

Supplementary Table 4: GRADE-CERQual - Evidence Profile Table

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References	
<b>1A ESTABLISHING THE PARENTAL ROLE</b>							
1	<p>It was important that new parents of infants receiving end-of-life care established themselves in a parental role - the surrounding of a NICU setting can present challenges to this. Physical separation and medical instability of their child was distressing and constraining for parents. For some, this led to hesitation or lack of confidence, with fathers in one study, particularly reporting discomfort at handling such fragile infants.</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> Very minor methodological limitations (five studies with no or very minor concerns and one study with minor methodological limitations)</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance</p>	38-43
2	<p>Encouragement and practical support from staff to hold their baby and provide caregiving enabled the establishment and enactment of the parent-child relationship</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> The studies appear to be rigorously conducted</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> The finding was coherent across all the studies</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> All perspectives and contexts are covered</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> All studies are directly relevant</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding</p>	38-44

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
					coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	
3 For parents of NICU babies who only lived a short time, it was particularly crucial to maximise time together as this allowed parent to get to know their baby and create an identity for them.	No/Very minor concerns  <b>Explanation:</b> Very minor concerns (three studies with no or very minor concerns and one study with minor methodological limitations)	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	38,39,41,43
<b>1B MAINTAINING IDENTITY AS A PARENT</b>						
4 Parents with children receiving end-of-life care needed to navigate maintaining their parental role. This relied on developing a collaborative and trusting team relationship with healthcare professionals based on a sense of common purpose and an understanding of each other's roles. This	Minor concerns  <b>Explanation:</b> Minor concerns regarding	Minor concerns  <b>Explanation:</b> Some minor concerns about the fit	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> Minor concerns	8,36-39,42,44-53

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
relationship was fragile and when broken could lead to parents feeling excluded.	methodological limitations because six of the sixteen studies had minor methodological concerns (unclear theoretical underpinnings, recruitment strategies, data collection and analysis)	between the data from primary studies and parts of the review finding			regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	
5 Parents had their own vision of how to express their role in terms of continued levels of involvement in the physical care of their child. Desired levels of involvement varied between parents, with some parents of older children expressing less of a need to be intimately involved in physical care. Parents of chronically ill children more accustomed to providing nursing care were keen to continue this role.	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> Minor concerns regarding adequacy as the richness of data was good, but only two studies discussed specific factors that may influence the parents view of their role	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	36,39,40,42,42,50,54

Finding		Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
6	Parents highlighted a need for space and privacy in order to preserve the family intimacy. Busy wards and unfamiliar intensive care settings provided little escape. Having unrestricted visiting hours and private family spaces enabled families to spend time together.	No/Very minor concerns  <b>Explanation:</b> Very minor concerns regarding methodological limitations - five of the seventeen studies had minor methodological concerns (unclear theoretical underpinnings, recruitment strategies, analysis, and clarity of findings)	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	8,36,38-41,43,44,47-49,51,54,56-58
<b>1C RESPONSIBILITY FOR THEIR CHILD</b>							
7	Parents were compelled to take some share of the ultimate responsibility for their child's end-of-life care planning and that this was central to their identity as parents.	Minor concerns  <b>Explanation:</b> Minor concerns regarding methodological limitations because minor concerns with one of the two studies (unclear theoretical underpinnings and	No/Very minor concerns  <b>Explanation:</b>	Moderate concerns  <b>Explanation:</b> Moderate concerns regarding adequacy because the quantity of data was limited, with only two studies contributing to the review finding	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding	39,43

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
	researchers' relationship)				adequacy (only two studies contributed to the finding), and No/Very minor concerns regarding relevance	
8	<p>Parents wanted healthcare professionals to provide complete, honest, and understandable information, while also listening to parents' views and concerns. Parents openness to planning and discussing end-of-life care varied and it was important that this was handled sensitively and tailored to parents' needs.</p>	<p>Minor concerns</p> <p><b>Explanation:</b> Minor concerns regarding methodological limitations because six of the sixteen studies had minor methodological concerns (unclear theoretical underpinnings, recruitment strategies, research relationships, data collection and analysis)</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance</p>	<p>8,36,38,39,42,45-53,55,58</p>
9	<p>Most parents wanted to advocate for their child and represent their best interests, and to be absolutely sure that both the healthcare professionals and the parents themselves had done everything they could. Others were overwhelmed and welcomed clinicians taking control, while a few fathers reported relying on their wives/partners to make decisions as they felt they were more involved and better informed.</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> Very minor concerns regarding methodological limitations</p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b></p>	<p>No/Very minor concerns</p> <p><b>Explanation:</b> No/Very minor concerns regarding methodological</p>	<p>8,36,38,39,42,44-47,49-51,53-56,58</p>

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
	because five out of the seventeen studies had minor concerns around methodology (unclear theoretical underpinnings, recruitment strategies, data collection and analysis)				limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	
<b>1D RECONSTRUCTING THE PARENTAL ROLE</b>						
10	Parents' view of how to express their role could shift with the trajectory of their child's illness and for some parents, accepting their child had reached the end of their lives, involved moving from a state of 'doing' to 'being', placing more emphasis on spending time together and supporting their child.	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> Minor concerns regarding adequacy as the quantity of data was limited, with only four studies contributing to the review finding	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance
11	For some parents taking their child home or moving into hospice care for end-of-life care, meant, regaining control	No/Very minor concerns	Minor concerns	Minor concerns	No/Very minor concerns	Minor concerns 38,40,46-49,51,56,57

