

Parental physical proximity in end-of-life care in the PICU.

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Abstract

Objective: Health professionals in PICUs support both child and parents when a child's death is imminent. Parents long to stay connected to their dying child but the high-tech environment and treatment implications make it difficult to stay physically close. This study explores in what sense physical aspects of end-of-life care in the PICU influence the parent-child relationship.

Design: Retrospective, qualitative interview study. **Setting:** Level 3 PICU in Erasmus Medical Center in the Netherlands. **Participants:**

Thirty-six parents of 20 children who had died in this unit 5 years previously.

Measurements and Main Results: Parents vividly remembered the damage done to the child's physical appearance, an inevitable consequence of medical treatment. They felt frustrated and hurt when they could not hold their child. Yet they felt comforted if facilitated to be physically close to the dying child, like lying with the child in one bed, holding the child in the hour of death, and washing the child after death.

Conclusions: End-of-life treatment in the PICU presents both a barrier and an opportunity for parents to stay physically connected to their child. Parents' experiences suggest that aspects of physicality in medical settings deserve more attention. Better understanding of the significance of bodily aspects - other than pain and symptom management - improves end-of-life support and should be part of the humane approach to families.

Keywords: end-of-life care, parenting, pediatric intensive care unit, qualitative

Introduction

When a child is treated in a pediatric intensive care unit (PICU), parents often feel at a loss in the alienating high-tech environment.(1, 2) Caring for their child

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themselves is often hampered by the necessary medical equipment and procedures such as insertion of IV lines and/or the presence of drains. Anxiety and stress levels can be high, especially when the child is in danger of dying. The staff is aware of this; concern for the families is naturally included in pediatric care, especially in palliative care.(3-5) In order to fulfill their role as a parent and to be there for their child, they need support from the medical and nursing staff. (6-8) However, it is not easy for PICU staff to give high-quality effective end-of-life care, including care for the parents.(9, 10) The time between the possibilities of cure and the imminence of death, the transition to end-of-life care, may be very short. End-of-life care is therefore often a matter of ad hoc decisions.

The needs and perceptions of parents who lose their child in the ICU have been investigated in international research programs. Effective communication, participation in decision making, and the possibility to fulfill the parent role until the very end proved important features. (9-11) Meeting their wishes is important as the child's death often leaves parents in long-term psychological distress. (12)

From the perspective of parents, preservation of the integrity of the parent-child relationship is one of the priorities of pediatric end-of-life care. (8, 13, 14) Having the opportunity to be the parent and to act accordingly is very important in this context. When parents can feel connected to the child in all phases of the bereavement process, they feel better able to adapt to the loss. (15) This connection does not end with death. In fact, bereaved parents experience continuous bonds with their child. (9, 16-19) Continuing the bond with a deceased loved one can be part of the process of adaptation to loss, as long as the reality of the death is also fully realized. (20)

Physical care provision and physical proximity have been recognized as essential expressions of the parent-child relationship and connection. (8, 14) Yet these conditions are hard to realize in a PICU, where the patient is almost never without tubes, lines, drips, bandages etc. How this affects physical attachments between parents and their sick child has not yet been explored in detail. The aim of this study was to explore in what sense physical aspects influence the parent-child relationship in end-of-life care in the PICU.

Materials and Methods

Design. This study is part of a larger research project exploring meaningful experiences of parents whose child died in the PICU. To identify features of meaning and significance, we applied a qualitative research design with unstructured indepth interviews with prompts given to elicit information from parents when necessary, five years after the death of their child.

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Setting. The setting for this study was the 34-bed multidisciplinary tertiary care PICU of the Erasmus MC-Sophia Children's Hospital, Rotterdam, the Netherlands. Interviews were conducted in 2013 and 2014.

Participants. In the years 2008 and 2009, 92 children had died in the PICU. Thirtyeight children were randomly selected using a random number generator. This approach, although not necessary in qualitative research, was chosen because the interviewer worked in the department and we wanted to make clear that the selection of parents was not based on personal preference. The parents of these children were invited by letter to have an interview concerning their experiences in the PICU at the time of death of their child. The letter explained that they need not respond if they did not want to participate and in that case would not be contacted again. Six letters came back unopened. Twenty of the remaining 32 invitations were accepted (response rate 62.5 %). After twenty responses data saturation was reached. It was left to the choice of the parents whether they wanted to be interviewed individually or as a couple.

