs who cared for their child.[14,66] We propose that bereavement care, including follow-up conversations, are important parts of the regular HCPs' activities. There are three main reasons for the integration of follow-up care into the HCPs activities. Firstly, parents often have outstanding questions about their child's care, illness, and their role in the period of the illness.[67] The regular HCPs are able to answer these questions since they have been part of the care prior to death. Secondly, the trustworthiness and bonds that already exist between the HCPs and parents are very important.[54] Thirdly, parents seek proximity to their child - an acknowledgement of his or her life, and the impact the life has made; it helps parents in the grieving process when the HCPs speak of their memories of the child, reflect on his or her unique identity, and are effected by the child's death.[14,45] Another important element of the conversations between the HCPs and parents could be psycho-education.[68,69] Psycho-education encompasses information about what parents are experiencing while preparing them for what they could encounter during their journey through the grieving process. It has been shown to have positive effects on the self-efficacy of informal caregivers. Psycho-education could strengthen parents in their transition to a new reality where the child is no longer physically present, if they understand which challenges they are going to face, and prepare them with helpful coping strategies.[68] Psycho-education might too have a positive effect on mental appraisals when a setback in the grieving process occurs and in validating the feelings parents experience as normal.[70]

Once a child dies, their parents are left with an overwhelming sense of grief. They describe the time passing as a blur.[44,54] Parents are not aware, during that period, of all the interventions and assistance HCPs could offer them. However, options could be presented to parents, and the most appropriate could be chosen. Therefore, it is important that HCPs offer parents a broad range of interventions.[71] This is also important because the key theoretical concepts are not sequential. Instead they form a continuum and the most dominant of these key concepts alter according to the demands at a given time.[18,20,21,27] Also, effective coping is defined by a process of alternating between two or more different coping strategies, depending on the demands at a specific time.[72] If HCPs could determine, in what stage parents were at a given time, or with which processes they experience difficulties, the appropriate components of intervention to aid that process could be selected.

STRENGTHS AND LIMITATIONS

The search was constructed using a recently developed method, PALETTE, in addition to PRISMA. This was helpful in identifying all the relevant articles in relatively young domains where terminology is still diffuse. To our knowledge, given the difficulty of measuring outcomes in the field of paediatric palliative care, this is the first systematic review to give insight into the theoretical effectiveness of bereavement interventions. In particular, the inclusion of replicable interventions provides HCPs with opportunities to implement them in their practice. A limitation of this systematic review concerns the inclusion and exclusion criteria. These eliminated less developed practices and potentially helpful professional attitudes and behaviours out of sight. It is possible that these contain strategies that can be considered supportive in parental grief. Also, we included replicable interventions which could be implemented in practice since these interventions are supported by a protocol or clear guidelines. However, most interventions are not tested and offer little evidence in their support. This is required before implementing an intervention. Testing these interventions might then be difficult due to the setting of paediatric palliative care. Therefore, the theoretical synthesis and alignment could only provide a form of theoretical support for the interventions we reviewed.

CONCLUSION

This review provides an overview of well-defined, replicable, bereavement interventions. The theoretical synthesis in this review provides a basis for the effectiveness of the components of intervention. All five of these cover multiple key concepts derived from theory. HCPs can choose multiple interventions for different components to provide parents with a continuous form of bereavement care, aiding the transition that parents have to go through following their loss. Future research is needed on how this continuous support can be established, which time points are crucial for providing bereavement care, and how new interventions can be developed that align with this transition, and thus, ultimately, help parents in adjusting to their new reality.

Additional file 1. Search strategy.

Search strategies for all databases, search performed on November 15, 2018

Ovid MEDLINE(R) ALL <1946 to November 15, 2018>
(((exp *health personnel/ or (((health or healthcare) adj3 (assistant or provider or professional* or personnel or staff)) or caregiver* or care-giver* or nurse* or nursing or physician* or clinicians* or surgeon* or pediatric* or paediatric* or neonatologist* or NICU).ti,ab,kf.) and (exp *parents/ or (mother* or father* or family or families or couple* or parent*).ti,ab,kf.)) or exp *Professional-Family Relations/) and (exp *bereavement/ or (bereave* or grief or grieving or mourning or mournful or mourned or “death of a loved one” or “premature demise” or ((child or patient) adj3 death)).ti,ab,kf.)

Embase Classic+Embase <1947 to 2018 November 15>
(((exp *health care personnel/ or (((health or healthcare) adj3 (assistant or provider or professional* or personnel or staff)) or caregiver* or care-giver* or nurse* or nursing or physician* or clinicians* or surgeon* or p?ediatric* or neonatologist* or NICU).ti,ab,kw.) and (exp *parent/ or (mother* or father* or family or families or couple* or parent*).ti,ab,kw.)) or *human relation/) and (exp *bereavement/ or exp *grief/ or (bereave* or grief or grieving or mourning or mournful or mourned or “death of a loved one” or “premature demise” or ((child or patient) adj3 death)).ti,ab,kw.)

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AND
(MM “Bereavement+”) OR (MH “Grief+”) or AB(bereave* or grief or grieving or mourning or mournful or mourned or “death of a loved one” or “premature demise” or ((child or patient) N3 death)) or TI(bereave* or grief or grieving or mourning or mournful or mourned or “death of a loved one” or “premature demise” or ((child or patient) N3 death))

Additional file 2. Synthesis of theories on grief and loss.

	Components concerning anticipatory grief	*Components concerning attachment working models and schemas*	*Components concerning appraisal processes*	*Components concerning coping*	*Components concerning continuing bonds*
Boelen[18]		A need to integrate the reality of the loss into the person's existing mental representations of the self, the world, and the relationship with lost person.	Maladaptive beliefs (about the self, life, the future, the world, and one's own responses to the loss) need to be changed into beliefs that foster adjustment.	Anxious and depressive avoidance strategies need to be replaced by more helpful strategies that facilitate adjustment.	
Bowlby[19,20]		A disruption of attachment working model results in a need for reorganizing representations of the lost person and the self.	Awareness of a constant mismatch between existing schemas and reality.		
Folkman[21]			Ongoing cognitive reappraisals of the stressful situation.	Dealing with the stressful situation using problem- and emotion-focused coping strategies.	
Hebert[22]	Preparedness as an important factor in end-of-life care. Importance of preparedness in the medical, psychosocial, spiritual, and practical dimensions				

Additional file 2. Synthesis of theories on grief and loss. (continued)

	Components concerning anticipatory grief	*Components concerning attachment working models and schemas*	*Components concerning appraisal processes*	*Components concerning coping*	*Components concerning continuing bonds*
Horowitz[23]		Need for reschematization of the person- and relation schemas after the loss.	In the process of reschematization, awareness of the inability of previously held knowledge structures to account for new information, and time to develop new meaning structures is needed.	The reaction of the person depends on how the event and context interact with preexisting personality structures and coping styles.	Reschematization accounts for the relationship with the deceased, and the attachment bond to live on in the mind.
Maccallum[24]		Revision of self-identity is needed to incorporate the reality of loss in the autobiographical memory.	Adjustment to loss requires that roles, personal goals, motivations, and future plans that were shared with the deceased are no longer entirely based on the deceased	Emotion regulation strategies are influenced by the self-identity. Need for flexible use of emotion regulation strategies.	
Neimeyer[25,26]		Importance of meaning making processes of the death. Need for change in (inter)personal systems of meanings and find significance both in the death and in own ongoing life.		Meaning-making is a process and differs over time, from finding an answer to the “why” of the death to the positive benefits of the loss for survivors.	

Additional file 2. Synthesis of theories on grief and loss. (continued)

	Components concerning anticipatory grief	*Components concerning attachment working models and schemas*	*Components concerning appraisal processes*	*Components concerning coping*	*Components concerning continuing bonds*
Rando[27]	Anticipatory mourning is experiencing loss or trauma in the awareness of life-threatening or terminal illness. Consists of: grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death.	Involves readjustment to the new world without forgetting the old world, developing a new relationship with the deceased, and forming a new identity.	Revision of the assumptive world, and adopting new ways to be in the new world.	During anticipatory mourning, coping can be directed toward disease related, dying related, or ongoing life processes.	
Shear [28]		Stress response because of absence of attachment figure, resolves when the permanence of the loss is integrated into the long-term memory and attachment representations are updated.	Continuous mismatch between the mental representation of the attachment figure and the reality of their death, this causes stress.	Stress activates the attachment system. However, unavailability of the attachment figure causes (even) more disruption of the effective functioning of the emotion regulation system. There is a need for effective coping strategies.	
Stroebe[29,30]				Adaptive coping with grief by alternating between confrontation and avoidance strategies, depending on the situation.	During loss orientation, a rebuilding of assumptions about the presence of the lost person in one's life takes place.

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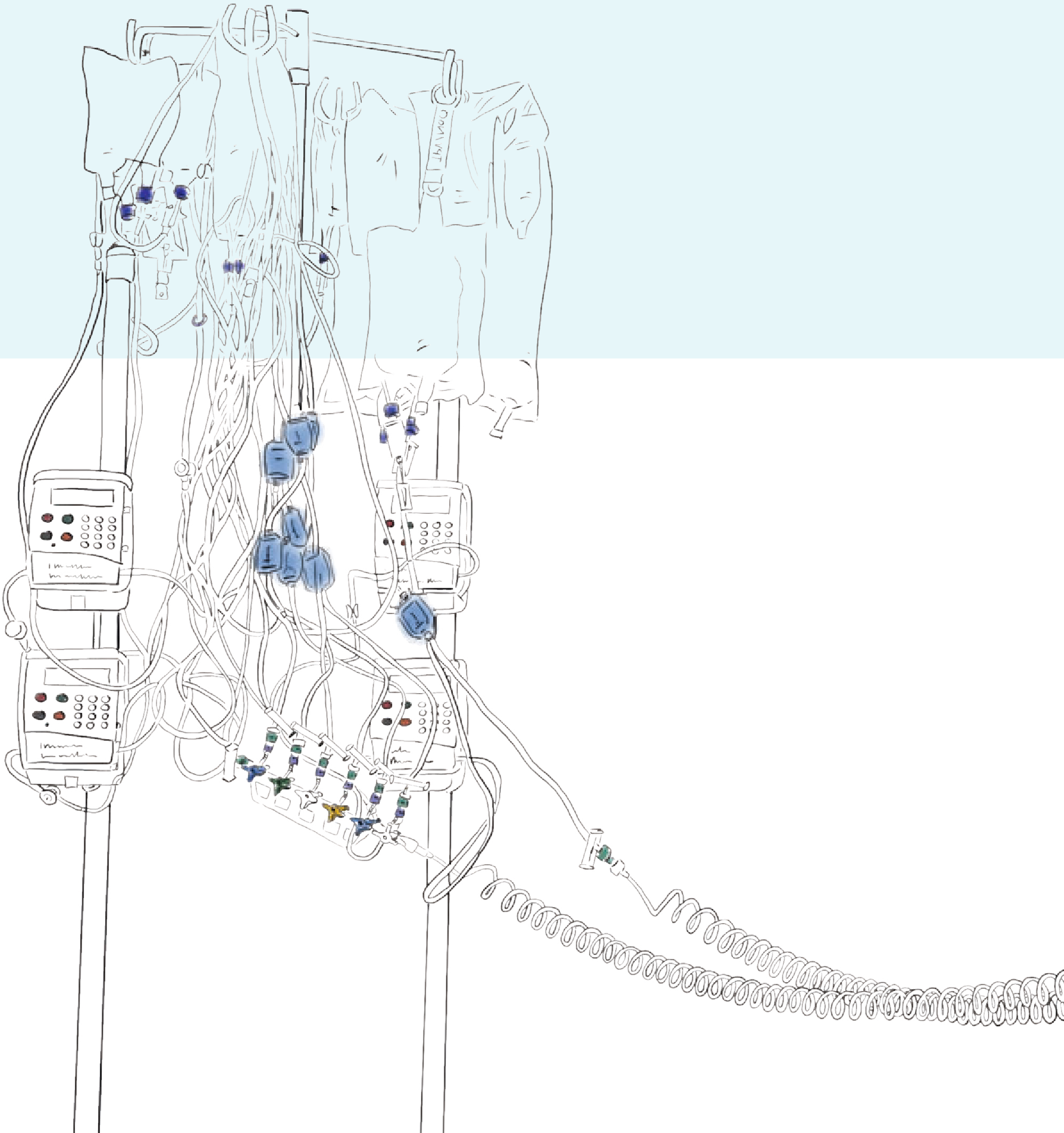

3

Health care professionals' experiences with pre-loss care in pediatrics; goals, strategies, obstacles and facilitators

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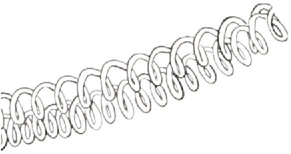

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ABSTRACT

Context
Although parents experience grief when confronted with their child's deterioration and imminent death, most bereavement care is focused on supporting parents after child loss. Insight into the health care professionals' (HCPs) intentions and strategies in pre-loss care during the end-of-life is still lacking.

Objectives
To create a starting point for improvement of pre-loss care, this study explores HCPs' experiences with providing support aimed at parental feelings of grief during the child's end-of-life.

Methods
Exploratory qualitative research using individual semi-structured interviews with clinicians in pediatrics and neonatology in hospital and homecare settings. Data were thematically analyzed by a multidisciplinary team.

Results
Nineteen HCPs participated. HCPs tried to ensure that (1) parents could reflect on the care received as concordant to their preferences and (2) were not hindered in their bereavement as a consequence of their professional actions. Strategies included maximizing parental presence, enabling parental involvement in decision making, and ensuring a dignified death. While employing these strategies, HCPs faced several difficulties: uncertainty about the illness-course, unpredictability of parental grief responses, and being affected themselves by the child's imminent death. It helped HCPs to develop a bond with parents, find comfort with colleagues and making joint decisions with colleagues.

Conclusions
HCPs strive to improve parental coping after the child's death, yet apply strategies that positively influence parental preparedness and wellbeing during the end-of-life as well. Individual HCPs are left with many uncertainties. A more robust approach based on theory, evidence and training is needed to improve pre-loss care in pediatrics.

INTRODUCTION

Losing a child is a devastating event for parents resulting in poor psychosocial and mental health outcomes[1,2] and increased levels of mortality.[3] To aid parents in coping with loss, a growing number of interventions have been developed by health care professionals (HCPs). These interventions mostly focus on bereavement care after child loss.[4,5] However, studies show that feelings of grief are felt by parents from diagnosis, throughout illness progression, and persist beyond the child's death.[6,7] HCPs experience a growing responsibility to aid parents in coping with experienced losses and feelings of grief during the end-of-life period.[8,9] Engaging in pre-loss care during the end-of-life might improve parental bereavement outcomes following the loss of a child. Yet, development of guidelines and concrete interventions aimed at supporting parents in experienced feelings of grief during the child's end-of-life are sparse. Studies identifying HCPs' support practices aimed at parental grief prior to the loss, are mostly limited to inventory surveys,[10,11] or experiences in critical care.[12] These studies predominantly focus on concrete interventions, while the goals and strategies underlying the HCPs provision of care remain unclear. Therefore this study aims to achieve a thorough understanding of the HCPs' intentions and experiences with providing pre-loss care aimed at supporting parental grief during the child's end-of-life.

METHODS

Design

An exploratory qualitative interview study, using thematic analysis, was conducted to gain insight into the HCPs' experiences.[13,14]

Sample

A purposeful sample of regular HCPs, defined as physicians or nurses who care for children during the end-of-life as part of their professional responsibilities, was included in this study. In line with the exploratory approach, maximum variation was sought with respect to setting, specialism and years of experience. Participants were recruited from three university children's hospitals and a child home care service. Participants were identified by key persons in their organizations, and invited by the research team.

Data collection

Data was collected through single, semi-structured interviews and a self-administered background questionnaire. All interviews started with a broad opening question, inviting the participants to share their experiences: “Based on your experience, what do you consider as care aimed at parental loss and feelings of grief?”, followed by more focused questions, based on literature and expert knowledge. HCPs were invited to share their experiences with providing care to children during their, approximate, last months of life until 6 months after death. The interview guide covered the following topics: the HCPs’ personal experiences with pre-loss care and bereavement care and current support practices aimed at parental grief and bereavement during end-of-life and after child-death; how HCPs perceive and respond to parental grief; experienced barriers and facilitators in care delivery. Data collection and analysis alternated, new insights from preliminary analyses were elaborated on in consecutive interviews. Data was collected until saturation was reached on the main concepts.[13]

Data analysis

Data were thematically analysed.[14] All interviews were audio-taped, transcribed verbatim and pseudonymized. The analysis team, consisting of a psychologist, trained in qualitative research (EK), a pediatric intensive care nurse and senior qualitative researcher (MK), a neonatal intensive care nurse and researcher (FJ), and an expert parent (RJ) ensured researcher triangulation.[14]

Five interviews were read closely by all members of the team individually, identifying and discussing meaningful fragments, using open coding. By axial coding, the team rearranged the preliminary codes into meaningful categories and sub-categories. An initial code tree was formed and further thematic coding was performed by one researcher (EK),[15] using software program NVivo12.[16] During the analysis, extensive memos were written, which facilitated in-depth discussion on interpretation from data towards outcomes. The working group provided peer review throughout the analysis. A medical student (EB) validated the results by checking five interviews (26% of the data) against the final outcomes. Descriptive analyses were performed on the background questionnaire using SPSS25.

Ethical consideration

This study was classified by the institutional review board as exempt of the Medical Research Involving Human Subjects Act (WAG/mb/19/006630). Informed consent was obtained from all participants.

RESULTS

Participants

Nineteen of the 24 invited participants, eight nurses and 11 physicians, participated (Table 1). The five remaining (response rate 79%) were not responsive to the invitation (n=3) or lacked time (n=2). The interviews were conducted at the participants' preferred location, either at their workplace or at home, and lasted 40 - 75 minutes.

HCPs' beliefs regarding pre-loss care

From the background questionnaire, we learned that HCPs believed it was important to provide pre-loss care to parents of children during the end-of-life (100%) and felt responsible to deliver such care (84.2%) (Table 2). During the interviews, most HCPs explained they had developed their skills 'on the job', by practice or learning from colleagues. HCPs have grown to feel more confident in providing care aimed at parental grief, yet they initially felt uncertain due to a lack of education. Most HCPs still wondered whether their approaches were currently considered best practice. All HCPs believed that care aimed at parental grief should start early in treatment, when a life-limiting diagnosis is shared with parents. Pre-loss care was intensified when no curative treatment options were left or symptoms started to accumulate.

From the interviews, we identified the HCPs' goals and strategies in employing pre-loss care during the end-of-life, difficulties in achieving these goals, and what empowered them to provide pre-loss care (Table 3).

Table 1. Participant Characteristics.

		n (%)
Gender	Female	15 (79)
	Male	4 (21)
Age	20-29	2 (11)
	30-39	3 (16)
	40-49	6 (32)
	50-59	8 (42)
Profession	Physician	11 (58)
	Nurse	8 (42)
Specialization	Neonatology	6 (32)
	Intensive Care	3 (16)
	Cardiology	2 (11)
	Child home services	2 (11)
	Metabolic disease	2 (11)
	Neurology	2 (11)
	General ward/medium care	1 (5)
	Pulmonology	1(5)
Additional Training	In palliative care	4 (21)
	In bereavement care	3 (16)
Years working experience in pediatric care	0-10	5 (26)
	11-20	7 (37)
	21-30	6 (32)
	31-40	1 (5)
Number of patients with life expectance <1 year, p/y	0-10	12 (63)
	11-20	2 (11)
	21-30	1 (5)
	30+	4 (21)
Number of deceased patients p/y	0-10	12 (63)
	11-20	4 (21)
	21-30	1 (5)
	30+	2 (11)

Table 2. Questionnaire on attitudes regarding pre-loss and bereavement care.

Statement (n=19), n (%)	**Strongly disagree/ disagree**	**Neutral**	**Agree/ Strongly agree**
1. I feel capable of providing care aimed at parental feelings of grief	0 (0)	3 (15.8)	16 (84.2)
2. I believe it is useful to talk about feelings of grief with parents	0 (0)	0 (0)	19 (100)
3. I feel capable of conducting a follow-up conversation with parents after the child's death	0 (0)	2 (10.5)	17 (89.5)
4. After I've had a conversation with parents on their feelings of grief, it sticks to me prolongedly	2 (10.5)	5 (26.3)	12 (63.2)
5. After I've had a conversation with parents on experienced losses and feelings of grief, I feel uneased	15 (78.9)	4 (21.1)	0 (0)
6. I perceive I can correctly assess the appropriate time to talk about feelings of grief with parents	0 (0)	7 (36.8)	12 (63.2)
7. I am sensitive regarding the feelings and emotions of parents	0 (0)	2 (10.5)	17 (89.5)
8. I feel responsible for supporting parents in their feelings of grief	1 (5.3)	2 (10.5)	16 (84.2)
9. In my daily practice, I experience sufficient time and opportunity to talk with parents about their grief	1 (5.3)	8 (42.1)	10 (52.6)
10. I feel it's undesirable to talk about feelings of grief with parents prior to their child's death, since it disrupts parents	17 (89.5)	2 (10.5)	0 (0)

Scores: 1 = strongly disagree; 2 = disagree; 3 = neutral; 4 = agree; 5 = strongly agree

Table 3. Quotes per (sub-)theme.

(Sub)theme		Quote
Goals		
Reflect on received care as concordant to parents' preferences	HCP 16	…in particular for parents to reflect upon the process positively, even though they are incredibly sad and the worst possible thing has just happened to them, but that the process surrounding all these events was satisfactory.
No hindering for parents in the grieving process	HCP 6	…to have all the uncertainties and ambiguities on the table at that time… so that parents don't have to ponder… that for the parents, it is clear what caused their child's death […] that parents have no disturbances to start their grieving process, without remaining questions, that could have been clarified..
Strategy		
(1) Maximizing parents' presence		
• Preserving the child's identity	HCP 8	That boy watched YouTube movies all day, clips of cars crashing into each other. He loved cars. Whenever someone walked into his room, the first thing he would ask was what kind of car you drive, and the specific type. That was funny, so we discuss these types of things as well. I think it is the impact the boy has made on us, what's of comfort to her, it helps, for parents, he has made an impact.
• Engaging parents in the moment	HCP 15	Both ways I think, for parents to still be able to support their child, but also for the child to be there for their parents, because they still need to exchange love. Other parents have their whole lives to exchange love and contact, and to teach things, whereas the parents who are here, have just heard the worst possible news, that their child is going to die. The parents have such limited time, so they have to use that time to the fullest.
• Facilitating the parental role	HCP 10	For them to experience the feeling of being a parent, they have solely seen their child here, connected to all tubes and lines… and then there's your child… you're still a parent. Especially when it's your first child, you are a parent, even though your child has died.
(2) Parental involvement in decision-making	HCP 15	You start off by stating the problem clearly, followed by breaking it up into pieces, so that parents can learn to cope with the situation, and to provide parents with room for questions. And in this, for me it is important to key into the experiences of parents and what they understand from what I'm explaining.
	HCP 16	I try to be open and receptive to the parents' wishes, naturally parents are unaware of all the possibilities at that time, so I feel obliged to inform them, […] parents must know the range of possibilities.

Table 3. Quotes per (sub-)theme. (continued)

(Sub)theme		Quote
• Normalizing parental feelings	HCP 4	You try to put into words the positive aspects, or at least the variegation of the moment. And with that, I think, you provide parents with a message, that death might be okay.
(3) Ensuring a dignified death	HCP 14	That the child has a dignified death and a death with which the parents can continue. In other words, that the death was dignified in the parents’ perception, and that they look back upon something that was unavoidable, but what happened correctly. So parents can feel at peace with it.
Difficulties in providing pre-loss care		
(1) Uncertainty about illness course.	HCP 1	It’s very individual, at least, in the patients with difficult diagnoses. And because of that, you conduct very individual, tailored conversations with parents, about the perspective, about how to continue, or about the unpredictability on how the illness will proceed, and about the fact that we might not be able to predict future perspectives at all.
(2) Unpredictable and diverse parental responses.	HCP 7	For example when parents ask me how they could possibly carry on after their child has died, I really don’t know.. I’m like “help”, I don’t know [...] because you try to respond, but sometimes, I’m unsure whether I’m saying the right things, or am I saying something weird... or you simply don’t know how to respond. And that’s when I feel uncomfortable, and then it becomes more difficult.
(3) HCPs feeling touched by the loss	HCP 4	The thing I notice is that, when there are too many, your ability to.. it slips... you develop some sort of shell around you, to protect you. That way it doesn’t hit so hard.. but to truly provide best care, you need to let the feelings in, but not too much. And if that happens too often, you tend to guard yourself and not feel as much, since then, it’s too much to handle.
What empowers HCPs in providing pre-loss care		
(1) Finding help in colleagues in making and communicating decisions	HCP 10	I think there’s a broad spectrum of doctors, nurses, and the parents.. and all disciplines that are involved, together you should carry that responsibility. If one person misses something, its everyone’s responsibility, it should be done together. Not solely the nurses or the doctors or just the parents.
(2) Developing a bond with the parents	HCP 15	It’s like... I find it hard to define when you have a connection with parents. I think it’s a matter of mutual respect and trust. A feeling of mutual respect and trust, it’s not something you can measure, but you can feel it [...] it develops by investing in the patient and their parents from the start, being honest. And at times... I think trust can’t by created. It needs to be given sometimes.
(3) Finding comfort with colleagues in own feelings of grief	HCP 8	I cry, and talk to my colleagues... And after this child died, another patient took a turn for the worst, then I told them I couldn’t take on that patient, so I called a colleague if they could take over, I needed to catch a breath before I could continue my shift.

Goals in pre-loss care

HCPs actively engaged in pre-loss care during the end-of-life and tried to minimize the potential for negative bereavement outcomes after child loss. This general belief on pre-loss care was practiced in two overarching goals: (1) that parents might be able to reflect on the care received as concordant to their values, goals and preferences, and (2) parents' grieving process after the child's death would not be hindered as a consequence of their professional actions when this could have been prevented.

Strategies in fulfilling pre-loss care aimed at parental grief during the end-of-life

HCPs used three strategies to accomplish the aforementioned goals: (1) maximizing the parents' presence for their child, (2) enabling parental involvement in decision making, and (3) ensuring a dignified death for the child.

1. Maximizing the parents' presence for their child

HCPs observed the parents' difficulty in caring for a child facing the end-of-life. For instance: insecurity about how to hold or take care of their child while attached to tubes and lines, struggling with their own emotions while also emotionally supporting the child, and being present in the moment. HCPs tried to mitigate these parental difficulties by:

- *Preserving the child's identity.* HCPs attempted to provide comfort to parents by showing that they genuinely see and acknowledge the uniqueness of the child as a person; for instance, by giving a compliment about a unique feature such as a beautiful smile or remembering a favorite hobby. Particularly in neonatal care, acknowledging the identity and uniqueness of the child was considered critical. Since it provides parents with pride and connectedness, as parents usually barely had the chance to hold or bond with their child, and family or friends had not been introduced yet.
- *Engaging parents in the moment.* According to the HCPs, parents' fears and worries about the dying process and the image of a future without their child could impair them from being "mentally" present, e.g. to truly engage with and be receptive to their child. In response, HCPs attempted to identify smaller concerns they could solve, to eliminate barriers for parents to experience meaningful moments. HCPs did this by emphasizing on the current presence of the child and by encouraging parents to interact with them. HCPs attempted to create meaningful situations, the memories of which could later be cherished by parents. HCPs tried to eliminate smaller

practical obstacles, to provide parents with more time to be physically present, next to their child.

- *Facilitating the parental role*. HCPs tried to help parents in preserving parenthood despite the child's deterioration, by encouraging them to bath, hold and comfort the child. HCPs involved in neonatology stressed the importance of helping parents to fulfill parental tasks since it validates parents in their feeling of being a parent, especially when the child will never come home. HCPs expressed the importance of respecting parents' voices when advocating for their child's wellbeing and engaging them as partners in care.

2. Enabling parental involvement in decision-making

HCPs stressed the importance of enabling parents to be valued partners in the decision-making process. With the aim to facilitate parents to reflect upon a trajectory where everything possible had been done and death had become inevitable. HCPs expressed this was of importance to prevent difficult bereavement reactions after the child's death and to provide parents with closure. HCPs explained that the level of parental involvement depended on the situation. In critical situations where decisions had to be made under pressure, HCPs tried to guide parents through the decision-making process and made sure parents fully understood and agreed with decisions made. HCPs tended to inform and guide parents by sharing their recommended decisions based on the team's expertise. However, HCPs expressed that in a foreseeable situation of progressive illness, they preferred to discuss end-of-life and treatment options prior to a critical situation. HCPs felt that, discussing these matters at an earlier stage, provided parents with some time to adjust to the fact their child would die and to prepare them for making difficult decisions on behalf of their child. HCPs viewed that discussing these matters in a stable situation aided parental preparedness and ensured parental presence with their child during end-of-life.

- *Normalizing parental feelings and making parents feel at ease.* HCPs noticed that parents struggled with the paradox of their parental instincts guiding them to protect their child and being unable to save them, given the fact that in this situation, best care might comprise comfort care. To alleviate this internal parental struggle and to strengthen parental coping with these paradoxical feelings, HCPs validated and normalized the range of emotions parents experienced. Some HCPs mentioned that endorsing these moments with parents and making them feel more at ease, could comprise acknowledging the diversity or serenity of the situation. Legitimizing the fact that parents might also experience positive feelings and emotions, was expected to aid parents in being able to reflect on the positive experiences during their child's end-of-life.

