

## ORIGINAL ARTICLE

# Primary palliative care in the delivery room: patients' and medical personnel's perspectives

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**OBJECTIVE:** To investigate circumstances of primary palliative care (PPC) in the delivery room (DR), medical personnel's experience with neonates who died under PPC in the DR and perceived sources of care-related distress in DR staff.

**STUDY DESIGN:** Retrospective chart review of all neonates who were cared for under PPC in the DR during the years 2000–2010 at Charité University Medical Center Berlin, and structured face-to-face interviews with DR nursing staff and physicians.

**RESULT:** Neonates undergoing PPC could be grouped as preterm infants at the limits of viability with a gestational age between 22<sup>0</sup>/<sub>7</sub> and 23<sup>6</sup>/<sub>7</sub> weeks ( $n=86$ , 76%) and newborn infants with complex chronic conditions ( $n=27$ , 24%). The median age of neonates at death was 59 min (interquartile range [IQR] 28–105 min). Most of DR staff did not report relevant signs of distress in dying neonates, and providing palliative care was not named as a relevant care-related source of distress by medical personnel. However, half of the participants reported on high degrees of caregiver's emotional distress in PPC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress.

**CONCLUSION:** Caregiver's emotional distress primarily originates from providing support to parents and not from providing medical care to the dying newborn. Implications for future practice include the need for structured education to improve DR staff's communication and counselling skills related to parents in PPC situations.

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## INTRODUCTION

Despite a recently increased focus on palliative care of neonates in the setting of a neonatal intensive care unit (NICU),<sup>1–7</sup> little is actually known about how neonates die under primary palliative care (PPC) in the delivery room (DR). There is some evidence to show that pharmacological analgesia or sedation in neonates undergoing palliative care differs grossly between DR and NICUs. Two studies published in 2011 by Garten *et al.*<sup>8</sup> and Janvier *et al.*<sup>9</sup> showed that none of the newborns who died in the DR received any 'comfort medication' such as analgesics or sedatives. Both studies were based on retrospective chart reviews and had insufficient data to address the question whether neonates dying in the DR showed any signs of discomfort or pain. In fact, no formal investigation ever appears to have addressed this question.

There is ample literature supporting the view that end-of-life care of neonates in the NICU can be highly stressful for medical staff, and factors intensifying this distress have been identified.<sup>10–13</sup>

In contrast, care-related distress when providing PPC to dying newborns in the DR and supporting parents about to lose their infant soon after birth has not been subject to systematic investigations.

In the present work, we asked the following questions: (i) What are the medical conditions associated with PPC in the DR?, (ii) What are the circumstances under which neonates under PPC die in the DR?, (iii) What are the experiences and needs of medical staff providing PPC in the special setting of a DR? and (iv) What are relevant sources of care-related distress to staff providing PPC in DR?

We hypothesized (1) that caregivers report signs of pain and agitation in newborns dying under PPC in the DR and that these

symptoms are a significant source of distress to the child and medical personnel and (2) that DR staff primarily wishes for a structured and regular education on providing medical care to neonates in PPC situations.

## METHODS

### Setting

All patients included in the study analysis were born on one of three DRs of the Charité University Medical Center Berlin (Germany) located at Campus Benjamin Franklin, Campus Virchow Klinikum or Campus Charité Mitte. Within the study period, all DRs were part of level III perinatal centers.

Perinatal centers of the Charité University Medical Center Berlin are referral centers for an area of approximately 900 square kilometers in a large metropolitan area in central Europe. During the time period analyzed average number per year for all three locations combined was (i) 5,700 for inborn deliveries, (ii) 15 for all DR deaths of neonates of >22<sup>0</sup>/<sub>7</sub> weeks gestational age and (iii) 12 for DR deaths under PPC of neonates of >22<sup>0</sup>/<sub>7</sub> weeks gestational age.

