

## Supplemental III

Table 3 Detailed characteristics of included studies

Authors (year), Location	Qualitative study aims	Setting	Participants	Characteristics of the children	Research methodology/ qualitative data collection method/ qualitative data analysis method
Mitchell, (2019), United Kingdom [18]	To provide in-depth insight into the experience and perceptions of bereaved parents who have experienced end-of-life care decision-making for children with life-limiting or life-threatening conditions in the PICU.	PICU (31 beds)	17 bereaved parents of 11 deceased children (5 single mothers and 6 coupled parents) The mean time between bereavement and interview was 11.8 months, median 10 months, and the shortest was 7 months.	< Age at death (N = 11) > <ul style="list-style-type: none"> <li>• 5 months (n = 2)</li> <li>• 6 months (n = 1)</li> <li>• 9 months (n = 1)</li> <li>• 1 year 11 months (n = 1)</li> <li>• 2 years (n = 1)</li> <li>• 2 years 11 months (n = 1)</li> <li>• 3 years (n = 1)</li> <li>• 11 years (n = 1)</li> <li>• 16 years (n = 1)</li> <li>• 18 years (n = 1)</li> </ul> < Type of death > Children with a pre-existing life-limiting condition.	In-depth qualitative interview study/ semi-structured interview/ thematic analysis

Liu , (2014), Taiwan [23]	To explore the parental experience of making a “do not resuscitate” (DNR) decision for their child who is or was cared for in a PICU in Taiwan.	PICU	16 bereaved parents (9 mothers and 7 fathers) All of the participants were approached to sign the DNR form by a physician who was involved in their child’s care.	N =11 Parents of children who were admitted for presumed or confirmed abuse, neglect, or accidental trauma were excluded. At the time of the interview, 6 children were living and 5 were deceased.	Qualitative study/ non-specified (interviews were held at the parent’s selected place)/ thematic content analysis
Abib, (2013), Brazil [28]	To evaluate the quality of care offered to terminally ill children and their families in the last days of life in two Brazilian PICUs from the parents’ perspectives.	2PICUs	15 bereaved parents of 9 deceased children	N = 10 <Age at death/ PICU length of stay (days)/ Main diagnosis(n) > • 2 months/13 days/ septic shock/ renal failure/ hepatic failure (n = 1) • 5 months/9 days/acute viral bronchiolitis(AVB)/ cardiogenic shock/congenital heart disease/Down’s syndrome/sepsis (n = 1) • 8 months/4 days/AVB/septic shock (n = 1) • 11 months/5 days/acute respiratory distress(ARDS) (n = 1) • 13 months/11 days/ AVB/ septic shock/ ARDS/ renal failure (n = 1) • 14 months/4 days/AVB/septic shock/ARDS (n = 1)	Qualitative exploratory descriptive study/ semi-structured interview/ thematic content analysis

				<ul style="list-style-type: none"> <li>• 27 months/8 days/AVB/septic shock/ARDS/renal failure (n = 1)</li> <li>• 48 months/32 days/Septic shock/ARDS/parainfluenza pneumonia /neuroblastoma (n = 1)</li> <li>• 60 months/16 days/ Short bowel syndrome/septic shock (n = 1)</li> <li>• 120 months/ 20 days/ AVB/septic shock/ARDS/renal failure/hyponatraemia (n = 1)</li> </ul> <p>&lt;Cardiopulmonary resuscitation&gt;</p> <ul style="list-style-type: none"> <li>• Yes (n = 6)</li> <li>• No (n = 4)</li> </ul>	
Lamiani, (2013), Italy [19]	To explore parents' experience with end-of-life care in a PICU in Italy.	PICU (6 beds)	12 parents of 8 deceased children	<p>&lt;Age at death (N = 8)&gt;</p> <ul style="list-style-type: none"> <li>• 2 months (n = 2)</li> <li>• 8 months (n = 1)</li> <li>• 9 months (n = 1)</li> <li>• 2 years (n = 1)</li> <li>• 3 years (n = 1)</li> <li>• 8 years (n = 1)</li> <li>• 13 years (n = 1)</li> </ul> <p>&lt;Type of admission (N = 8)&gt;</p> <ul style="list-style-type: none"> <li>•Emergency (n = 7)</li> <li>•Planned (n = 1)</li> </ul> <p>&lt;Length of the last PICU stay (N = 8)&gt;</p> <ul style="list-style-type: none"> <li>•4 days (n = 1)</li> <li>•8 days (n = 1)</li> <li>•9 days (n = 2)</li> </ul>	Hermeneutic-phenomenology approach/ semi-structured interview/ phenomenological analysis