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
and being in a place where some sense of family life and parenting could return	<b>Explanation:</b>	<b>Explanation:</b> Minor concerns regarding coherence because variations in the data apparent with some families uncomfortable with prospect of being at home	<b>Explanation:</b> Minor concerns regarding adequacy because limited data about experiences of hospice care	<b>Explanation:</b>	<b>Explanation:</b> No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	
12 For some children, end-of-life comfort care meant being released from the constraints of medical equipment, and so parents had unrestricted access to hold them, sometimes, for the first time.	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> Minor concerns regarding coherence because data highly coherent across two out of three studies	Moderate concerns  <b>Explanation:</b> Moderate concerns regarding adequacy because only two studies provided specific data supporting this finding, the third provided little detail	No/Very minor concerns  <b>Explanation:</b>	<b>Explanation:</b> No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence, Moderate concerns regarding adequacy (only three studies contributed to the finding), and No/Very minor concerns	40,41,54

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
regarding relevance						
<b>1E CONTINUING PARENTING THROUGH DEATH AND BEYOND</b>						
13	Being prepared for their child's death as far as was possible, enabled parents to be with their child as they died, to hold them and to say goodbye.	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> Fourteen of the studies provided data that supported the finding	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance
14	The need to fulfil the parental role did not end when a child died and for those who were able to, spending time with their child's body was important and helped parents 'take leave'. Parents who were initially reluctant reflected that they were grateful that this was encouraged by the nursing staff	No/Very minor concerns  <b>Explanation:</b>	<b>Explanation:</b> No concerns about coherence - data was similar across studies	<b>Explanation:</b> Rich data across a range of settings and child age and conditions	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding



Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References	
					coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance		
15	Memories and keepsakes generated during end-of-life care were deeply cherished and helped parents to remember and tell the story of their child's life and identity and their time together as a family. For parents of NICU babies these served as physical evidence of their child's existence	No/Very minor concerns  <b>Explanation:</b> Very minor concerns as two out of the eight studies that contributed to this finding had minor concerns about methodology	Minor concerns  <b>Explanation:</b> Minor concerns regarding coherence with similar data across studies	Moderate concerns  <b>Explanation:</b> Moderate concerns regarding adequacy because very rich data from two of the eight studies contributing to this study, with thinner data from the other six	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence, Moderate concerns regarding adequacy (2 out of 8 studies with rich data), and No/Very minor concerns regarding relevance	8,38-41,43,57,59
16	Parents acknowledged the need for bereavement support both before and after death.	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> Minor concerns regarding adequacy because	Minor concerns  <b>Explanation:</b> Minor concerns regarding relevance because	Minor concerns  <b>Explanation:</b> No/Very minor concerns regarding	36,37,39,43,52

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
			the findings reflect the data, although two studies with thinner data	review excluded studies that only focused on parents' experiences after a child died which could cover bereavement support	methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and Minor concerns regarding relevance (excluded studies focused solely after child's death)	
<b>2A DIRECT SUPPORT OF THE PARENT</b>						
17	Some parents experienced a loss of the relationship with the teams who had cared for their child, and so maintaining this contact served as a reminder of their identity as a parent and in some cases helped adjust to their loss.	Minor concerns  <b>Explanation:</b> Minor concerns regarding methodological limitations because three of the six studies contributing to this finding had minor concerns about methodological quality unclear theoretical underpinnings, researcher relationships with	No/Very minor concerns  <b>Explanation:</b> Very minor concerns about coherence as similar data across all studies contributing to this finding	Minor concerns  <b>Explanation:</b> Minor concerns regarding adequacy because data were less rich in two of the studies contributing to this finding	No/Very minor concerns  <b>Explanation:</b> Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	8,37,39,45,48,52

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
	participants and data analysis)					
18 Parents valued professionals who cared for them directly both practically and emotionally. This enabled them to be better parents.	No/Very minor concerns  <b>Explanation:</b>	Moderate concerns  <b>Explanation:</b> Moderate concerns regarding coherence because the data was varied with some families not feeling that direct care	Minor concerns  <b>Explanation:</b> Minor concerns regarding adequacy because this finding is only supported by four studies	No/Very minor concerns  <b>Explanation:</b>	Minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, Moderate concerns regarding coherence as some data is conflicting, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	38,42,50,57
<b>2B EMOTIONAL COMFORT</b>						
19 Many parents were touched when staff showed compassion and sensitivity and felt comforted by demonstrations of kindness, empathy, and emotional responses	No/Very minor concerns  <b>Explanation:</b> Very minor concerns with only five out of seventeen studies having any minor concern about methodological quality	No/Very minor concerns  <b>Explanation:</b> Data were similar across all the studies supporting this finding	No/Very minor concerns  <b>Explanation:</b> Rich data from seventeen studies	No/Very minor concerns  <b>Explanation:</b>	No/Very minor concerns  <b>Explanation:</b> No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding	8,36-39,41-50,55,59

Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
					coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	