Guidelines issued by the German Society for Neonatology and Pediatric Intensive Care call resuscitation to be performed in virtually all infants with a gestational age of least 24 weeks, while comfort care is reserved for all preterm infants with a gestational age below 22 weeks.

In preterm infants at the limits of viability (PILV), defined by a gestational age between 22<sup>0</sup>/<sub>7</sub> and 23<sup>6</sup>/<sub>7</sub> weeks, comfort care is to be performed unless parents explicitly agree to start resuscitative attempts.

During the study time no written specific clinical practice guidelines regarding PPC in the DR were implemented in any of the three perinatal centers. Since November 2011 voluntary educational opportunities in 'bereavement support for parents' and 'communication with parents of sick neonates' were offered to clinical staff members of the perinatal centers.

In August 2010, the Departments of Obstetrics and Neonatology at Campus Benjamin Franklin were closed and medical personnel was

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transferred to Campus Virchow Klinikum or Campus Charité Mitte. Therefore, all nursing staff and physicians taking part in the interviews were actually working in the DRs of Campus Virchow Klinikum or Campus Charité Mitte.

## Patients

We reviewed the medical reports of all neonates who died under PPC in the DRs between 1 January 2000 and 31 December 2010 and their mothers. PPC was defined by (i) withholding any measures of cardiopulmonary resuscitation and (ii) providing primary comfort care measures to enable a peaceful dying without suffering.

We excluded termination of pregnancies, stillborn neonates, neonates < 22 <sup>0</sup>/<sub>7</sub> weeks of gestation, and neonates who died while receiving cardiopulmonary resuscitation or after starting cardiopulmonary resuscitation followed by re-direction of care.

## Interviews

A qualitative interview study of the PPC experiences of nursing staff and physicians was undertaken. This approach was chosen to register aspects of complex attitudes and interactions, which quantitative methods are unable to reflect.<sup>14</sup>

Semistructured open-ended interviews lasting up to 1 h were conducted in person following an interview guide (Table 1). The interview guide primarily focused on exploring respondent views on the following main topics: (1) assessment and management of suffering in end-of-life care and (2) causes of caregiver's stress in PPC situations in the DR and selfcare practices. No sample-size calculation was performed as this was an explorative, descriptive study.

Eligible respondents were staff providing care to childbearing mothers and their newborns in the DRs of the Charité Berlin University Medical Center. There was no control or comparison group. In December 2011 and January 2012, potential staff participants were informed about the study via short lectures by LG and SG and asked to contact the study researcher if they were interested in participating in the study. The venue for staff interviews was at the choice of the interviewed, but all interviews took place on hospital premises. From February 2012 to April 2013, SG undertook all interviews and signed consent was obtained from each participant at the outset of their interview. Staff interviews took on average 30 min. Each participant received an €15 gift card per interview. All interviews were audio-recorded and transcribed after removal of identifying personal information.

Transcripts were reviewed for accuracy and loaded into MAXQDA 10 (VERBI GmbH, Berlin, Germany) for data management. Emblematic verbatim statements were identified and used to represent characteristic responses.

## Approval by Ethics Committee

The study was approved by the local institutional review board (Ethikkommission der Charité, #EA2/135/1).

## Statistical analysis

Patients' baseline characteristics are described as proportions (%) or median (range), respectively. Descriptive statistics consisted of frequency distributions of the variables. Data were compared by the Mann–Whitney *U*, Kruskal–Wallis or Chi-squared tests, as appropriate, assuming *P*-values < 0.05 to indicate statistical significance. All statistical calculations employed SPSS 20.0 (SPSS, Chicago, IL, USA).

Interview transcripts were analyzed iteratively by SG and JS using a qualitative content analysis approach to develop a clinically useful summary of medical staff's reports.<sup>15</sup> Emergent themes were discussed to develop a coding frame. Codes were added or revised as new themes emerged. Blocks of interview text were labeled by codes to characterize staff's statements. When this process was complete, the codes were merged into larger category labels that encapsulated the sample's shared responses. Emblematic verbatim statements from staff were identified and used to represent staff's characteristic responses to PPC processes in the DR.