3. Ensuring a dignified death for the child

Many HCPs emphasized the importance for parents to hold their dying child close, and to look back at a calm and peaceful death for their child without suffering. HCPs mentioned that, when a death had not been peaceful, parents were often left with intrusive images causing psychosocial problems and hindering the bereavement process. To the best of their abilities, HCPs tried to ensure a dignified death for the children, through providing anticipatory medication, asking parents whether the child is sufficiently comfortable, and explaining symptoms related to the process dying process, such as gasping, as normal.

Difficulties in providing pre-loss care

When pursuing the above mentioned goals, HCPs encountered three main difficulties:

1. Uncertainty about the illness course

HCPs struggled with the unpredictability of the illness course in seriously ill children, resulting in an inability to provide parents with a clear prognosis. HCPs experienced tension in preparing parents, while at the same time not causing unnecessary feelings of loss and disruption. Many HCPs mentioned to solve this problem by introducing a 'two-way track' approach, that informed parents that they should realize that the child might not recover and die within short time, but that the opposite scenario could also occur because children can be remarkably resilient in the face of death. The timing of introducing this two-way track proved to be difficult for HCPs since they did not want to diminish hope in parents. However, HCPs felt obliged to inform parents about the possible negative outcomes in order to maximize parental presence during the child's possible end-of-life. Uncertainty was mentioned to increase in two situations. Firstly, when HCPs had previously informed parents about the possible negative outcomes, resulting in the situation of informing parents of negative outcomes over and over again. Secondly, when parents seemed to be non-receptive to the poor prognosis of their child, and HCPs felt they could not get parents 'on the same page' as they were.

2. Unpredictable and diverse parental responses

Many HCPs found the unpredictable variety in parental responses to breaking bad news challenging. Parents could, amongst others, scream, cry, become numb, anxious, angry, or show disbelieve. Management of these reactions required a flexibility of HCPs which was reported to be difficult. Furthermore, parents occasionally asked questions HCPs felt unable to answer, such as 'How can I possibly continue when my child is gone?'. These type of existential questions reflect on the intensity of the parents' feelings of grief and caused discomfort to some HCPs, since they felt unable to adequately help parents.

3. Being affected by the child's imminent death and the parents' grief

Many HCPs experienced being involved during the child's end-of-life, as a period in which they had close and frequent personal contact with the child and/or their parents. HCPs' involvement with the families and witnessing the child deteriorate and eventually die, evoked feelings of grief in the HCPs, which could make it challenging to provide end-of-life care. Some HCPs worried that the involvement with the family could cloud their judgement in evaluating meaningless extension of curative care. Additionally, some HCPs experienced a sense of failure when a child died, since they were trained to cure.

What empowers HCPs' in providing pre-loss care aimed at supporting parental grief

HCPs found various ways to overcome aforementioned difficulties and to feel empowered:

1. Obtaining support from colleagues when making and communicating difficult decisions

HCPs often felt strengthened by the input of their colleagues, which could take on several forms. Firstly, it helped HCPs when decisions or advice to parents was formulated from a team perspective and not their personal decision. Secondly, when HCPs could not connect with parents, they felt supported when a colleague could assist them in the next conversation.

2. Developing a bond with the parents

HCPs strived for optimal end-of-life care to both children and parents. HCPs expressed it is key to develop a bond with parents, in order to tailor care to their specific needs and wishes. HCPs defined the bond by 'feeling a connection' with the parents, but were unable to specify what exactly constituted this 'connection'. HCPs expressed three ways in which the bond helped them in providing pre-loss care. Firstly, creating a bond with parents and becoming more familiar, made parental reactions more predictable. This eliminated a barrier in talking about difficult topics such as the end-of-life or uncertain prognoses. Secondly, HCPs tried to gain parents' trust, since HCPs perceived that if parents trusted them in handling care truly in their child's best interest, parents could let go of some preconditions and fully focus on being with and supporting their child. Thirdly, most HCPs expressed that creating a bond with parents made the job meaningful for them. Most HCPs acknowledged that, although caring for children at the end-of-life can be challenging, the bond and the potential impact during the worst moments of parents' life, felt as one of the most valuable aspects of their job. Some HCPs acknowledged the uniqueness and the intimacy of the moment when a child is dying and they felt humble to be present.

3. Finding comfort with colleagues in handling their own feelings of grief

All HCPs expressed that support from colleagues regarding their feelings of grief was of major importance for them. HCPs experienced comfort through sharing their story with colleagues who could relate to their feelings and their situation. Colleagues could go over the course of events with the HCPs, reassuring and comforting them that there was nothing the HCPs could have done otherwise. However, some HCPs expressed that support from colleagues was limited due to time restricts or the emotional load of their colleagues. HCPs experienced that sharing their story with colleagues helped them to not take their grief home and provided some form of closure. Furthermore, in environments where frequent pediatric death occurred, HCPs valued if colleagues volunteered to take over other seriously ill patients from them, when the HCP felt that another end-of-life trajectory would ask too much.

DISCUSSION

HCPs feel responsible to support parents in feelings of grief during the child's end-of-life and after death. Their overall goal is to ensure that parents, once the child has died, can reflect on the care received as concordant to their values, goals and preferences and will not be hindered in their grieving process as a consequence of professional action which could have been prevented. Key strategies to accomplish these goals entailed maximizing parental presence, enabling parental involvement in decision making, and ensuring a dignified death for the child. While delivering pre-loss care, HCPs encountered difficulties but also found ways to manage them.

A remarkable finding is that the perceived goals of the HCPs were focused on a positive evaluation after the child's death. Similarly, most developed bereavement interventions are aimed at supporting parents after the death of their child.[4,5,17] However, the importance of aiding parents in their coping with grief prior to their child's death is becoming more evident in research and in theories on loss and grief.[7,18,19] Theories emphasize that bereaved parents have to adjust to a 'new reality' where the child is physically absent. In order to make this transition parents have to cope with several conflicting emotions, to eventually adjust their plans and integrate the loss in their autobiographical memory.[4,20–23] An important aspect of this adjustment, that characterizes the process of bereavement, are two components of anticipatory grief;[7,24] preparedness and awareness time on the impending death.[25,26] Studies have shown that HCPs are able to positively influence parental preparedness by conducting end-of-life conversations, in which topics such as prognoses, future scenario's, and grief and loss are discussed.[25] Discussing prognoses and sharing honest information can positively influence parental awareness time.[26] HCPs might be able to accelerate the awareness time for some parents, since HCPs are often aware of the impending death prior to the parents.[27] Addressing the preparedness and awareness time of parents could then result in improved clinical outcomes for parents, such as satisfaction with clinical care and mental health outcomes. It provides parents with the opportunity to experience their child's last days more vividly. Practically, some of the strategies HCPs employ to assist parents in their grief are not only important for the parents' future coping with the loss, but additionally aid them through the bereavement process prior to the loss of the child; for instance maximizing parental presence, facilitating decision making and managing uncertainties with parents. These strategies might deserve to be more valued at the time of employing them.

Strategies that HCPs could employ in order to aid parental preparedness, including discussing end-of-life topics, have been proven difficult for them due to a lack of confidence[28–30] and the emotional demands.[12,31] However, studies have shown that parents would be open to and value conversations on end-of-life topics.[32,33] Our results show that, at the start of their career, HCPs experienced 'cold feet' addressing end-of-life topics, due to a lack of education and training. After experiencing end-of-life conversations more frequently and by learning from their colleagues, they have grown more confident in conducting these conversations themselves. Several HCPs even stated that they valued being part of end-of-life care and felt humble to be present during these intimate moments. Although HCPs have grown more confident, a lingering uncertainty remains on whether the care they provide is "state-of-the-art" and whether improvement might be necessary.

It is important to eliminate the identified barriers and promote HCPs' confidence on their abilities to provide pre-loss care during the end-of-life. Firstly, uncertainty on the illness course, could be tackled by incorporating knowledge on how to address uncertain situations in the initial curricular and further training. Uncertainty on the illness course is intertwined in the nature of pediatric palliative care. Strengthening HCPs' abilities on tolerating uncertainty and teaching them how to communicate uncertain situations with parents, might help HCPs to overcome this barrier. Conversations during the end-of-life require sensitivity of HCPs which seems to be acquired mostly through socialization and highlights the importance of educated and experienced HCPs engaging their younger colleagues in these conversations early on in their career. Secondly, a barrier for HCPs consisted of the unpredictability of parental emotions and responses. For parents, effective coping with loss an grief comprises a flexible alternation of coping strategies.[23,34,35] Feelings of grief can be expressed in many forms such as fear, anger or sadness, which are normal reactions to having a child facing the end-of-life. These feelings are tied to the nature of palliative care, while HCPs experience a need to respond to or to 'solve' certain emotions. However, as long as parental emotions do not inhibit them in standing next to their child, HCPs could learn to accept emotions as being part of pediatric palliative care and learn to not interpret the emotions as a reflection on their care delivery. Knowing how parents respond emotionally and their manner of coping, might reduce HCPs' fear of emotionally loaded conversations and thus eliminate barriers to talk about the end-of-life.

This study provides insight into the manner HCPs perform pre-loss care during the child's end-of-life in daily practice. The inclusion of physicians and nurses from various specialties and settings enabled us to provide an overview based on a variety of experiences covering the entire range of pediatrics. Recruitment by key persons could have resulted in inclusion of HCPs more experienced in pediatric palliative care leading towards a more positive picture of pre-loss care than what is commonly practiced. Solely including physicians and nurses was a deliberate choice, since the goal was to explore how pre-loss care is integrated in regular care for these families. However, we acknowledge that in practice more professionals are involved, such as psychologists or child life specialists. Gaining insight into the full spectrum of available care is needed to further develop pre-loss care.

In conclusion, HCPs feel responsible to aid parents in their feelings of grief during the child's end-of-life and valued providing pre-loss care. However, novel HCPs experience uncertainty on how to provide such care and the lingering uncertainty remains even in more experienced HCPs. In order to promote HCPs' confidence to provide pre-loss care aimed at parental grief, HCPs require education and training that matches their needs. It is important to emphasize that the strategies HCPs employ, could be more valued during the child's end-of-life, since these strategies positively influence parental awareness and preparedness.

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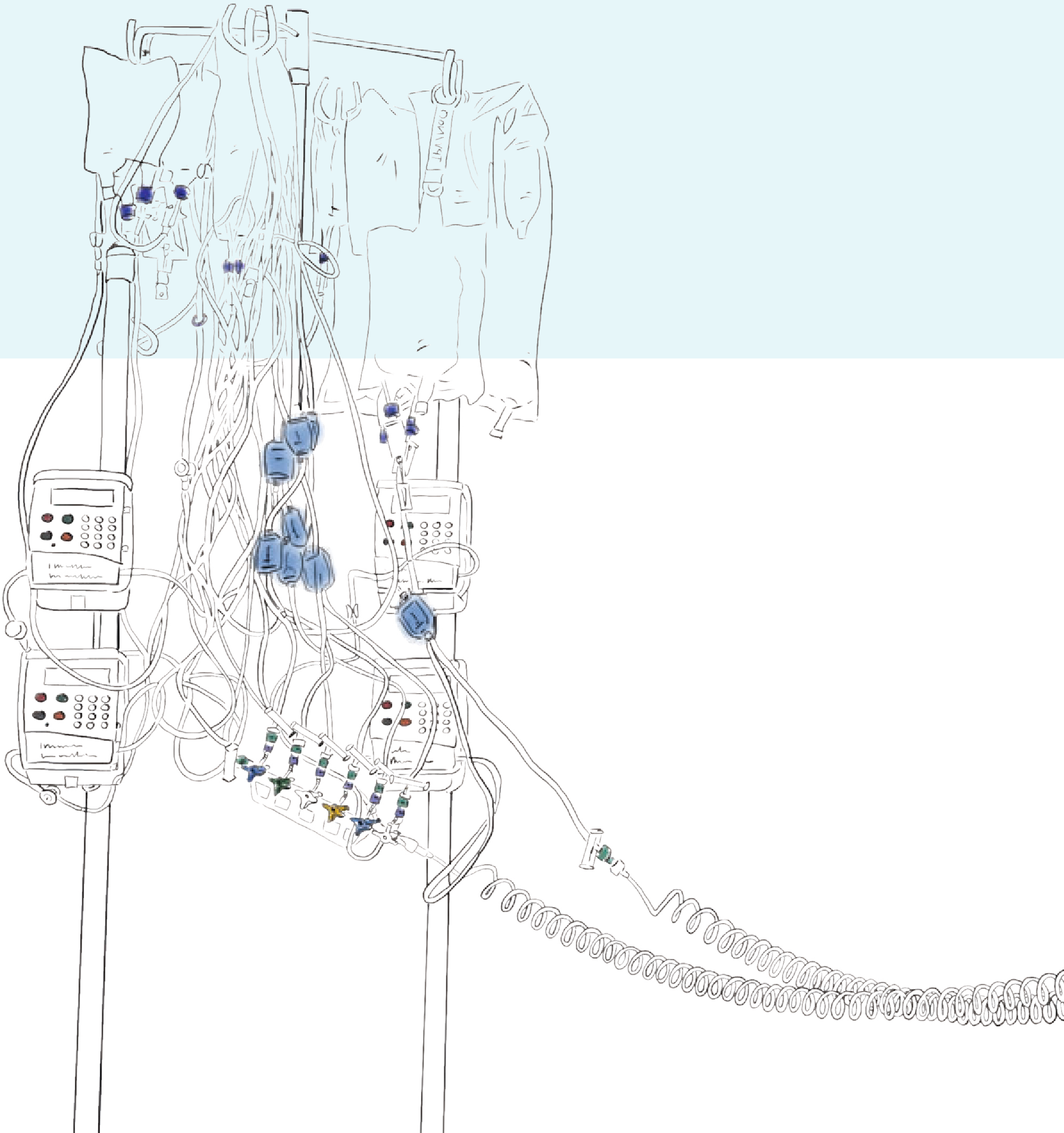

4

Challenges in preloss care to parents facing their child's end-of-life: A qualitative study from the clinicians perspective

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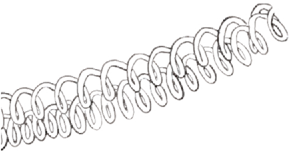

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ABSTRACT

Introduction

Bereavement care for parents predominantly focuses on care after child loss. However, Health Care Professionals (HCPs) feel responsible for supporting parents who are grieving losses in their child's end-of-life. Preloss care is tailored to the parents' needs, thus highly varying. To better understand the nature of preloss care, this study aims to gain insight into the challenges HCPs encounter while providing care for parents during their child's end-of-life.

Methods

Exploratory qualitative research using semi-structured interviews with physicians and nurses working in neonatology and pediatrics in 3 university pediatric hospitals and 1 child home care service. A multi-disciplinary team thematically analyzed the data.

Results

Twenty-two HCPs participated in this study. From the HCPs' inner perspective, three dyadic dimensions in preloss care delivery were identified that create tension in HCPs: sustaining hope versus realistic prospects, obtaining emotional closeness versus emotional distance, and exploring emotions versus containing emotions. Throughout preloss care delivery, HCPs weighed which strategies to use based on their perception of parental needs, the situation, and their own competencies. HCPs remained with lingering uncertainties on whether the preloss care they provide constituted optimal care.

Conclusion

As a result of the experienced tension, HCPs are at risk for prolonged distress and possibly even compassion fatigue. In order to maintain a positive emotional balance in HCPs, education should focus on adapting positive coping strategies and provide hands-on training. Furthermore, on an institutional level a safe environment should be fostered and well-being could be enhanced through learning by sharing as a team.

INTRODUCTION

The life expectancy of children with severe illnesses has increased, which results in a growing number of children receiving palliative care. These children are mostly seen by regular health care professionals (HCPs) in neonatology and pediatrics, who are thus increasingly involved in end-of-life care and confronted with child loss in their daily practice. During the child's end-of-life, parents experience incremental losses resulting in feelings of grief.[1,2] Although bereavement care is mostly provided to parents after their child's death, HCPs are well aware parents have to cope with loss and related feelings of grief during the end-of-life phase, and feel responsible to support parents to the best of their abilities.[1–3] Care aimed at supporting parents in feelings of grief during the child's end-of-life phase, in which symptoms start to accumulate and death becomes increasingly imminent, is commonly referred to as preloss care. Adequate preloss care delivery is experienced as complicated by HCPs, which is often attributed to uncertainty and a lack of training.[4–6]

A recent study showed that the goals HCP strive to achieve in preloss care are: to ensure that parents could reflect on the received care as concordant to their preferences and were not hindered in their bereavement as a consequence of their professional actions.[1] To obtain these goals, HCPs need to tailor care to the parents' specific needs, values, and wishes, which are highly variating. Other studies show that several specific situations might complicate preloss care and account for distress in HCPs, such as end-of-life decision making or treatment withdrawal.[7–11] To better understand the broader nature and variety of preloss care, this study aims to gain insight into the challenges HCPs encounter from their lived experience in providing care for parents during their child's end-of-life.

METHOD

Design

An exploratory qualitative design was used. Semi-structured interviews were conducted and thematically analyzed to gain insight into the inner perspective of HCPs in providing preloss care aimed at parental losses and feelings of grief.[12,13] Given the richness of the data two manuscripts were developed. The first one presented HCPs' goals, strategies, barriers and facilitators while providing preloss care.[1] Based on the lived experience of HCPs, the current study presents three domains that inflict tensions in providing preloss care.

Sample

A purposive sample of pediatric nurses and physicians employed in a variety of specialties in which child death could occur were eligible for this study, such as neonatology, neurology, cardiology, intensive care, metabolic disease, or pulmonology. Additionally, HCPs had to be involved in at least one end-of-life trajectory in the previous year. The pediatric palliative care trajectory can be divided in four stages.[14,15] Stage one and two entail the diagnosis of a life-limiting disease and the following period in which adjustment to a new 'normal' is acquired. We operationalized the end-of-life phase as stage three and four; respectively the stage in which symptoms cumulate and the terminal stage. Maximum variation was sought with respect to specialties and the level of experience in preloss care. Participants were recruited in three pediatric university hospitals and in one child home care service in the Netherlands. Participants were invited by the research team after being identified by key persons in their organization.

Data collection

Data collection consisted of single semi-structured interviews. A background questionnaire was filled out by the participants prior to the interview. Interviews were conducted at a time and place chosen by the participants. All interviews were conducted in Dutch and started with a broad opening question: "Based on your experience, what do you consider as care aimed at parental grief during their child's end-of-life?" Subsequently, topics regarding their experiences with parental losses, grief, and bereavement were explored more thoroughly. Data collection and analysis alternated, new insights from preliminary analyses were elaborated on in consecutive interviews.

Data analysis

All interviews were audio-recorded, transcribed verbatim, and pseudonymized; field notes were made directly after each interview. Data were thematically analyzed supported by Nvivo 12.[12,13,17] During the data analyses, researcher triangulation was attained by a multi-disciplinary research team consisting of:[13] a psychologist trained in qualitative research (EK), a NICU nurse and researcher (FJ), an expert parent (RJ), and a senior qualitative researcher and former PICU nurse (MK). On several occasions, the findings were discussed in a more extensive research group, including one senior researcher and registered nurse (ST) and two senior researchers with a background in psychology (PB, MG).

At first, open coding was performed on five interviews by all members of the analysis team, identifying meaningful fragments and discussing interpretations.

From these discussions tentative themes became clear that were initially coded as ‘response to emotions’, ‘emotional closeness towards parents’ and ‘hope’. During the analysis, theoretical notes and narratives were constructed in order to facilitate in-depth discussions. From these discussions, it became clear that the three tentative themes were actually dyadic domains of tension. Based on this insight the team decided to restart coding all 19 interviews and construct narratives for all 19 interviews to better understand these tensions. The narratives and theoretical notes facilitated the interpretation of the data using researcher triangulation to gain consensus on the meaning of the themes. In contrast to the first manuscript, three additional interviews were conducted to deepen our understanding of these tensions, obtain saturation and validate the results. The working group, consisting of HCPs working in pediatrics and neonatology, provided peer review and validated the results throughout the analysis.

Ethical consideration

This study was classified by the institutional review board as exempt of the Medical Research Involving Human Subjects Act (WAG/mb/19/006630). Informed consent was obtained from all participants.

RESULTS

In total 22 of the 28 invited HCPs participated in this study, 13 pediatricians and nine nurses, 17 participants were female (Table 1). Reasons for non-participation were non-responsiveness to the invitation (n=4) or lack of time (n=2). Interviews were conducted face to face at home (n=2), workplace (n=19), or via video conferencing (n=2), and lasted 40-75 minutes.

Table 1. Participant Characteristics.

		n (%)
Gender	Female	17 (77)
	Male	5 (23)
Age	20-29	2 (9)
	30-39	4 (18)
	40-49	7 (32)
	50-59	9 (41)
Profession	Physician	13 (59)
	Nurse	9 (41)
Specialization	Neonatology	7 (32)
	Intensive care	5 (23)
	Cardiology	2 (9)
	Child home services	2 (9)
	Metabolic disease	2 (9)
	Neurology	2 (9)
	General medium care	1 (5)
	Pulmonology	1 (5)
Additional Training	Palliative care	6 (27)
	Bereavement care	3 (14)
Years working experience in pediatric care	0-10	6 (27)
	11-20	8 (36)
	21-30	7 (32)
	31-40	1 (5)
Number of patients with life expectance <1 year, p/y	0-10	13 (59)
	11-20	4 (18)
	21-30	1 (5)
	30+	4 (18)
Number of deceased patients p/y	0-10	13 (59)
	11-20	6 (27)
	21-30	1 (5)
	30+	2 (9)

All HCPs emphasized the importance of supporting parents to the best of their abilities in response to the emotional demands parents face and experienced grief, since parents could not redo the end-of-life phase of their child. HCPs were afraid to fail the parents by being unable to meet their needs, enhancing pressure to provide optimal care. HCPs felt that preloss care is less standardized then other aspects of palliative care, such as medical interventions and treatment of symptoms for which protocols are available, and more dependent on alignment to the individual parental needs, preferences and wishes. Therefore, it remains unclear what “optimal care” exactly constitutes. Goals of care in HCPs’ regular care delivery, such as open communication and respecting autonomy might not always constitute best care for parents facing their child’s end-of-life. HCPs had to maneuver delicately to understand parents’ wishes and the child’s needs to tailor and provide preloss care in a manner that was perceived as optimal for the parents and their child and that could be justified based on their expertise as a HCP. We learned that almost all HCPs struggled to move along three dyadic dimensions that inflict tension: (1) sustaining hope versus realistic prospects, (2) obtaining emotional closeness versus emotional distance, and (3) exploring emotions versus containing emotions (for illustrative quotes, see Table 2.).

(1) Sustaining hope versus realistic prospects

All HCPs felt obligated to inform parents honestly about the child’s condition and deterioration, medical information, and their professional opinion. HCPs expressed the importance of making sure parents understood the information and severity of the child’s situation in order to comfort their child, take part in decision making, share love and thoughts when not much time was left, and prepare for the inevitable death. Simultaneously, HCPs emphasized the importance of supporting the parents’ coping and enabling parents to endure the tasks related to caring for a dying child. One aspect that HCPs viewed as essential to uphold parents’ ability to endure the situation was by sustaining hope. All HCPs believed that hope should never be taken away. However, HCPs perceived that informing parents about the child’s deteriorating condition and explaining the lack of life sustaining treatment options by continuous updates inevitably meant that parents had to adjust to the situation and adapt their focus of hope. HCPs feared that sharing new insights could diminish parents’ hope, which they deemed important to keep parents going, leading HCPs to experience distress in sharing information and realistic prospects.

Table 2. Quotes per theme.

Theme	Respondent	Quote
(1) Sustaining hope versus realistic prospects	HCP 11, Physician, Neonatology	You don't have to deprive them [parents] of all hope of course, some colleagues are really good at that. So that is tough. And that is the challenge in such conversations, on the one hand you try to be realistic, in which you share the possible negative outcomes as in a bad-news conversation. At the same time you present the other side, maybe there is an 80% chance of a negative outcome, but that leaves 20% chance for a positive outcome as well. So you shouldn't take away that hope, cause parents need it to endure and keep going.
	HCP 14, Physician, Intensive care	It think it is important to discuss it only once, at an early stage. So, you discuss at the start that the machine [ECMO], that the child is dependent on the machine, and if not on it than the child would die. And that the treatment comes with all sorts of risks, which means the child could acutely die while being on the machine. Despite that… after that conversation, you shouldn't bring it up too often. Like… you should… if you have doubts whether parents understood the conversation you should have it again, but you cannot bring it up everytime you see parents and ask them whether they are aware their child might die. Because that… you can't, that is impossible for parents to endure […] And sometimes I tell parents, with parents that stay optimistic and positive, I tell them we do have hope.
(2) Obtaining emotional closeness versus emotional distance	HCP 5, Nurse, Intensive care	Yes, that involvement. And what I have learned is that you may show your emotions, as long as it stays professional. So I don't mind sheading a tear, it also affects me when a child that you are really close with, or parents…. And sometimes I leave the room for a bit, because it gets too overwhelming. But I don't try to withhold a tear, because it provides comfort for parents too.
	HCP 8, Physician, Intensive care	I think that the risk for [experienced] people like me, is that the more professional you become, you might be perceived by people as more distant. I think the younger you are, you are more involved with people. Maybe even share more in their emotions […] Yeah it gets to you. But for me, I can rationalize fairly easily by thinking that, medically speaking, there was nothing more we could do. It had become impossible, and continuing this way was not an option. So for me, I can remain rational - separate the rational from my emotions at those times. And that is something I need to be aware of, because when I think about this mother – oh shit, she will go home by herself - you can get caught up by your emotions, then she goes home, all alone.
(3) Exploring emotions versus containing emotions.	HCP 2, Physician, Metabolic disease	…the really obvious emotions, I don't think you need to name or label them. Because it is obvious… sure, when it is some sort of pathological grief or when people do not function anymore, or when it all goes wrong - then you have to do something with it [emotions] I guess. Or when there is no sign of grief or sadness at all in a situation when you would expect it to be. But when the emotions are appropriate to the situation, then it is okay, I think.
	HCP 11, Physician, Neonatology	I definitely don't avoid it [exploring emotions]. I think we can name it and provide room for it. And then, depending on the parent and their needs we will respond to it. […] and if the emotions are very prominent it is also hard to have a conversation. So then usually the information we share is limited and you should focus on the emotions and provide room for those at first before you can get back to having a conversation… and if there are very limited emotions, we also worry. And then we usually tell parents to let it sink in, and that we can continue the conversation tomorrow and hopefully at that time the emotions will show. So I do think it is practical to provide attention and time to those [emotions].

To manage this distress, HCPs tried to balance providing information while sustaining hope. HCPs described that the focus of hope could shift over time. For example, hope for a cure or extension of life expectancy could move to hope for a good quality of life or a last moment of contact. Sharing information while trying to maintain hope in some form was mostly attempted using the following two approaches. Firstly, by informing parents about bad news straight away, and then going through the information in fragments in order for parents to understand and process the information. This approach was mostly chosen when a severe diagnosis was shared or when the child's life expectancy was limited. In this approach, hope for a cure or substantial extension of their life-expectancy was immediately taken away. However, during these conversations HCPs tried to reestablish certain directions for hope by building an understanding of which options in shaping their child's last days were left. The second approach consisted of guiding parents through the changes in the condition of the child over several days or in separate conversations. This way HCPs explained the different treatment options that had been employed but unfortunately had not been effective. In this approach, HCPs aimed to not immediately diminish hope entirely, and parents could adjust to the child's deteriorating condition.

(2) Obtaining emotional closeness versus emotional distance

HCPs explained that emotional closeness with parents enabled them to provide compassionate care, which they perceived as an aspect of optimal care for parents of children during the end-of-life. However, HCPs simultaneously feared that becoming too close with parents could inhibit them in fulfilling their professional tasks, such as deciding on medical interventions with a risk of over- or under treatment, or being able to endure parental grief.

Feeling close to parents was characterized as experiencing a connection with parents. This could be built over time by gaining parents' trust, showing expertise, being present, and developing a personal connection. Experiencing closeness made HCPs feel more comfortable standing next to parents once medical interventions became futile and made HCPs more comfortable exploring and responding to parental needs. HCPs showed their emotional closeness by sharing memories and characteristics of the child that had made an impact on them and by physically standing next to parents in the room, laying a hand on their shoulder, or stroking their child. Emotional closeness fulfills HCPs' needs as well: HCPs emphasized the unique intimacy and being of value for the parents in such a delicate situation, which makes their job meaningful and fulfilling. The need for emotional fulfillment among HCPs was high since HCPs expressed they are trained to cure and felt a sense of failure or disappointment when they could not save the child. When HCPs did not experience emotional closeness with parents, they felt out of place being near them in such intimate settings and thus less able to provide optimal care and, consequently, experienced less fulfillment.