The study was approved by the Erasmus MC medical ethical review board (No. 2011-436). Written informed consent was obtained from all participants.

Interviews. All interviews were held at the homes of the family and lasted between 1 and 2 hours. The interviewer followed the flow of the narrative when the parents responded to the general question what happened to their child in the PICU. When necessary, additional questions addressed support from the PICU staff and meaningful events before, during and after the death of their child. The interviews were audio-taped and transcribed verbatim. Parents were also sent a draft copy of the interview.

Data Analysis. The anonymized transcripts were analyzed by the interviewer (JLF) and a second investigator (MvD) independently, using Atlas-Ti 7.0 for coding and selection of themes. Any discrepancies between the coders were resolved through discussion, until consensus was reached. In the first phase of coding we found that the child's body was often mentioned, not in the medical sense but rather in the sense of having special meaning in the parent-child relationship. We then analyzed the data set with a focus on the theme of the significance of the child's body in the experience of parents. Through renewed coding we identified the following subthemes: 'the damaged body', 'the experienced physical distance to the child' and 'the importance of holding and touching', which we will describe in our results. Relevant quotes related to these themes were selected from the transcripts and are also presented in the Results section.

Results

Participant characteristics. 16 couples, three mothers and one father participated. The children's age at the time of death varied from 2 weeks to 14

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years. Length of stay in the PICU varied from 2 hours to over 5 months. Characteristics of the children are listed in Table 1.

Variables	N (%) ¹
Age Group	
Newborns	2
One month - 1 year	11
> 1 year to 6 year	3
> 6 years to 14 years	4
Sex	
Boys	13 (65)
Girls	7 (35)
Diagnosis	
Complex cardiac anomaly	8
Respiratory insufficiency	3
Congenital diaphragmatic hernia	2
Trauma	2
Neuromuscular disease	2
Metabolic disorder	1
Ateriovenous malformation	1
Oncological	1
ECMO	15 (25)
LOS hospital admission in days	
Median (IQR)	19 (3-34)
LOS ICU last admission in days	
Median (IQR)	12 (3-31)
Abbreviations: ECMO=extracorporeal membrane oxygenation, LOS=length of stay, IQR=interquartile range	

Aspects of physicality in the experience of parents in end-of-life care. A striking feature in the parents' narratives was the child's physicality. We found two major themes regarding the perception of the body of the child that were meaningful to parents, even after five years: the disfigurement of the body and the importance of physical closeness.

1. Disfigurement of the body. The importance of the integrity of the child's body was apparent from each story. Many parents described the body as 'damaged'. They not only referred to disfigurement of the body due to life-saving medical interventions - drips, cuts, bruises etcetera-, but also to physical consequences of treatment or disease, such as edema. This 'extra' damage done to the body was something they accepted as inevitable in the efforts to save the life of the child, but they found it painful to realize that it had all been to no avail. Table 2 gives some quotes of parents with regard to the impact of disfigurement of their child's physical appearance.

On the other hand, seeing the child's familiar, undamaged body, while knowing it was internally damaged, could be confusing as well. "The first day after the accident it really struck me, it was terrible, incomprehensible; when you looked at her, she seemed alright. She was warm, she was beautiful and like she really was. But the readings showed something else." (mother of twelve-year-old girl)

One of the families donated their daughter's body for organ transplantation. One of the things that made a lasting impression on the mother, was that the body was warm when they said their goodbyes to her and it was cold when they saw her again.

Table 2: Quotes on 'Disfigurement of the body

Child's age	Quote
13 years	Mother: "It is of course a shame, looking back. She had this long blond hair. They shaved a large part of her head for the surgery which had little chance of success. That was horrible, you know. Because they took away so much and that was actually very awful."
11months	Mother: "It was terrible, after the resuscitation his ribs were broken. He looked black. It was awful, really awful."
8 months	Mother: "I was there when they drilled with a 'Black and Decker' machine into his legs to get the medication in, because he no longer had blood circulation. I had always promised him: everything you have to undergo, we will do together. I will be there. And I've kept my word, though it wasn't really human to be present there."
7 months	Father: "I will never forget in the hospital when we saw her again: it wasn't our E at all. She was all wrapped up, with a turban, under her chin, wrapped up. I remember saying: "This is not the way we are going to do it. The back of her head is damaged, not the rest of her. The bandage is going off, we put on her own cap and we take our E. home.""
8 months	Father: "The hard thing is, being a parent: seeing your child from a healthy child turned into a child full of tubes and full of machineries..."
3 months	Mother: "Yes when you saw him in the end, his belly was so swollen, it was all shining. I asked: 'Can it burst?' Yes, she said, it could burst at a certain point. Because of all the fluid that it is so tight. He was already filled up but it only got worse. Then I said: 'You may go to grandfather' (i.e.'die').
10 months	Father: "Her brother came a few times to the hospital. Once he came in and said: 'Who is this?' He didn't recognize his own sister. She was so terribly swollen."

