

# Challenges in Preloss Care to Parents Facing Their Child's End-of-Life: A Qualitative Study From the Clinicians Perspective

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

From the Julius Center for Health Sciences and Primary Care (EM Kochen, SCCM Teunissen, and MC Kars), University Medical Center Utrecht, Utrecht University, Utrecht, the Netherlands; Department of Clinical Psychology (PA Boelen), Utrecht University, Utrecht, the Netherlands; ARQ National Psychotrauma Centre (PA Boelen), Diemen, the Netherlands; Department of Woman and Baby, Wilhelmina Childrens Hospital (F Jenken), University Medical Center Utrecht, Utrecht University, Utrecht, the Netherlands; Center for Research and Development of Education (RR de Jonge), University Medical Center Utrecht, Utrecht University, Utrecht, the Netherlands; and Department of Psycho-Oncology (MA Grootenhuis), Princess Máxima Center for Pediatric Oncology, Utrecht, the Netherlands

The authors declare that they have no competing interests.

Address correspondence to Eline M. Kochen, MSc, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Internal mail no St 6.131, P.O. Box 85500, 3508 GA Utrecht, the Netherlands (e-mail: [e.m.kochen@umcutrecht.nl](mailto:e.m.kochen@umcutrecht.nl)).

Received for publication February 5, 2021; accepted August 21, 2021.

## ABSTRACT

**OBJECTIVE:** 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 semistructured interviews with physicians and nurses working in neonatology and pediatrics in 3 university pediatric hospitals and 1 child home care service. A multidisciplinary 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.

**CONCLUSIONS:** 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.

**KEYWORDS:** bereavement; end of life care; health personnel; palliative care; pediatrics

ACADEMIC PEDIATRICS 2021;XXX:1–8

## WHAT'S NEW

Three dyadic dimensions are identified that cause tension for health care professionals in providing preloss care to parents in pediatrics. Uncertainty about optimal care delivery complicates experiencing emotional fulfillment for health care professionals and results in enduring feelings of distress.

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.<sup>1,2</sup> 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.<sup>1–3</sup> 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.<sup>4–6</sup>

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.<sup>1</sup> To obtain these goals, HCPs need to tailor care to the parents' specific needs, values, and wishes, which are highly variable. 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.<sup>7–11</sup> 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. Semistructured 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.<sup>12,13</sup> Given the richness of the data 2 manuscripts were developed. The first one presented HCPs' goals, strategies, barriers, and facilitators while providing preloss care.<sup>1</sup> Based on the lived experience of HCPs, the current study presents 3 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 4 stages.<sup>14,15</sup> Stages 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 stages 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 3 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 semistructured 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.<sup>12,13,16</sup> During the data analyses, researcher triangulation was attained by a multidisciplinary research team consisting of<sup>13</sup>: a psychologist trained in qualitative research (E.K.), a NICU nurse and researcher (F.J.), an expert parent (R.J.), and a senior qualitative researcher and former PICU nurse (M.K.). On several occasions, the findings were discussed in a more extensive research group, including one senior researcher and registered nurse (S.T.) and 2 senior researchers with a background in psychology (P.B., M.G.).

At first, open coding was performed on 5 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 toward 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<sup>17</sup> 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 9 nurses, 17 participants were female (Table 1). Reasons for nonparticipation 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 to 75 minutes.

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

**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 expectancy <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)

meet their needs, enhancing pressure to provide optimal care. HCPs felt that preloss care is less standardized than 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](#)).

## 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.

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 2 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.

## 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

**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].

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 2 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 2 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 undertreatment. 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 toward 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.

### 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 3 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, 3 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 3 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.<sup>18,19</sup> 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.<sup>20,21</sup> Compassion fatigue is defined as a secondary trauma from being confronted with suffering patients<sup>22</sup> and may negatively impact HCPs' well-being.<sup>21</sup> 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.<sup>23,24</sup> Burnout forms a threat to the pediatric workforce, since burnout symptoms are already highly prevalent among pediatric residents.<sup>25,26</sup> 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.<sup>8,27,28</sup> This emotional fulfillment is also known as compassion satisfaction,<sup>29</sup> 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 is through *education* and *learning as a team*.<sup>28,30</sup> Regarding education, The Canadian Paediatric Society and the RCPSC Paediatric Specialty Committee created various CanMEDS roles,<sup>31</sup> 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.<sup>32–34</sup> 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 toward discussing end-of-life topics, which improves care delivery to their pediatric patients and their parents.<sup>35–38</sup> Education could focus on: adapting positive coping strategies both in their professional and personal life,<sup>23,28,39</sup> 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.

Strength of this study is that HCPs from a variety of specialties 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 multidisciplinary 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.