At the same time, to stand by parents and support them, HCPs' explained they had to manage their own emotional load and their fear of becoming too emotionally involved by maintaining some distance. HCPs mentioned two forms of distance: emotional and physical. Emotional distance was described as maintaining a distinction in HCPs' professional and personal side, for example by reminding themselves that they are present as a professional caregiver and not as a relative or friend. Physical distance could be obtained by not meeting parents or patients outside the care facility or providing the parents with privacy in intimate settings. Both emotional and physical distance were sought when HCPs feared becoming emotionally too involved with the parents, which might harm their goals of care in two ways. (1) HCPs feared a lack of distance could cloud their judgment and objectivity in what constitutes the best treatment and care, running the risk of over- as well as under treatment. Fearing this loss of objectivity was amplified in situations where medical interventions became futile, and comfort care was considered the best care in response to the child's suffering. (2) HCPs maintained emotional distance towards parents to ensure their own sadness or grief would not overwhelm them; becoming overwhelmed by grief could burden the parents or even result in parents having to comfort them in which the roles would become reversed. However, most HCPs believed that showing some emotion was acceptable and reflected their involvement and closeness towards parents.

(3) Exploring emotions versus containing emotions

HCPs believe that optimal preloss care for parents entailed paying attention to and providing room for parental emotions; this was expected to relieve parents' burden in the roller coaster of emotions they experienced during the end-of-life phase. HCPs assumed that sharing their emotions would enhance the parents' ability to fulfill their parental role and being emotionally present with their child. HCPs attended to parental emotions by asking parents how they were holding up and responding to cues, and perceived this level of support as sufficient for most parents. Aligning to the parents' emotions was evaluated as a safe option since HCPs perceived it would minimize the risk of disrupting the parents' coping. Once invited to share emotions, some parents displayed stronger emotions than expected, which according to HCPs required more active support in coping. Actively engaging was difficult for HCPs, since they feared it would disrupt parental coping and harm their emotional balance even further. The distress caused by navigating this precarious balance for HCPs was amplified when the HCP lacked confidence in conducting emotionally loaded conversations and not knowing how to respond. Thus, HCPs were puzzled at times whether optimal care would entail actively engaging with parental grief and emotions, running the risk to disrupt parental coping even further. As such, actively supporting parents could be either: exploring or containing emotions. HCPs were more prone to explore parental emotions that they felt comfortable with and to contain emotions they perceived as more challenging to respond to, which differed per HCP. Furthermore, HCPs were less prone to explore and preferred to contain emotions when they experienced time pressure, or their own emotional load was high.

Exploring parental emotions entailed actively inviting parents to share their emotions and ask questions to gain an understanding of parents' thoughts. HCPs felt it helped when parents could share deeper emotions and then tried to identify and minimize obstacles that resulted in the strongly experienced emotions. Containing emotions entailed the opposite and consisted of not elaborating on parental cues and limit questions. In both approaches, HCPs tried to put parents back in the saddle when they finished the conversation and encouraged them to live by the day. Two factors triggered the need for HCPs to actively assist parents in balancing their emotions and coping. (1) When HCPs noticed that emotions took the upper hand, limiting the parents' ability to fulfill their parental role or participate in decision making. (2) When HCPs evaluated the parents' emotions as non-congruent to the situation. This could be either the absence of emotions in situations that were expected to be emotionally difficult for parents, as well as very emotional responses in situations HCPs did not expect it or found it undesirable. HCPs interpreted non-congruent emotions as signs that parents did not understand the situation correctly; this led HCPs to fear they might have been unclear in their explanation or did not get through to parents.

Impact of the uncertainties on the HCPs

Throughout the interviews, it became evident that HCPs have to deal with lingering uncertainties in their preloss care delivery. Shaping preloss care within the three dimensions differed per HCP, parent and situation. HCPs learned to cope with the insecurities on the job by encountering positive experiences and learning from colleagues. At the same time, HCPs expressed the need to be of significance to parents and add meaning to the difficult situations parents were in, as a last contribution. Searching for their positive contribution to the parents situation while being unsure when that is reached made it hard for HCPs to experience satisfaction or feel confident regarding their preloss care delivery. HCPs expressed a need to know how parents evaluated preloss care and experienced distress when parents reflect on the received care as insufficient. Additionally, HCPs mentioned that their uncertainty on preloss care delivery was amplified when caring for parents with a different or less familiar cultural or religious background; they found it more challenging to get on the same page with these parents or to speak 'the same language.'

DISCUSSION

From the lived experience of HCPs providing preloss care to parents during their child's end-of-life, three dimensions that pose tension are identified: (1) sustaining hope versus realistic prospects, (2) obtaining emotional closeness versus emotional distance, and (3) exploring emotions versus containing emotions. HCPs aim to provide emotional assistance in preloss care to the best of their abilities, yet what constitutes 'best' differs per parent and is not always clear. To assist parents in their psychological needs of support, HCPs have to decide which approach fits best given the situation, and balancing these decisions is experienced as challenging. The strategies chosen are also dependent on what is perceived as feasible in terms of the HCPs' own emotional load and competencies.

While many HCPs passionately strive to provide the most optimal preloss care to support parental grief, they are unsure what optimal care for each parent would entail. Especially in the three identified dimensions, where it is impossible to state a standard approach that should be upheld for all parents. Uncertainty about the added value of their efforts and not knowing whether they have done the right thing puts a strain on HCPs. This is amplified by the feelings of sadness and grief they experience themselves when a child dies and, in some HCPs, guilt caused by not being able to save the child.[18,19] The increased strain on HCPs involved in pediatric palliative care might leave them at risk to experience distress and possibly develop compassion fatigue or burnout.[20,21] Compassion fatigue is defined as a secondary trauma from being confronted with suffering patients[22] and may negatively impact HCPs' well-being.[21] Burnout is characterized by exhaustion, negativism against one's job, and reduced effectiveness, which often leads to reduced job satisfaction and increased turnover in HCPs.[23,24] Burnout forms a threat to the pediatric workforce, since burnout symptoms are already highly prevalent among pediatric residents.[25,26] While the strain on HCPs' well-being is considerable, HCPs also value providing preloss and bereavement care. HCPs feel humble to be present in such intimate, personal settings and report personal growth.[8,27,28] This emotional fulfillment is also known as compassion satisfaction,[29] known to protect HCPs' well-being and counterbalance the experienced distress and risks of compassion fatigue.

Two main approaches to assist HCPs in maintaining their emotional balance, minimize distress, and strengthening resilience are through *education* and *learning as a team*.[28,30] Regarding education: The Canadian Paediatric Society and the RCPSC Paediatric Specialty Committee created various CanMEDS roles,[31] in which HCPs should develop competencies to ensure patient safety. However, in the domains of medical aspects of palliative care and dealing with death and bereaved parents, pediatricians report deficiencies in knowledge and skills.[32–34] To experience emotional fulfillment and confidence in the preloss care one provided, a positive attribute would be to enhance HCPs' self-efficacy. Pediatric palliative care is inherently linked to unpredictable illness courses where optimal treatment might differ per child due to the child's unique situation and the parents' wishes and coping. Becoming aware of HCPs' natural tendency to aim for a cure and experience a sense of failure when the preferred outcomes become impossible to reach might alleviate discomfort for HCPs. Furthermore, several studies have shown that education and simulation training results in more confident HCPs with enhanced self-efficacy towards discussing end-of-life topics, which improves care delivery to their pediatric patients and their parents.[35–38] Education could focus on: adapting positive coping strategies both in their professional and personal life,[23,28,39] skills training on handling end-of-life conversations and responding to parental emotions, as well as theoretical knowledge tailored to match their practice on supporting parental grief. The second approach assisting HCPs is by applying the concept 'learning by sharing' as a team. On an institutional level, organizations could foster a safe learning environment by acknowledging that preloss care encompasses many uncertainties and discuss fears and worries of and with colleagues. Regular debriefing with learning by sharing, assisting newer colleagues on the job, and maintaining a diverse caseload create a more supportive environment.

A strength of this study is that HCPs from a variety of specialisms and institutions were included as participants, providing a broad insight into the areas that pose challenging situations for HCPs working in pediatric end-of-life care. Furthermore, this study focused on the HCPs' lived experience, which provided insight into challenges presented throughout preloss care delivery as a whole. A limitation of this study is that it solely focused on physicians and nurses, although palliative- and preloss care is characterized by the multi-disciplinary team involved in care.

The current study provides a starting point in understanding the HCPs' experience of providing preloss care. Future research could focus on the added value of an interdisciplinary team approach and explore the differences in how the challenges in navigating the three dimensions is experienced by different types of health care professionals.

Several occasions are known to evoke substantial emotional distress in HCPs. This study has shown that demanding situations causing distress in HCPs are intertwined in preloss care delivery during the child's end-of-life as a whole. Preloss care in pediatrics needs to be tailored to the specific situation of a child and their parents and is characterized by many uncertainties, which makes it unclear what might constitute optimal care. This leads HCPs to experience less emotional fulfillment and might put them at risk of experiencing disproportional distress. Providing HCPs with tools to develop positive coping mechanisms, enhance self-efficacy and create supportive environments for HCPs, might help manage these challenging situations while providing – and recovering from – preloss care.

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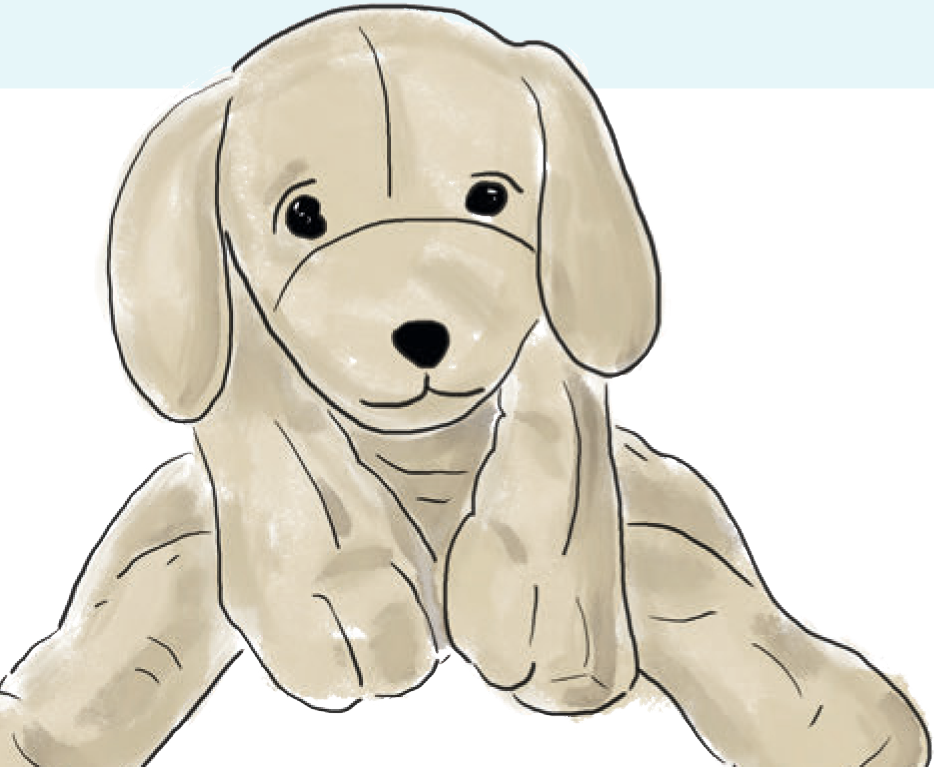

5

A grounded theory study on the dynamics of parental grief during the children’s end of life

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ABSTRACT

Aim
Parents are increasingly confronted with loss during their child's end of life. Healthcare professionals struggle with parental responses to loss. This study aimed to understand parental coping with grief during their child's end of life.

Methods
A grounded theory study was performed, using semi-structured interviews with parents during the child's end of life and recently bereaved parents. Data were collected in four children's university hospitals and paediatric homecare services between October 2020 and December 2021. A multidisciplinary team conducted the analysis.

Results
In total, 38 parents of 22 children participated. Parents strived to sustain family life, to be a good parent, and to ensure a full life for their child. Meanwhile parents' grief increased because of their hypervigilance towards signs of loss. Parents' coping with grief is characterised by an interplay of downregulating grief and connecting with grief, aimed at creating emotional space to be present and connect with their child. Parents connected with grief when it was forced upon them or when they momentarily allowed themselves to.

Conclusion
The parents' ability to engage with grief becomes strained during the end of life. Healthcare professionals should support parents in their search for a balance that facilitates creating emotional space.

INTRODUCTION

Despite medical advantages, many parents are still confronted with child loss due to preterm birth, trauma, or life-threatening illnesses. Losing a child is considered the ultimate loss that any parent can experience. Bereaved parents are at risk of developing adverse psychological and physical consequences,[1–3] and are prone for prolonged grief disorder.[4,5]

Grief is a natural response to the loss of someone, or something, meaningful and encompasses a range of emotions including separation distress, anxiety, and dysphoria.[6] Bereavement care is an integral part of paediatric palliative care, and yet it is developed mostly in order to support parents in their grief after child loss.[7,8] However, parents are confronted with continual incremental losses from the moment they begin to worry about symptoms that might lead to the diagnosis of a serious illness, continuing throughout the course of the illness, and finally, in the end of life.[9,10] In this context, loss refers to losing a meaningful aspect in life, such as someone's health, physical functioning, or beliefs about their world and future.[11] In parents, losses are related to the child's decline, the loss of communication and of normal family life, forcing parents to revise their goals and world views.[9,10,12] The pervasive sadness and grief regarding these continual losses is described as chronic sorrow.[13,14] Parents also experience grief towards the bereavement itself, known as anticipatory grief.[11] How parents experience and manage grief during the child's end of life is less well understood.

The position of parenting, and what parents value in bereavement care in the context of increased losses during the end of life, is still largely unclear. Consequently, healthcare professionals experience difficulty in delivering adequate pre-loss care to parents during the end of life.[15,16] Insight into parental coping with grief during their child's end of life is needed to facilitate pre-loss care aligned to the parents' needs, which could contribute to effective and holistic bereavement care for parents. Therefore, this study aimed to gain insight into how parents experience and cope with losses and grief during their child's end of life.

METHODS

Design

A grounded theory design was used to investigate the parents' experiences with loss and grief, and to clarify the underlying meaning and processes.[17,18] This study is part of the emBRACE project (towards Embedded BeReAvement Care in pEdiatrics) exploring the parents' and the healthcare professionals' experiences with loss and bereavement in paediatric end-of-life care.

Sample

In line with qualitative methods, a purposive sample was included, consisting of both parents caring for a child during the end of life, as well as recently bereaved parents. During the end of life was operationalised as follows: (1) parents of children with an advanced illness and a life-expectancy of less than three months. (2) parents of children who went through a life-threatening event with an expected reoccurrence within one year assessed by the treating physician. Bereaved parents were included in the study after the follow-up conversation, taking place approximately six weeks, and before six months, after their child's death. Given the difficulty of interviewing parents during the terminal stage, bereaved parents were included because they could contribute valuable information about the last days or week of their child's life. Additional criteria for inclusion consisted of parents ≥ 18 years, children ≤18 years, sufficient knowledge of the Dutch language to be interviewed, and not being referred for prolonged grief disorder. We excluded parents after a stillbirth. Maximum variation in our sample was sought with respect to the child's age and diagnosis.

The clinicians of four Dutch university paediatric hospitals and one paediatric home care organisation, identified eligible parents, informed them about the study and asked for consent to share their contact information with the researchers

Data collection

The data collection consisted of face-to-face, semi-structured, in-depth, interviews, conducted by an interviewer trained in qualitative interviewing, (EK). The interviews were conducted between October 2020 and December 2021, at the parents' preferred location. A background questionnaire was filled out prior to the interview. The interview guide consisted of topics regarding experiencing loss and grief, coping with emotions and demands, and the experienced support. At the start of the interview, parents were invited to introduce their child. Thereafter, they were asked to describe how the past days or weeks, or their child's last weeks of life, were experienced, depending on the timing of the interview. Their answers provided insight into their child's situation and allowed parents to elaborate on loss and grief in the context of losing their child. The interviewer could then align to the parents' experiences and invite them to share their experiences on the sensitive topic of coping with loss during the end of life more in-depth. Field notes were made after each interview. Data were collected until saturation of the main categories were reached and relationships between categories could be established.[19]

Data analysis

All interviews were audiotaped and transcribed verbatim. The transcripts were verified against the audio-recording and pseudonymised. Data collection and analysis alternated, enabling newly developed categories and insights to be explored in consecutive interviews. Researcher triangulation was achieved by working in a multidisciplinary team consisting of a psychologist (EK), a senior qualitative researcher in paediatric palliative care (MK), paediatricians (MH, JF), a neonatologist (MLT), an experienced parent (RdJ), and rotating medical students.

To begin, 12 interviews were read closely and open coded by the research team. In bi-weekly meetings the open coding and interpretations of the interviews were discussed, focusing on the dynamics of grief in parents, the tasks and demands that parents were confronted with, and interactions between parents and healthcare professionals. These discussions evolved to the construction of a more conceptual overview of relevant codes and categories and their relationship for each interview. From these discussions, tentative categories were identified.[17] A code tree was formed and axial coding was performed on all interviews using the software program NVivo 12.[20] Lastly, relations between categories were constructed and developed using selective coding.[17] Throughout the analysis memos were written to develop the categories and relations between categories, and to facilitate discussions in the research team. Throughout the analysis, feedback on, and validation of, the preliminary results, was obtained from a larger expert board, the emBRACE-working group, consisting of healthcare professionals involved in paediatric palliative care.

Ethical considerations

This study was classified by the institutional review board as exempt from the Medical Research Involving Human Subjects Act (WAG/mb/19/046086). Informed consent was obtained from all participants prior to data collection.

RESULTS

In total, 38 parents of 22 children participated in this study, including 21 mothers and 17 fathers (Table 1). We conducted 23 interviews, which comprised 15 couples interviewed together, one couple interviewed individually, and, in six cases, one parent participating. Of these, five were conducted at the hospital, nine at the parents' home, and nine through video conferencing. Interviews lasted between 57 and 124 minutes. Eight cases were included during the child's end of life, involving 7 mothers and 6 fathers. Fourteen cases were included after the child's death, involving 14 mothers and 11 fathers. See Table 1 for characteristics.

From the analysis, a model of parental coping with grief during their child's end of life was created (Figure 1). Parental coping was largely influenced by the need to keep going to fulfil parenthood, yet parents were continuously confronted with incremental triggers of loss during their everyday life. Parents tried to create emotional space by bringing their grief into manageable proportions. We identified several strategies parents used to downregulate grief and situations during which parents experienced grief. A description of the separate components of the model is presented below. Illustrative quotes are provided in Table s1.

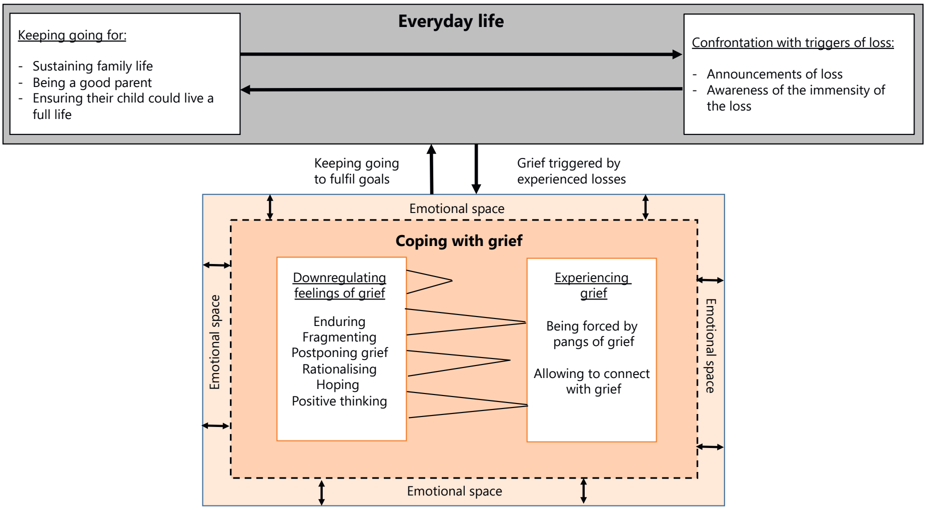

Figure 1. Parental coping with grief during their child's EOL

Table 1. Baseline characteristics of parents and children

Parents characteristics	Parents	n	Missing (n)
Gender			0
	Female	21	
	Male	17	
Age			4
	<30 years	2	
	30-35 years	14	
	36-40 years	11	
	>40 years	7	
Education			4
	Low*	3	
	Middle**	6	
	High***	25	
Relational status			0
	Married/in relationship	37	
	Separated	1	
Religion			3
	Atheist/none	26	
	Christian	6	
	Islamic	3	

Low: Primary school, lower secondary general education, lower vocational education. Middle: Higher secondary general education, intermediate vocational education. ***High: Higher vocational education, university.*

Child characteristics	Children	n	Missing (n)
Moment of interview			0
	During EOL	8	
	After child's passing	14	
Gender			0
	Female	12	
	Male	10	
Age (at time of passing or at time of interview)			0
	<6 months	9	
	6-12 months	4	
	1-5 years	4	
	6-10 years	1	
	>10 years	4	

Table 1. Baseline characteristics of parents and children (continued)

Child characteristics	Parents	n	Missing (n)
Diagnosis/disorder			0
	Neonatal disorder	5	
	Genetic disorder	6	
	Cardiac disorder	3	
	Oncological disorder	2	
	Neurological disorder	4	
	Metabolic disorder	1	
	Gastro-intestinal disorder	1	

The need to keep going in everyday life

During their child's end of life, all parents felt a paramount need to keep going in order to sustain family life, be a good parent, and ensure their child could lead a full life (Figure 1).

Sustaining family life meant parents wanted to retain normality at home by keeping routines. This was important for parents to endure their child's end of life with its strain on their well-being and uncertainty about how long this period will last. Parents emphasised the importance of their child having been at home and been able to keep their place in the family.

Being a good parent meant parents wanted to be there for their child, practically and emotionally. They felt a paramount need to do right to their child and did everything in their power to experience the time left as a family. Therefore, parents had to adapt to their child's condition and learn new skills to ensure the child's and the family's well-being. Normal caring acts took on more importance and meaning for parents, simply because they were still able to do so and thereby engage their child in normal family life and connect with them.

Ensuring their child could live a full life meant parents wanting their child to feel loved, experience joy, and be able to bond with their family. In order to provide their child with a full life, parents did everything in their power to manage their child's symptoms and advocate for their child's interests with healthcare professionals. Parents would argue for the best treatment plans that gave their child the best balance in prolonging their life while being able to be comfortable.

Being confronted with triggers of loss in everyday life

The parents' ability to keep going was threatened by the continuous awareness of their child's vulnerability and the approaching death. Parents mentioned to be hypervigilant towards triggers of loss that inevitably increased their awareness of the impending death of their child and in doing so threatened their parenting goals. Triggers of loss consisted of announcements of loss and experiencing the immensity of the loss (Figure 1).

Announcements of loss entailed triggers that forced parents to see their child's vulnerability and the inevitability of the approaching death. Parents were constantly alert to all signals that might give them an indication of their child's condition, and for situations in which they had to intervene quickly. Parents were monitoring their child's breathing, energy, and need for medical support. During admissions parents were alert to all the monitors that provided them with information and feared a rapid decline every time the monitor registered information. Triggers were experienced more intensely when parents witnessed their child suffering and felt unable to comfort their child despite their best efforts. Interactions with healthcare professionals could also bring with them announcements of loss for parents, even when healthcare professionals did not intend to, since parents were constantly interpreting the information, their tone of voice, or body language.

Awareness of the immensity of the loss were the brief moments in which parents experienced the extent of the forthcoming loss and felt through what it will mean to continue their lives without their child. Truly imagining a life without their child felt unthinkable and unbearable, and confronted parents with existential questions, fears, and sadness. These moments were triggered by imagining future moments in which their child will be lost, milestones that will not be reached, awareness of the intensity of their love for their child or confrontations with the dying process and organising farewells.

Parental coping with grief during their child's end of life

Parents tended to downregulate their grief, however, when feelings of grief accumulated, parents had to or chose to experience grief. The interplay of downregulating and experiencing grief results in creating emotional space (Figure 1).

Downregulating feelings of grief

Many parents explained that grief was always present but increased due to incremental losses during the end of life. Parents constantly downregulated their feelings of grief to keep grief within manageable proportions, to keep going to fulfil parenthood. Parents refrained from thoughts and triggers of loss that could confront them with the emotional pain of losing their child. We identified six protective strategies parents employed, which contained both conscious and subconscious components.

Firstly, by maintaining a state of endurance, in which parents were able to remain strong and resist the hardship they experience. An important component of this is the tendency of parents to suppress their emotions by dismissing any thoughts or observations that could trigger grief. Parents described how suppressing their emotions could also occur automatically, for instance when confronted with an emergency situation in which they needed to intervene.

Secondly, by fragmenting, parents pushed back signals of the approaching death through focusing on smaller portions of a larger whole. For instance, focusing on one symptom at a time enabled parents to perceive it as an isolated problem which is less threatening than facing the complete picture of all symptoms that reflect the further deterioration and announcement of the loss. A similar fragmentation occurred in time. Parents focused on a single moment, hour, or day, which enabled them to experience of the occurrence of pain or suffering as temporary or strengthened them in experiencing joyfulness and cherish good moments.

Thirdly by postponing feelings of grief, parents deliberately chose not to engage in negative or hurtful emotions and pushed these forward in time on purpose. Many parents were aware of the inevitability of experiencing grief at some point, yet mentioned they chose to postpone their grief until after their child’s passing. Parents felt that while their child was still here it was unfair to be concerned with his or her death or with their own feelings of grief. Instead, they chose to enjoy the time they still had together.

Fourthly, rationalising enabled parents to think or have conversations about their child’s treatment or condition in an abstract manner, causing them not to engage in the emotional load of such thoughts or conversations. Parents could also talk about their own emotions in a distanced and rational manner when people enquired how they were coping.

The fifth strategy was for parents to hold on to hoping amidst all the perceived uncertainty surrounding their child’s prognosis. This enabled them to engage in positive scenarios instead of scenarios that could trigger grief. To strengthen their hope, parents internalised positive cues more strongly, either from their child, the monitors, or conversations with healthcare professionals, and would try to focus on joyful or positive cues and events.

Finally, positive thinking was a more active measure in which parents did not want to imagine possible negative outcomes and wanted solely to envision positive outcomes. Some parents did not want to discuss negative scenarios with the healthcare professionals or interact with healthcare professionals who showed incredulity with parents' positive beliefs as these staff could endanger the parents' personal views and in doing so their ability to keep going.

Experiencing grief

In spite of their continuous attempts to distance themselves from emotions that disrupt their ability to sustain their care, there were moments in which parents experienced grief. This could be either through pangs of grief or connecting with grief (Figure 1).

Pangs of grief were described as short, temporary moments during which intense and overwhelming feelings of grief force themselves upon the parent in response to confrontations with loss or after downregulating grief for a profound period. Parents felt unable to hold back their emotions and could feel an intense and overwhelming sadness, distress, or panic. Parents feared pangs of grief, because they were experienced as overpowering and disruptive. Parents felt they were losing control and feared they would not be able to regain their composure. Although parents tried to avoid pangs of grief, they were experienced, at times, as inevitable given their situation. And yet, several parents mentioned that pangs of grief had, at the same time provided, a form of emotional relief often followed by a moment of realisation and reflection towards the factors triggering their emotions.

By connecting with grief, parents, temporarily, allowed their grief to be felt and were able to engage with their thoughts towards the loss. However, to achieve this, parents needed to feel sufficient distance and peace of mind. Some went for a walk, took exercise, or meditated, enabling them to be alone with their thoughts and not distracted by everyday demands. Parents could then take a moment to reflect on the situation and emotions that were continuously surrounding them. This made these thoughts more comprehensible and allowed them to gain an understanding of their own needs. Parents could connect with grief and thus find a relief from their suffering, since it allowed them to let go of some of the built up emotional pressure. Afterwards, parents felt better able once more to take in and manage the continuous triggers of loss. In situations where parents had shared their emotions, thoughts or fears with others, relief was also found in experiencing emotional support, being comforted, and asking for help.

Parents were able to connect with their grief under two conditions. Firstly, parents did not want to connect with their grief when their child was close by. They did not want their child to see them while grieving since it could upset their child and they did not want their child to feel the need to comfort them. Secondly, parents needed to feel assured that their child's care was in good hands and their child's condition could not suddenly deteriorate.

Creating emotional space

The interplay between downregulating grief and the experiencing of it allowed parents to bring their grief into manageable proportions, and thus to create emotional space in which they could experience other emotions in addition to their grief (Figure 1). Enabling parents in their ability to downregulate feelings of grief created emotional space to experience joyful moments or to be emotionally present. By connecting with feelings of grief, parents could let go some of the built-up stress and tension associated with grief in order to assuage it - to push it to the back of their minds, at least, temporarily. The interplay between downregulating and connecting with grief leads to variation in emotional space at any given time. More emotional space meant parents could engage in everyday life more easily, whereas less emotional space could lead parents' experience of grief being all-consuming. Parents' means of coping with grief were influenced by demands, the triggers they were exposed to, and the current state of their emotional space. This means that every parent might have a different emotional response to the same situation at any given time. Parents wanted to be supported in their manner of coping with grief: strengthened in downregulating grief when they needed to and comforted when they had to or chose to experience grief.