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2. *The importance of physical closeness.* It was important to the parents to get near to their child at all times. Yet this was not always possible.

a. Physical separation. The child's medical condition and technology prevented parents of thirteen children to hold the child or provide the physical care they desired to give. This was especially painful to the parents whose child was admitted to the PICU right after birth. Four of these children never left the PICU until they died. The parents of three of them explicitly said that for this reason they had not been able to form any kind of parent-child relationship. They did not feel connected to their child. They held their child close for the first time at the hour of death, which in one case was after four months. One of these mothers had a breakdown after the birth of her next child and then realized that she had never 'received' anything from her firstborn, as there had never been any real contact. The fourth mother who did have the opportunity to hold her daughter skin to skin a few times, said: "When I held her to my chest for the first time, my body started to react! Then I thought: yes this is really my baby".

ECMO-treatment, which was given to five of the 20 children, was remembered as exceptionally traumatic. In most cases they were lying on an elevated bed to advance venous flow, which means that parents had to stand on their toes to see the child. In all cases the child was swollen from edema due to the inevitable systematic inflammatory response syndrome, could hardly if at all open the eyes, and could in most cases not bear physical touch. An additional barrier was the physical condition of the mothers who had just had cesarean delivery. They could not stand on their feet or sit on a high chair and could not reach their child for a couple of days.

Table 3 shows some of the quotes on physical separation from the child.

Table 3: Quotes on 'Physical separation'

Child's age	Quote
3.5 years	Mother: "He was also not responsive. If only you could talk to him, or he would blink his eye. But there was nothing. No contact at all. If you want to hold him, you can only touch his finger. Everywhere there are these stickers; I can't touch anything, can't pick him up. Not at all. We are on the sideline."
1 month	Father: "In a certain way, he never really was our child, because you haven't been able to do normal things with him. You couldn't hold him, you couldn't tend to him. We had started with

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	babymassage. Only once. Then he got worse again and didn't like the touch anymore."
1 month	Mother: "I wanted to, but could not hold him. It was such a contrast to the intense contact with my firstborn daughter after her birth. But I couldn't do that with him. Not at all. There just was never a moment that holding was really possible, because of equipment. And that, looking back, is quite a shame"
8 months	Mother: "I came to the ICU and there you see a large space full with machinery and equipment and somewhere in between lies your baby. You have to search for your baby between all machines."
4 months	Mother: "You were allowed to hold him. Then you held him for maybe five minutes a day. But he was placed on a pillow on my lap because of the tubes and everything. You didn't feel him! You felt the pillow. You didn't really have that contact. You could hold his hand, but it was not that you really held him!

b. Physical intimacy. Getting the opportunity to get physically close to their child was of great significance to parents; holding the body close before, during and after the child's dying. One mother refused to leave the side of her three-month-old son in the three weeks of admission to the PICU. She had promised him they would get through it together and that she would not leave him. She slept in a chair by his side, until finally the doctor arranged for a large bed, so she could sleep next to her son.

Physical intimacy was felt as a necessity. Especially when children were admitted after trauma or sudden illness, the parents wanted to be at the bedside, getting as close as possible. This urge to be physically close was most intense in the final moments, which the quotes in Table 4 illustrate.

Table 4 Quotes on 'Physical intimacy'.

Child's age	Quote
13 years	Mother: "We really crept into the bed with her, to hold her."
2 weeks	Mother: "We washed her ourselves and put on her clothes. It was wonderful. We finally had her without tubes. Free.."