## COLLABORATORS

This study was conducted in collaboration with 3 university pediatric hospitals, of which collaborators are part of the emBRACE-working group: Maria-Luisa Tataranno, 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; A.C. Molderink, Emma Children's Hospital, Amsterdam University Medical Center.

## ACKNOWLEDGMENTS

We thank all the health care professionals who took part in this study and provided us with their personal experiences with pre-loss and bereavement care.

**Financial statement:** This publication is part of the emBRACE-study (EMbedded BeReAvement Care in paEdiatrics), 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.

**Authorship statement:** E.K. took part in the conception and design of the research, performed the data collection, took part in the data analysis and drafted and critically revised the manuscript. M.K. took part in the conception of and design of the research, data analysis and critically revised the manuscript. F.J. and R.J. took part in data analysis and critically revised the manuscript. P.B., S.T., M.G. took part in the conception and design of the research and critically revised the manuscript. All members of the embrace-working group were involved in the data collection, took part in data analyses, and critically revised the manuscript. All authors approved the final version of the manuscript.

## REFERENCES

- Kochen EM, Boelen PA, Teunissen SCCM, et al. Health care professionals' experiences with preloss care in pediatrics: goals, strategies, obstacles, and facilitators. *J Pain Symptom Manage*. 2020. <https://doi.org/10.1016/j.jpainsymman.2020.11.001>.
- 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. <https://doi.org/10.1017/S1478951517001249>.
- 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. <https://doi.org/10.1089/jpm.2015.0430>.
- Jones BL, Sampson M, Greathouse J, et al. Comfort and confidence levels of health care professionals providing pediatric palliative care in the intensive care unit. *J Soc Work End-of-Life Palliat Care*. 2007;3:39–58. [https://doi.org/10.1300/J457v03n03\\_05](https://doi.org/10.1300/J457v03n03_05).
- Cortezzo DE, Sanders MR, Brownell EA, et al. End-of-life care in the neonatal intensive care unit: experiences of staff and parents. *Am J Perinatol*. 2014;32:713–723. <https://doi.org/10.1055/s-0034-1395475>.
- Haines ER, Frost AC, Kane HL, et al. Barriers to accessing palliative care for pediatric patients with cancer: a review of the literature. *Cancer*. 2018;124:2278–2288. <https://doi.org/10.1002/cncr.31265>.
- Bartholdson C, Lützn K, Blomgren K, et al. Experiences of ethical issues when caring for children with cancer. *Cancer Nurs*. 2015;38:125–132. <https://doi.org/10.1097/NCC.0000000000000130>.
- McConnell T, Scott D, Porter S. Healthcare staff 's experience in providing end-of-life care to children- a mixed-method review. *Palliat Med*. 2016;30:905–919. <https://doi.org/10.1177/0269216316647611>.
- McCabe ME, Hunt EA, Serwint JR. Pediatric residents' clinical and educational experiences with end-of-life care. *Pediatrics*. 2008;121. <https://doi.org/10.1542/peds.2007-1657>.
- Price J, Jordan J, Prior L. A consensus for change: Parent and professional perspectives on care for children at the end-of-life. *Compr Child Adolesc Nurs*. 2013;36:70–87. <https://doi.org/10.3109/01460862.2013.779765>.
- McCloskey S, Taggart L. How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *Int J Palliat Nurs*. 2010;16:233–240.
- Charmaz K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage; 2006.
- Dierckx de Casterle B, Gastmans C, Bryon E, et al. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49:360–371. <https://doi.org/10.1016/j.ijnurstu.2011.09.012>.
- Kars MC, Grypdonck MHF, van Delden JJM. Being a parent of a child with cancer throughout the end-of-life course. *Oncol Nurs Forum*. 2011;38:E260–E271. <https://doi.org/10.1188/11.onf.e260-e271>.
- Wood F, Simpson S, Barnes E, et al. Disease trajectories and ACT/RCPC categories in paediatric palliative care. *Palliat Med*. 2010;24:796–806. <https://doi.org/10.1177/0269216310376555>.
- Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. 2017;27:591–608. <https://doi.org/10.1177/1049732316665344>.
- QSR International Pty Ltd. Version 12. NVivo qualitative data analysis software. Published online 2018.
- Plante J, Cyr C. Health care professionals' grief after the death of a child. *Paediatr Child Health (Oxford)*. 2011;16:213–216. <https://doi.org/10.1093/pch/16.4.213>.
- Ffrench-O'Carroll R, Feeley T, Crowe S, et al. Grief reactions and coping strategies of trainee doctors working in paediatric intensive care. *Br J Anaesth*. 2019;123:74–80. <https://doi.org/10.1016/j.bja.2019.01.034>.
- Maytum JC, Heiman MB, Garwick AW. Compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. *J Pediatr Heal Care*. 2004;18:171–179. <https://doi.org/10.1016/j.pedhc.2003.12.005>.
- Kase SM, Waldman ED, Weintraub AS. A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the United States. *Palliat Support Care*. 2019;17:269–275. <https://doi.org/10.1097/MPH.0000000000001548>.
- Figley CR. Compassion Fatigue: Toward a New Understanding of the Costs of Caring. In: Stamm BH, ed. *Secondary Traumatic Stress: Self-Care Issues for Clinicians, Researchers, and Educators*. Derwood: The Sidran Press; 1995.
- Shanafelt TD, Noseworthy JH. Executive leadership and physician well-being: nine organizational strategies to promote engagement and reduce burnout. *Mayo Clin Proc*. 2017;92:129–146. <https://doi.org/10.1016/j.mayocp.2016.10.004>.
- World Health Organization. Burn-out an "occupational phenomenon": international classification of diseases. Published 2019. Available at: <https://www.who.int/news/item/28-05-2019-burn-out-an-occupational-phenomenon-international-classification-of-diseases#>. Accessed June 8, 2021.
- Pantaleoni JL, Augustine EM, Sourkes BM, et al. Burnout in pediatric residents over a 2-year period: a longitudinal study. *Acad Pediatr*. 2014;14:167–172. <https://doi.org/10.1016/j.acap.2013.12.001>.
- Kemper KJ, Schwartz A, Wilson PM, et al. Burnout in pediatric residents: three years of national survey data. *Pediatrics*. 2020;145:1–13. <https://doi.org/10.1542/peds.2019-1030>.
- Beaune L, Muskat B, Anthony SJ. The emergence of personal growth amongst healthcare professionals who care for dying children. *Palliat Support Care*. 2018;16:298–307. <https://doi.org/10.1017/S1478951517000396>.