DISCUSSION

All parents involved in this study were well aware of their child's vulnerability and impending death. Parents needed to keep going in order to sustain family life, be a good parent, and ensure their child could live a full life. While pursuing these goals, parents were hypervigilant towards signals that could announce the loss of their child or confront them with the immensity of the loss. Both triggered grief. Parents coped with grief by downregulating their feelings of grief using protective strategies. At times parents felt forced to experience grief or allowed themselves to connect with grief. Parents' coping with grief was aimed at bringing grief into manageable proportions, and thus creating emotional space.

Most theories on coping with grief are based on responses after a death has occured.[7,21] These theories emphasize that a healthy adjustment in bereavement is established by a process of oscillation between loss-oriented and restoration-oriented coping strategies.[21] Yet our results suggest that during the end of life, the parents' ability to engage in loss-oriented coping or to employ alternating coping strategies is increasingly strained by the threat of ongoing losses and their attempts to safeguard their ability to keep going. Parents experienced grief at certain times, but these encounters were partly forced upon them by pangs of grief or by short periods of time in which parents willingly allowed themselves to connect with grief. Healthcare professionals should be aware that downregulating feelings of grief is a beneficial coping strategy for parents during their child's end of life and that they do not always need to evoke or search for an emotional response in conversations. Downregulating feelings of grief enables parents to be present for their child and, after bereavement, positively reflect upon parenthood. At least two practical implications for healthcare professionals can be derived from these insights.

Firstly, triggers confronting parents with loss and disrupting their ability to downregulate their grief are far more intertwined with everyday life and interactions than healthcare professionals might be aware of. For parents triggers in everyday life may be experienced during interactions with their child, and triggers around hospitals could be formed by the ward environment, verbal or non-verbal interactions with healthcare professionals. Parents are constantly searching for information about their child's condition, prognosis, and the remaining means from which their child could benefit. They, often find such signals in small interactions. Parents' hypervigilance towards these indicators might take away the emotional space that enables them to engage with their child in the moment and employ coping strategies that are beneficial for them. Open communication with parents about the insecurities that accompany an end of life trajectory might help to decrease the triggers experienced by parents because it makes them feel more secure about the completeness and honesty of the information received. Parents emphasise the importance of being involved in their child's care and this requires being informed about the possible outcomes and scenarios.[22–24] Being involved in the treatment is also important for parents' perceptions of being a good parent.[24,25] Healthcare professionals experience difficulty in sharing uncertainty with parents, yet learning to tolerate and share uncertainty could enhance parents' trust and satisfaction with the care their child receives.[26,27]

Secondly, parents' tendency to downregulate their grief, and to refrain from their emotions in conversations with healthcare professionals, does not mean that parents are unaware of the prognosis. From previous research, we learned that healthcare professionals feared parents were unaware of the severe prognosis as they showed limited emotions. Healthcare professionals felt the urge to repeat themselves, or search for an emotional response in parents to be sure parents understood the message.[15,16] Yet parents in this study appear to be well aware of their child's impending death and their own active tendency to downregulate their grief during conversations with healthcare professionals. The latter is done because parents want to remain a stable partner in the conversation in order to safeguard their child's care. Parents might benefit from being informed about the nature of conversations in advance, so they know when to brace themselves and to regulate their grief accordingly. Besides, parents should also be given some respite from discussing emotionally loaded topics since not all healthcare professionals need to discuss such topics with them. Often parents show with which healthcare professionals they would like to share their experiences more in-depth. Alternatively, a limited number of healthcare professionals should open a discussion on how parents are holding up. That way parents do not have to answer emotionally loaded questions from all healthcare professionals that enter the room and, therefore repeat themselves, but rather create a trusting bond with a few healthcare professionals who can explore parents' needs in pre-loss care.

STRENGTHS AND LIMITATIONS

A strength of this study was that parents were included during their child's end of life or shortly after their child's death. Many studies on parental grief included parents whose child had died years before. Here, emotional memories might have been altered due to coping and rearranging experiences to fit the parents' narrative. Although we included parents soon after their child's death, some adaptation might already have occurred. However, the participation of bereaved parents was the only way to gain insight into the last days of life. We encountered many similarities in the experiences of bereaved parents and those of parents interviewed during the end of life. However, bereaved parents appeared to be better able to reflect on their experiences and explain their coping, which helped us to deepen our understanding of coping with grief in these last days. As such, it was helpful to validate the strategies and process of downregulating grief which we identified from interviews with parents during the end of life and bereaved parents. Furthermore, parents of children of different ages and diagnosis were included, providing a conceptual presentation of grief among a diverse group of bereaved parents strengthening the grounded theory approach. A limitation of our study was the lack of diversity in educational, religious, and cultural backgrounds. Most parents were atheists or had a Christian background but were not actively involved in religion. It might be that people experience different triggers, or ways to cope with grief, with different conceptions of death and the afterlife, or different cultural needs and ways of releasing grief.[28] This calls for future research.

CONCLUSION

Based on qualitative interpretative analysis using grounded theory we learned that parental coping with grief during the end of life is characterised by an interplay of downregulating feelings of grief and experiencing grief, aimed at creating emotional space. Progressing through the end of life, parents' ability to engage in grief-oriented coping is increasingly strained. Healthcare professionals should align themselves to parental coping and decrease possible triggers of loss in order to help parents create emotional space to experience their child's final weeks to the fullest.

Supplementary table 1. Quotes resembling parents' everyday life and coping with grief

Mother (M) and father (F) of a nine month old daughter who developed severe heart failure due to leukaemia treatment.	
Keeping going to sustain family life and to provide their child with a full life.	F: We also have a two year old son, on the one hand that makes it very difficult, but at times also very rewarding, because he gets you through it. That serves as a driving force, that there is still more out there. That gives me some new energy, from my perspective. M: I think the quality of her life is most important. But that is difficult to determine, so more subjectively… […] if she recovers a bit and could go home with us. But every month she recovers, and then she is constantly back in the hospital for another three to four weeks, at an intensive care or other ward, and that is basically her first year of life, and maybe even longer. Personally I don't think that is quality of life. F: No… M: We decided that if, at a given moment, we see the frequency of admissions increasing, or shortly following each other, or that many… F: that it is no longer feasible… M: Yes that is, that there is no longer a chance for her to recover at all… we have talked about it and discussed that we do not want to continue treatments at all costs… F: No. M: Because, for who are we doing it then? F: Yes, Yes most important for us is that she is as comfortable as possible and preferably also developing as good as possible, that are the two things you hope for.
Confrontations with loss	*Hypervigilant towards announcements of loss* F: You, as a mother, are definitely more caring. You notice it at home. You catch onto signals more quickly than I do, I think, for instance when her breathing changes. And in that she was always proven right, because then when we act upon it, she was always right. *Confrontations with the immensity of the loss through sustaining family life and fulfilling parenthood* F: We always liked to talk about the future. M: Yes, with nice plans and thoughts we have. But now I'm more afraid to look into the future. Because when you do, it makes me sad and anxious, since there is a good chance that it might not be with the four of us.

Supplementary table 1. Quotes resembling parents' everyday life and coping with grief (continued)

Mother (M) and father (F) of a nine month old daughter who developed severe heart failure due to leukaemia treatment.	
Downregulating grief	*Fragmenting in time* M: we are living day by day. You live from one moment to the next, that way it is also somewhat more manageable. But you keep hoping, and that hope will remain. That hope is what gets you through it. F: That's true. A long term vision has sailed a long time ago. M: These short periods of time, with short horizons which we work towards, that provides us with some calm and peace, and that's something to hold onto.
	Enduring F: But in these moments of panic there is no room for grief, because then it is like a switch happening in your body, you switch to survival mode.
	Postponing grief M: I recognize that, that I can get overwhelmed by emotions if I think about it [their child's end-of-life] too much. F: I agree. M: Maybe in that sense I just block it out because you don't have to deal with it just yet. F: I agree, it is easier to block it out. M: What is the use to be sad about it right now, about a situations that hasn't even occurred yet.
Experiencing grief	*Connecting with grief to find support* I find relief in talking to a friend or my mom, just to share my worries and fears. Not that I expect them to tell me it will all be okay, but sometimes I just want to get it off my chest and that someone is there to listen and comfort me. That gives me some peace, because if you hold it all in, then it all gets tangled up.
	Pangs of grief M: Just an intense and overwhelming sadness, how can you best describe it.. just intense sadness. I don't know how else to describe it.
	Connecting with grief by taking some distance F: It really helps me to order my thoughts and process things. As if you store everything neatly in a filing cabinet, or have a look at it from a distance, and then things become easier to grasp. Because then… if not, it results in a tangle of emotions and thoughts, and this helps me to regain some overview of my feelings. […] if you're in panic and your head is spinning from worst case scenarios, and everything that needs to be taken care of and…. Everything else that's important. You can get lost in your thoughts. And if you literally take some distance and be with your thoughts, they automatically become more sorted and that in itself provides some peace.

Supplementary table 1. Quotes resembling parents' everyday life and coping with grief (continued)

Mother (M) and Father (F) of a five year old daughter, after she died of cancer	
Keeping going to sustain family life and provide their child with a full life	F: In the end, it helped me the most that we had a great time, just with the four of us. And making sure we didn't constantly had to think about the future. M: I think one of our strengths was that we were able to live by the day. We are so grateful for the days we have had together with her. [...] We have always told ourselves... we are going to do it right, for her. And for that, you have to make sure that you push your own grief and fears aside. We also ensured that she could live in her own free bubble [...] we didn't hold on to her and keep her near at all times, instead we said go, go explore the world. Although we know, we know it might be for a short time. For us it was the most important thing, to let her be herself. And really, just together as a family, the only thing we did is ensure we could live our normal lives together as a family. We didn't have a bucket list or suddenly felt the urge to do all sorts of things, none of that.
Confrontations with loss	*Announcements of loss and experiencing grief* F: You always live towards the next scan or result. I felt a lot of tension from that, and felt frightened as well. Nine out of ten times it was bad news indeed, and that realisation was a big hit each time. And it differed, sometimes we needed days to process the blow and other times it took us weeks, I think the time in September we were devastated for about a month. You feel a sense of desperation, fear, sadness, all at once. *Being hypervigilant towards announcements of loss* M: 24 hours a day I was looking for cues on how she was doing. I lay on one ear all night and if I heard a sound, I would jump up and check on her. If her teacher called I would sprint to the phone, cause what could have happened at school? I just didn't know what could happen and when it could happen... and that made it so intense and demanding.
Downregulating grief by rationalising and postponing grief	F: That the ultimate loss will be huge, intense and brutal. I could image that, but at the same time I couldn't. Eventually, you don't know what it will be like, what will happen, how intense the longing would be, and how it will feel. So we didn't want to deal with those feelings back then. And sure at times, I was upset realising some day she will not be here in the near future, and in those moments I was very upset. But then I tried to tell myself, I have a long time ahead in which I can be sad and grieve... you will be, so for now make sure you have a good time together. And you don't do that by hiding the feelings away, but to enjoy the moments you do have together.
Experiencing grief	*Connecting with grief and enduring* M: I have someone with who I discuss how I experience everything, and also what is yet to come. So when I discuss those things [loss and grief] I sort of step into the moment. So I make an appointment and that is the time I will engage with those things. And sometimes it overwhelms you. You are sitting at home, at night, crying on the couch. So I just choose a moment to engage with it [grief], and after that moment, well you carry it with you at all times, it is always inside you, in your heart and you are on high alert and anxious... but you just try to continue. F: I felt anxious or upset when I sat alone on the couch at night. When you experience the calm and the space to think and the thoughts just come flooding into your mind. Those were the moments that I mostly experienced grief. And at times she [his daughter] did or said something and that it triggered something inside you.

Supplementary table 1. Quotes resembling parents' everyday life and coping with grief (continued)

Father of a 14 year old boy who lives with a hereditary disorder and has multiple disabilities	
Downregulating grief to ensure keeping going to fulfil parenthood and a full life for their child.	When I think about all that has happened and is to happen, I feel the emotional load. I also notice it now while talking to you, that my emotions rise. It truly is putting your head in the sand. But in a sense, it is always there. But if you think about it too much you can't live. And if we can't live, he can't live. So it is mostly the times in which he takes a turn for the worse, then it rises to the surface, and then you worry, and that really gets to you. But other than that, I just make sure to do as many things, fun things. I try to shape our lives into something beautiful.
Downregulating grief by enduring and rationalising in response to announcements of the loss.	It's a combination, the frustration you experience in that moment in which you are unable to alleviate his suffering. When he is throwing up, feels nauseous, I would want to take over from him, just give it to me. But I can't. So I try to be there for him, but you can't help him, other than being there and providing him with medicine against the nausea. What we call chemically sedating, because if he sleeps it doesn't bother him. And in that way, help him get through this rough patch. So that is one part of the frustration. On the other hand, the constant worrying. There is always that agonising feeling, what if we cannot get it under control, could that mean that this is the beginning of the end? And then I try to rationalize and tell myself that most of the time, we do get it under control. So why would this time… try to shake it off. But that switch is not always as easy to make.
Postponing grief and fulfilling parenthood	I don't see the use in it, to experience grief now. I enjoy my time with him so much, why would I ruin that by thinking about what if he… off course it will happen, you know that, you realize that. But I am not actively going to think about it, because then, I don't help myself with it, and I think it is not fair towards him as well.
Experiencing grief	*Pangs of grief* I think I can best describe the grief as a feeling of powerlessness. And sometimes that translates into sadness, tears, anger. At times I am just like… I just want to punch a wall. Or just want to scold everyone. And sometimes it is just tears, powerlessness. So it just depends. I've never thought about it too much, but I think it's also dependent on how well I feel about myself at a given moment. *Connecting with grief* There are times in which my emotions become tangled up. And that has two sides to it. I think it is allowing myself to experience it [grief] and believing it is okay to let it be there. But it can only be there, if there is someone watching over my son, then it is okay to give in. Although I do find it hard. Because I find it very hard to have to admit that at times, I cannot take care of him. And so it's not something I do quickly. But when it becomes too much, overwhelming, and there is a possibility, then I can surrender to those feelings by asking someone else to briefly take over care. […] Then I walk away, cry my eyes out, sometimes it is just going outside for a smoke. I am never far away, because I want to stay near him. But that's also, I think some sort of desire to control, I want to be there. I think it is a combination of… in that time having a lot of overwhelming emotions, being intensely sad, and at the same time having to care. And that combination is hard to handle at times. So at times it helps to let others take over care, to let go for a second, give yourself and your emotions some space, to reset, and thereafter be better able to continue again.

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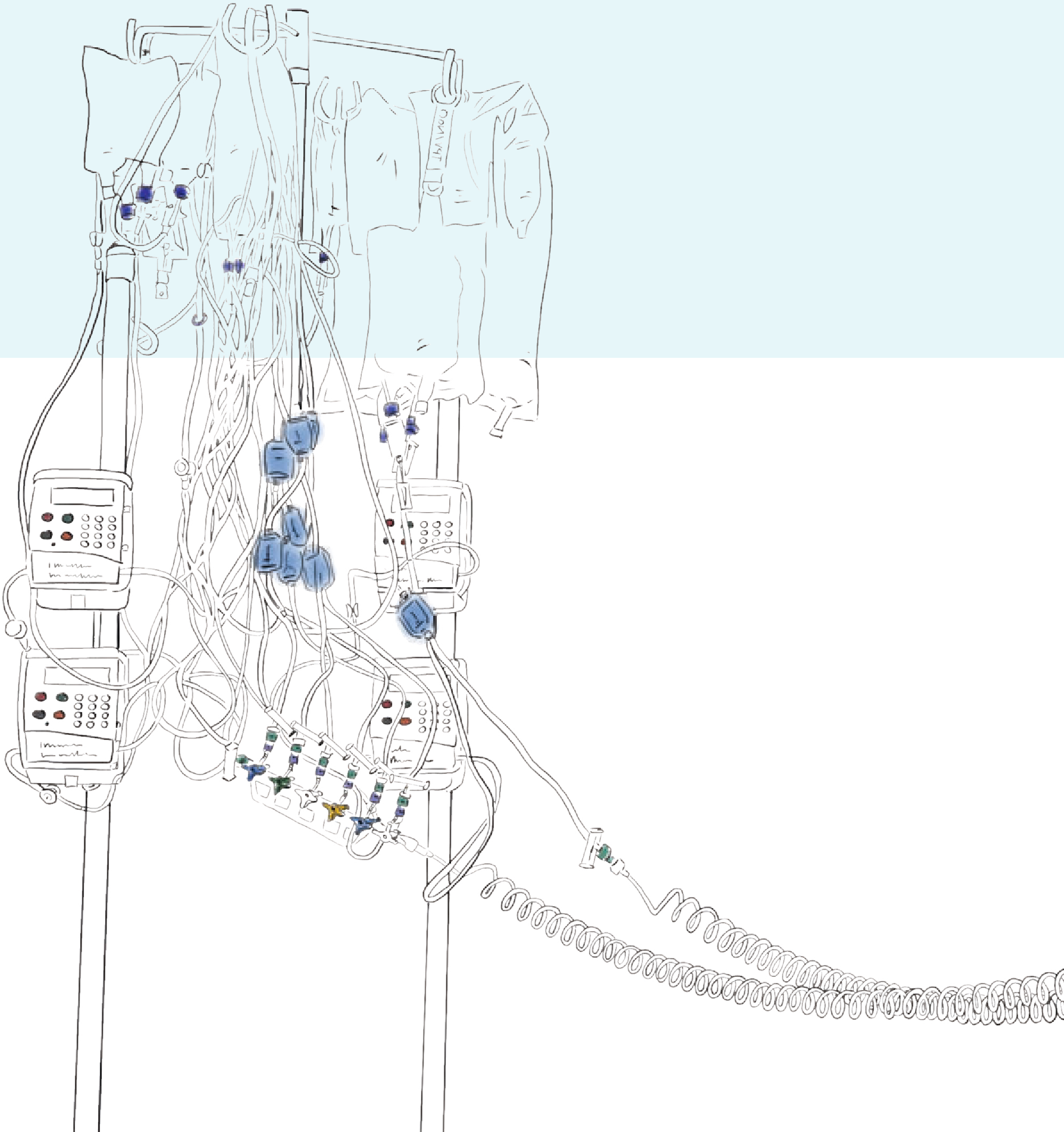

6

Insight into the content of- and experiences with follow-up conversations with bereaved parents in pediatrics: A systematic review

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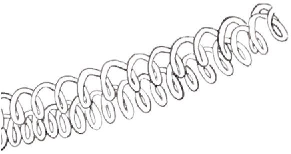

ABSTRACT

Aim

A follow-up conversation with bereaved parents is a relatively well established intervention in pediatric clinical practice. Yet, the content and value of these conversations remain unclear. This review aims to provide insight into the content of follow-up conversations between bereaved parents and regular health care professionals (HCPs) in pediatrics and how parents and HCPs experience these conversations

Methods

Systematic literature review using the methods PALETTE and PRISMA. The search was conducted in PubMed and CINAHL on February 3, 2021. The results were extracted and integrated using thematic analysis.

Results

Ten articles were included. This review revealed that follow-up conversations are built around three key elements: (1) gaining information, (2) receiving emotional support and (3) facilitating parents to provide feedback. In addition, this review showed that the vast majority of parents and HCPs experienced follow-up conversations as meaningful and beneficial for several reasons.

Conclusion

An understanding of what parents and HCPs value in follow-up conversations aids HCPs in conducting follow-up conversations and improves care for bereaved parents by enhancing the HCPs' understanding of parental needs.

INTRODUCTION

Despite advances in pediatrics, some parents still have to cope with the most devastating type of bereavement by losing their child due to premature birth, trauma or a life threatening illness. The loss of a child is a dreadful event in the life of parents and may result in psychosocial and health related problems up to years after the death of the child.[1–4]

Many parents of deceased children or neonates feel supported by, and appreciate, bereavement care provided by regular health care professionals (HCPs).[5,6] Over the past years, several bereavement practices and parent-focused interventions have been developed to assist parents during their child's end-of-life and/or after child-loss.[6–10] Among the various types of bereavement practices and interventions, several follow-up support services exist, such as follow-up conversations, sending a condolence letter or sympathy card, making a phone call, sending flowers etcetera.[6,8,10] The follow-up conversation, often described as the first scheduled meeting after the death of the child between the parents and the HCPs, is in itself relatively well established as part of bereavement practices in neonatology and pediatrics. Previous studies underline the significance of organizing at least one meaningful follow-up encounter between parents and involved HCPs after the death of a child.[6,10] Such an organized follow-up encounter helps parents feel cared for, reduces their sense of isolation and improves their coping.[6,8,10] When follow-up contact is missing, parents may feel abandoned by the HCPs who cared for their child which can add additional feelings of loss to the already present devastating loss of the child, known as secondary loss.[10]

Although follow-up conversations are mentioned as an important support practice, the goals and content of these conversations are hardy explicated and how parents experience these conversations remains unclear. Also, HCPs lack clear guidelines for conducting meaningful follow-up conversations. Bereavement care, including conducting follow-up conversations, is largely practice-based and a matter of learning on the job, that relies on the individual HCP's opinion, bond with the parents, and experience.[11–13] In addition, many HCPs face difficulty conducting follow-up conversations because they feel uncertain about the effects their actions might have on the parents and keep wondering if the current way of carrying out the follow-up conversation is actually beneficial for parents.

In order to better align follow-up conversations to the bereaved parents' needs and to provide HCPs with guidance, this systematic review aims to gain insight into the content of follow-up conversations and to explore how these conversations are experienced by both, parents and HCPs.

METHODS

Design

A systematic review was performed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[14] Since this review is conducted in a relatively young field and terminology addressing follow-up conversations is diffuse, the Palliative cAre Literature rEview iTeraTive mEthod (PALETTE) was used to establish the literature search.[15] This systematic review was registered in Prospero (registration number: CRD42021241506).

Databases and searches

Relevant articles that met all inclusion criteria and, as such, should inevitably be part of the systematic review are referred to as golden bullets. According to the PALETTE method,[15] a set of golden bullets was identified from articles suggested by experts in the field of pediatric palliative care, preliminary searches, and by back- and forward reference checking. From these articles, synonyms around the concepts of 'follow-up conversations' and 'pediatrics' were extracted and terminology became more clear, a process known as pearl growing. Subsequently, the search was built around the established terminology supported by an information specialist from the University Medical Library. The search was adjusted and repeated until all golden bullets emerged in the search results. At that point the search was validated. Lastly, the final literature search was conducted in the databases PubMed and CINAHL. For the full search strings see additional file 1.

Study selection

The included studies were limited to original research articles published in peer-reviewed English language journals between January 1, 1998 and February 3, 2021. We included 1998 as a starting point because the World Health Organization (WHO) officially defined pediatric palliative care in 1998. From this point on, research in pediatric palliative care had a more focused and well defined terminology. Included articles must address the content of follow-up conversations and/or the experiences of parents and/or HCPs with these conversations. The studies must address a follow-up conversation defined as the first scheduled meeting between the parents of the deceased child and the HCPs, who have been involved during the child's end-of-life. The term parents refers to the primary caretakers of the child, which indicates the biological parents, adoptive parents, substitute parents or other guardians. Furthermore, HCPs were defined as all types of regular HCPs who primarily provide care and/or treatment in the field of neonatology or pediatrics. These HCPs encounter bereavement care in their daily practice, yet are not specialized in this type of care. Children were defined as from the age of 0 through 18 years old. Studies that purely focus on prenatal death and stillbirth were excluded, since the field of stillbirth lies more closely to prenatal care and obstetrics which requires a different kind of support. Furthermore, we excluded studies addressing follow-up conversations within complex bereavement care. Complex bereavement care is focused on parents who experience a serious disruption in adapting to the loss of their child. Therefore, those follow-up conversations are mainly performed by specialists in bereavement care.

Articles that emerged from the searches in PubMed and CINAHL were imported into EndNote, where duplicates were removed. The remaining articles were imported into Rayyan, a web based screening tool that facilitated blind title/abstract screening by two researchers independently (MvK, EK). Thereafter, the eligible articles were full-text screened by the same researchers. Consensus was reached for all articles after deliberation. Lastly, the references of the relevant articles were checked to identify additional articles that met the inclusion criteria.

Data extraction and quality assessment

Data were extracted using a pre-designed form. Extracted data consisted of: the country, aim, design, setting of the study, method of data collection, sample, the content of the conversations, experiences of parents, and experiences of HCPs. The data regarding the content of the follow-up conversations and parents' and HCPs' experiences, were then analyzed using a thematic analysis approach. The data from the three main predefined categories (content, parent experience, and HCP experience) were categorized in sub themes, reflected in the different paragraphs of the results section.

Each article underwent a quality assessment which was performed by two researchers independently (MvK, EK). Qualitative studies were assessed using the Consolidated criteria for REporting Qualitative research (COREQ), recommended by Cochrane Netherlands.[16] The COREQ consists of 32 items covering the following three domains: Research team and reflexivity, study design, and analysis and findings. Items could be scored with 0 points when not reported in the articles, 0.5 points when partly described, and 1 point when fully reported. Quality appraisal did not affect inclusion of the article in the systematic review due to its descriptive nature.[17]

RESULTS

The search generated 1538 individual articles, of which nine met the inclusion criteria[18–26] and one was added following an additional reference check[27] (for full study flow, see Figure 1). All included articles represented qualitative studies.[18–27] Two articles were unclear in research design, they were assessed as qualitative studies based on the methods of data collection and data-analysis: using video-recordings[24] and a thematic analysis.[26] An overview of the included articles and their baseline characteristics is provided in Table 1.

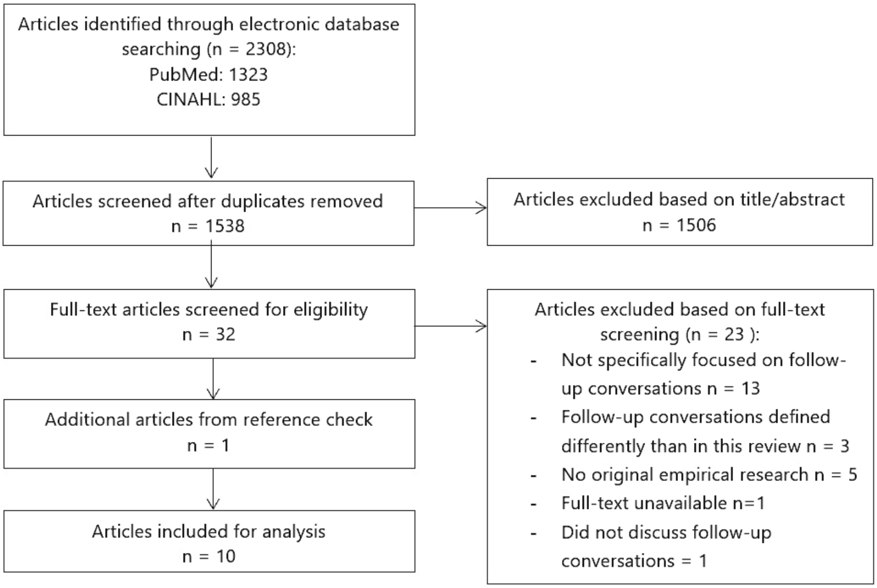

Figure 1. Study flow literature search and selection

Eight studies addressed follow-up conversations in the field of pediatrics.[18–25] Of these, seven studies focused on the Pediatric Intensive Care (PICU)[18–20,22–25] and one focused on pediatric oncology.[21] One study addressed follow-up conversations in the field of neonatology, concentrating on the Neonatal Intensive Care Unit (NICU).[27] One study addressed follow-up conversations in the field of both pediatrics and neonatology, consisting of the PICU, the Cardiac Critical Care Unit (CCCU) and several other pediatric wards.[26] Five studies brought out the perspective of the parents,[18,22,25–27] three studies the perspective of the HCPs,[20,21,23] and two studies the perspectives of both the parents and the HCPs.[19,24] Seven of the studies provided insight in the content of follow-up conversations based on interviews with both the parents and the HCPs.[18–23,27] Hereafter, an overview will be provided on firstly the content of follow-up conversations, secondly the experiences of parents regarding these conversations and lastly the experiences of HCPs with the conversations.

(1) The content of follow-up conversations

The preferable content of the follow-up conversation is built around three key elements: (I) Gaining information, (II) Receiving emotional support, and (III) Facilitating parents to provide feedback. These three key elements were described from both the perspectives of the parents and the HCPs (Table 2).