## RESULTS

### Patients

Data were collected on 113 infants. Regarding the leading life limiting diagnoses using clinical data all infants included in the analysis could be separated into two main subgroups: (1) PILV with a gestational age between 22 <sup>0</sup>/<sub>7</sub> and 23 <sup>6</sup>/<sub>7</sub> weeks [according to Stephens *et al.*<sup>16</sup>] and (2) neonates with complex chronic conditions [CCC; according to a modified classification by Feudtner *et al.*<sup>17</sup> and Carter *et al.*<sup>18</sup>].

**Table 1.** Interview guide

#### *Respondent's experience with symptoms of dying neonates in the delivery room*

Please, report any symptoms you have observed in dying neonates in the delivery room.

Did you ever observe signs of pain, dyspnea or agitation in dying neonates in the delivery room?

Do neonates experience distress when dying under primary palliative care in the delivery room?

How should stressful symptoms in dying neonates under primary palliative care in the delivery room be treated sufficiently?

Do you think in cases of severe distress caused by pain, dyspnea or agitation, drugs (e.g., opioids or benzodiazepines) should be applied to dying neonates?

What are important aspects of a pharmacological therapy in end-of-life situations in the delivery room to you?

What could be reasons for insufficient symptom control in end-of-life care in the delivery room?

#### *Respondent's experience with caregiver's stress in end-of-life care in the delivery room and selfcare practices*

Do you have access to any professional exchange at your working place—such as individual or team counselling, structured education or staff support groups—focusing on palliative care in neonates? If not, should there be any professional exchange focusing on palliative care in neonates? What kind of professional exchange would you wish for?

What do you think causes relevant difficulties in primary palliative care the delivery room? How could these problems be met?

Did you gain positive experiences in primary palliative care situations in the delivery room?

Are there special aspects of primary palliative care in the delivery room that cause major distress to you personally? What could be helpful to you?

#### *Sociodemographic data and practice information*

How old are you?

For how long have you been working in the delivery room?

On average, how many deliveries do you care for in a year?

On average, how many primary palliative care situations do you manage per year?

When was the last time you cared for a newborn under palliative care in the delivery room?

Do you have children of your own?

Do you belong to any religion?

Does religion have an impact on your work?

Were you born in Germany?

**Table 2.** Data of mothers and prenatal counselling

	PILV	CCC	
N	86 (76%)	27 (24%)	
Mother's age <sup>a</sup>	28 years (25–33 years)	27 years (23–32 years)	n.s.
Medical treatment for infertility provided	N = 5 (4.4%)	N = 1 (0.08%)	n.s.
Gravidity <sup>a</sup>	2 (1–3)	2 (1–3)	n.s.
Parity <sup>a</sup>	1 (1–2)	1 (1–3)	P = 0.013
Admission to hospital before birth <sup>a</sup>	1 day (0–5 days)	1 day (0–4 days)	n.s.
Diagnosis of infant known before birth	N = 55/78 (70.5%)	N = 24/25 (95.0%)	P = 0.009
Time period diagnosis was told to parents before birth <sup>a</sup>	1 day (0–2 days)	5 days (0–9 days)	P = 0.001
<i>Prenatal screening and diagnosis</i>			
None	N = 12/82 (14.6%)	N = 1/25 (4.0%)	n.s.
By local obstetricians	N = 7/82 (8.5%)	N = 4/25 (16.0%)	
By local and in-house obstetrician	N = 15/82 (18.3%)	N = 7/25 (28.0%)	
By in-house obstetrician	N = 48/82 (58.5%)	N = 13/25 (52.0%)	
<i>Prenatal counselling by neonatologist</i>			
None	N = 45 (52.3%)	N = 5 (18.5%)	P = 0.001
Extern and intern	N = 0 (0%)	N = 1 (3.7%)	
Intern (1 ×)	N = 25 (29.1%)	N = 8 (29.6%)	
Intern (> 1 ×)	N = 16 (18.6%)	N = 13 (48.1%)	
Documented EOLD	N = 40 (46.5%)	N = 20 (74.1%)	P = 0.012