- 2 months Father: "After his death we thought: now what? The nurse said (this was just natural for her): 'My, what would you like? Shall we bathe him nicely, put on nice clothes? What would you like?' That was so nice, to have something to grasp hold of. So we indeed bathed him nicely. That sort of things.."
- 11 months Mother: "We all held him in our laps, when he had died. He was dead and we held him!"
- 3 months Mother: "I wanted to bathe him myself. The children helped, they wanted to. They touched him constantly. I let them get on with it: if you want to, then do it; if you don't want it, you don't need to. But they just did. Until the last moment: just holding hands, yes. That I could do that myself, that was nice."
- 2 months Mother (when her son's dead body had to be transferred): "The nurse said: you may carry him if you want. I said: may I? Then he won't go back to his cot. All these weeks he had been laid up. Now finally I can hold him again."
- 13 years After the child had died, her 16-year-old sister washed her, washed her hair... Father: "Yes, and we helped. I brushed her teeth like I always used to do with the kids until a certain age and it felt so good."
- 8 months Mother: "And I sit with my little man on my lap and the nurse comes: I think it is over. I say: no, no way. He is still here. And next she listened ten times, and every time I shook my head: he is still here. Then I had a strange feeling. Whether it was in my head, or that I really saw it, it was a kind of light and it looked like hands... Then I said: it is over. And she came said: My condolences, he has died."
- 9 months Mother: "In the end he died quietly. On daddy's lap. I said: He was born from my womb, he may go from daddy's lap.."

In many situations the nursing staff provided a large bed to enable the parents to lie down with their child. In one case this was especially comforting to parents as their child could not be touched or held, due to "the deterioration of muscles" as parents described it. Lying next to her, being as close as possible, gave the parents a valuable memory of having been there for their daughter, until the very end. The parents of adolescents had also been encouraged to lie down in the bed holding their child.

All families but one washed the child's body after death with the aid of the nurse. Some parents were initially reluctant but were encouraged by staff or family members to do so and all looked back with satisfaction upon this final act of parental care. Not only the actual holding and touching of the child was significant. They remembered all the rituals surrounding the death of the child, which are part of the protocol of providing end-of-life care for many years in our unit. Photographs, cast footprints, a lock of hair, these were all physical mementos of the child. Some of the parents had collected tubes, sticking plasters, bandages, a shoe with a drop of the child's blood, the soap that was used for the bathing after death, etcetera.

Stimulated by the hospital staff, most parents took their child home by car themselves, which is allowed under Dutch Law. Some kept the body at home until the funeral, continuing the physical intimacy until the last moment.

Discussion

Our study shows that physical contact with their dying child is a necessity for mothers and fathers in the abnormal, alienating environment of a PICU. Physical care, holding, kissing and touching are basic expressions of the parent-child relationship. Research in neonatal care shows that touch and physical closeness, preferably in skin-to-skin contact with their parents, is important for the development of newborn babies.(21, 22) It helps them form secure attachments, which are a psychobiological need to find safety and security in life.(23, 24) Physical contact is also crucial for the well-being of parents in bonding to their child.(25)

The same is true in the parent-child relationship, when death is imminent: physical contact helps parents to express the continuing bond with their child. Our results are in line with findings from the work of McGraw and Meyer that in end-of-life care, it is beneficial for parents to stay physically close to their dying child.(8, 14) In the PICU setting bodily contact is not always possible. This is a frustrating experience which remains impregnated in the memories of the parents even after five years.

The impact of lack of proximity in end-of life situations is not always recognized. Research into palliative care for children, exploring physical concerns, examines mostly pain and symptom management.(10, 26, 27) Parents have a different perspective on care than healthcare professionals, who are usually trained to focus on the biomedical aspects of the body. (28-30) Parents look at the body of their child from an emotional, relational point of view.

To the parents in this study, the body was the unique expression of their child's individuality. They realized that bodily damage could be involved in the medical effort to save the child and did not question the necessity of the actions. None of the parents doubted the choices made by the doctors. But what still remained

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with them after five years was the painful memory of the child's unique physical appearance being damaged.

These findings seem to correlate with the renewed interest in the fields of health, medicine and psychology in the way patients view the body. As Shildrick and colleagues put it: "The body is never merely an object but is the very condition of being a self at all." (31) This also holds true for parents with regard to their child's body, in its manifestation of 'selfness'. This may explain why any parents of a sick child in the PICU will put up a picture near the bedside of the child in normal, happy conditions. As if to say: this is who he or she really is!