I. Gaining information

The majority of the articles showed that gaining information encompassed an opportunity for parents to gain an understanding of all the events surrounding the child's end-of-life and to ask remaining or new emerging questions. According to the parents the information should be provided in an understandable manner.[24]

Gaining an understanding of all the events surrounding the child's death is important since parents described that the intense emotions they experienced during their child's end-of-life and surrounding their death, inhibited their ability to accurately and efficiently process information, and to comprehend information provided at that time.[22] Therefore, during the follow-up conversation parents found it crucial to be provided with a clear and detailed overview of all the occurred events to build up a cohesive picture of what exactly happened, which facilitated acceptance and moving forward in their lives.[18,24,27] It was mentioned that the description of the proceeded events must at least include the chronological course of the child's illness, the provided treatment, the cause of death and the genetic risk to other children/family members.[19–23,25,27] Besides addressing previously known information, parents and HCPs emphasized the importance of disclosing all new information that became available since the death of the child.[18,20,23] New information mainly consisted of the autopsy results,[22,23] which posed an additional source of information that increased the parents understanding of the child's treatment and cause of death.[22]

Table 1. Baseline characteristics

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Brink et al. (2017) DK	To identify parents' experience of a follow-up meeting and to explore whether it was adequate to meet the needs of parents for a follow-up after their child's death in the PICU.	Generic qualitative study. Semi-structured interviews 2—12 weeks after the follow-up conversation.	University Hospital, Pediatric Intensive Care Unit (PICU)	Parents (n=10) attending a follow-up meeting 4-8 weeks after the death of their child Children (n=6) who died in the PICU with a variety of causes of death	- Information: Discuss various topics and, provide answers, give a causal explanation after a unexpected death. - Emotional support: Discuss how parents are dealing/coping, staff showing emotions. - Feedback: Parents want to provide feedback in order to improve practice.	- Nervousness and tension before but all pleased to have participated. Opportunity to enhance grieving process. -Emotional involvement from HCP's enables better coping. - Closure of the course in the PICU. Helps to find encouragement to grieve. -Meaningful that the meeting was interdisciplinary; attention for treatment and care - Experienced no time pressure - Important that HCPs involved in the meeting were those who had been present through hospitalization and the time of the child's dead since this felt safe for them. - Regarding location: stressful to return, helpful to revisit, felt as a 'second home'. Mostly willing to return to the hospital		21 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Eggly et al. (2011) USA	To describe the development of a framework to assist pediatric intensive care unit physicians in conducting follow-up meetings with parents after their child's death. .	Generic qualitative study. Telephone interviews 3-12 months after the death of a child	Seven academic tertiary care children's hospitals participating in the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN), Pediatric Intensive Care Unit (PICU)	A framework for follow-up meetings based on the experience/ perspectives of parents (n=56) of children who died in an CPCCRN PICU and PICU attendings and fellows (n=70) practicing or training at a CPCCRN site Children (n=48) who died in a CPCCRN affiliated PICU.	- The framework is a general set of principles adaptable to the specific context of each family's circumstances. - Balance of different aspects based on the parents' needs. - Opportunity for parents to express their thoughts and feelings and identify their issues. - Gaining information: Chronological course of the illness and provided treatment, the last hours of life and risks for the surviving children should be discussed using understandable terminology. - Assess how parents are coping so professional referrals can be made. - Parents need to gain reassurance that both the family and the medical team did everything they could to prevent the child's death. - Parents want an opportunity to provide feedback regarding the care. -Meetings should be multidisciplinary so varying needs can be addressed. - Meetings should be with the HCPs who cared for the child.		-Felt the meetings were beneficial to parents and to themselves. - Benefits for them: a better understanding of parents' perspectives, an opportunity to increase skill and experience to assist future families,, a chance to reconnect with families and find out how they are coping, an opportunity to reach closure and professional gratification. - Benefits may seem trivial, but may serve to counteract burnout and compassion fatigue.	11 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Eggly et al. (2013) USA	To examine physicians conceptualization of closure as a benefit of follow-up meetings with bereaved parents	Generic qualitative study. Semi-structured telephone interviews.	Seven academic tertiary care children's hospitals participating in the CPCCRN, Pediatric Intensive Care Unit (PICU)	Pediatric critical care physicians and fellows (n=67) practising or training at a CPCCRN clinical centre and conducting follow-up meetings with bereaved parents. Children who died in a CPCCRN affiliated PICU.	HCPs and parents should: - Review details of the death - Discuss new information - Address new or lingering questions	Parents can move toward closure by: - Gaining a better understanding of the causes and circumstances of the child's death - Considering the child's end-of-life in retrospect - Reconnecting or resolving relationships with HCPs. - Gaining reassurance that HCPs did everything possible relieves parental quilt and increases trust in the medical team - Providing feedback; allows them to contribute their experiences as information that would ultimately improve care for others - Moving on and accepting the reality of dead; the follow-up meeting is a point in time from which parents can move on.	- Some HCPs feel the word 'closure' does not accurately reflect the concept they want to describe. HCPs can move toward closure by: - Reconnecting with families; Want to see how parents are coping. - Further exploring the causes and circumstances of the death - Fulfilling professional duty; their work is not complete until they provide parents with final explanations. .	19,5 out of 32
Granek et al. (2015) CA	To examine follow-up practices employed by pediatric oncologists after patient death.	Generic qualitative study. Interviews	Two pediatric hospitals, Pediatric Oncology Department	Pediatric oncologists (n=21) conducting follow-up practices with bereaved families. Children who died from cancer.	- Parents and HCPs can talk about what had happened. - Parents can ask any lingering questions. - Parents want to hear that everything possible was carried out for their child.	- The follow-up meetings can be a beginning of the process of slowly disconnecting from the HCPs that were a major part of their lives for so long and who they may have felt close to.		16,5 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
McHaffie et al. (2001) SCO	To explore parents' experiences of bereavement care after withdrawal of newborn intensive care	Generic qualitative study. Semi-structured face to face interviews	Three neonatal referral centers, Neonatal Intensive Care Unit (NICU)	Parents (n=108) attending a follow-up appointment after newborn intensive care was withhold/ withdrawn. Neonates/infants (n=62) who died after treatment withholding / withdrawing in newborn intensive care.	Full frank information: - Should be given sensitively so parents can build a clear picture of what happened and assess their future risks. - Should answer parents' questions. - Should be understandable for parents in order to learn and accept the facts. - Reassurance about what had been done, the decision and future risks needs to be given where possible, but no false reassurance. - Sharing memories and experiences is important for emotional support. -Care and respect for the whole family is ensured.	- Wanting to find out how the parents are coping is of great value. - Showing compassion and understanding, communicating effectively and demonstrating a personal interest was appreciated. - Multidisciplinary is important because it is a burden to go to multiple separate follow-up appointments. - Appreciated an unhurried approach. - Should be with the neonatologist who had cared for the baby before the death. - Prefer to be seen soon after the death. Early contact is desirable since parents want to piece together a coherent picture in order to make progress in their grieving, to assess the risks of recurrence or the genetic implications, and to contemplate another pregnancy. - Revisiting the hospital can be painful.	- Barriers in conducting follow-up conversations can be: workload, resources, availability of support from colleagues.	12 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Meert et al. (2007) USA	To investigate parents' perspectives on the desirability, content, and conditions of a physician-parent conference after their child's death in the PICU	Generic qualitative study. Audio-recorded telephone interviews 3-12 months after the death of a child.	Seven academic tertiary care children's hospitals in the National Institute of Child Health and Human Development CPCCRN PICU	Parents (n=56) attending a physician-parent conference after their child's death in a CPCCRN affiliated PICU. Children (n=48) who died in a CPCCRN affiliated PICU.	Parents should: - Gain information about their child's illness and death. Topics: chronology of events, cause of death, treatment, autopsy, genetic risk and steps toward prevention, medical documents, withdrawal of life support, ways to help others, bereavement support and what to tell family. - Be able to seek emotional support. Reassurance they did everything they could. Sense that HCPs still care about them. - Be able to voice complaints, provide feedback and express gratitude. Improve care for other families.	The most important component is the provision of information. - Difficult to comprehend information at the time of the child's demise. - Highest in importance related to treatment and cause of death. - Review of the sequence of events to make sense of what happened. - Medical records and autopsy reports can increase the understanding. - Appreciate the follow-up meeting being with the HCPs who had close relationships with their child. - The majority is willing to return to the hospital and want to meet within the first three months. - Early enough to have any benefit, not too soon cause parents need to be able to comprehend was is being said. Some wanted to meet earlier, others wanted to wait until the distress of acute grief had begun to subside.		20 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Meert et al. (2011) USA	To investigate critical care physicians experiences and perspectives regarding follow-up meetings with parents after a child's death in the PICU	Generic qualitative study. Semi-structured, audio-recorded telephone interviews.	Seven academic tertiary care children's hospitals in the National Institute of Child Health and Human Development CCCRN, PICU.	Critical care physicians (n=70) practicing or training at a CPCCRN clinical center. Children who died in a CPCCRN affiliated PICU.	<u>Elements of the meetings:</u> - Providing information (past and new information available) - Emotional support (family coping, providing reassurance and expressing condolences) - Receiving feedback - Informational topics included: autopsy, questions, hospital course, cause of death, genetic risk, bereavement services, and legal or administrative issues. - Discuss whatever the family wants to discuss	- Desire a follow-up meeting with the HCP(s) who cared for their child. - Benefits of the meetings included: an opportunity to ask questions and gain information, closure, reassurance, reconnection with staff, talk through feelings, professional referrals, and greater trust in the healthcare team.	- Majority perceived that follow-up meetings were beneficial to parents and themselves. - Some report no benefit for themselves, the follow-up meetings just allows them to fulfill their professional obligations to parents. - The same HCPs desire to consider the meetings on a 'case-by-case' basis because there is a need for emotional protection. - Benefits included: understanding of parents' perspectives, opportunity to increase skill and experience assisting families, reassurance, reconnection with families, closure and professional gratification. - Barriers included time and scheduling, parents and physician unwillingness, distance and transportation, language and cultural issues, parents' anger and lack of a system for meeting initiation and planning. - Logistic barriers can be overcome. Personal barriers are more prohibitive. - The majority participated in follow-up meetings that were located at the hospital and occurred within 3 months after death. - Need for flexibility in timing: meet when families are ready and autopsy results are available.	18 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Meert et al. (2014) USA	To evaluate the feasibility and perceived benefits of conducting physician-parent follow-up meetings after a child's death in the PICU according to a framework developed by the CPCCRN	Observational study. Video-recorded follow-up meetings using the CPCCRN framework and evaluation surveys completed by parents and critical care physicians.	Seven academic tertiary care children's hospitals in the National Institute of Child Health and Human Development CPCCRN, PICU	Follow- up meetings (n =36). between bereaved parents (n=50) and critical care physicians (n=36). Children (n=194) who died in a CPCCRN affiliated PICU.		- Most parents find the meeting helpful and think it will help them cope in the future. - The following aspects are the most helpful: The opportunity to gain information, receive emotional support, provide feedback, honest, unhurried and nonthreatening style of communication. - Most parents could understand the information.	- Were willing to be trained to use the structured CPCCRN follow-up meeting framework. - The majority thinks that the meeting is beneficial to parents and to themselves. - HCPs benefited by: reconnecting with parents, gaining a deeper understanding of parents' perspectives and achieving a sense of closure - Most of the HCPs find the framework easy to use	23,5 out of 32 .

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Meert et al. (2015) USA	To identify and describe types of meaning-making processes that occur among parents during bereavement meetings with their child's intensive care physician after their child's death in a PICU	Secondary data analysis of an observational study, Video-recorded follow-up meetings using the CPCCRN framework.	Seven academic tertiary care children's hospitals in the National Institute of Child Health and Human Development CPCCRN, PICU.	Follow-up meetings (n=35) between bereaved parents (n=53). Children (n=35) who died in a CPCCRN affiliated PICU.		Four major meaning making processes were identified: 1. Sense making: Seeking biomedical explanations, revisiting prior decisions and roles, and assigning blame. Explain why they made the decisions they did, and sought reassurance from HCPs that the best decisions had been made 2. Benefit finding: Exploring positive consequences of the death, including ways to help others, such as giving feedback to the hospital, making donations, participating in research, volunteering and contributing to new medical knowledge and donating organs. 3. Continuing bonds: Parents' ongoing connection with the deceased child manifested by reminiscing about the child. Parents recalled actions of HCPs that showed dignity and respect for the child. 4. Identity reconstruction: Changes in parents' sense of self, including changes in relationships, work, home and leisure.	- May facilitate meaning-making processes by providing information, emotional support and an opportunity for feedback.	22 out of 32

Table 1. Baseline characteristics (continued)

Author, year, country	Aim of the study	Study design Method of data collection	Setting	Sample Deceased subjects	Content of the conversations	Parents' experiences	HCPs' experiences	Quality appraisal
Midson et al. (2010) UK	To explore the experiences of parents with end of life care issues in a tertiary treatment centre.	Generic qualitative study. A survey about parents' experiences during an interview.	A tertiary treatment hospital, PICU + Neonatal Intensive Care Unit (NICU), Cardiac Critical Care Unit (CCCU) and other wards	Parents (n= 28 families) attending a follow-up visit after the death of their child. Children between 3 days and 17 years old who died in a tertiary treatment center		- Some found that the follow-up visit was helpful in explaining and answering questions. - Other parents were left with unanswered questions and felt frustrated if further research did not answer their questions. - Other parents felt that the follow-up conversations made them re-live the whole experience and left them with a lot of questions. - Some parents were not ready for the follow-up meeting but kept the contact details for later.		16,5 out of 32

Table 2. Summary of the content of follow-up conversations

The content of follow-up conversations
• Gaining information: o A description all the proceedings during the child's illness and death. o An answer/solution to the lingering questions/concerns parents may still have.
• Receiving emotional support: o Parents want to feel that the HCPs care about them and their deceased child. o The HCPs should ask the parents how they are coping with the loss. o Parents want to gain the reassurance that they did everything that they could and made the right decisions.
• Facilitating parents to provide feedback o Parents want to provide feedback on aspects of the care that need to be improved. o Parents also want to express their appreciation and gratitude for the care they received.

In many articles it was mentioned that parents and HCPs found it important that parents get an opportunity to address their new or lingering questions and concerns during the follow-up conversation.[18–21,23,27] According to the parents and HCPs, these questions or concerns should be resolved during the follow-up conversation in order to prevent parents from delaying their process of grief.[18,19,27] Addressing the questions or concerns that parents may have, provided an opportunity to talk about their thoughts and feelings.[19] In one article it was mentioned that allowing parents to speak and be heard at the follow-up conversation increased parents' satisfaction and reduces possible conflict with HCPs.[22]

II. Receiving emotional support

Parents and HCPs described the second key element that should be part of follow-up conversations as receiving emotional support. Receiving emotional support consisted of feeling cared for by HCPs, attention for parents' everyday life and their coping, and reassurance. Overall parents considered emotional support from HCPs important since it enabled them to cope with the loss of their child and gave them some sort of comfort.[18,27]

Firstly, parents stressed that they want to feel cared for- and respected by the HCPs, and not be abandoned by them.[22,25,27] HCPs could perform multiple acts that contributed to parents feeling cared for, such as: starting the follow-up conversation by expressing their condolences to the parents[20,24], sharing memories and experiences of the deceased child[28] and carrying out actions that demonstrated dignity and respect for the deceased child.[25,28]

Secondly, several articles mentioned that receiving emotional support included asking the parents how they deal with everyday life and how they cope with the loss after their child's death.[18,19,23] The response of parents to the death of their child must be critically appraised by the HCP, since signs of complicated grief may be present. An unusual absent or excessive reaction could indicate that parents need further professional help and the HCP could refer parents to a specialist in the field of bereavement.[19]

Lastly, both the parents and the HCPs often mentioned that an important part of emotional support is providing reassurance.[19,22–25,27] Multiple studies addressed that parents sought reassurance from the HCP on several facets. They wanted to hear that HCPs did everything they could to prevent the child's death. Moreover, parents often felt guilty and wanted to be reassured that the child's death was not a result of their actions, that they had made the right decisions, had done everything they could do, and they were not to blame for the child's death.[19,22,25,27] One article mentioned that gaining reassurance on these aspects relieved parental guilt and increased their trust in the decisions made by the medical team.[20]

III. Facilitating parents to provide feedback

The majority of the articles emphasized the importance of facilitating parents to provide feedback on the care their child received. [18,19,22,23,25] From the parents' perspective it was learned that parents wanted to provide feedback on aspects of the care that needed to be improved. Parents often felt the need for something positive to result from their experience by a means of ultimately preventing other families from experiencing similar problems as they did while losing a child.[20,22,25] Several articles mentioned that besides the constructive feedback, parents often wanted to express their appreciation and gratitude for the care they received from the HCPs.[18,22,25]

The importance of tailoring the conversation to the parents' needs

One article highlighted that the three key elements that illustrated the content of a follow-up conversations were applicable to all situations. However, these key elements always needed to be tailored to the specific circumstances of each family.[19] Different situations may raise different kinds of concerns and questions for parents. For example, parents feel a greater need for a causal explanation when their child died sudden and unexpected.[18]

(2) The experiences of parents with follow-up conversations

The vast majority of the parents experienced the follow-up conversation after the death of their child as meaningful and helpful.[18,19,23,24,26] Nearly all parents felt nervous and tense prior to the conversation but afterwards were pleased to have participated.[18] Firstly, we will describe the positive experiences of parents with follow-up conversations, secondly the negative experiences, and lastly the location and timing of the follow-up conversation about which disunity prevailed among parents.

Positive experiences with the follow-up conversation

The parents with an overall positive experience pinpointed one particular benefit that they gained from attending the follow-up conversation: moving towards closure.[18,20,23] Parents stated that the follow-up conversation facilitated a definitive closure of the course in the hospital which helped them in moving closer towards accepting the reality of the death, finding encouragement to grieve, coming to terms with the loss and moving forward in their grieving process.[18,24] Experiences during the follow-up conversations that contributed to the concept of closure were acquiring a better understanding of the causes and circumstances surrounding the child's death,[26] considering the child's end-of-life in retrospect, momentarily reconnecting with the HCPs, gaining reassurance, and providing feedback.[18,20] One article mentioned that parents who went through a protracted time of illness before the child's death, as is often the case in oncology, experienced the follow-up conversation to contribute to the process of slowly disconnecting from the HCPs. Since the HCPs had been a major part of parents' lives for a long time, slowly letting go of the constant presence and support of the HCPs further facilitated closure.[21]

Besides the particular benefit of gaining closure, multiple articles showed a number of practical aspects of the follow-up conversation that the majority of parents evaluated as positive: the interdisciplinarity, the absence of time pressure, and the presence of the HCPs who had cared for the child during the end-of-life.[18,20,22,27]

Interdisciplinarity, is defined as the presence of different types of HCPs, e.g. physicians, nurses and (para-)medics. It was shown that the interdisciplinarity during the follow-up conversation was appreciated by the parents since questions about both the treatment provided by the physicians and the bedside care conducted by the nurses can be answered. Parents experienced the presence of the nurses as pleasant since most nurses possessed the ability to approach the parents with adequate tenderness and empathy.[18,27] Interdisciplinarity in the field of neonatology encompassed the presence of different specialties such as obstetrics. Parents were grateful for this sort of interdisciplinarity because it relieved the burden of attending separate follow-up conversations of each individual specialty.[27]

Absence of time pressure was experienced by parents through the unhurried approach during the follow-up conversation. Parents experienced no time pressure despite the predetermined time frame that most of the follow-up conversations do have.[18,27]

Attendance of the HCPs who had been present through hospitalization and the time of the child's death was important for parents.[18,20,22,27] Parents often had an intimate and intense relationship with these HCPs and felt safe discussing their emotions and feelings with them.[18,20] Their absence during the follow-up conversation could feel as an abandonment.

Negative experiences with the follow-up conversation

Despite the positive experiences, some parents did not benefit from the follow-up conversation. A few parents were left with unanswered questions after the visit which made them feel frustrated. Other parents re-lived traumatic experiences during the conversation without resolving the aspects that firstly caused the trauma.[26]

Experiences with the location and timing of the conversation

Disunity prevailed among parents regarding the location and timing of the follow-up conversation. Regarding the location of the follow-up conversation, some parents found it stressful, painful and traumatic to return to the hospital,[18,27] while a large group of parents experienced no problems returning.[18,22,27] For some parents, revisiting the hospital is even helpful because it had felt like a second home for a long time.[18]

Parents' opinions on the preferred timing for the follow-up conversation differed, which may be related to a difference in pediatrics versus neonatology. One article stated that the majority of parents would like to meet with the HCPs within the first three months after the death of their child.[22] This period provided parents with enough time to let the acute feelings of distress and despair subside, while still being soon enough after the child's death to gain benefit from of the follow-up conversation.[22] However, other articles emphasized that in particular parents of deceased neonates preferred to meet the HCPs sooner than three months after the child's death since they often wanted to assess the risks of recurrence, to discuss the genetic implications and to contemplate a subsequent pregnancy.[22,27] In another article it was suggested that it is wise to have some sort of flexibility in the timing for the meeting so it can take place whenever the parents are ready.[23]

(3) The experiences of HCPs with follow-up conversations

From the HCPs' perspective it was learned that the vast majority believed that follow-up conversations were not only beneficial for the parents but also for themselves.[19,23,24] Hereafter the benefits HCPs gained from follow-up conversation and barriers towards the conversation are discussed.

Benefits gained from the follow-up conversation

The benefits HCPs gained from the follow-up conversations included learning from parents, reconnecting with parents and gaining closure.[19,20,23,24]

Regarding learning from parents, HCPs stated that they gained a deeper understanding of the parents' perspectives during the follow-up conversations. HCPs mentioned that they took the parents' perspectives and feedback into account to reflect on the consequences their actions had on them. These insights facilitated HCPs to improve their future practice and increased their skill and experience to assist future families under their care.[19,20,23,24]

Concerning reconnecting, HCPs mentioned that caring for a child and their parents had often been intimate and intense. An abrupt end to their relationship with the parents directly after the child had passed away, felt unsettling to the HCPs because they wanted to keep an eye on parents. HCPs considered it beneficial to reconnect with parents during the follow-up conversation and find out how they were coping.[19,20,23,24]

HCPs mentioned that in conducting follow-up conversations, they fulfilled their professional duties, obtained professional gratification and thereby gained closure for each deceased child they cared for.[19,20,23,24] Most HCPs described follow-up conversations as part of their jobs and felt like their work was not complete until they had provided parents with final explanations.

The previously stated benefits may seem minor but may serve to prevent burnout and compassion fatigue in HCPs.[19]

Barriers to follow-up conversations

Besides the benefits HCPs gained by conducting follow-up conversations, two articles also identified multiple barriers that made conducting follow-up conversations more difficult for HCPs. These barriers can be divided into different categories, namely emotional and practical barriers for the HCPs, emotional and practical barriers for the parents seen from the HCPs perspective, and a systemic barrier.

Emotional and practical barriers for the HCPs, included HCPs unwillingness, time, and scheduling. HCPs' unwillingness can be based on existing emotional discomfort. The emotional barrier and discomfort arose from the fact that conducting a follow-up conversation can remove a form of self-protection for HCPs. Some HCPs wanted to put the death of the child aside after a while to protect themselves from feeling overwhelmed and emotionally exhausted. Yet, conducting follow-up conversations repeatedly confronted them with intense and overwhelming situations. These confrontations can increase the risk of burnout and compassion fatigue.[23] HCPs that experienced this level of discomfort with the conversation, did not find any personal benefit in conducting follow-up conversations and tried to sustain their emotional stability by not meeting with parents.[23] The practical barriers for HCPs consisted of busy clinical days, a high work load, and conflicting schedules. These aspects made it harder for the HCPs to schedule follow-up conversations and to spend as much time as the family needed.[23,27]

Emotional and practical barriers for the parents seen from the HCPs perspective included parents' unwillingness and parents' anger or distrust, distance and transportation, language and cultural issues. Distance and transportation formed a barrier because some parents needed to travel a long distance.[23] Language created an issue when there needed to be a translator present to be able to conduct the follow-up conversation with non-English speaking parents.[23]

A lack of a system for conversation initiation and planning formed an additional barrier for HCPs. The HCPs had faith in overcoming the practical barriers with a little bit of effort. However, the personal and emotional barriers were viewed as more limiting.[23]

DISCUSSION

In this systematic review, the content of follow-up conversations after the death of a child and an overview on how these conversations are experienced by parents and HCPs is described. Follow-up conversations are built around three key elements: (1) gaining information, (2) receiving emotional support, and (3) facilitating parents to provide feedback. The vast majority of parents experienced the follow-up conversation as meaningful and helpful in their grieving process. One particular benefit parents gained was moving towards a definite closure of the course in the hospital. Furthermore, parents perceived the interdisciplinarity, the absence of time pressure and the continuation of the bond with HCPs as strengths of the follow-up conversations. The vast majority of HCPs believed that the follow-up conversations they had conducted were beneficial to them. The benefits HCPs derived from conducting follow-up conversations included learning from the parents, reconnecting with the parents and gaining a sense of closure from the deceased child they have cared for. HCPs identified the following barriers in conducting follow-up conversations: finding time and scheduling, parents' and HCPs' unwillingness, distance and transportation, language and cultural issues, parents' anger or distrust, and a lack of a system for conversation initiation and planning.

After the death of a child, parents' lives and their view on the world and themselves are largely disrupted. In order to adjust to their new reality in which their child is physically absent, parents need to incorporate the loss into their autobiographical memory, e.g. adjust how they view themselves and the ongoing bond with their child.[6,28,29] To incorporate the loss, parents need a fitting picture of all the events that lead to the death of their child.[6] In particular HCPs involved in childcare can aid parents in gaining a full understanding of the proceedings surrounding the death, which is acknowledged as an important element of the follow-up conversation by both parents as well as HCPs.[18,22,27] Sense making, creating such a comprehensive picture, is a component of meaning making.[30,31] Meaning making is known as an important element required to make such an adjustment after child loss,[31,32] and aids parents in coming to terms with the loss in which parents might find comfort and reassurance.[32] The inability to 'make sense' of the of the situation is known to enhance grief intensity in parents.[33]

Another parental need this systematic review puts forward is that parents seek reassurance on having been 'a good parent' during the end-of-life and whether they have made the right decisions. What is perceived as being 'a good parent' differs per individual, yet a common theme consist of having done right to the child, including in health related decisions.[34–36] Additionally, parents need reassurance on having made the right decisions,[37] and on the fact that HCPs did everything they could and no mistakes were made.[38]

Most of the time, these two goals: the desire to gain a comprehensive picture of the events and the search for reassurance regarding parenthood and decision making, will complement each other. Yet what if the full picture enhances doubts or creates new uncertainties? In that case, the follow-up conversation may have an adverse effect on parents and increase feelings of guilt which has a negative impact on parental readjustment.[39] Moreover, guilt in bereavement may have severe impact on parents' psychological and physical health and general well-being.[40] Hence, the balance between providing an honest and accurate picture on the one hand and reassurance on the other, is a delicate subject for HCPs. Future studies should focus on how to address and uphold this balance in follow-up conversations.

A goal HCPs brought up regarding the follow-up conversation is to assess whether parents require additional support. Over time most parents will be able to cope with child loss, yet about 10-25% of bereaved parents develop complicated grief or "prolonged grief disorder" (PGD).[41–43] PGD is an disorder listed in the DSM-V and ICD-11 manual, and known as a serious and longitudinal disruption in the grieving process, for which additional guidance by a mental health care specialist is required.[41,44] The follow-up conversation could be a fitting time to assess which parents might be at risk to prevent further disruption, since parents who lost a child are known as a high risk group to develop PGD.[41–43,45] An overview of indicators to identify these parents is currently lacking. Future research could focus on identifying indicators and predictors of PGD in bereaved parents.

Based on the insights provided in this review various suggestions for clinical practice can be made in order to improve follow-up conversations in neonatology and pediatrics. An important note is that all these suggestions should be incorporated while arranging and conducting the follow-up conversations, but always tailored to the specific circumstances of each family.

The first suggestion is that HCPs should first and foremost explore the parents' concerns, fears, doubts and needs for more information, not only regarding the illness trajectory and decision making, but also regarding their parenting during the end-of-life.

The second suggestion is that HCPs should facilitate parents' making meaning of their experiences with losing their child by offering the opportunity to provide feedback on the care received. By providing feedback on aspects of care that parents have experienced as non-pleasant they can prevent other parents from encountering the same problems in the future. Providing feedback is helpful for parents since they often want something meaningful to arise from their child's death and being of meaning to other parents.

The third suggestion is that follow-up conversations should be conducted interdisciplinary, including the HCPs who have been involved in the child's end-of-life care and without time pressure. This enhances the opportunity for parents to ask questions, provide feedback, reflect on their parenting and the uniqueness of their child.

Furthermore, this review uncovered that the difficulties HCPs face while conducting follow-up conversations are unlikely to be solved by just drawing up a guideline based on the previous given suggestions. Multiple studies included in this review point out that some HCPs can experience discomfort discussing death and bereavement related issues with parents due to a lack of (communication) training and inexperience.[19–21,23,24] Removing the barrier of discomfort may contribute in facilitating HCPs in carrying out follow-up conversations. Additionally, other studies underline the lack of structured training on bereavement care for medical and nursing staff.[13,46–48] Therefore the final and last suggestion for clinical practice is to provide structured training and education for HCPs, including coaching, skills training and learning on-the-job. Besides focusing on follow-up conversations in training, broader attention should be provided on maintaining their emotional balance while providing bereavement care which is emotionally challenging. The educational forms should be focused on important aspects such as theories on grief, the psychological processes of bereavement and communications skills.[19–21,26,49]

This review has several strengths including gaining insight into the content of follow-up conversations and both the parents and the HCPs perspectives, providing the reader with a robust description of the available knowledge regarding follow-up conversations from the perspectives of all persons involved. In addition, the parents' and HCPs' experiences are separately presented, thereby resulting in more clarity on differences and similarities between their perceptions. Another strength is the inclusion of studies from different sub-specialisms and departments within pediatric and neonatal medicine. Both the Pediatric Intensive

Care Unit (PICU) and the Neonatal Intensive Care Unit (NICU), and pediatric oncology were addressed in this review. Therefore, the results are applicable to a variety of situations, enhancing transferability and possibilities for uptake in clinical practice. A limitation could be that no studies solely included follow-up conversations with parents of children with chronic diseases and disabilities with a slow deterioration. These children often have long hospitalization on the children's ward and at home. These circumstances are likely to affect the content of a follow-up conversation. Another limitation could be that six of the included articles are conducted by the same research group. Although the separate studies rely on rather large samples and a variety of data sources including parents, HCPs, and video or audio recordings of follow-up conversations. Yet less diversity in our results may occur than is actually the case in current practice.