Abbreviations: CCC, neonates with complex chronic conditions; EOLD, end-of-life decision; IQR, interquartile range; PILV, preterm infants at the limits of viability (gestational age between 22<sup>0</sup>/<sub>7</sub> and 23<sup>6</sup>/<sub>7</sub> weeks). <sup>a</sup>Data are presented as median and IQR.

**Table 3.** Population profile of analyzed deceased patients

	PILV	CCC	
Sex (female:male), N = 113	40:46	16:11	n.s.
Gestational age <sup>a</sup>	22.7 weeks (22.0–23.3 weeks)	26.6 weeks (23.0–35.0 weeks)	P < 0.001
Birth weight <sup>a</sup>	500 g (440–540 g)	840 g (600–1860 g)	P < 0.001
<i>Multiple births</i>			
Twins	N = 35 (40.7%)	N = 3 (11.1%)	P = 0.003
Triplets	N = 6 (7.0%)	N = 0 (0%)	
<i>Delivery mode</i>			
Vaginal delivery	N = 81 (94.2%)	N = 20 (74.1%)	P = 0.031
Instrumental delivery	N = 2 (2.3%)	N = 3 (11.1%)	
Cesarean section (planned)	N = 2 (2.3%)	N = 3 (11.1%)	
Cesarean (emergency)	N = 1 (1.2%)	N = 1 (3.7%)	
<i>Apgar</i>			
1 min <sup>a</sup>	2 (1–2)	1 (1–2)	n.s.
5 min <sup>a</sup>	1 (1–1)	2 (1–2)	n.s.
10 min <sup>a</sup>	1 (1–1)	1 (1–1)	n.s.
Age at death <sup>a</sup>	57 min (25–98 min)	53 min (28–100 min)	n.s.
Received any medication for symptom control	2	0	n.s.

Abbreviations: CCC, neonates with complex chronic conditions; IQR, interquartile range; n.s., not significant; PILV, preterm infants at the limits of viability (gestational age between 22<sup>0</sup>/<sub>7</sub> and 23<sup>6</sup>/<sub>7</sub> weeks). <sup>a</sup>Data are presented as median and IQR.

In all, 76% of all neonates were PILVs and 24% were neonates with CCC. The median age of all neonates at death was 59 min (interquartile range [IQR] 28–105 min), showing no significant difference between the two subgroups. Detailed data of mothers, prenatal counselling and the deceased neonates are summarized in Tables 2–4.

#### Interviews

A total of 51 nurses and 23 physicians were invited to participate in the study, 24 nurses and 14 physicians agreed to participate and all were interviewed. Thirty-eight audio-recorded interviews were completed. All participants were currently working on one of the DRs at the Charité University Medical Center of Berlin. Basic

**Table 4.** Diagnoses within the group of infants with complex chronic conditions (modified classification from Feudtner *et al.*<sup>17</sup> and Carter *et al.*<sup>18</sup>)

Complex chronic condition	N (%)
Oncologic/hematologic	0 (0)
Cardiovascular	10 (37.0)
Neuromuscular	4 (14.8)
Respiratory	1 (3.7)
Renal	3 (11.1)
Metabolic	0 (0)
Gastrointestinal	0 (0)
Other congenital/genetic	9 (33.3)