				<ul style="list-style-type: none"> <li>•10 days (n = 1)</li> <li>•11 days (n = 1)</li> <li>•31 days (n = 1)</li> <li>•44 days (n = 1)</li> </ul> <p>&lt;Type of death (N = 8) &gt;</p> <ul style="list-style-type: none"> <li>•Withdrawing of life support (n = 3)</li> <li>•Withholding of life support (n = 1)</li> <li>•Withholding and withdrawing of life support (n = 2)</li> <li>•Failed CPR (n = 2)</li> </ul>	
McGraw, (2012), United States [24]	To explore how parents of children dying in the PICU understood their role and discuss implications for clinical care and policy.	2 PICUs	18 bereaved parents (17 mothers)	<p>N = 18</p> <p>&lt;Age at death / Range (n)&gt;</p> <ul style="list-style-type: none"> <li>• Infant / .3–7 (n = 6)</li> <li>• Toddler•Child / 1.5–4 (n = 3)</li> <li>• Pre-teen•adolescent / 10–12 (n = 2)</li> <li>• Adult / 19–37 (n = 7)</li> </ul> <p>&lt;Type of condition (n)&gt;</p> <ul style="list-style-type: none"> <li>• Acute (n = 3)</li> <li>• Chronic (n = 15)</li> </ul> <p>&lt;Diagnosis (n)&gt;</p> <ul style="list-style-type: none"> <li>• Leukemia (n = 5)</li> <li>• Other cancer (n = 4)</li> <li>• Other (n = 4)</li> <li>• Congenital diaphragmatic hernia (n = 3)</li> <li>• Cystic fibrosis (n = 1)</li> </ul>	Qualitative study/ semi-structured telephone interviews/ analytically, a series of iterative steps were employed using Atlas.ti to facilitate the coding.

				<ul style="list-style-type: none"> <li>• Trauma/burns (n = 1)</li> </ul> <Length of stay in PICU (n)> <ul style="list-style-type: none"> <li>• 0–7 days (n = 5)</li> <li>• 8–14 days (n = 5)</li> <li>• 15–21 days (n = 2)</li> <li>• 22–28 days (n = 3)</li> <li>• 29 days + (n = 3)</li> </ul>	
Gordon, (2009), United States [25]	To present parents' descriptions and narratives of communicative experiences they had with PICU clinicians, focusing on how parents use accounts to evaluate the communicative behaviors they report.	Not specified	Bereaved parents (N = 51)	Not specified	Semi-structured audio-recorded telephone interview/ discourse analysis
Butler, (2018), Australia [21]	To explore bereaved parents' judgements of healthcare providers in the PICU, as part of a	4 PICUs	26 bereaved parents (10 individual mothers and 8 couples)	< Age at death (N = 18) > <ul style="list-style-type: none"> <li>• Infant; &lt; 1 year (n = 9)</li> <li>• Toddler; 1–5 years (n = 4)</li> <li>• Teenager; 13 years (n = 5)</li> </ul> <Illness type (N = 18)>	Constructivist grounded theory study/ semi-structured interviews (in the parents' home environment or phone)

	larger study which aimed to explore their interactions with HCPs when their child died in the PICU.		Range of time since death: 7 months to 3 years 8 months	<ul style="list-style-type: none"> <li>• Chronic (n = 7)</li> <li>• Acute (n = 11)</li> </ul> <Type of death (N = 18) > <ul style="list-style-type: none"> <li>• Withdrawal (n = 17)</li> <li>• CPR (n = 1)</li> <li>• Unsuccessful (n = 1)</li> </ul>	interviews)/ the constant comparative analysis method was used to analyze the data, alongside open, focused and theoretical coding.
Butler, (2018), (secondary analysis of 2018 [21] study), Australia [27]	To explore bereaved parents' perspectives of parent and staff roles in the PICU when their child was dying, as well as their relationships with healthcare staff during this time.	Same as above	Same as above	Same as above	Same as above
Butler, (2019) (tertiary analysis of 2018a study), Australia [26]	To describe bereaved parents' recommendations for improvements in end-of-life care and bereavement follow-up when a child dies in intensive care.	Same as above	Same as above	Same as above	Same as above

