Original Article

Health Care Professionals' Experiences With Preloss Care in Pediatrics: Goals, Strategies, Obstacles, and Facilitators

Eline M. Kochen, MSc, Paul A. Boelen, PhD, Saskia C.C.M. Teunissen, PhD, RN, Floor Jenken, MSc, RN, Roos R. de Jonge, PhD, Martha A. Grootenhuis, PhD, and Marijke C. Kars, PhD, RN, on behalf of the emBRACE Working Group

Julius Center for Health Sciences and Primary Care (E.M.K., S.C.C.M.T., M.C.K.), University Medical Center Utrecht, Utrecht University, Utrecht; Department of Clinical Psychology (P.A.B.), Utrecht University, Utrecht; Arq Psychotrauma Expert Group (P.A.B.), Diemen; Department Woman and Baby (F.J.), Wilhelmina Children's Hospital, University Medical Center Utrecht, Utrecht University, Utrecht; Center for Research and Development of Education (R.R.d.J.), University Medical Center Utrecht, Utrecht University, Utrecht; and Department of Psycho-Oncology (M.A.G.), Princess Máxima Center for Pediatric Oncology, Utrecht, The Netherlands

---

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 intentions and strategies of the health care professionals (HCPs) in preloss care during the end of life is still lacking.

Objectives. To create a starting point for improvement of preloss 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 semistructured 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 parents could reflect on the care received as concordant to their preferences and 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 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.

Conclusion. HCPs strive to improve parental coping after the child's death, yet apply strategies that positively influence parental preparedness and well-being 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 preloss care in pediatrics. J Pain Symptom Manage 2021;62:107−116.

Key Words

Health personnel, bereavement, terminal care, child loss, end of life, palliative care

---

Key Message

During the child's end of life, health care professionals use strategies aimed at improving parental coping after child loss. In addition, the used strategies appeared to enhance parental preparedness and thus facilitate parenting and parental coping during the child's end of life. Even experienced health care professionals remain uncertain when providing preloss care and need robust education and training.

Address correspondence to: Eline M. Kochen, MSc, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Internal mail no Str. 6.131, P.O. Box 85500, 3508 GA, Utrecht, The Netherlands. E-mail: e.m.kochen@umcutrecht.nl

Accepted for publication: November 2, 2020.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2020.11.001

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 preloss care during the end of life might improve parental bereavement outcomes after 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 before the loss are mostly limited to inventory surveys[10,11] or experiences in critical care.[12] These studies predominantly focus on concrete interventions, whereas 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 preloss 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 were collected through single semistructured 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 the literature and expert knowledge. HCPs were invited to share their experiences with providing care to children during their, approximate, last months of life until six months after death. The interview guide covered the following topics: the HCPs' personal experiences with preloss 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; and experienced barriers and facilitators in care delivery. Data collection and analysis were alternated; new insights from preliminary analyses were elaborated in consecutive interviews. Data were collected until saturation was reached on the main concepts.[13]

Data Analysis

Data were thematically analyzed.[14] All interviews were audiotaped, transcribed verbatim, and pseudonymized. The analysis team, consisting of a psychologist, trained in qualitative research (E. M. K.), a pediatric intensive care nurse and senior qualitative researcher (M. C. K.), a neonatal intensive care nurse and researcher (F. J.), and an expert parent (R. R. d. J.) 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 subcategories. An initial code tree was formed, and further thematic coding was performed by one researcher (E. M. K.),[15] using NVivo 12 software program (QSR International Pty Ltd.; https://qsrinternational.com/nvivo/nvivo-products/).[16] During the analysis, extensive memos were written, which facilitated in-depth discussion on interpretation from data toward outcomes. The working group provided peer review throughout the analysis. A medical student (E. B.) validated the results by checking five interviews (26% of the data) against the final outcomes. Descriptive analyses were performed on the background questionnaire using SPSS, Version 25, software (IBM Corp., Armonk, NY).

Results

Participants

Nineteen of the 24 invited participants, eight nurses and 11 physicians, participated (Table 1). The five remaining participants (response rate 79%) were not responsive to the invitation ($n = 3$) or lacked time ($n = 2$). The interviews were conducted at the

Table 1
Participant Characteristics

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 of 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 expectancy <1 yr, 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)

p/y = patients per year.

participants' preferred location, either at their workplace or at their home, and lasted 40–75 minutes.

HCPs' Beliefs Regarding Preloss Care

From the background questionnaire, we learned that HCPs believed it was important to provide preloss 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 because of 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. Preloss 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 using preloss care during the end of life, difficulties in achieving these goals, and what empowered them to provide preloss care (Table 3).

Goals in Preloss Care

HCPs actively engaged in preloss care during the end of life and tried to minimize the potential for negative bereavement outcomes after child loss. This general belief on preloss 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 Preloss 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. Because 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, for example, to truly engage with and be receptive to their child.