**Table 5.** Sociodemographic data of DR staff interviewed (N=38)

Sample	Nursing staff	Physicians
<i>n</i>	24	14
<i>Age, years</i>		
20–30	9	2
30–40	7	7
>40	8	5
Sex (female:male), <i>n</i>	24:0	9:5
Have children, <i>n</i>	11 (44%)	7 (50%)
Years working in DR	9 (3–20)	6 (3–12)
Average number of deliveries cared for per year	100 (75–110)	300 (250–300)
Number of neonates cared for in end-of-life situations per year	3 (2–6)	2 (1–4)
Last time when cared for a dying neonate in the DR, months	6 (3–9)	6 (2–12)
<i>Religion, n</i>		
Yes:No	11:13	7:7
<i>Religion has an impact on work?</i>		
None	6/10	0/8
Moderate	3/10	2/8
Strong	1/10	6/8
<i>Foreign-born, n</i>		
Yes:No	1:23	3:11

Abbreviation: DR, delivery room.

sociodemographic data of all participants are summarized in Table 5.

**Assessment and management of suffering in end-of-life care.** When asked for symptoms observed in dying neonates, most participants (30/34) reported respiratory symptoms such as hypopnea/apnea, gasping or dyspnea/tachypnea. Other symptoms observed were tachycardia or bradycardia (21/34), 'abnormal movements' (17/34) and vocal expression such as crying or whining (7/34). When asked if they thought that the neonates they cared for were experiencing distress, more than half (14/34) stated that they did not observe any stressful symptoms: 'I do not think they [neonates under palliative care] suffered from any stress, because we as a team allowed for privacy and calmness ... I really think they passed away peacefully.'

Any distress reported was related to dyspnea (9) and agitation (5). Treatment of first choice applied by participants to control stressful symptoms in dying neonates was providing external warmth and skin contact (11/34). Oxygen supplementation or pharmacological analgesia/sedation was mentioned just once. Nearly all participants (30/34) agreed that in cases of relevant signs of distressing symptoms despite non-pharmacological measures (for example, skin contact) neonates under PPC should receive pharmacological pain/agitation management. Important demands on pharmacological pain treatment were (in the order of reported frequency): (1) treatment should not interfere with the dying process of the child (no acceleration or extension); (2) medication should be easy to apply (for example, no i.v.-medication) and (3) application of medication should not disturb the parent-child interaction or cause oversedation ('If there is relevant pain or distress, yes, that should be treated ... but a child should not be sedated so deeply that parents cannot distinguish between death and sleep.'). When asked for potential reasons for insufficient pain control in dying neonates in the DR, main problems seen by staff were personnel's ignorance to

methods of pain and distress assessment in neonates, insufficient pharmacological expertise and fear of legal consequences when giving drugs such as opioids ('I think it is very difficult in fact and law. It seems so hard to decide, when to give [opioids].' Also, 'If there were official guidelines, no doubt, I would feel better giving strong pain killers if necessary.')

**Caregiver's stress: causes and selfcare practices.** Fifty percent of participants reported to experience high degrees of emotional stress in PPC situations: 'For sure, this (palliative care in the DR) causes emotional distress—definitely for everybody.'

Being insecure how to communicate with parents losing their newborn child was the most common source of distress identified ( $n=20/34$ ): 'To find the right words... you cannot just say flowery phrases like 'I am sorry' or something like this ... this is always so difficult.' Another stated: 'How should you react? Should you show that you are sad or not? What is right and what is wrong? I do not know...'

Staff considered communication to be especially problematic if parents' wishes or decisions in end-of-life situations were difficult to accept or to put into practice by the DR team ( $n=14/34$ ). Furthermore, situations in which team members were insecure how to relieve the perceived needs or how to meet the witnessed emotions of parents lead to higher levels of stress ( $n=9/34$ ): 'It's very difficult for me, especially when decisions were made by parents, that I would never make by myself.' Also, 'Sometimes mothers feel like being punished for whatever. .... Sometimes this is hard to witness knowing you cannot help.'

Additionally, certain environmental factors were mentioned by more than half of participants as sources of stress, for example, shortage of staff ( $n=16/34$ ). Some of the DR team members found the lack of appropriate rooms providing a family-centered atmosphere additionally stressful ( $n=7/34$ ).