Even though medical staff may realize that parents need intense physical contact with their child, they will of course give precedence to life-saving action. Yet it would be commendable if they would be willing to reconsider the necessity of intruding the body's integrity in some cases of end-of-life care. Gentle, careful touch of the sick body is highly valued by parents. It would be worthwhile to stimulate awareness of these physical aspects in educational palliative care programs aimed at PICU staff.

The cohesive finding emerging from this research is the positive evaluation of medical and nursing staff's efforts to support parents in the hour of the child's death. (32) The opportunity to get physically close to the child, for instance by sharing a bed when holding the child in their arms was no longer possible, was very meaningful to parents and gratefully remembered. After the moment of death, all parents felt at a loss as to what they were supposed to do next. Taken by the hand by the nurse, invited to wash and dress the child unhurriedly was of great help to both the parents and siblings. All parents described this aspect of saying goodbye to their child as very valuable, and some even in terms of evoking a sense of "happiness". It helped them to connect to their child, which was of great significance to in their further grieving process. Not all continuous connections or bonds are helpful in the grieving process. Field showed that the relation between continuous bonds and adaptation to grief is complex.(20) Whether continuous bonds help to adjust to the loss depends on individual differences and for instance the way attachments bonds were formed. (20, 33) Yet, both our research and literature show that the experience of a continuous bond with the deceased child is at least meaningful to grieving parents. (8, 18, 34-36) The mementos they received from the hospital (such as lock of hair, footprint; but also last used bandages) are direct references to the bodily reality of the child and had great supportive value to them, in line with earlier studies. (11, 37)

A possible limitation of the study is that the participants were predominantly native Dutch parents. We addressed parents of six children who had another nationality and a different cultural background, but only one mother responded and participated. The significance of physical aspects of palliative care could be different for parents from other cultural backgrounds and be influenced by religion. It would be desirable for future research within the field of end-of-life

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care to focus on the specific needs of parents from different cultural and religious backgrounds. Another limitation of the study is that the interviews were held in Dutch and then translated into English. This process of translation could have caused potential loss of nuanced meaning.

Strength of the study is that it shows what still remains fixed in the memories of grieving parents concerning their experiences in the PICU, after considerable time has elapsed. An additional strength is that the interviews were administered in person at their homes instead of by telephone and that both fathers and mothers participated.

Conclusion

Integrity of the child's body and physical closeness are significant features for parents caring for their dying child. It helps them to create or strengthen the bond that may continue after death. All parents valued the physical aspects of the care for their child at the end of life. Awareness of nursing and medical staff for these concepts could improve end-of-life care and the way it is remembered by parents.

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References

1. Balluffi A, Kassam-Adams N, Kazak A, et al. Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatr Crit Care Med* 2004;5(6):547-553.
2. Meert KL, Briller SH, Schim SM, et al. Exploring parents' environmental needs at the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008;9(6):623-628.
3. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000;106(2 Pt 1):351-357.
4. Jones BL, Contro N, Koch KD. The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring. *Pediatrics* 2014;133 Suppl 1:S8-15.
5. Boss R, Nelson J, Weissman D, et al. Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board. *Pediatr Crit Care Med* 2014;15(8):762-767.
6. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit:

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American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med* 2007;35(2):605-622.

7. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet* 2008;371(9615):852-864.
8. McGraw SA, Truog RD, Solomon MZ, et al. "I was able to still be her mom"--parenting at end of life in the pediatric intensive care unit. *Pediatr Crit Care Med* 2012;13(6):e350-356.
9. Longden JV. Parental perceptions of end-of-life care on paediatric intensive care units: a literature review. *Nurs Crit Care* 2011;16(3):131-139.
10. Polikoff LA, McCabe ME. End-of-life care in the pediatric ICU. *Curr Opin Pediatr* 2013;25(3):285-289.
11. Aschenbrenner AP, Winters JM, Belknap RA. Integrative review: parent perspectives on care of their child at the end of life. *J Pediatr Nurs* 2012;27(5):514-522.
12. Meert KL, Donaldson AE, Newth CJ, et al. Complicated grief and associated risk factors among parents following a child's death in the pediatric intensive care unit. *Arch Pediatr Adolesc Med* 2010;164(11):1045-1051.
13. Kars MC, Grypdonck MH, van Delden JJ. Being a parent of a child with cancer throughout the end-of-life course. *Oncol Nurs Forum* 2011;38(4):E260-271.
14. Meyer EC, Ritholz MD, Burns JP, et al. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics* 2006;117(3):649-657.
15. Meert KL, Briller SH, Schim SM, et al. Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. *Death Stud* 2009;33(8):712-740.
16. Rosenblatt P. *Parent Grief. Narratives of Loss and Relationship*. Philadelphia: Taylor & Francis; 2000.
17. Talbot K. *What forever means after the death of a child. Transcending the Trauma, living with the Loss*. New York and London: Routledge; 2002.
18. Tedeschi RG, Calhoun, L.G. *Helping bereaved parents; a clinical guide*. New York: BrunnerRoutledge; 2004.
19. Klass D, Silverman, P.R., Nickman, S.L., editor. *Continuing bonds: New understandings of grief*. Washington,DC: Taylor & Francis; 1996.
20. Field N. Whether to relinquish or maintain a bond with the deceased. In: Stroebe MH, R.O; Schut,H; Stroebe, W, editor. *Handbook of bereavement research and practice: Advances in theory and intervention*. Washington: American Psychological Association Press; 2008. p. pp. 113-132.