In conclusion, this systematic review provides insight into the content of follow-up conversations in pediatrics and the experiences of parents and HCPs with these conversations. These insights contribute to a better alignment to the needs of bereaved parents. Future research should explore the parental position towards closure and towards identifying parents that might be at risk for complicated grief. In addition, a better understanding of how to balance providing reassurance versus providing a realistic and complete picture of the events surrounding the child's death is needed to align to parental needs. Lastly, studies on how to optimally support HCPs in conducting follow-up conversations should be performed and practical tools to support HCPs should be developed.

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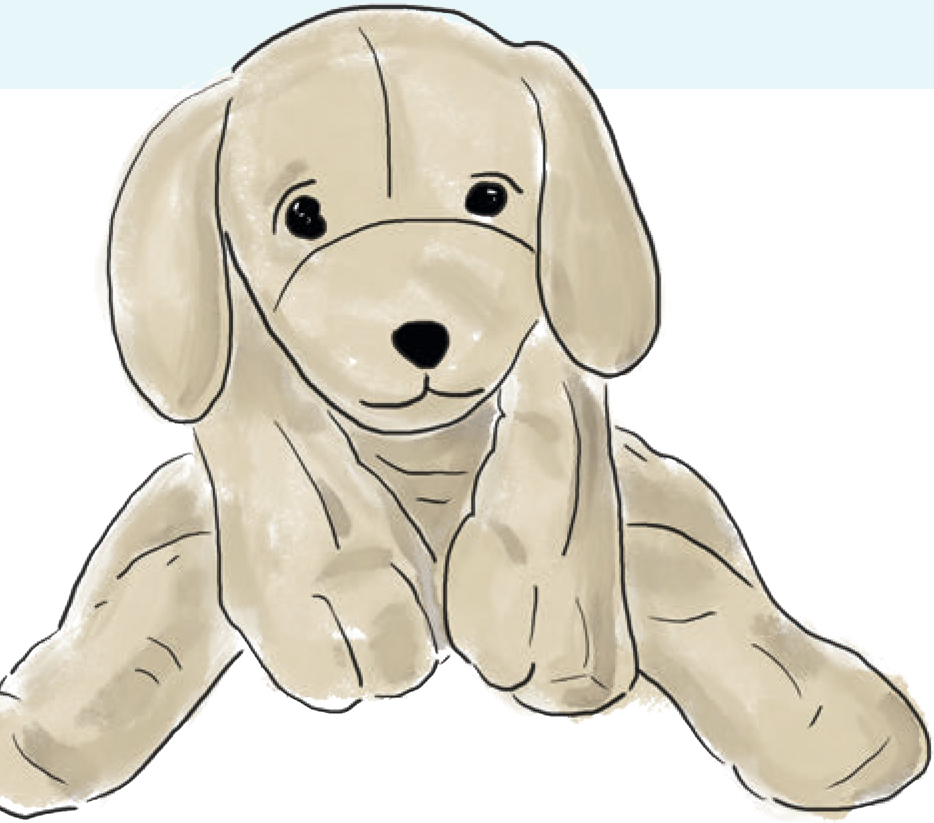

7

Developing a meaningful narrative: a qualitative study on parents' and healthcare professionals' experiences with follow-up conversations in pediatrics

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ABSTRACT

Context
Follow-up conversations are a relatively well-embedded form of pediatric bereavement care and the first scheduled contact between parents and healthcare professionals (HCPs) after a child's death. These conversations revolve around obtaining information, receiving emotional support and providing feedback, yet the experiences with these conversations remain largely unclear.

Objective
To gain insight into how parents and HCPs experience follow-up conversations after child death, and from what aspects of the conversations parents and HCPs derive meaning.

Methods
Exploratory qualitative research was performed on recorded follow-up conversations and consecutive semi-structured interviews with parents and HCPs. A multidisciplinary research team examined the data using thematic analysis.

Results
Nine follow-up conversations were included, connected with nine deceased children. Afterwards, 8 interviews with 15 parents, and 27 HCP-interviews were conducted. Central to the follow-up conversations was the development of a meaningful narrative that helped parents to make sense of all what happened and parents were able to relate to. The narrative was constructed through shared reflection on the medical trajectory and parenthood, for which parents and HCPs had different underlying goals. Additional relevant aspects were: reconnecting once more and making sure the other is faring well, keeping the child's identity alive, and moving towards closure of the hospital period.

Conclusion
Parents and HCPs sought ways to relate to their involvement and role during the child's EOL through the development of a meaningful narrative. HCPs should enable parents to build their narrative by being transparent yet emphasizing on helpful reflections and cognitions through displays of parenthood.

INTRODUCTION

Losing a child is considered the most devastating loss parents can experience. Grief is the emotional response following the loss and encompasses emotions such as distress, anxiety, and dysphoria.[1] Whereas most parents overtime incorporate the loss in their life story, the grief itself may never be resolved. Bereaved parents are at risk to develop adverse psychological and physical health responses[2–4] and prolonged grief.[5,6] Multiple bereavement practices and interventions have been developed to support parents in their bereavement. Such practices include: caring for the deceased child by washing and dressing, collecting mementoes, remembrance activities, sending cards or support groups.[7–9] One relatively well embedded form of bereavement care is the follow-up conversation between the bereaved parents and the health care professionals (HCPs) who took care of the child during life.[7,10] This is the first organized contact in the hospital and usually takes place 6 to 8 weeks after a child's death. A recent systematic review explored the content and the parents' and HCPs' experiences with follow-up conversations.[11] Preferable content is described along three key-elements: obtaining information, receiving emotional support, and providing feedback to HCPs. Parents and HCPs were positive about reconnecting and formally moving towards closure of their relationship.[12–17] To what aspects of the conversation parents and HCPs derive meaning from remains unclear.[11] Therefore, this study explored how parents and HCPs experience follow-up conversations and to what aspects of the conversation parents and HCPs derive meaning.

METHODS

Design

An exploratory qualitative study design was employed, using thematic analysis to analyze the recordings of the conversation and semi-structured interviews with parents and HCPs.[18,19]

Sample

A purposive sample of follow-up conversations in pediatrics and consecutive interviews with all participants was included. A follow-up conversation was defined as the first scheduled meeting that is part of bereavement care, offered to bereaved parents with HCPs who took care of their child during (the end of) life, approximately 6-8 weeks after the child's death. Parent was defined as the primary caretaker of a child and should be over 18 years old, children ≤18 years. All follow-up conversations in pediatric departments were eligible, there were no restrictions on place of death or diagnoses. Parents who's HCPs believed to be at risk for prolonged grief disorder, based on their expertise, were excluded. Maximum variation was sought with respect to the child's age and diagnosis.

HCPs of four pediatric hospitals identified eligible parents who were scheduled for a follow-up conversation. HCPs introduced the study and if parents were open to receive information, their contact information was shared with the research team, who informed them and arranged their participation.

Data-collection

Data were collected between March 2021 and March 2022. Data collection consisted of an audio-recording of the follow-up conversation and consecutive interviews with all participants. In the participating centers the follow up conversation was offered to bereaved parents as part of standard care. Conversations took place in their natural course: researchers were not involved in the planning, nor present. The HCP arranged the audio-recording of the conversation. Afterwards, all involved parents and HCPs were approached for an individual, semi-structured interview about their experiences with the conversation and were asked to fill out a background questionnaire. A trained qualitative interviewer conducted the interviews (EK), at the participants' preferred location. All interviews started with a broad opening question: "How did you experience the follow-up conversation?". This was followed by more focused questions regarding expectations about the follow-up conversation, the discussed topics, perceived benefits and what the follow-up conversation meant for parents regarding their grieving process. Data were collected until saturation of the main categories was reached.[20]

Data analysis

The audio recordings of the follow-up conversation and the consecutive interviews were transcribed verbatim. Data analysis took place in a research team, ensuring researcher triangulation and consisted of: a psychologist trained in qualitative research (EK), a pediatrician (JF), a senior qualitative researcher and former PICU nurse (MK), and a medical student (FR).

During the analysis, a case approach was adopted, in which per case the follow-up conversation and individual interviews with all participants were discussed simultaneously. At first, open coding was performed on three cases, to identify meaningful fragments in relation to our research questions and develop preliminary themes. Narratives were written that provided an overview of the meaningful fragments of all transcripts within one case. A coding three was formed and axial coding was performed, using NVivo.[21] Throughout the analysis, memos were written that guided the establishment of the themes and facilitated discussion in the research team.

Ethical consideration

This study was classified by the institutional review board as exempt from the Medical Research Involving Human Subjects Act (WAG/mb/19/046086). Informed consent was obtained from all participants prior to data collection.

RESULTS

A total of nine follow-up conversations were included, connected to nine deceased children. Afterwards, eight interviews with 15 parents, and 27 HCP interviews were conducted (Table 1). Amongst parent participants, two couples were lost to follow up, one couple considered it too confrontational to be interviewed after the follow-up conversation and one couple was nonresponsive to multiple invitations. For an overview of cases and their corresponding participants, see Table 2. Parent interviews were held face-to-face at home (n=3), by telephone (n=2), or videoconference (n=3). Amongst HCP participants, six were lost to follow up due to nonresponsiveness. Interviews with HCPs were held face-to-face in the hospital (n=11), or via videoconferencing (n=16). Follow-up conversations lasted between 35 and 110 minutes, parent interviews between 30 and 75 minutes, and HCP interviews between 20 and 75 minutes.

Goals and expectations prior to the follow-up conversation

Despite the announced invitation, parents did not know what to expect prior to the follow-up conversation. They had been living in a haze after their child's death and most decided to wait and see what the conversation would bring. For many parents the hospital period felt incomplete if they could not reunite with their child's HCPs once more. Parents explained they had gone through the most intense and memorable moments together with their child's HCPs, and it did not feel right to let the devastating period surrounding their child's passing be their last interaction. Some parents felt the follow-up conversation took a toll on them, because they had to return to the hospital once more and be confronted with the memories. Most parents experienced a combination of both.

Table 1. Participant Characteristics

HCPs		**Parents**	**line**	**Children**	
Characteristics	**n (%)**	**Characteristics**	**n (%)**	**Characteristics**	**n (%)**
Gender		**Gender**		**Gender**	
Female	22 (81)	Female	7 (47)	Female	3 (33)
Male	5 (19)	Male	8 (53)	Male	6 (67)
Age (year)		**Age (year)**		**Age (year)**	
20-29	1 (4)	30-39	3 (20)	<1	4 (44)
30-39	8 (30)	40-49	6 (40)	1-5	1 (11)
40-49	5 (19)	50-59	3 (20)	6-10	1 (11)
50-59	3 (11)	Unknown	3 (20)	11-17	2 (22)
60+	4 (15)	**Nationality**		unknown	1 (11)
Unknown	6 (22)	Dutch	14 (93)	**Place of death**	
Profession		Other	1 (7)	Home	7 (78)
Physician	13 (48)	**Education**		Hospital	2 (22)
- In training	1 (4)	Low*	3 (20)	**Main diagnosis**	
Nurse	7 (26)	Middle**	2 (13)	Oncological	3 (33)
- In training	2 (7)	High***	8 (53)	Cardiac	2 (22)
Physician assistant	2 (7)	Unknown	2 (13)	Neurological	1 (11)
Social worker	1 (4)	**Life Philosophy**		Trauma	2 (22)
Physiotherapist	1 (4)	None	8 (53)	Gastro-intestinal	1 (11)
Specialization		Protestantism	3 (20)		
Intensive care	10 (37)	Catholicism	1 (7)		
Oncology	9 (33)	Unknown	3 (20)		
Neurology	1 (4)				
Cardiology	1 (4)				
Gastro-enterology	1 (4)				
Urology	1 (4)				
General	4 (15)				
Additional training					
Palliative care	10 (37)				
Bereavement care	0 (0)				
Unknown	5 (19)				

Table 1. Participant Characteristics (continued)

HCPs		**Parents**	**line**	**Children**	
Characteristics	**n (%)**	**Characteristics**	**n (%)**	**Characteristics**	**n (%)**
Years experience in pediatrics					
0-10	8 (30)				
11-20	5 (19)				
21-30	7 (26)				
30+	1 (4)				
Unknown	6 (22)				
Follow-up conversations past 2 years					
0-5	15 (56)				
6-10	5 (19)				
11+	1 (4)				
Unknown	6 (22)				

Low: Primary school, lower secondary general education, lower vocational education. Middle: Higher secondary general education, intermediate vocational education. ***High: Higher vocational education, university.*

Table 2. Overview of cases

	Follow-up conversation	**Parent interview (m: mother, f: father)**	**HCP interviews**
Case 1	1	Lost to follow-up	2
Case 2	1	1 (m+f)	4
Case 3	1	Lost to follow-up	3
Case 4	1	1 (f)	2
Case 5	1	1 (m+f)	3
Case 6	1	2 (m+f)	3
Case 7	1	1 (m+f)	3
Case 8	1	1 (m+f)	4
Case 9	1	1 (m+f)	3

HCPs intended to identify what parents needed from them to move towards closure and to align the conversation to their needs. When asked about the goals of the follow-up conversations, HCPs noted that it presented as a moment for them to gain comfort in assessing whether they had done the right things for this family, to detect whether any issues parents were not satisfied about or could not relate to needed to be resolved, and to disengage from their care-relationship with the parents.

Experiences during the follow-up conversation

The follow-up conversations mainly consisted of sharing information and experiences, which appeared to result in the development of a meaningful, shared narrative, that both parents and HCPs are able to relate to. By doing so, three relevant aspects of the conversation came to light: reconnecting once more and making sure the other is faring well, keeping the child's identity alive, and lastly moving towards closure of the hospital period.

Developing a meaningful narrative

From the recordings, we learned that, on the initiative of one of the involved HCPs, all follow-up conversations started with a chronological recollection of key-moments leading up to the child's death. Important decisions were reflected on, uncertainties were discussed, and questions were answered. The HCPs initiated the discourse, and parents often contributed by wanting to discuss their reflections on impactful moments. One implicit theme that seemed to guide the development towards a shared narrative was: how do we perceive and speak about all what happened and are we able to relate to our role in the process? The narrative needed to be complete, make sense, and as such, help in reflecting on the period in the future and in discussing it with others. From the reflections during the interviews, we learned that parents and HCPs were aware they could not relive the child's EOL, how they fulfilled their role, and sought for underpinning and reassurance of having done things right.

Parents' experiences while developing their narrative

Parents shared their need to develop a complete picture of their child's EOL, since memories were often blurred in the highly distressing situations. Through reflecting on the medical trajectory, parents sought to fully comprehend all that happened and come to terms with the inevitability of their child's death. Parents asked questions, reflected on why certain decisions were made, revisit key-moments, and discussed (non)verbal signs that were observed in their child. Parents expressed their need for honest information from the HCPs, expressing that only knowing the full truth could do justice to their child and give them peace of mind. Parents did not want false reassurances but rather answers that made sense, they hoped that knowing the full truth would lead to feeling reassured that they did right by their child in treatment- and parenting choices. Doubts and rumination could be enhanced after their child's passing, since parents had time to reflect on the medical trajectory and played scenario's over-and-over. Often, parents mentioned they knew the answers to some of these doubts yet needed to be reassured by the HCPs once again.

Parents also sought reassurance of having been a good parent throughout their child's illness trajectory. What entailed being a good parent was different for all parents and could for instance involve advocating for their child and not giving up on them or being present throughout the illness course and providing the child with comfort. Parents sought confirmation in HCPs' reflections and recollections of their acting as a parent. One period that parents wanted to reflect on with the HCPs was the time surrounding their child's passing, which symbolized the last parental act parents could fulfill. As such, they sought consolation in HCPs' reflections that their child's passing was dignified, and their child had not suffered. Parents' evaluation of having been a good parent throughout the EOL could be jeopardized in several ways, such as feeling guilty about not having done everything to save their child, not providing their child with the chance to live his/her life to the fullest, or when their child had suffered. These doubts on parenting could be strengthened when parents felt they might have overtreated their child and overlooked the quality of life, or when they experienced friction between them and the HCPs when symptoms were not under control.

HCPs' experiences while supporting parents in developing their narrative

HCPs reflected on the important decisions or events that were apparent during the child's illness, which served three purposes for them. First, it provided them with some hold to guide the conversation. Second, most HCPs believed it helped parents if they were provided with the complete discourse of their child's illness. Some HCPs mentioned that knowing the full story would enable parents to internalize and recall the narrative in the future in a comprehensible manner, which would also be helpful in communicating their story with others. In reflecting on perceived suffering or uncertainty in decisions, HCPs tried to alleviate the weight or responsibility, by helping parents sketch a bigger picture, correct false beliefs or assumptions, or take on the responsibility of decisions made if possible. Thirdly, HCPs sought reassurance regarding their own unease about not knowing if parents still felt the same way as before about the trajectory, including all considerations and decisions made. They hoped parents could still relate to the chosen path and that they had not caused parents any obstacles in their grieving process. HCPs especially felt uncertain when decisions had been made which already carried a heavy load at the time itself. The assessment is thus a general reflection of parents' feeling of acceptance towards the chosen path, their ability to carry the consequences, and the evaluation of the HCPs' professional actions. The latter two goals were further elaborated on through obtaining feedback from parents, which sometimes was actively asked for and other times prepared by parents.

Receiving feedback enabled HCPs to improve care and their understanding of the parents' perspective.

As parents searched for ways to alleviate any doubts whether they have done right by their child and regarding the fulfillment of their parenthood, HCPs actively tried to provide parents with reassurance and empower them by emphasizing on aspects of meaningful parenthood they had witnessed. HCPs frequently complimented parents on their strength, continuous presence, and endurance. They tried to include details that were unique for this family, for parents to take the observations and reassurance at heart. HCPs would not lie to parents to take away hardship, but mentioned to put more emphasis on helpful thoughts and reflections, since parents could not undo what had happened and needed to find acceptance in the discourse.

Three additional aspects that were of meaning to parents and HCPs

Reconnecting once more and making sure the other is faring well

Many parents mentioned they had formed a unique bond with the HCPs, since they were present with, and supported, them, amidst highly distressing and emotional times. Parents often felt the story of their child was incomplete when their child had died at home or HCPs had not been present during their child's terminal stage. Most parents wanted to share how they had experienced the last couple of weeks, and felt it would be helpful for the HCPs to know how parents were coping and holding up. Many parents reached out to their HCPs to offer them consolidation, either intentional or more subconsciously. Parents shared that, although their loss differed from the loss the HCPs suffered, it was also a loss and tragic event for HCPs. In a way, ascribing these feelings to the HCPs positively correlated to the impact their child had made: the heavier the loss experienced by the HCPs, the greater the impact their child had left on them.

Most HCPs similarly experienced a lack of closure, and wanted to assess how parents reflected on their child's farewells and how they were holding up, both for their personal closure as well as to assess whether parents needed additional support. HCPs tried to provide parents with what they needed to relate to the loss, yet at the same time, they were uncomfortably aware that they stood empty-handed since the child, i.e. their patient, had died. They could revisit decisions or take away ambiguity, which provided them with a sense of purpose and being able to help. HCPs normalized the grieving processes and lift the stigma of psychological care and they showed their presence by offering an opportunity for a secondary meeting and encouraged parents to call them if they needed.

Some HCPs mentioned that the follow-up conversation is less about being the health care provider, but more about being present as a person, which could be a vulnerable experience for them. They tried to connect through, for example, dressing in their regular clothes, sharing personal memories, and ensuring their presence by asking colleagues to take over pagers and phones.

Keeping the child's identity alive and recollecting the last memories

All parents found comfort in talking about the strength and uniqueness of their child. It was important for parents to conclude that their child had lived a full life although critically ill. For example by recalling how (s)he had played, enjoyed moments, and had stayed true to her-/ himself. Retrieving these memories often strengthened the parents' confidence of having been a good parent. HCPs were often one of the few people who had witnessed these moments during periods of invasive treatments, hospital admissions, and critical illness. Most parents found comfort in the acknowledgement by HCPs that their child had made a lasting impact on them and was not just another patient. Furthermore, this impact strengthened the feeling that HCPs did everything they could for their child, since their child had mattered to them as well.

Most HCPs emphasized upon the parents that their child will not be forgotten and therefore actively shared their memories of the child with parents. HCPs felt this brought comfort for the parents, but also brought them, as a HCP, emotional fulfillment because they felt it was an important source of comfort they were able to provide.

Experiencing closure from the hospital period

From the recordings, we learned that most conversations ended when parents and HCPs concluded that everything had been said, silences started to occur, and/or topics were repeated. A limit in time was never the reason for finishing the conversation. Afterwards, parents were invited to visit the ward where their child had been admitted, and one of the HCPs joined them.

During their interviews, parents expressed how much they appreciated that HCPs made them feel important and seen, by their presence and by the absence of any time restricts. Some parents mentioned they would like to visit the hospital again one time, and others mentioned that after this farewell they never wished to return. Yet every parent expressed a sense of closure of the hospital period after the conversation. This was caused by a combination of having their narrative completed, closure in their relationship with the HCPs, and having said goodbye to this environment which left such a big mark on their child's memory. The invitation to visit the ward or having a second conversation added to the experience of the conversation having a natural ending and enlarged the feeling that this was not a forced farewell.

HCPs explained they did not want to feel rushed during the follow-up conversations and would usually make sure to not schedule any other appointment directly after. Some HCPs asked if parents wanted to meet other HCPs not present at the conversation, to be able to say goodbye from anyone important to them. HCPs felt the conversation brought them closure as well, as everything was said and a story to which both parents and HCPs could relate was developed.

DISCUSSION

This study on the parents' and HCPs' experiences with follow-up conversations, showed that the conversations started with discussing the illness trajectory and revisiting the decisions made. Meanwhile, parents and HCPs appeared to develop a meaningful shared narrative, which enabled parents to make sense of all that had happened, to relate to the decisions made and to feel reassured of having been a good parent. In addition, the conversations gave parents and HCP the valued opportunity to reconnect once more and making sure the other is faring well, to keep the child's identity alive, and lastly to move towards closure of the hospital period.

Previous studies have identified the elements that are discussed during follow-up conversations, such as the illness trajectory, the child's identity, and the ability to seek closure.[11–13] This study is unique in showing how these elements facilitate parents in their bereavement, by enabling the underlying mechanism of incorporating the loss into their life story, for which it is crucial that parents make sense of and are able to relate to, everything that has happened.[22,23] Therefore, we identified two aspects that parents obtained from the follow-up conversation. The first were the missing pieces of information and answers to lingering questions and uncertainties. In line with research on pediatric palliative care, which emphasizes the parental need for clear and honest information.[24–27] The second is minimizing experienced distress caused by uncertainties regarding their parenthood. Many parents experienced distress due to the reflections on their actions or choices which were not fully aligned to their belief systems, causing cognitive dissonance.[28] While developing a meaningful narrative, parents continued the process of aligning their actions during the end of life to their beliefs or adapting their existing beliefs, for which they seek reassurance regarding their parenting from the HCPs and is part of the bereavement process.[7] In our study, HCPs experienced the appeal from parents to share the truth, and tried to share openly while putting emphasize on helpful reflections and cognitions, since parents are not able to change their actions and some uncertainties may remain. This led parents to be strengthened in their positive cognitions while obtaining reassurance from experiencing they were fully informed. Therefore, we might argue that creating a narrative that parents are able to relate to and encompasses helpful reflections, might be more important than continuing to seek objective truth in the discourse, especially given the finality and persistent uncertainty.

Another noteworthy finding is that parents and HCPs wanted to make sure the other was faring well, which was closely connected to upholding the child's identity. Through learning about the impact of their child's death on the HCP, parents experienced comfort in being reconciled, it enhanced positive reflections on the impact their child had made, and provided reassurance that their child had received optimal care since the HCPs also personally had cared about their child. Therefore, the follow-up conversation is not only crucial because the harm by secondary loss is minimized, e.g. the sudden detachment from HCPs,[29–31] but the reconnection with HCPs also serves as a nurturing interaction in parents' bereavement journey. HCPs often remain with lingering uncertainties of whether they have provided optimal care and fear they have created obstacles in parents' grieving.[32,33] Their unease was intensified by a feeling of empty-handedness because their patient has died. During the conversation, HCPs more or less fear the confrontation with the answers to these uncertainties. Increasing awareness on the positive impact the follow-up conversation holds for parents and observing their development of a meaningful narrative, might support HCPs in gaining closure and experience fulfillment, which is important to counterbalance the emotional load of pediatric palliative care and minimize their risk of compassion fatigue or burn-out.[34]

Four recommendations for clinical practice can be made. First, it is helpful for parents and HCPs to discuss the illness trajectory and revisit key-moments as a starting point to develop a meaningful narrative. They both need to be aware that it is important to reflect on the decisions considering the available knowledge at that time, to comprehend why decisions were made in this specific way. Second, parents require honest information, yet HCPs are able to adapt the tone and put emphasis on helpful cognitions and reflections if it adds to the development of parents' narrative. Third, to be able to positively reflect on their parenthood and the impact their child has made, HCPs could put emphasis on positive or meaningful displays of parenthood and highlight the unique features of the child and family. Fourth, the follow-up conversation should be routinely implemented and both parents and HCPs should receive information about the goals and content of the conversation upfront. The conversation could be more meaningful for both, when they had a chance to prepare for the conversation and as such can reflect on what they find important to discuss or share.

STRENGTHS AND LIMITATIONS

The major strength is the integrated case approach, including both the follow-up conversation and interviews with involved parent and HCPs. This provided a unique opportunity to understand the meaning of the follow-up conversation for all participants. Furthermore, we included a maximum variation sample with respect to relevant aspects such as specialization, discipline, diagnoses, and age. A limitation of the study is the recruitment by HCPs, which might have led to the inclusion of parents who reflect positively on the received care. Another limitation is that by only recording the conversation part of the encounter we had no access to what was shared during the informal start of the meeting, and the visitation of the ward afterwards.

CONCLUSION

Parents and HCPs appear to develop a meaningful and shared narrative during the follow-up conversation, to enable parents to understand and relate to all that had happened, and that supports them in carrying on the communication with others. The narrative is constructed through discussing the medical trajectory and reflecting on parenthood during their child's illness. Both parents and HCPs shared three additional meaningful aspects of the follow-up conversation: reconnecting once more and making sure the other is faring well, keeping the child's identity alive, and lastly moving towards closure of the hospital period.

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8

General Discussion

INTRODUCTION

Over the last decades, childhood death has decreased significantly, yet around 1000 to 1200 children die each year due to preterm birth, critical illness, or trauma. Parents are confronted with incremental losses from the moment their child is diagnosed with a life-limiting or life-threatening illness and these losses accumulate throughout the end of life.[1–4] At the same time, parents try to fulfill parenthood to the best of their abilities. How parents cope with loss and grief during the end-of-life (EOL) phase, amidst the dynamics of parenting whilst facing the child's deterioration, is not yet understood.

Preloss and bereavement care are inherently linked to optimal pediatric palliative care. Healthcare professionals (HCPs) have developed several support practices, which have mostly been developed 'on the job' because HCPs perceived an unfulfilled need in parents, yet the effectiveness of, or experiences with, these practices have not yet been explored.[5] Bereavement practices have not been standardized, which makes the care highly dependent on the individual HCP that parents encounter. Furthermore, most support practices have been developed to support parents after the loss of their child and little is known about support during the uncertain period of the final palliative phase.

Both parents as well as HCPs acknowledge the need for integrated bereavement care for parents during their child's EOL. In response to these gaps in knowledge, this thesis aimed to understand parental grief during the child's EOL from the parents' perspective and the HCPs' perspective, and challenges in providing preloss and bereavement care, in order to understand what this care entails to ultimately optimally support parents. The specific research questions, methods, sample, and main outcomes described in all chapters are shown in Table 1.

Table 1. Research questions, methods, sample, and main outcomes per chapter

	Research question	Methods	Sample	Main findings
Chapter 2	Which well-defined bereavement interventions performed by regular HCPs are available to support parents in coping with loss and grief, both during the end of their child's life and after their child's death? What is the effectiveness of (components of) bereavement interventions and are the current practices substantiated by theoretical knowledge on loss and grief?	Systematic review	21 articles	Five overarching components of intervention were identified covering the content of all identified interventions. These were: the acknowledgement of parenthood and the child's life; establishing keepsakes; follow-up contact; education and information; and remembrance activities. Since most interventions lacked empirical evidence, these were evaluated against the key theoretical concepts which showed that all identified components of included interventions had a theoretical base. A range of interventions, supporting different needs, should be presented to parents. Bereavement interventions should focus on the continuous process of the transition parents experience in readjusting to a new reality.
Chapter 3	What are the HCPs' intentions and experiences with providing preloss care aimed at supporting parental grief during the EOL?	Exploratory qualitative research using thematic analysis	19 interviews with health care professionals	HCPs tried to ensure that parents could reflect on the care received as concordant to their preferences and were not hindered in their bereavement as a consequence of the HCPs' professional actions. Preloss care strategies included: maximizing parental presence, enabling parental involvement in decision making, and ensuring a dignified death. HCPs faced several difficulties in employing these strategies and found ways to overcome them. HCPs strive to improve parental coping after the child's death, yet they apply strategies that positively influence parental preparedness and well-being during the end of life as well. Individual HCPs are left with many uncertainties regarding optimal care delivery.