When asked to name factors enabling staff to function effectively and cope with stress three main areas were reported to be vital to participants: First, personal exchange ('unloading' on people being close) with one's family and friends ( $n=12/38$ ) ('I often go and see friends ... you cannot deal with this emotional stress on your own.' or 'To have a shoulder to cry on—that's really important in dealing with these situations.'). Second, to keep professional distance ( $n=7/38$ ) and being satisfied with own work ( $n=5/34$ ). And third, positive experiences during PPC, for example, witnessing a 'good' and harmonious emotional interaction between parents and their dying newborn ( $n=13/34$ ) or getting positive feedback from parents ( $n=9/34$ ), also decreases stress levels: 'Once I got a letter written by parents who lost their newborn baby... they were deeply grateful. They remembered me touching the dead baby's hand when I left the delivery room because my shift ended. They wrote that this little gesture deeply touched them and still means a lot to them... Things like this, that's what really helps me in dealing with the strain.' Another stated: 'My task is to be an empathetic companion. To support parents in standing this horrible situation ... sometimes we see parents so in love with their baby, they enjoy every second with their dying child while in parallel starting grieving for the loss ... and they say 'it is so cruel and unfair' but you feel they will get through this, then I personally think I did a good job.'

Surprisingly, only three participants mentioned that palliative care is a genuine part of their personal concept of profession.

Most ( $n=22/34$ ) reported that professional exchange about PPC cases in their working place consists of communication between staff members: 'Yes, there is a lot of exchange within the team, but not in a structured way ... it's more often short talks between colleagues during shift change or when we make a short break.' Also, 'The more stressful the situation is, the more I prefer talking to one or two close colleagues and not to many.'

However, less than a quarter ( $n=8/34$ ) of staff members said that this casual and unstructured exchange serves as a good

coping strategy. Nearly 50% ( $n=17/38$ ) wished for a more professional structured exchange/education. Participants' first wish to improve their situation was to establish structured lectures in palliative care ( $n=13/38$ ). Special topics that should be addressed to were (1) symptom/pain assessment and control in dying neonates ( $n=7/34$ ) and (2) communication with parents losing a child/bereavement support ( $n=5/34$ ).

Tests of significance were used to determine differences in answers by demographic characteristics such as age, having children, being foreign-born or impact of religion on work. All results were statistically non-significant. Obviously, the small sample size, coupled with homogeneity based on geographic location and cultural background, significantly limits the generalizability of our study findings.

## DISCUSSION

This study retrospectively analyses data of neonates who died under PPC in the DR. Furthermore, the value of this qualitative interview-based study lies in examining the experiences of medical personnel who deliver PPC in the DR. The following answers can be gained from the study to answer the questions posed at its onset:

*'What are the medical conditions resulting in PPC in the DR?' and 'What are the circumstances under which neonates under PPC die in the DR?'*

PILV with a gestational age between 22  $\frac{0}{7}$  and 23  $\frac{6}{7}$  weeks formed the main subgroup among neonates that died under PPC in the DR (three quarters of all patients). The remaining patients were newborns with CCC, mainly with cardiovascular, neuromuscular or genetic diseases. There was no significant difference between these two subgroups with regard to age at death, which was about 1 h for all patients. When asked whether they thought that dying neonates they have cared for were experiencing significant distress, more than half of DR staff stated that they did not observe any stressful symptoms.

Remarkably, only 2 out of 113 patients received pharmacological treatment for symptom control. This finding is consistent with formerly published data addressing the frequency of 'comfort medication' such as analgesics or sedatives medication in dying neonates in the DR.<sup>8,9</sup> Why should there be no need for pharmacological analgesia or sedation in neonates who die under PPC in the DR?

We hypothesize that there are four unique aspects of PPC in the DR why these end-of-life situations are distinct from other end-of-life situations and thus could explain our observation.