Table 2
Questionnaire on Attitudes Regarding Preloss 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 have 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 have 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 is undesirable to talk about feelings of grief with parents before their child's death because it disrupts parents	17 (89.5)	2 (10.5)	0 (0)

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

In response, HCPs attempted to identify smaller concerns they could solve and to eliminate barriers for parents to experience meaningful moments. HCPs did this by emphasizing on the current presence of the child and 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 because 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 well-being 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. The aim was to facilitate parents to reflect on 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 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 the 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 before a critical situation. HCPs felt that, discussing these matters at an earlier stage provided parents with some time to adjust

Table 3
Quotes per Subtheme

Subtheme		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
Parents not hindered in their 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
• 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 preloss 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 being affected 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 preloss 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

(*Continued*)

Table 3
Continued

Subtheme		Quote
		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

HCP = health care professional.

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 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 dying process, such as gasping, as normal.

Difficulties in Providing Preloss Care

When pursuing the aforementioned 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, whereas 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, which 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 because they did not want to diminish hope in parents. However, HCPs felt obliged to inform parents about the possible negative outcomes to maximize parental presence during the child's possible end of life. Uncertainty was mentioned to increase in two situations. First, 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. Second, when parents seemed to be nonreceptive 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, among 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 types of existential questions reflect on the intensity of the parents' feelings of grief and caused discomfort to some HCPs because 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 judgment in evaluating meaningless extension of curative care. In addition, some HCPs experienced a sense of failure when a child died because they were trained to cure.

What Empowers HCPs' in Providing Preloss 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. First, it helped HCPs when decisions or advice to parents were formulated from a team perspective and not their personal decision. Second, 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 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 preloss care. First, 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. Second, HCPs tried to gain parents' trust because 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. Third, 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 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 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 evaluate 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 because of 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 preloss care, HCPs not only 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 before their child's death is becoming more evident in research and 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. 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, which 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 scenarios, 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 because HCPs are often aware of the impending death before 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 use to assist parents in their grief are not only important for the parents' future coping with the loss but in addition aid them through the bereavement process before 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 using them.

Strategies that HCPs could use to aid parental preparedness, including discussing end of life topics, have been proven difficult for them because of 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 because of 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 preloss care during the end of life. First, 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. Second, a barrier for HCPs consisted of the unpredictability of parental emotions and responses. For parents, effective coping with loss and 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 preloss 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 toward a more positive picture of preloss care than what is commonly practiced. Solely including physicians and nurses was a deliberate choice because the goal was to explore how preloss 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 preloss care.

In conclusion, HCPs feel responsible to aid parents in their feelings of grief during the child's end of life and valued providing preloss care. However, novel

HCPs experience uncertainty on how to provide such care, and the lingering uncertainty remains even in more experienced HCPs. To promote HCPs' confidence to provide preloss care aimed at parental grief, HCPs require education and training that matches their needs. It is important to emphasize that the strategies HCPs use could be more valued during the child's end of life because these strategies positively influence parental awareness and preparedness.

Disclosures and Acknowledgments

The authors thank all the HCPs who took part in this study and provided them with their personal experiences with preloss and bereavement care. The authors thank Esther Broddin for validating the results in this article. They also thank Matthew Grant for his help in editing the manuscript.

This publication is part of the EMbedded BeReAvement Care in pEdiatrics study, which is supported by The Netherlands Organisation for Health Research and Development (grant number: 844001506). The funding party did not take part in the conception and design, data collection and analysis, neither in drafting or revising the manuscript. The authors declare no conflicts of interest.

Collaborators: This study was conducted in collaboration with three university pediatric hospitals, of which collaborators are part of the EMbedded BeReAvement Care in pEdiatrics working group: Manon J. N. L Benders, Wilhelmina Children's Hospital, University Medical Center Utrecht; F. M. C. van Berkestijn, Wilhelmina Children's Hospital, University Medical Center Utrecht; J. L. Falkenburg, Sophia Children's Hospital, Erasmus Medical Center Rotterdam; I. M. E. Frohn-Mulder, Sophia Children's Hospital, Erasmus Medical Center Rotterdam; H. Knoester, Emma Children's Hospital, Amsterdam University Medical Center; and A. C. Molderink, Emma Children's Hospital, Amsterdam University Medical Center.

Ethical approval: 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.

References

1. Rosenberg AR, Baker KS, Syrjala K, Wolfe J. Systematic review of psychosocial morbidities among bereaved parents of children with cancer. Pediatr Blood Cancer 2012;58:503–512.

2. Kreicbergs U, Valdimarsgóttir U, Onelöv E, Henter JI, Steineck G. Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: a population-based follow-up. Psychol Med 2004;34:1431–1441.

3. Valdimarsdóttir UA, Lu D, Lund SH, et al. The mother's risk of premature death after child loss across two centuries. Elife 2019;8:1–13.

4. Kochen EM, Jenken F, Boelen PA, et al. When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. BMC Palliat Care 2020;19:28.