Table 1. Research questions, methods, sample, and main outcomes per chapter (continued)

	Research question	Methods	Sample	Main findings
Chapter 4	What challenges do HCPs encounter while providing preloss care aimed at supporting parental grief during the EOL?	Exploratory qualitative research using thematic analysis	22 interviews with health care professionals	Three dyadic dimensions in preloss care delivery were identified that create tension in HCPs: - Sustaining hope versus realistic prospects - Obtaining emotional closeness versus emotional distance - Exploring emotions versus containing emotions. HCPs weigh which strategies to use based on their perception of parental needs, the situation, and their own competencies. HCPs remain with lingering uncertainties on whether the preloss care they provide constitutes optimal care, thereby putting them at risk for prolonged distress and compassion fatigue.
Chapter 5	How do parents experience and cope with loss and feelings of grief during their child's EOL?	Explanatory qualitative research using grounded theory	38 interviews with parents of 22 children	A model of parental coping with grief during their child's EOL was developed, which shows that: - Parents experience a growing tension between the need to keep going to fulfil parental tasks while being increasingly confronted with loss during their child's EOL. - Parents' coping with grief is characterized by an interplay of downregulating and experiencing grief, aimed at creating emotional space to connect with their child.
Chapter 6	What is the content of follow-up conversations in pediatrics and what are the parents' and HCPs' experiences with these conversations?	Systematic review	10 articles	Follow-up conversations are built around three key elements: (1) gaining information, (2) receiving emotional support and (3) facilitating parents to provide feedback. Most parents and HCPs experienced follow-up conversations as meaningful and beneficial for several reasons.
Chapter 7	What are parents' and HCPs' experiences with follow-up conversations in pediatrics and to what aspects do they derive meaning?	Exploratory qualitative research using thematic analysis	9 follow-up conversations, 8 interviews with 15 parents and 27 health care professional interviews	Central to the follow-up conversations was the creation of a meaningful narrative to which parents were able to relate to and helped them to make sense of all that has happened. The narrative was constructed through reflecting on the medical trajectory and parenthood, for which parents and HCPs had different underlying goals. Three relevant aspects were: reconnecting once more and making sure the other is faring well, keeping the child's identity alive, and moving towards closure of the hospital period. HCPs should enable parents to build their narrative by being transparent yet emphasizing on helpful reflections and cognitions through displays of parenthood.

INTEGRATING THE MAIN FINDINGS

Throughout this thesis, we learned that, during the child's EOL, parents find themselves in a rapidly evolving, turbulent, and unpredictable period. A period that is difficult to control and that highly depends on the illness course and what is feasible in medical terms. Parents are forced to face a reality in which they are confronted with a variety of losses and have to eventually let their child go. Amidst this reality, preloss and bereavement care have to take form. Preloss care is dependent on the manner in which parents relate to the loss, cope with grief, and HCPs' abilities to support parents. Furthermore we learned that although most bereavement care is not formally developed and HCPs feel uncertain about their abilities, they do provide parents with guidance on a practical and emotional level, in response to the distress they witness.

WHAT IS OPTIMAL PRELOSS AND BEREAVEMENT CARE?

Preloss care for parents during their child's EOL should be aimed at facilitating meaningful parenthood and connectedness with their child in a setting in which this is not self-evident. This means that care and goals should be adapted to revolve around what parents derive a sense of meaningfulness from and to facilitate being present with their child. After the child's death, optimal bereavement care should involve facilitating parents to look back on their child's life in a manner that enables them to grieve, to carry the loss and to integrate the loss in their life story. Therefore, parents have to create a meaningful narrative that enables them to explain, and make sense of, all that has happened. This provides reassurance that there is nothing they could have done to prevent this outcome, and facilitates their reflection on having been a good parent for their child.

Parents' grief journey after the loss of their child and the manner in which bereavement care can take form are thus highly dependent on the level of preloss care and on how parents reflect on their parenthood during their child's EOL. These findings will be elaborated upon, following three key concepts: (1) experiencing meaningful parenthood, (2) coping with grief, and (3) bereavement care following child-loss. Thereafter, three implications for clinical practice will be discussed.

1. Experiencing meaningful parenthood

Meaningful parenthood during the EOL is centered around parental beliefs on what being a good parent entails. Parents inherently want to be a good parent for their child, especially when their child is terminally ill (Chapter 5 & 7). A growing body of literature explains that being a good parent encompasses multiple facets, among which the medical aspects of advocating for their child, making the right decisions, and making sure their child could live a full life and symptoms are optimally controlled.[6–8] Secondly, and maybe even more vital for the reflection on parenthood in bereavement, it encompasses having been able to be present with their child, and to experience closeness and connectedness.[1,7–10]

What parents experience as meaningful parenthood depends on their views of being a good parent and to what they derive meaning.[11] When a child is terminally ill, parents are required to find meaning in other parenting-goals as opposed to those prior to their child's illness, because of their child's changing abilities and needs. Park has described meaning making as processes that set in when parents experience distress as their situational meaning is discrepant towards their global beliefs.[12,13] Common global beliefs that are challenged are beliefs that parents should not outlive their child or that being a good parent may involve choosing comfort care. The more parents are confronted with loss and the more they have to revise their beliefs, the greater their distress. Meaning making processes aim to alleviate the distress and result in altered goals and identity, acceptance or understanding towards the loss.[14,15]

In research on pediatric palliative care, it has become evident that (1) parents have to transition their goals from well-defined treatment goals towards care that is centered around their child's needs and comfort, and (2) that being a good parent involves being present and experiencing connectedness during their child's EOL.[2,16] If parents succeed in making this adjustment, it may not only benefit them during the EOL, but also facilitate their bereavement and reflections upon their parenthood after the loss.[17,18] Indeed, we learned that parents positively evaluate preloss care when it was centered around their good parenting beliefs and they felt supported by HCPs in being able to provide parental acts that were meaningful to them (Chapter 5 & 7). In order to arrange preloss care around meaningful parenthood, the goals of care need to be aligned to create a nurturing environment in which meaningful parenthood can be explored and is at heart.

2. Parents' coping with grief

When parents are striving to experience meaningful parenthood while constantly being confronted with increased losses, they experience grief as a result (Chapter 5). Grief is the emotional response following a significant loss.[19] In the widely used model of coping with grief, the Dual-Process Model, successful coping with grief has been described as an oscillating process between loss- and restoration-oriented coping strategies.[20] Loss-oriented coping consists of engaging with grief, intrusions of grief and avoiding restoration of daily life or bonds with the deceased. Restoration-oriented coping is characterized by engaging in new roles in everyday life, distraction from grief, and forming a new bond with the deceased. Stroebe and Schut explain that successful coping constitutes a flexible alternation of both strategies.[20] This take on coping with grief is currently dominant in grief-literature and fits in explaining coping after a significant loss. However, from this research project we learned that during the end of a child's life, this form of coping is not fully suitable regarding the demands parents are faced with. Parents are faced with a process in which continuous losses occur that parents inevitably have to relate to, dictated by the child's deterioration, while they are aware that the ultimate loss is yet to come. In this stage of forced loss, many parents do not experience time to restore and recover from the losses, nor by restoration-oriented coping, nor by loss-oriented coping. The overwhelming need to remain standing for their child, despite the ongoing losses, leads parents to engage in strategies that reform grief into manageable proportions (Chapter 5).

In Chapter 5, a model on parental coping with grief during their child's EOL is presented. This model explains parents' efforts and strategies in bringing grief into manageable proportions by an interplay of downregulating grief and experiencing grief, thereby safeguarding emotional space. Emotional space is needed to enact meaningful parenthood through being present and experiencing connectedness with their child. Parents need support in their manner of coping with grief and HCPs should therefore be careful when to disrupt parents' emotion regulation and coping. Gross explained emotion regulation as a continuous process in which individuals are able to influence how they experience and express their emotions.[21,22] Individuals employ several strategies to regulate their emotions. In antecedent-focused strategies they aim to alter the situation, their attention or appraisal prior to the emotion evoking situation. Response-focused strategies include modulating the emotional response. A growing body of research has also shown the importance of flexibility in emotional expression, where emotional suppression and inhibition may be favorable at times in response to situational demands.[23,24] These studies support our model on parental coping with grief in which parents are actively downregulating their grief by various strategies to suit different situational demands. However, when parents employ strategies to reform their grief to manageable proportions, HCPs may experience discomfort. HCPs often interpret strategies such as 'postponing grief' or 'hoping and positive thinking' as parents not having fully grasped the severity of the situation or as unrealistic expectations for the future which might cause them more harm later on. On the other hand, when parents experience grief, HCPs fear parents might not be able to get back up (Chapter 3 & 4). In both scenarios, HCPs fear that parental coping might inhibit them from making informed decisions for their child in a manner they can positively reflect on in the future. Therefore, HCPs are hesitant to follow parents in their coping with grief, since they perceive it might be harmful to the HCPs' goals in delivering preloss care, which entail that parents should not be hindered in their bereavement as a result of their professional actions (Chapter 3).

3. Bereavement care following child-loss

After their child's death, parents have to incorporate the loss in their life story and find meaning in their altered reality (Chapter 2 & 7). Two valuable elements in bereavement care to support parents in this process are: helping parents to (1) create a fitting narrative and (2) helping them in finding reassurance and meaning.

1. Parents often live in a haze during their child's EOL. They explain this as a feeling of being lived and being unable to completely register everything that is happening; days may be blurred and the rationale for decisions may have been forgotten (Chapter 6 & 7). Moreover, their coping during the EOL, which includes suppressing emotions, may result in a reduced memory of these stressful events.[25] To incorporate the loss, parents must develop a fitting, coherent, narrative about the events that lead to their child's death and their parenting in this period, including a comprehension of their thoughts and emotions in those moments (Chapter 7).[26] HCPs play a vital role in helping them to develop their narrative in follow-up conversations.

2. Besides knowing the full story, parents have to integrate the story into their personal beliefs, views on themselves, and their own personal history. In other words, parents have to create a narrative from which they derive meaning. Parents seek reassurance in having provided their child with a full life and in having been a good parent (Chapter 7). HCPs are able to support parents in finding meaning,[27] through providing reassurance on having seen their child's uniqueness and interactions between parents and their child. Furthermore, HCPs are able to strengthen parents' good parent beliefs by emphasizing on displays of meaningful parenthood, and encouraging them to foster positive reappraisals about their own role during their child's EOL.

LESSONS LEARNED FOR CLINICAL PRACTICE

Throughout this thesis, we learned that HCPs support parents in various ways, ranging from being available to parents amidst difficult moments and providing comfort when emotions take over, towards arranging keepsakes, follow-up conversations and other tangible support services (Chapter 2, 3, 4 & 6). HCPs enable parental presence and guide parents through decision making in order to facilitate parental bereavement after the loss, yet they are often unaware of the positive impact these strategies have on parental preparedness and how they serve as preloss care (Chapter 3). Although HCPs perform various valuable support services, we also learned that HCPs often misinterpret parental grief responses which enhances uncertainty in their preloss care delivery (Chapter 3 & 4). The approach on preloss and bereavement care as described in this discussion provides HCPs with a framework to align care in a more conscious manner, and this might support them in moving from isolated moments of care towards a continuous attitude they are able to integrate in their daily practice. Therefore, at least three practical implications can be derived from the insights of this thesis and the key concepts from this discussion: (1) HCPs should be aware of their role as a guide in the process of facilitating meaningful parenthood in the extraordinary situation of losing a child, (2) preloss care should be aligned to the parents' coping with grief, and (3) HCPs should support parents in creating a meaningful narrative, through providing omitting information about the illness and disease trajectory in a manner that enables parents to relate to the loss, and reflect on their parenting in a manner that fosters helpful reflections and positive reappraisals.

1. HCPs should be aware of their role as a guide in the process of facilitating meaningful parenthood in the extraordinary situation of losing a child

Preloss care should be provided in a continuous manner in which meaningful parenthood is at heart. Parents are confronted with a range of new challenges and try to do right for their child in a rapidly changing and precarious situation. HCPs may play a vital role in guiding parents through the EOL and their transition towards new objectives in experiencing meaningful parenthood, by helping them discover what acts of parenting they can still perform and from which they derive value. For instance, by searching for ways to uphold routines parents previously had with their child or joyful activities they did together as a family. Besides, HCPs are able to reaffirm parents when they display meaningful parenthood or to guide them towards developing and strengthening cognitions that are aimed at experiencing connectedness and comfort care.

We learned that HCPs are able to take on this role more naturally when their goals and parents' objectives are aligned: for example during the terminal phase when parents and HCPs agree the focus is only on comfort, connectedness, and meaningful interactions; or enabling presence for parents to be with their sick child and supporting them in performing caring tasks.[28,29] These examples are highly appreciated moments of care by parents, and moments in which HCPs experience emotional fulfillment (Chapter 3, 5 & 7). Attuning preloss care towards meaningful parenthood is more difficult for HCPs when their views on optimal care and meaningful parenthood are discrepant to parental views. For example, when parents insist on invasive treatments whereas HCPs think these would do more harm, yet parents derive meaning from knowing they never gave up on their child. In this example, HCPs would have been able to provide some guidance in explaining to parents, that they did everything they could, provide alternatives in continuing to do so, and providing them with helpful cognitions that place parents' actions within the context that is changing.

To bridge these different views, HCPs first need to gain insight into what is meaningful to parents, for example by advance care planning (ACP), or other well-embarked conversations in relatively stable periods of time.[30] ACP conversations offer the opportunity for parents to share their deepest thoughts and value-based perspectives, yet parents need HCPs to actively invite them to share on that level.[30] Consequently, HCPs could discover and understand what is meaningful for parents and together search for ways to align care to these beliefs.[6,8,31] HCPs are able to validate parents in their goals and beliefs of being a good parent, sustain hope, and make parents feel seen and heard in being present.[32] Of course, HCPs are at times bound by medical or organizational limitations, yet understanding the core of what parents find meaningful leaves room to find a common goal with parents. Since parental goals and beliefs on meaningful parenthood shift over time, multiple conversations throughout the illness course are needed, to enable HCPs to adjust their care from isolated moments of support towards supporting parents in their process of bereavement and finding meaning.

A barrier in conducting these conversations with parents is the tremendous uncertainty that accompanies the EOL (Chapter 3 & 4). Uncertainty exists in the manner parents might respond to such questions, the illness trajectory, and their own uncertainty on what constitutes optimal care.[33,34] If we embrace uncertainty as inherent to pediatric palliative care, it may open doors to explore meaningful centered preloss care, since these options may then be discussed simultaneously to more curative approaches.[34,35] This approach might even benefit parents in exploring their own ambivalence while making their transition in the search of meaningful care.[36] Therefore, HCPs need sufficient training in conducting these conversations and in (meta-)communication skills.

2. Providing preloss care aligned to the parents' coping with grief

For parents to be able to exert meaningful parenthood, it is important that preloss care is aligned to their coping with grief. Continuous exposure to feelings of grief may inhibit parents to be present, to experience meaningful moments with their child, and to exert parenting tasks.[23,37] By helping parents regulate their emotions in a manner that is consistent with their coping efforts, parents are able to look back on the received preloss care as concordant with their needs. HCPs are able to reinforce parental efforts of bringing grief into manageable proportions by informing parents about the nature of conversations upfront, such as when to expect bad news. That way, parents are supported as they can prepare for the situation and modulate their emotional response, which may result in less overwhelming emotions in the moment. As a result, parents are better able to remain present and to focus on connectedness, since they do not have to brace themselves on each account and stay hyper vigilant towards threats of loss.

HCPs should be aware that experiencing grief is a normal response to the continuous, forced confrontation with loss parents experience. At times, grief may take the upper hand either in conversations or in moments HCPs do not expect it. Expressing grief does not mean parents are not able to get back up or that they are not able to carry the load of the given information. Yet it is a normal response to this abnormal situation of losing their child. Consequently, when parents become emotional, this does not always have to be explored or contained. Parents value compassionate HCPs who leave room for them to experience the emotions when they have to, or chose to, and who provide information in a compassionate manner.[38,39] Reassuring parents that HCPs are not taken back by their emotional response might help in not having to suppress their emotions in conversations. On the other hand, HCPs might find reassurance in the fact that these emotions are a normal part of the EOL-trajectory for parents and therefore do not need to be 'resolved' or 'explored'. When HCPs feel the need to explore parents' thoughts and emotions, they should assess whether parents experience sufficient emotional space to engage in a such a conversation. Therefore, information about the nature of grief and parental coping should be integrated in vocational education.

3. Support parents in developing a meaningful narrative which they can integrate in their life story

Many HCPs shared that they hope to provide parents with the missing pieces of the puzzle during follow-up conversations, so parents are able to develop a meaningful and fitting narrative they can relate to (Chapter 7). HCPs help parents in developing their narrative by reflecting on their parenthood, revisiting turning points and explaining the course of illness (Chapter 6 & 7). It is important for those moments to be reviewed in the light of the knowledge parents and HCPs had back then. Parents ultimately have to carry the weight of the discourse and all that has happened during their child's EOL. Therefore, they have to understand how their decisions connect with their beliefs of parenthood and optimal care in order to develop a meaningful narrative.[15] Multiple conversations with several HCPs that were involved in the child's care may be needed in order to develop the full picture, since these HCPs may have been involved in different aspects of care, and therefore may provide different pieces to the puzzle.

Creating a fitting narrative is also helpful for parents in communicating with their social circle outside of the hospital. Parents have to explain what has happened to their child in order to receive social support. When the narrative is unclear, it might inhibit parents from sharing their story, whilst talking about the events leading up to their child's death is beneficial for parents to process and integrate the loss.[40,41]

Additionally, meaning may be found in a spiritual manner: parents see or feel their child around them or believe their child still influences the space around them.[42] Some find meaning in their faith and in knowing their child is in a better place. Others may find comfort and meaning in knowing their child has lived a full life, although shortened. HCPs should empower parents in their beliefs and perceptions of meaning to enhance their bereavement outcomes.[43]

PRACTICAL AND SOCIETAL IMPLICATIONS

Based on the results and multidisciplinary collaborations within this research project, several practical tools have been developed to empower parents and support HCPs. With these tools we aim to support parents in finding information about grief and normalizing their experiences. We intend to support HCPs to incorporate preloss and bereavement care in a continuous manner and to enable them to adopt a different attitude towards preloss care in their daily practice. These practical tools, which are elaborated upon below, are available at no costs and pose as a starting point towards a more integrated, evidence-based form of bereavement care. Information is available at www.kinderpalliatief.nl/rouwzorg.

1. The guideline pediatric palliative care (in Dutch: 'Richtlijn palliatieve zorg voor kinderen'), which was developed in 2013, was revised during the course of the emBRACE-study. During an interdisciplinary gathering, absence of bereavement care in the current guideline was identified, as well as the need to incorporate this in the revised version. Care aimed at loss, grief, and bereavement, came forth as one of the most pressing topics to be included. In close collaboration with the researchers involved in the revision of the guideline and a group of HCPs working in diverse settings and specialisms in pediatrics, the main researchers of the emBRACE-project took the lead for writing the new chapter "loss and bereavement" in the revised guideline for pediatric palliative care (in Dutch: 'Zorg bij verlies en rouw'). While constructing the guideline, literature studies were conducted, experts were consulted and insights from the emBRACE-study were assembled. The guideline is supported and endorsed by parental- and vocational associations. This guideline forms the base for providing preloss and bereavement care for all HCPs involved in pediatric palliative care in the Netherlands.

2. An e-module for HCPs is in development (in Dutch: 'e-module omgaan met verlies en rouw'), to provide them with practical guidance to gain insight into parents' experiences with loss and coping with grief during their child's EOL. This e-module will be available for all HCPs who are involved in pediatric palliative care. HCPs receive practical tips which enable them to tailor care to the parents' perspective and needs. After following the e-module, HCPs will have more hands-on information to incorporate preloss care in their daily practice.

3. Three short informative films have been developed to provide parents with information about grief, to provide comfort and to normalize their experiences. Each film focusses on a different time period: the EOL (in Dutch: 'Als je kind ernstig ziek is'), the period after the death of their child (in Dutch: 'Leven met verlies'), and the follow-up conversation (in Dutch: 'Nazorggesprek'). These films are available for parents and promoted by parent associations and the Kenniscentrum Kinderpalliatieve Zorg.

4. Lastly, we developed informational leaflets for both parents (in Dutch: 'Informatiefolder voor ouders') and HCPs (in Dutch: 'Handreiking voor

zorgverleners, het nazorggesprek') regarding the follow-up conversation. Parents may find this folder useful in preparing themselves for the follow-up conversation, as it can provide them with more control over the topics that can be discussed. HCPs may use these folders to gain insight into which topics can be discussed and why these topics are important for parents.

CONCEPTUAL REFLECTIONS

While writing this thesis, a recurring point of discussion was the definition of bereavement care prior to the death of the child.

In current palliative care literature, we can distinguish multiple interpretations of the term bereavement care. The narrower definition of bereaved consists of: to be bereaved, and thus care aimed at parental grief following the loss of a child. The broader term of bereaved: to lose something or someone dear. In the latter, bereavement encompasses multiple types of losses and could also reflect the deterioration of the child, loss of function, loss of communication or future plans for the child.[2,31]

The field of pediatric palliative care is rapidly evolving. First there was a distinction of phases in curative-, palliative-, and bereavement care, the field is now moving towards a more integrated approach in which curative- and palliative care can co-exist. While writing this thesis, the awareness that bereavement care should not only be provided after a child's death, but also during the EOL, is growing. Since parents also face numerous losses during the EOL which result in experiencing grief, we opt for the use of bereavement care for interventions initiated during the EOL as well. Using the same terminology emphasizes the continuous nature of bereavement care and additionally implies that both forms, during the EOL and after death, are equally as important. However, this approach caused some confusion while presenting or communicating our work to others. Therefore, during this research project, we have chosen to use the term 'bereavement' to refer to grief after the loss of the child and care delivered from this point. The care that is delivered during the child's end-of-life, is referred to as 'preloss care'.

METHODOLOGICAL REFLECTIONS

The major strength of the emBRACE-study is that we engaged all relevant stakeholders throughout all parts of the research project, in three ways. First, a substantial number of semi-structured interviews have been conducted with parents and HCPs which enabled us to gain insight into parents' and HCPs' inner perspectives and experiences with preloss and bereavement care. Second, the data were analyzed in a multi-disciplinary team, consisting of pediatricians, nurses, an experienced parent, psychologist, and researchers, ensuring triangulation. Lastly, during the construction of the output, all relevant stakeholders, including HCPs, parents, academic and societal stakeholders, were asked to provide feedback on the content and design.

Another strength is that this research covered preloss and bereavement care both during the EOL and shortly after the death of a child, which enabled us to gain insight into the dynamics of grief at multiple points in time. In the parent-interviews during the EOL, we were able to gain a unique perspective on their experiences of grief at that particular moment instead of a retrospective recollection. During the interviews we noticed parents' coping with grief firsthand by visibly downregulating grief and at times connecting with grief if parents wanted to share a specific experience. In addition, we interviewed parents shortly after their child's death. In these interviews, they could reflect on their child's last days. This approach helped us to understand the process that parents experience and how they actively cope with their feelings of grief.

This thesis has some limitations as well. The first limitation is that although we sought for maximum variation in our sample, this was not fully acquired, neither for parents nor HCPs. We tried to include parents with a range of socio-economic statuses and different cultural backgrounds, however most of our sample is middle to highly educated and were Caucasian, atheist or (non-practicing) Christian. This might be due to gatekeeping by HCPs,[44] e.g. HCPs being more hesitant to invite parents of other cultural and religious backgrounds with which they are less familiar, parents refusing to participate and language barriers. When interpreting our results and comparing the results to the literature of grief in different cultures, we reflect that the nature of grief might be comparable over cultures.[45] The need to keep going for their child and therefore trying to downregulate their grief and at times experiencing grief might be a universal experience. However, the goals that parents strive to uphold, the manner in which their family is involved, how parents downregulate grief and what parents experience as a loss might be culturally dependent. Furthermore, HCPs were probably more likely to invite parents to participate that reflected positively on the received care. At times, parents shared moments in which they did not appreciate the received care or missed support, but these parents were still generally content with the care they received. There are some limitations to the sample of HCPs that participated. In the first study regarding HCPs' experiences, HCPs working in oncology were not included due to logistical reasons. However, since HCPs from both chronic and acute care setting participated and from different specialties, we believe the results are generalizable to HCPs across other settings as well. Another restraint is that we might display an overestimate of the current state of preloss and bereavement care, since the largest proportion of the HCPs we interviewed and/or were engaged in this project, were mostly HCPs that are involved in pediatric palliative care and that find the topic important. These professionals form the leading HCPs in preloss and bereavement care delivery in pediatrics. They are more confident to participate in pediatric palliative care and have more experience and insight into bereavement care.

RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the results of this research project, several recommendations for future research can be made.

1. Research into the dynamics within couples while redefining meaning
Research has shown that couples might experience shared goals for their child at first, but then embark on a different trajectory within the transition of goals.[36] Since every person finds meaning in different aspects of life and at a different pace, insight is required in how couples navigate this quest to find meaningful parenthood together, in order to align support accordingly.

2. Development of methods for child-participation and a family-centered approach in research on preloss care
Parents find meaning within their role of having been a good parent, which is inherently linked to their children's well-being. Children were not included in our research project, yet their views on their wishes, goals and conversations with parents could have a major impact on parental coping with grief. Some parents have shown to feel regret when they have not talked with their child about their terminal illness,[46] which for example might impact their quest for meaning and their ability to carry the loss. Furthermore, parents have shared their wish to support grieving siblings but often feel empty handed. Insight into the needs of the critically ill children and of their siblings is needed to improve preloss care.

3. Systematic insight into valued (non-)verbal communication skills of HCPs
In the systematic reviews that were conducted in this research project, we focused on well-defined interventions and follow-up conversations. However, during the

interviews, we noticed more subtle ways in which HCPs try to support parents. In the general discussion, we also advocate for an approach in which HCPs take on the role of a facilitator in parents' process of coping with loss. Future research could focus on these (non-)verbal communication skill relaying interventions: what components of these support practices are valued by parents and how could these be thought to other HCPs?

4. Longitudinal research into the development of parental grief over time

Insight into to development of grief over time from the moment of diagnosis, throughout the EOL and after the child's passing, would be helpful to further develop a process approach to preloss care. A longitudinal design in which parents could be followed at multiple periods in their child's illness could be used to identify parents who might benefit from additional support and who are at risk to develop adverse effects. Following these parents and being able to look back on which periods were crucial to intervene could benefit parents in the future with earlier intervening. In this process the value of bereavement care and the effects of bereavement care on parental coping with grief could be better understood which could support HCPs in implementing bereavement care more routinely in their care setting.

5. Implementation and evaluation studies on the guideline and develop tools

Within this project, we aimed to develop practical guidelines and tools to facilitate comprehensive preloss and bereavement care. The evaluation of these tools and implementation were not part of this project. The effects of the guideline and e-learning should be evaluated on their effectives and new means to incorporate preloss and bereavement care in curricula should be sought. Institutions and organizations should facilitate parents and HCPs to implement the use of these tools in current practice.

CONCLUSION

Parents ultimately have to integrate the loss of their child in their life story, a long journey that lies ahead, while the grief itself may never be resolved. Optimal preloss care should enable parents of a child with a life-threatening disease to experience meaningful parenthood and connectedness. Bereavement care involves facilitating parents to look back on their child's life in a manner that enables them to carry the loss, make sense of the loss, and being able to integrate the loss in their life story. After the loss, parents have to create a meaningful narrative that fosters helpful reflections on their parenthood, hence, preloss care is pivotal for parental bereavement experiences. HCPs play a vital role in guiding parents through their child's EOL. They should guide parents in their transition towards finding meaningful parenthood in altered goals of comfort care and experiencing connectedness. Therefore, parents need to be able to reform their grief to manageable proportions and create emotional space. HCPs should support parents in upholding their coping with grief, which may include containing grief at times, to enhance parents' ability to experience meaningful parenthood. This individualized approach implies that optimal preloss and bereavement care rely on HCPs' abilities to guide parents throughout the EOL with multidimensional and continuous support. The new developed chapter loss and bereavement in the national guideline on pediatric palliative care and practical tools based on the studies in this thesis are ready to use to ameliorate daily EOL practice.

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Appendices

SUMMARY

Over the last decades, childhood death has significantly decreased, yet around 1000 to 1200 children die each year due to preterm birth, critical illness, or trauma. Parents are confronted with incremental losses from the moment their child's gets diagnosed with a life-threatening illness and these losses accumulate throughout the end-of-life (EOL). At the same time, parents try to fulfill parenthood to the best of their abilities. How parents cope with loss and grief during the EOL phase of their child, amidst the dynamics of parenting whilst facing the child's deterioration, is not yet understood.

Grief is a natural emotional response following loss and bereavement, and encompasses a range of emotions such as feelings of anxiety, depression, sadness and despair. What is considered a loss differs per person, but is defined as losing something or someone meaningful. In this thesis preloss care refers to the care aimed at parental grief prior to the death of their child, and bereavement care to the support for parents after their child's death.