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© Falkenburg, J.L., Tibboel, D., Ganzevoort, R.R., Gischler, S.J., Hagoort, J. & van Dijk, M.

21. Bergman NJ, Linley LL, Fawcus SR. Randomized controlled trial of skin-to-skin contact from birth versus conventional incubator for physiological stabilization in 1200- to 2199-gram newborns. *Acta Paediatr* 2004;93(6):779-785.
22. Duhn L. The importance of touch in the development of attachment. *Adv Neonatal Care* 2010;10(6):294-300.
23. Mikulincer MS, P.R. An Attachment Perspective on Bereavement. In: Stroebe MH, R.O; Schut,H; Stroebe, W, editor. *Handbook of bereavement research and practice: Advances in theory and intervention*. Washington: American Psychological Association Press; 2008. p. p.87-112.
24. Sullivan R, Perry R, Sloan A, et al. Infant bonding and attachment to the caregiver: insights from basic and clinical science. *Clin Perinatol* 2011;38(4):643-655.
25. Flacking R, Lehtonen L, Thomson G, et al. Closeness and separation in neonatal intensive care. *Acta Paediatr* 2012;101(10):1032-1037.
26. Himmelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliat Med* 2006;9(1):163-181.
27. van der Geest IM, Darlington AS, Streng IC, et al. Parents' Experiences of Pediatric Palliative Care and the Impact on Long-Term Parental Grief. *J Pain Symptom Manage* 2013.
28. Miceli PJ, Clark PA. Your patient--my child: seven priorities for improving pediatric care from the parent's perspective. *J Nurs Care Qua* 2005;20(1):43-53; quiz 54-45.
29. Mack JW, Hilden JM, Watterson J, et al. Parent and physician perspectives on quality of care at the end of life in children with cancer. *J Clin Oncol* 2005;23(36):9155-9161.
30. Latour JM, van Goudoever JB, Duivenvoorden HJ, et al. Differences in the perceptions of parents and healthcare professionals on pediatric intensive care practices. *Pediatr Crit Care Med* 2011;12(5):e211-215.
31. Shildrick M, McKeever P, Abbey S, et al. Troubling dimensions of heart transplantation. *Med Humanit* 2009;35(1):35-38.
32. Mourik M, Tibboel D, Hunfeld JA, et al. [Care and experiences of 20 set of parents concerning the death of children in a surgical intensive care unit]. *Ned Tijdschr Geneesk* 1994;138(19):958-963.
33. Stroebe M, Schut H, Boerner K. Continuing bonds in adaptation to bereavement: Toward theoretical integration. *Clin Psychol Rev* 2010;30(2):259-268.
34. Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during

Falkenburg, J.L., Tibboel, D., Ganzevoort, R.R., Gischler, S.J., Hagoort, J. & van Dijk, M.
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- bereavement: a qualitative study. *Pediatr Crit Care Med* 2005;6(4):420-427.
35. Barrera M, O'Connor K, D'Agostino NM, et al. Early parental adjustment and bereavement after childhood cancer death. *Death Stud* 2009;33(6):497-520.
 36. Robinson MR, Thiel MM, Backus MM, et al. Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics* 2006;118(3):e719-729.
 37. Widger K, Picot C. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatr Nurs* 2008;34(1):53-58.