5. Donovan LA, Wakefield CE, Russell V, Cohn RJ. Hospital-based bereavement services following the death of a child: a mixed study review. Palliat Med 2015;29:193–210.

6. Kars MC, Grypdonck MHF, De Korte-Verhoef MC, et al. Parental experience at the end-of-life in children with cancer: "preservation" and "letting go" in relation to loss. Support Care Cancer 2011;19:27–35.

7. Coelho A, de Brito M, Teixeira P, Frade P, Barros L, Barbosa A. Family caregivers' anticipatory grief: a conceptual framework for understanding its multiple challenges. Qual Health Res 2020;30:693–703.

8. Jensen J, Weng C, Spraker-Perlman HL. A provider-based survey to assess bereavement care knowledge, attitudes, and practices in pediatric oncologists. J Palliat Med 2017;20:266–272.

9. Wiener L, Rosenberg AR, Lichtenthal WG. Personalized and yet standardized: an informed approach to the integration of bereavement care in pediatric oncology settings. Palliat Support Care 2018;16:706–711.

10. Foster TL, Dietrich MS, Friedman DL, Gordon JE, Gilmer MJ. National survey of children's hospitals on legacy-making activities. J Palliat Med 2012;15:573–578.

11. Currin-Mcculloch J, Pelletier W, Jones B, Wiener L, Sardi-Brown V, Brown P. Psychosocial standards of care for children with cancer and their families: a national survey of pediatric oncology social workers. Soc Work Health Care 2018;57:221–249.

12. Grimston M, Butler AE, Copnell B. Critical care nurses' experiences of caring for a dying child: a qualitative evidence synthesis. J Adv Nurs 2018;74:1752–1768.

13. Charmaz K. Constructing grounded theory: A practical guide through qualitative analysis. London: Sage, 2006.

14. Dierckx de Casterle B, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. Int J Nurs Stud 2012;49:360–371.

15. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.

16. QSR International Pty Ltd. Version 12. NVivo qualitative data analysis software 2018. Published online.

17. Lichtenthal WG, Sweeney CR, Roberts KE, et al. Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. Pediatr Blood Cancer 2015;62:S834–S869.

18. Bloomer MJ, Endacott R, Copnell B, O'Connor M. "Something normal in a very, very abnormal environment" - nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia. Intensive Crit Care Nurs 2016;33:5–11.

19. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive

care unit: parents' priorities and recommendations. Pediatrics 2006;117:649−657.

20. Boelen PA, Van Den Hout MA, Van Den Bout J. A cognitive-behavioral conceptualization of complicated grief. Psychology C. Clin Psychol Sci Pract 2006;13:109−128.

21. Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. J Health Soc Behav 1980; 21:219−239.

22. Horowitz MJ, Bonanno GA, Holen ARE. Pathological grief: diagnosis and explanation. Psychosom Med 1993;55: 260−273.

23. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. Death Stud 1999;23:197−224.

24. Rando TA. Clinical dimensions of anticipatory mourning. Champaign Ill: Research press, 2000.

25. Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. J Palliat Med 2006;9:1164−1171.

26. Valdimarsdóttir U, Kreicbergs U, Hauksdóttir A, et al. Parents' intellectual and emotional awareness of their child's impending death to cancer: a population-based long-term follow-up study. Lancet Oncol 2007;8:706−714.

27. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. J Am Med Assoc 2000;284:2469−2475.

28. Jones BL, Sampson M, Greathouse J, Legett S, Higgerson RA, Christie L. Comfort and confidence levels of health care professionals providing pediatric palliative care in the intensive care unit. J Soc Work End Life Palliat Care 2007;3:39−59.

29. Cortezzo DE, Sanders MR, Brownell EA, Moss K. End-of-Life care in the neonatal intensive care unit: experiences of staff and parents. Am J Perinatol 2014;32:713−723.

30. Haines ER, Frost AC, Kane HL, Rokoske FS. Barriers to accessing palliative care for pediatric patients with cancer: a review of the literature. Cancer 2018;124:2278−2288.

31. Granek L, Barrera M, Scheinemann K, Bartels U. Pediatric oncologists' coping strategies for dealing with patient death. J Psychosoc Oncol 2016;34:39−59.

32. De Vos MA, Bos AP, Plötz FB, et al. Talking with parents about end-of-life decisions for their children. Pediatrics 2015;135:e465−e476.

33. Kars Marijke C, Grypdonck Mieke HF, Beishuizen Auke, Meijer-van den Bergh Esther MM, van Delden Johannes JM. Factors influencing parental readiness to let their child with cancer die. Pediatr Blood Cancer 2010;54:1000−1008.

34. Verberne LM, Kars MC, Schouten-van Meeteren AYN, et al. Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study. Eur J Pediatr 2019;178:1075−1085.

35. Darlington ASE, Korones DN, Norton SA. Parental coping in the context of having a child who is facing death: a theoretical framework. Palliat Support Care 2018;16: 432−441.