



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.

KEYWORDS

bereavement, coping with grief, end of life, loss, palliative

1 | 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, yet it is developed mostly in order to

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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.

2 | METHODS

2.1 | 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 paediatrics) exploring the parents' and the healthcare professionals' experiences with loss and bereavement in paediatric end-of-life care.

2.2 | 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 <3 months. (2) parents of children who went through a life-threatening event with an expected reoccurrence within 1 year assessed by the treating physician. Bereaved parents were included in the study after the follow-up conversation, taking place approximately 6 weeks, and before 6 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

Key Points

- 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 end of life.
- Parents' coping with grief is characterised by an interplay of downregulating and experiencing grief, aimed at creating emotional space to connect with their child.
- Healthcare professionals should align to the parental need to downregulate grief and be reserved in exploring emotions.

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.

2.3 | 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

2.4 | 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.

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.

3 | 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 min. Eight cases were included during the child's end of life, involving seven mothers and six 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.

3.1 | 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).

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 ^a	3	
Middle ^b	6	
High ^c	25	
Relational status		0
Married/in relationship	37	
Separated	1	
Religion		3
Atheist/none	26	
Christian	6	
Islamic	3	
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	
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	

^aLow: Primary school, lower secondary general education, lower vocational education.

^bMiddle: Higher secondary general education, intermediate vocational education.

^cHigh: Higher vocational education, university.

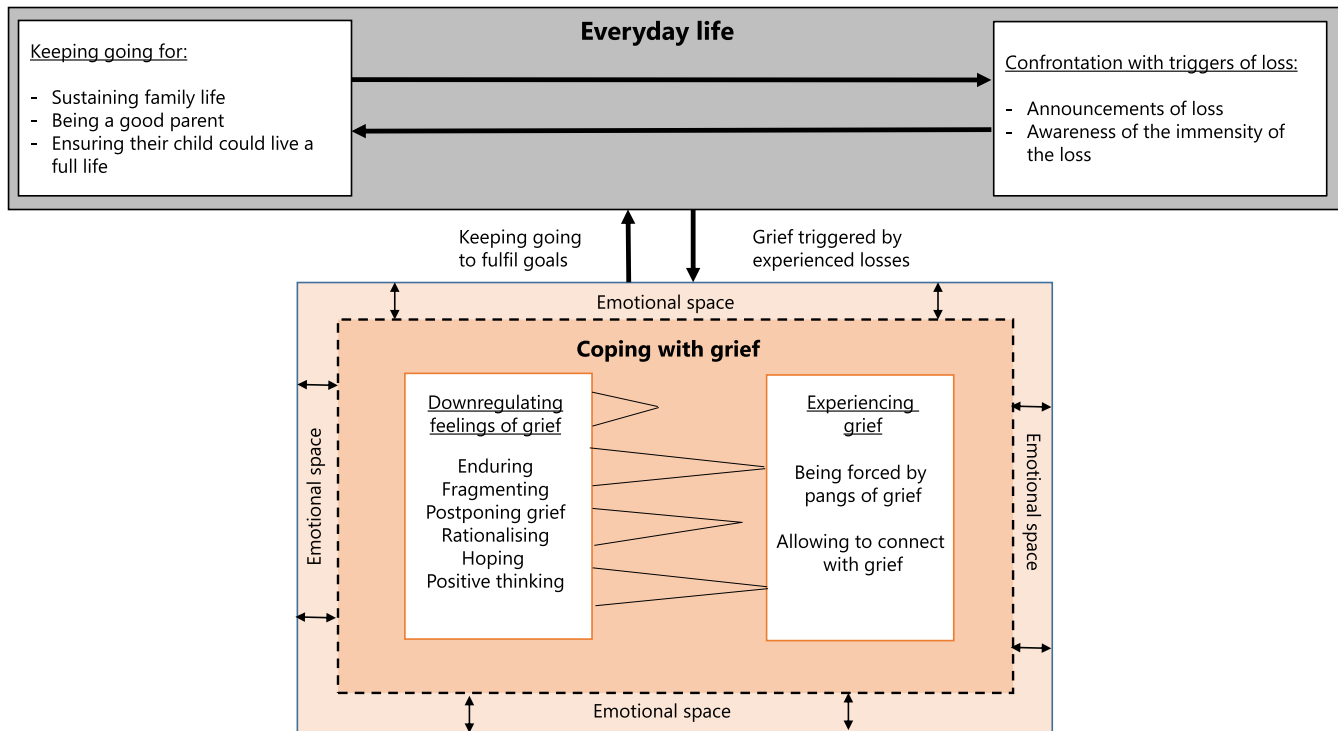


FIGURE 1 Parental coping with grief during their child's EOL.

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.

3.2 | 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.

3.3 | 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).

3.3.1 | 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.

3.3.2 | 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.

3.4 | 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.

4 | 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 occurred.^{7,21} These theories emphasise 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.

5 | 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.

6 | 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.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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