First, neonates cared for under PPC in the DR are usually born breathing inadequately or being primarily apnoeic due to immaturity or other reasons. Unless heavily stimulated, they die from prolonged central apnea. Without a respiratory drive, there are also no feelings of suffocation. Gasping at the end of life is not to be confused with dyspnea.<sup>19</sup> Second, in these end-of-life situations progressive hypoxia and hypercapnia could serve as a 'natural sedative'. Third, arginine-vasopressin, which acts via the vasopressin receptor 1A as a potent endogenous pain killer and has been strongly implicated in perinatal analgesia, is released at high quantities during birth.<sup>20,21</sup>

Finally, neonates in the DR receiving adequate PPC do not suffer from procedure-related pain and are rarely exposed to disease-related pain. Prospective research regarding systematic documentation of clinical circumstances and distress symptoms in dying neonates under PPC in the DR is needed to continue exploring these hypotheses.

*'What are the experiences and needs of medical staff providing PPC in the special setting of a DR?' and 'What are relevant sources of distress to staff providing PPC in DR?'*

Half of the participants reported to experience high degrees of emotional stress in PPC situations. In contrast to our hypothesis medical care to the patient, such as assessment and treatment of pain or agitation, was not named as a relevant source of care-related distress. Being insecure how to communicate with parents losing their newborn child was the most common source of distress identified. This finding is in agreement with other reports to the effect that medical staff working in palliative care experiences emotional distress mainly in communicating with patients and relatives.<sup>22–25</sup> We consider this an important finding, as lack of self-confidence in professionals' own communication skills with patients and relatives was already identified as the main risk for burnout in health-care providers working in the field of palliative care.<sup>26,27</sup> It seems reasonable to hypothesize that these aspects have a greater role in the DR than in a palliative care unit. People attracted to working in the DR environment enjoy applying their skills and energy to care for healthy babies or for preterm or sick newborns getting better under medical care and surviving. Caring for a dying patient remains the exception, not the normal case. Furthermore, Boss *et al.*<sup>28</sup> showed that medical NICU staff is highly trained in the technical skills necessary to care for critically ill and dying neonates but are inadequately trained in the communication skills that families identify as critically important when facing end-of-life situations.

There are several limitations of this study. We conducted the interviews at a single institution that poses obvious limits to number of staff participating in the interviews. The participants were those nurses and physicians who were willing to spend their time to participate in the interviews. Those who chose to respond may have had a special interest or strong beliefs regarding this subject or their experiences, which may have differed from those of non-responders. For these reasons, we cannot be sure that our findings are applicable to all staff members working at our institution, or to medical staff working outside our institution. In addition, reporting bias is difficult both to prevent and to estimate. Finally, the data analysis of the deceased patients was retrospective, and documentation bias is difficult to control for in such a setting.

In conclusion, death in the DR causes relevant emotional distress to medical staff and will continue to be a reality. This study underscores an impressive need to support medical personnel to handle this unique palliative care situation. DR staff is to be encouraged to continuously improve communication skills with parents and have an active role in helping parents to cope with PPC situations. In addition, continuous structured education in basic skills of palliative care could be offered. Main topics of education should include symptom assessment and non-pharmacological and pharmacological ways of symptom control. This is supported by earlier studies that show education by individuals experienced in palliative care may positively affect medical personnel comfort level in supporting and aiding families with these experiences.<sup>29–31</sup>

Furthermore, for the reasons mentioned above, we believe that DR staff could be reassured that in most PPC situations in the DR emphasis should be placed on avoiding painful procedures and, exposure to cold, alongside establishing an atmosphere of physical and emotional intimacy, rather than pharmacologic intervention, to enable a peaceful dying without somatic suffering. Future prospective studies are needed regarding distress in dying neonates under PPC in the DR using structured assessment tools to determine the appropriate balance of measures.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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