Falkenburg, (2016), Netherlands [31]	To explore in what sense physical aspects influence the parent-child relationship in end-of-life care in the PICU.	PICU (34 beds)	16 couples and 3 mothers and 1 father individually participated	<p>&lt; Age at death (N = 20) &gt;</p> <ul style="list-style-type: none"> <li>• Newborns (n = 2)</li> <li>• 1 month to 1 year (n = 11)</li> <li>• &gt; 1 to 6 years (n = 3)</li> <li>• &gt; 6 to 14 years (n = 4)</li> </ul> <p>&lt;Diagnosis (N = 20)&gt;</p> <ul style="list-style-type: none"> <li>• Complex cardiac anomaly (n = 8)</li> <li>• Respiratory insufficiency (n = 3)</li> <li>• Congenital diaphragmatic hernia (n = 2)</li> <li>• Trauma (n = 2)</li> <li>• Neuromuscular disease (n = 2)</li> <li>• Metabolic disorder (n = 1)</li> <li>• Arteriovenous malformation (n = 1)</li> <li>• Oncologic (n = 1)</li> </ul> <p>&lt;Extracorporeal membrane oxygenation treatment&gt;</p> <ul style="list-style-type: none"> <li>• n = 5 (25.0%)</li> </ul> <p>&lt; Length of stay ICU last admission &gt;</p> <ul style="list-style-type: none"> <li>• 12 days (median)</li> </ul>	Qualitative study/ unstructured in-depth interviews/ coding and selection of themes
Falkenburg, (2018) (secondary analysis of 2016 study), Netherlands	To learn what interactions of grieving parents with medical and nursing staff remain meaningful in the	Same as above	Same as above	Same as above	Same as above

[20]	long term when facing the existential distress of their child's death in the PICU.				
Falkenburg, (2020) (tertiary analysis of 2016 study), Netherlands [22]	To learn more from the stories of bereaved parents about the specific features and function of the spirituality that is part of the confrontation with death.	Same as above	Same as above	The children's age at the time of death varied from 2 weeks to 14 years. Length of stay in the PICU varied from 2 hours to over 5 months. Four children had been hospitalized from birth until death.	Qualitative study/ unstructured face-to-face interviews (in the parents' home environment)/ coding and selection of themes
Michelson, (2011), United States [30]	To examine clinicians' and parents' reflections on PICU family conferences (FCs) in the context of discussion about end-of-life care decision making.	PICU (A university-based hospital)	18 bereaved parents (11 Female, 7 Male)	N = 13 Parents of a child $\geq$ 8 years old (younger children who rarely have the capacity to assent to treatment and participate in end-of-life decisions). <Age at death (years)> • Mean 1.9 • Median 0.53 • Range 0.06–6.5 <Limitations of medical therapies identified (n)>	Retrospective qualitative study/ semi-structured one-on-one interviews/



				<ul style="list-style-type: none"> <li>• Yes (n = 12)</li> <li>• No (n = 1)</li> </ul> <p>&lt;Cause of death (n)&gt;</p> <ul style="list-style-type: none"> <li>• Neoplasm (n = 7)</li> <li>• Heart disease (n = 3)</li> <li>• Bowel perforation (n = 1)</li> <li>• Sepsis (n = 1)</li> <li>• Trauma (n = 1)</li> </ul> <p>&lt;PICU length of stay (days)&gt;</p> <ul style="list-style-type: none"> <li>• Mean 8.7</li> <li>• Median 3</li> <li>• Range 0–38</li> </ul>	
Michelson, (2013) (secondary analysis of 2011 study), United States [29]	To describe issues important in PICU end-of-life care decision making and identify possible methods for improving the decision-making process for parents.	Same as above	Same as above	Same as above	Retrospective qualitative study/ one-on-one interviews/ open coding (labeling of data based on ideas, concepts, patterns, and properties identified) of the entire dataset. From this coding, the category emerged.