28. Muskat B, Greenblatt A, Anthony S, et al. The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital. *Death Stud.* 2020;44:105–116. <https://doi.org/10.1080/07481187.2018.1526829>.
29. Stamm B.H. Measuring compassion satisfaction as well as fatigue: developmental history of the compassion satisfaction and fatigue test. In: C.R. Figley (Ed.), *Psychosocial Stress Series*, No. 24. *Treating Compassion Fatigue*. Routledge: Oxfordshire; 2002:107-119.
30. Berkowitz LR, Dzara K, Simpkin AL. Building your “Educational Peloton:” cycling together for success during uncertain times. *J Contin Educ Health Prof.* 2021;41:8–9. <https://doi.org/10.1097/ceh.0000000000000325>.
31. Frank JR, Jabbour MTP, et al. Skills for the new millennium: report of the Societal Needs Working Group. CanMEDS 2000 project. *Ann R Coll Physicians Surg Can.* 1996;29:206–216.
32. Lieberman L, Hilliard RI. How well do paediatric residency programmes prepare residents for clinical practice and their future careers? *Med Educ.* 2006;40:539–546. <https://doi.org/10.1111/j.1365-2929.2006.02479.x>.
33. Kumar G, Ni A, Lawrence SE, et al. Incorporating CanMEDS and subspecialty training into paediatric residency programs: why are we still deficient? *Paediatr Child Health (Oxford).* 2012;17:7–11. <https://doi.org/10.1093/pch/17.1.e7>.
34. Malcolm C, McGirr D. Educational needs and preferred learning approaches of the paediatric palliative care workforce: a qualitative exploratory study. *Nurse Educ Today.* 2020;89:(July 2019) 104417. <https://doi.org/10.1016/j.nedt.2020.104417>.
35. Brown CM, Christopher Lloyd E, Swearingen CJ, et al. Improving resident self-efficacy in pediatric palliative care through clinical simulation. *J Palliat Care.* 2012;28:157–163. <https://doi.org/10.1177/082585971202800305>.
36. Levine S, O’Mahony S, Baron A, et al. Training the workforce: description of a longitudinal interdisciplinary education and mentoring program in palliative care. *J Pain Symptom Manage.* 2017;53:728–737. <https://doi.org/10.1016/j.jpainsymman.2016.11.009>.
37. Peng NH, Lee CH, Lee MC, et al. Effectiveness of pediatric palliative care education on pediatric clinicians. *West J Nurs Res.* 2017;39:1624–1638. <https://doi.org/10.1177/0193945916680615>.
38. Brock KE, Cohen HJ, Sourkes BM, et al. Training pediatric fellows in palliative care: a pilot comparison of simulation training and didactic education. *J Palliat Med.* 2017;20:1074–1084. <https://doi.org/10.1089/jpm.2016.0556>.
39. Rourke MT. Compassion fatigue in pediatric palliative care providers. *Pediatr Clin North Am.* 2007;54:631–644. <https://doi.org/10.1016/j.pcl.2007.07.004>.