Preloss and bereavement care are inherently linked to optimal pediatric palliative care. Healthcare professionals (HCPs) have developed several support practices, which have mostly been developed 'on the job' because HCPs perceived an unfulfilled need in parents, yet their experiences with, and effectiveness of, these practices have not been explored. Bereavement practices have not been standardized, which makes the care highly dependent on the individual HCP parents encounter. Furthermore, most support practices have been developed to support parents after the loss of their child and little is known about support during the EOL.

The general introduction (**Chapter 1**) provides an overview of the field of pediatric palliative-, preloss and bereavement care, and addresses the gaps in knowledge that led to the research questions answered in this thesis. In this thesis we aimed to understand parental grief during the child's EOL from the parents' perspective and the HCPs' perspective, and challenges in providing preloss and bereavement care, in order to understand what this care entails to ultimately optimally support parents.

Available preloss and bereavement interventions and their effectiveness

Through a systematic review (**Chapter 2**) we started with the identification of available well-defined interventions, that regular HCPs can employ to support

parents in their grief, both during the EOL and after their child's death. The search yielded 5144 unique articles, of which 21 articles were included. We found that most interventions were developed to support parents in their bereavement after their child's death. The content of these interventions could be categorized into five overarching components of intervention: the acknowledgement of parenthood and the child's life; establishing keepsakes; follow-up contact; education and information; and remembrance activities. Since the evidence for the effectiveness of identified interventions was mostly lacking, the five components of intervention were evaluated against theoretical key concepts derived from a synthesis of theories on coping with grief. These theorical key concepts consisted of anticipatory grief, attachment working models and plans, appraisal processes, coping, and continuing bonds. We found that all components could be substantiated from a theoretical perspective and therefore we hypothesized they would have added value in supporting parents in their grieving process. Parents should be presented with a range of interventions, covered by a variety of theoretical components, and aimed at supporting different needs. Bereavement interventions should focus on the continuous process of the transition parents experience in readjusting to a new reality.

HCPs' experiences with and views on preloss and bereavement care

To better understand what support HCPs would require to further incorporate preloss and bereavement care in their daily practice, we must first understand their current experiences and views. Through 19 semi-structured interviews that were thematically analyzed, we learned that the HCPs all valued providing preloss and bereavement care and felt responsible to support parents (**Chapter 3**). HCPs' goals in providing preloss care consisted of ensuring that parents could reflect on the care received as concordant to their preferences and that parents were not hindered in bereavement as a consequence of their professional actions. Strategies they employed were maximizing parental presence, engaging parents in decision making and ensuring a dignified death. While using these strategies, HCPs faced several difficulties: uncertainty about the illness course, unpredictability of parental grief responses, and being affected themselves by the child's imminent death. It helped HCPs to develop a bond with parents, find comfort with colleagues, and making joint decisions with colleagues. Although the goals were aimed at supporting parents in their grieving process after their child's death, we learned that some strategies they employed were also valuable to support parents in their grief during the EOL as they enhance parental preparedness.

We performed a secondary analysis on the 19 interviews and administered an additional three interviews (**Chapter 4**). In understanding the lived experience of the HCPs, we learned that, while providing preloss care, the HCPs experienced tension in three dyadic dimensions: sustaining hope versus realistic prospects, obtaining emotional closeness versus emotional distance, and exploring parental emotions versus containing emotions. HCPs constantly weighed where to stand on the continuum of the three dimensions based on parents' needs, the child's prognosis and their own emotional load and competences. Many HCPs remained with lingering uncertainties whether the care they provided constituted optimal care, which over time could lead them to experience distress and make them at risk for compassion fatigue.

Parents' experiences and coping with grief during their child's EOL

To further develop preloss care, an understanding must be built on how parents experience loss and cope with grief during their child's EOL (**Chapter 5**). Parents were interviewed during their child's EOL or shortly after their child's death, these semi-structured interviews were analyzed using grounded theory. In total, 38 parents of 22 children participated, of which parents of eight children participated during the EOL. The analysis led to the development of a model on parental coping with grief during their child's EOL. Parents experienced a growing tension between the need to keep going to fulfill parental tasks while constantly being confronted with triggers of loss. These parental tasks entailed sustaining family life, being a good parent, and ensuring a full life for their child until the end. Meanwhile parents experienced grief because of their hypervigilance towards signs of, and confrontations with, loss. Parental coping with grief is characterized by an interplay of strategies to downregulate feelings of grief and experience grief. This leads parents to reduce their grief to manageable proportions and as such find the emotional space to connect with their child and to fulfil their tasks as a parent. During the EOL, parents' ability to engage in grief-oriented coping strategies is increasingly strained. HCPs should follow parents in their coping with grief to support them in fulfilling parenthood and experiencing connectedness with their child.

The content of- and parents' and HCPs' experiences with follow-up conversations

Follow-up conversations are a relatively well-embedded form of bereavement care. These conversations are often the first scheduled contact between parents and HCPs and they take place six to eight weeks after the child's death. To gain insight into the content of follow-up conversations and into how parents and HCPs experience these conversations, a systematic review was conducted (**Chapter 6**). The search yielded 1538 unique articles of which 10 were included. Conversations were mostly built around three core themes: discussing the disease trajectory and EOL, reconnecting with parents and sharing memories about their child, and parents providing feedback to HCPs. For parents, the follow-up conversations marked closure of the hospital trajectory of their child, enabling them to move one step further in their bereavement. For HCPs these conversations provided an opportunity to evaluate how parents were coping, to reflect on the care they had provided and to obtain closure of their professional relationship with the parents.

After the systematic review, a qualitative study was performed to gain further insight into the parents' and HCPs' experiences with follow-up conversations in pediatrics and to what aspects they derive meaning (**Chapter 7**). Nine cases were included consisting of nine recordings of the follow-up conversation, eight interviews with 15 parents, and 27 HCP interviews. Parents and HCPs appeared to develop a meaningful and shared narrative during the follow-up conversation, to enable parents to make sense of, and relate to, all that happened. The narrative is constructed through discussing the medical trajectory and reflecting on parenthood during their child's illness. Both parents and HCPs shared three relevant aspects of the follow-up conversation: reconnecting once more and making sure the other is faring well, keeping the child's identity alive, and lastly moving towards closure of the hospital period.

General discussion

The general discussion provides a reflection on the main findings of this thesis, practical recommendations, methodological and conceptual reflections, strength and limitations, and suggestions for future research (**Chapter 8**). Optimal preloss care should enable parents to experience meaningful parenthood and connectedness. Bereavement care involves facilitating parents to look back on their child's life in a manner that enables them to carry the loss and that enables them to integrate the loss in their life story. After the loss, parents have to create a meaningful narrative that fosters helpful reflections on their parenthood, hence, preloss care is pivotal for parental bereavement experiences.

What entails meaningful parenthood shifts over time as goals transition from curation towards comfort care. HCPs play a vital role in guiding parents through their child's EOL and in their transition towards finding meaningful parenthood in altered parenting goals part of comfort care and experiencing connectedness. Therefore, parents need to reform their grief to manageable proportions and create emotional space. Parents create emotional space through an interplay of downregulating feelings of grief and experiencing grief. HCPs should support parents in upholding their coping with grief, which may include containing grief at times, in service of their ability to connect with their child and conduct their parenthood in a meaningful way. This approach implies that optimal preloss and bereavement care are founded on HCPs guiding parents throughout the EOL in a multidimensional and continuous manner.

During this research project several practical tools have been developed to support parents in their bereavement and to support HCPs to integrate preloss and bereavement care in their daily practice. These tools, which are ready to use and freely available, include: a chapter on loss and bereavement in the newly revised guideline on pediatric palliative care, a brochure for parents and HCPs regarding the follow-up conversation, informational films for parents, and an e-learning for HCPs which is still in progress.

Methodological strengths of the research in this thesis consisted of the involvement of all relevant stakeholders in all parts of the research project. Interviews were conducted with parents before and after the child's death and with HCPs from different specialisms and disciplines. The data were analyzed in a multidisciplinary team ensuring researcher triangulation. Another strength is that parents also participated during their child's EOL, which enabled us to gain unique insights into parents' coping firsthand. Some limitations included that, although we sought for maximum variation in our sample, this was not fully acquired, neither for parents nor HCPs. The HCPs that participated in our study were mostly comfortable in sharing their experiences with preloss and bereavement care since they were often more involved in this type of care, which might provide an overestimation of the current state of knowledge.

Future research is needed in order to further develop preloss and bereavement care. Studies might focus on the dynamics in couples while redefining meaning, involving children/siblings as meaning is often found within the family context, and longitudinal research in the development of grief and bereavement needs over time. Furthermore, more insight into helpful (non-)verbal communication skills of HCPs is needed to optimally support parents and the practical tools that have been developed should be implemented and evaluated.

SAMENVATTING

De afgelopen decennia is het aantal kinderen dat overlijdt sterk afgenomen. Echter overlijden er jaarlijks nog 1000 tot 1200 kinderen ten gevolge van vroeggeboorte, levensbedreigende ziektes of ongelukken. Ouders worden geconfronteerd met een opeenstapeling aan verliezen vanaf het moment dat hun kind wordt gediagnosticeerd met een levensbedreigende of levensbekortende ziekte. Deze verliezen stapelen zich verder op gedurende het naderende levenseinde van hun kind. Tegelijkertijd proberen ouders hun ouderschap zo goed mogelijk vorm te geven. Hoe ouders omgaan met de verliezen en het verdriet dat zij ervaren gedurende de levenseindefase van hun kind, te midden van de dynamiek die het ouderschap van een ernstig ziek kind met zich meebrengt, is nog onvoldoende onderzocht.

Rouw is de emotionele reactie op verlies en behelst een grote diversiteit aan emoties, zoals angst, somberheid, verdriet en wanhoop. Wat iemand als een verlies ervaart verschilt per persoon. Het wordt omschreven als het verliezen van iemand of iets waarmee een betekenisvolle relatie bestond. Met rouwzorg wordt de zorg aan ouders in de omgang met de ervaren verliezen en het verdriet aangeduid, zowel gedurende de levenseindefase als na overlijden van hun kind.

Rouwzorg gedurende de levenseindefase en na het overlijden van een kind is onlosmakelijk verbonden met optimale kinderpalliatieve zorg. Zorgverleners hebben diverse rouw ondersteunende interventies ontwikkeld. Deze zijn voornamelijk vanuit de praktijk ontstaan door zorgverleners die hiermee probeerden om de behoeften van ouders te vervullen. Daarbij ontbrak echter het inzicht in de ervaringen met en de effectiviteit van, deze ondersteunende interventies. Rouwzorg interventies zijn veelal niet gestandaardiseerd, waardoor het aanbod in grote mate afhankelijk is van de zorgverlener die ouders treffen. Daarnaast zijn de meeste ondersteunende interventies ontwikkeld om ouders na het overlijden van hun kind te steunen. Er is minder bekend over beschikbare steun aan ouders gedurende het naderende levenseinde van hun kind.

De algemene introductie (**Hoofdstuk 1**) geeft een overzicht van het kinderpalliatieve zorgveld, rouw, de ervaringen van ouders en zorgverleners, en de huidige rouwzorg. Ook geeft het inzicht in de kennishiaten die tot de onderzoeksvragen in dit proefschrift hebben geleid. In dit proefschrift willen wij inzicht geven in de wijze waarop ouders omgaan met verdriet gedurende de levenseindefase van hun kind en de ervaringen van ouders en zorgverleners met rouwzorg gedurende het naderende levenseinde- en na overlijden van een kind. Hiermee willen we uiteindelijk begrijpen hoe we ouders optimaal kunnen ondersteunen in de omgang met verlies en verdriet.

Beschikbare rouwzorg interventies en hun effectiviteit

Door middel van een systematische review (**Hoofdstuk 2**) werd gestart met het identificeren van goed omschreven interventies, die door reguliere zorgverleners worden ingezet om ouders te ondersteunen in de omgang met verdriet, gedurende de levenseindefase en na het overlijden van hun kind. De literatuursearch resulteerde in 5144 artikelen, waarvan er 21 werden geïncludeerd. Hieruit bleek dat de meeste interventies gericht zijn op het ondersteunen van ouders na het overlijden van hun kind en in mindere mate op het verdriet wat ouders gedurende het naderende levenseinde van hun kind ervaren. De inhoud van de interventies kan verdeeld worden in vijf overstijgende interventie-componenten: ouderschap in stand houden, tastbare herinneringen, contact na het overlijden, educatie en informatie, en herdenkingsactiviteiten. Aangezien er weinig bekend is over de effectiviteit van deze interventies, zijn de interventie-componenten langs theoretische hoofdconcepten gelegd, die voortkwamen uit een synthese van theorieën over verlies en rouw. Deze theoretische hoofdconcepten waren gericht op: anticiperende rouw, (hechtings-) schema's, evaluatieprocessen, coping, en het continueren van de band met het kind. De effectiviteit van alle interventie-componenten kon onderbouwd worden op een conceptueel theoretisch niveau. Daarmee onderschrijven we het belang van deze componenten om ouders te ondersteunen in hun rouwproces. Ouders moeten een diversiteit aan interventies aangeboden krijgen, die aansluiten op verschillende theoretische componenten en dus gericht zijn op verschillende behoeften. Rouwzorg interventies dienen gericht te zijn op het ondersteunen van ouders in het continue proces wat zij doormaken waarbij zij zich voortdurend moeten verhouden tot een nieuwe realiteit.

De ervaringen met- en perspectieven van zorgverleners op rouwzorg

Om te begrijpen hoe we zorgverleners kunnen ondersteunen om rouwzorg aan ouders gedurende de levenseindefase van hun kind te integreren in hun dagelijkse praktijk, dienen we eerst hun huidige ervaringen met het verlenen van deze zorg te begrijpen. Middels 19 semigestructureerde interviews die thematisch geanalyseerd zijn, hebben we vastgesteld dat zorgverleners het allen waardevol vinden om rouwzorg aan ouders te bieden en zich daar ook verantwoordelijk voor voelen (**Hoofdstuk 3**). De doelen die zorgverleners nastreven zijn: zorgen dat ouders na het overlijden kunnen terugkijken op zorgverlening die passend was bij hun wensen en zorgen dat ouders niet gehinderd worden in hun rouwproces ten gevolge van acties van de zorgverlener. Strategieën die zorgverleners hiervoor hanteren zijn: het maximaliseren van nabijheid voor ouders met hun kind, de ouders betrekken in de besluitvorming en zorg dragen voor een waardige dood. Hoewel de doelen gericht zijn op het faciliteren van het rouwproces van ouders na het overlijden van hun kind, ontdekten we dat sommige strategieën die zorgverleners hanteren ook waardevol zijn in de ondersteuning van ouders gedurende het naderende levenseinde. Bij het hanteren van deze strategieën ervaren zorgverleners diverse belemmeringen: onzekerheid over het ziektebeloop, onvoorspelbaarheid van de rouwreacties van ouders en het zelf aangedaan zijn door de aanstaande dood van het kind. Het hielp zorgverleners om een band met ouders op te bouwen, steun te ontvangen van collega's en besluiten in gezamenlijkheid met collega's te nemen.

Vervolgens hebben we een secundaire analyse op de 19 interviews uitgevoerd waarbij ter validering drie additionele interviews zijn afgenomen (**Hoofdstuk 4**). Vanuit de ervaringen van de zorgverleners leerden we dat zorgverleners bij het verlenen van rouwzorg gedurende de levenseindefase, spanning ervaren in drie dyadische dimensies: (1) ondersteunen van hoop versus het bieden van realistische perspectieven, (2) emotionele nabijheid versus emotionele afstand, en (3) het exploreren van emoties versus het klein houden van emoties. Zorgverleners wegen continu af waar zij in het continuüm van deze dimensies gaan staan, afhankelijk van de behoefte van ouders, de prognose van het kind en de eigen emotionele ruimte en kwaliteiten van de zorgverleners. Veel zorgverleners ervaren blijvende onzekerheid over of de door hun verleende zorg wel de optimale zorg was. Deze twijfel kan zorgverleners langdurige stress geven en vatbaar maken voor emotionele uitputting.

De ervaringen van ouders en hun omgang met verdriet gedurende het naderende levenseinde van hun kind

Om de ontwikkeling van rouwzorg gedurende het naderende levenseinde van een kind verder te verbeteren, dienen we eerst te begrijpen hoe ouders verlies en rouw gedurende deze fase ervaren en hoe zij daarmee omgaan (**Hoofdstuk 5**). We hebben ouders geïnterviewd gedurende het naderende levenseinde of kort na het overlijden van hun kind. Deze interviews zijn geanalyseerd middels de 'grounded theory' methode. In totaal hebben 38 ouders van 22 kinderen deelgenomen, waarvan ouders van acht kinderen gedurende het naderende levenseinde van hun kind zijn geïnterviewd. De analyse heeft geresulteerd in de ontwikkeling van een model over de omgang met verdriet door ouders. Gedurende de levenseindefase van hun kind ervaren ouders een groeiend conflict in hun behoefte om staande te blijven om ouderschapstaken te vervullen, terwijl zij continu geconfronteerd worden met (triggers van) verlies. De ouderschapstaken omvatten voortgang willen geven aan het gezinsleven, een goede ouder zijn en hun kind een goed en volwaardig leven bieden. Ondertussen ervaren ouders verdriet doordat zij continu alert zijn op, en geconfronteerd worden met, signalen van (naderend) verlies. De omgang met het verdriet wordt gekenmerkt door een samenspel van strategieën die ouders gebruiken om het verdriet te reguleren naar kleinere proporties en de mate waarin zij het verdriet toelaten en ervaren. Hierdoor kunnen ouders het verdriet meer hanteerbaar houden en daarmee emotionele ruimte creëren om aanwezig te zijn bij hun kind en die verbinding te ervaren. Gedurende de levenseindefase van hun kind wordt het voor ouders steeds lastiger om de confrontatie met hun verdriet aan te gaan. Zorgverleners wordt aangeraden om ouders zoveel mogelijk te volgen in de manier waarop zij het verdriet hanteerbaar houden, om hen op die manier te ondersteunen in het vormgeven van ouderschap en het ervaren van verbinding met hun kind.

Nazorggesprekken en de ervaringen van ouders en zorgverleners met deze gesprekken

Nazorggesprekken zijn een relatief goed ingebedde vorm van rouwzorg in de kindergeneeskunde. Deze gesprekken zijn vaak het eerste georganiseerde contactmoment tussen ouders en zorgverleners en vinden zes tot acht weken na overlijden van het kind plaats. Om inzicht te krijgen in de inhoud van nazorggesprekken en de ervaringen van ouders en zorgverleners met deze gesprekken, hebben we een systematische review uitgevoerd (**Hoofdstuk 6**). De literatuursearch leverde 1538 artikelen op, waarvan er 10 geïncludeerd werden. Gesprekken zijn voornamelijk opgebouwd rondom de volgende drie kernthema's: het bespreken van het ziektetraject en het levenseinde van het kind, het opnieuw verbinden met ouders en het delen van herinneringen over het kind, en daarnaast om ouders de mogelijkheid te bieden om feedback te geven. Voor ouders markeerde het nazorggesprek de afronding van de ziekenhuisperiode en het ondersteunde hen om een volgende stap in hun rouwproces te zetten. Voor zorgverleners vormden de gesprekken een mogelijkheid om in te schatten hoe ouders omgaan met het verlies, om te reflecteren op de zorg die zij verleend hebben en om hun professionele relatie met ouders af te sluiten.

Na de systematische review is er een kwalitatief onderzoek uitgevoerd, om inzicht te krijgen in de betekenis van nazorggesprekken voor ouders en zorgverleners (**Hoofdstuk 7**). Negen casussen werden geïncludeerd. Die bestonden uit: negen gespreksopnames, acht interviews met 15 ouders, en 27 interviews met zorgverleners. Ouders en zorgverleners bleken samen naar een betekenisvol en gedeeld verhaal toe te werken tijdens het nazorggesprek. Het betekenisvolle verhaal ondersteunt ouders in het begrijpen van en zich verhouden tot alles wat er gebeurd is. Het verhaal krijgt vorm door het bespreken van het medische traject en door te reflecteren op het ouderschap gedurende de levenseindefase. Zowel ouders als zorgverleners deelden drie relevante aspecten van het nazorggesprek die daaraan bijdroegen: nog eenmaal verbinden en zorgen dat het de ander goed vergaat, het levend houden van de identiteit van het kind en het toeleven naar afsluiting van de ziekenhuisperiode.

Algemene discussie

De algemene discussie geeft een reflectie op de belangrijkste bevindingen in dit proefschrift. Er worden praktische aanbevelingen gedaan, methodologische en conceptuele reflecties gegeven, de sterke kanten en de beperkingen van het onderzoek worden besproken, en daarnaast worden er suggesties gegeven voor vervolgonderzoek (**Hoofdstuk 8**). Optimale rouwzorg gedurende de levenseindefase, zou ouders moeten ondersteunen bij het ervaren van betekenisvol ouderschap en verbondenheid met hun kind. Rouwzorg na het overlijden dient ouders te ondersteunen bij het reflecteren op de levenseindefase van hun kind, op een manier die ze helpt om het verlies te dragen en te integreren in hun levensverhaal. Na het overlijden van hun kind, hebben ouders er behoefte aan een betekenisvol verhaal te creëren, dat waardevolle reflecties op hun ouderschap omvat. Daarvoor is goede rouwzorg gedurende de levenseindefase van cruciaal belang.

Wat iemand onder betekenisvol ouderschap verstaat, verandert in de loop der tijd als doelen verschuiven van curatie naar comfort. Zorgverleners kunnen een belangrijke rol spelen in het gidsen van ouders bij het verschuiven van de doelen van betekenisvol ouderschap naar het ervaren van comfort, verbinding en nabijheid. Daarvoor is het van belang dat ouders hun verdriet mogen terugbrengen tot kleinere proporties, waarmee het verdriet meer hanteerbaar wordt en ouders emotionele ruimte voor zichzelf creëren. Ouders creëren emotionele ruimte door een samenspel van het reguleren van het verdriet en het ervaren van verdriet. Zorgverleners kunnen ouders ondersteunen door hen in de omgang met het verdriet te volgen, wat ook inhoud dat zij ouders soms helpen om het verdriet wat ‘kleiner te houden’, om zo betekenisvol ouderschap te kunnen ervaren. Deze aanpak impliceert dat optimale rouwzorg gestoeld is op het vermogen van zorgverleners om ouders op een multidimensionale en continue manier door de levenseindefase van hun kind te gidsen.

Als onderdeel van dit onderzoekstraject zijn een aantal praktische handvatten ontwikkeld die bedoeld zijn om reguliere zorgverleners te ondersteunen in het bieden van rouwzorg. Deze handvatten zijn gratis beschikbaar en omvatten: het nieuwe hoofdstuk “Zorg bij verlies en rouw” in de herziene richtlijn kinderpalliatieve zorg, een brochure voor ouders en zorgverleners ter voorbereiding op het nazorggesprek, informatieve films voor ouders over de omgang met verlies en rouw, en een e-learning voor zorgverleners die nog in ontwikkeling is.

Methodologisch sterke kanten van dit onderzoek zijn het betrekken van alle relevante partijen bij alle onderdelen van het onderzoekstraject. Ouders en zorgverleners met verschillende beroepen en specialismen werden geïnterviewd. De data werd geanalyseerd door een multidisciplinair team om onderzoekerstriangulatie te waarborgen. Dat ouders ook tijdens het naderende levenseinde van hun kind hebben deelgenomen aan dit onderzoek, gaf unieke inzichten in de omgang met verdriet. Dit onderzoek kent ook enkele beperkingen, ondanks dat we hebben geprobeerd om maximale variatie onder de deelnemers na te streven, bleek dit voor zowel ouders als zorgverleners niet volledig haalbaar. Daarnaast heeft het grootste deel van de zorgverleners die deelnamen aan dit onderzoek veel ervaring in het bieden van rouwzorg en voelden zij zich daardoor comfortabeler in het delen van hun ervaringen. Mogelijk heeft dit tot een overschatting van de huidige kennis over rouwzorg in de praktijk geleid.

Toekomstig onderzoek is nodig om volwaardige rouwzorg gedurende de levenseindefase en na het overlijden van een kind verder door te ontwikkelen. Toekomstig onderzoek kan zich mogelijk richten op: de dynamiek tussen koppels in het zoeken naar betekenisgeving; het betrekken van kinderen, broers en zussen in het onderzoek aangezien betekenis veelal in de gezinscontext tot stand komt; en een onderzoek dat langduriger de ontwikkeling van verdriet en rouw over de tijd heen volgt. Daarnaast is meer inzicht in de (non-)verbale communicatievaardigheden van zorgverleners nodig om optimale rouwzorg aan ouders te kunnen verlenen. Als laatste suggestie, zou vervolg onderzoek zich kunnen richten op het verder implementeren en evalueren van de praktische handvatten die naar aanleiding van dit onderzoek ontwikkeld zijn.

CURRICULUM VITAE

Eline Maria Kochen was born on November 11th 1993, in Voerendaal, The Netherlands. She studied psychology at the Erasmus University in Rotterdam from 2013 to 2016. During her bachelor, Eline followed a minor in medical psychology, volunteered for the Kindertelefoon and supported several research projects by data collection and analysis. She continued her studies at Leiden University, where she followed the masters in Clinical Neuropsychology (focus on child and adolescent neuropsychology) from 2016 to 2018. During her masters she followed two internships at the Erasmus Medical Center – Sophia Children's Hospital. First, her research internship aimed at neurocognitive outcomes in children previously admitted to the PICU, at the research department of Child- and Adolescent Psychiatry/Psychology. Then, her clinical internship with the developmental disorders team, at the clinical department of Child and Adolescent Psychiatry/Psychology. In July 2018, Eline started as a PhD candidate at the Center of Expertise Palliative Care Utrecht, at the department of General Practice, Julius Center for Health Sciences and Primary Care at the University Medical Center Utrecht. She worked on the emBRACE-study: towards embedded bereavement care in pediatrics. During her PhD, she actively participated in several committees in the UMC Utrecht and was a tutor in the course on qualitative research methods in the premaster program Clinical Health Sciences. In May 2022, she started working as a psychologist at GGZ Centraal – Fornhese, which offers specialized mental health care to children aged 6 through 18 years old.

PHD PORTFOLIO

Name	Eline Kochen
PhD period	July 2018 – April 2022
Graduate School	Graduate School of Life Sciences (GSLS), Utrecht University
Promotor	Prof. Dr. Saskia Teunissen & Prof. Dr. Martha Grootenhuis
Co-promotor	Dr. Marijke Kars

PhD training

Course	Institution	Year
Course on qualitative research methods	University of Antwerp	2019
Academic writing in English	GSLS	2019
Basiscursus regelgeving en organisatie voor klinisch onderzoekers (BROK)	NFU	2019
Castor Training	UMC Utrecht	2019
Masterclass palliative care by em. prof. Sheila Payne	Amsterdam UMC	2019
Giving Effective Presentations	GSLS	2020
De dood bespreekbaar maken in de behandelkamer	RINO Amsterdam	2020
Supervising master students	GSLS	2020
Individual coaching sessions in teaching qualitative research methods	Dr. Marijke Kars, UU	2020
Transferable Skills	Career Services UU	2021

Research meetings

Research meeting	Year
Monthly research meetings Center of Expertise Palliative Care Utrecht	2018-2022
Monthly research meetings Junior oncology	2018-2022
Weekly Julius Seminars	2018-2019
NVPO Research day	2019

Conferences and symposia

Conferences	Year
4th Maruzza international Congress on Paediatric Palliative Care, Rome, Italy	2018
7 e Nationaal Congres Palliatieve Zorg, Lunteren, Nederland	2018
Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Antwerpen, België *- Oral and poster presentation*	2019
11th World Research Congress of the European Association for Palliative Care, Palermo, Italy (digital conference) - *Oral and poster presentation*	2020
8e Nationaal Congres Palliatieve Zorg, Nederland (digital conference)	2020
17th World Congress of the European Association for Palliative Care, Childrens day, (digital conference) - *Poster presentation*	2021
NVK congres (Nederlandse Vereniging voor Kindergeneeskunde) (digital conference) - *Oral Presentation*	2021
Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Tiel, Nederland *- Oral presentation*	2022
18th World Congress of the European Association for Palliative Care, Childrens day (online conference) - *Oral and poster presentation*	2022
5th Maruzza international Congress on Paediatric Palliative Care, Rome, Italy *- Oral presentation*	2022

Symposium	Year
Trauma en Veerkracht, RINO Utrecht	2019
Symposium Kinderpalliatieve Zorg, Kenniscentrum Kinderpalliatieve Zorg	2019
Post EAPC Symposium, Palliactief	2019
ZonMw Projectleidersbijeenkomst: Diversiteit in de palliatieve zorg	2019
Webinar NIK: Rouw en de kracht van de familie en zijn culturele achtergrond	2020
Webinar NIK: Wat als een kind komt te overlijden - *Oral presentation*	2021

Teaching

Teaching and supervising	Year
Supervision of 5 medical students for a 6 week internship	2018-2022
Supervision of 7 medical students for a 12 week internship	2018-2022
Supervision of 1 medical students for a 16 week internship	2022
Tutor for the course Methods of Qualitative Research in the Premaster program Clinical Health Sciences	2020-2022

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