National Institute for Health and Care Excellence

Final version

End of life care for infants, children and young people with life-limiting conditions: planning and management

Appendix G

NICE guideline NG61

Evidence tables

December 2016

Final

Developed by the National Guideline Alliance,
hosted by the Royal College of Obstetricians
and Gynaecologists

Contents

Appendix G: Evidence tables

G.1 Review question: Communication

What are the barriers and facilitators to effective communication between the infant, child or young person, the family and the healthcare professionals about the life limiting condition and likelihood of imminent death?

Study details	Participants	Methods	Findings/results	Comments
Full citation Baverstock, A., Finlay, F., What can we learn from the experiences of consultants around the time of a child's death?, Child: Care, Health & Development, 34, 732-9, 2008 **Ref Id** 350497 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims**	**Sample size** N=61 consultants **Characteristics** **Total response rate**: 61/100 (61%) **Questionnaire from tertiary consultants**: 22/34 (65%) **Questionnaire from DGH consultants**: 39/66 (59%) **Gender:** 40 males (66%); 20 females (34%) **Inclusion criteria** Not reported	**Setting** Questionnaire for consultants with open-ended questions **Data collection** 100 questionnaires were sent out to paediatric consultants working either in district general hospitals or tertiary hospitals. Four district general hospitals were chosen at random and the appropriate number of	**Themes/categories** **Good planning, honesty and mutual respect, time, privacy: (consultants)** Consultants spend a lot of time talking to parents and families **around the time of a child's death.** These discussions are often intense. Consultants thought discussions tend to "go well" when there has been good planning and introductions, **honesty and mutual respect and the "right environment" (time, privacy, separate room, tea, etc.**). Many consultants emphasized the need for pauses in conversation, allowing the	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection methods clearly reported; whether data saturation was achieved was not reported; **Data analysis:** The analytical process was not described in detail, no description of how "themes" were arrived at; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g.,

Study details	Participants	Methods	Findings/results	Comments
To describe how paediatric consultants report dealing with child and neonatal deaths as part of their daily work. **Study dates** Not reported **Source of funding** Not reported	**Exclusion criteria** Not report	consultants picked randomly from the staff list by a secretarial colleague. The tertiary consultants were also selected randomly by the same person. **Data analysis** The questionnaires were analysed separately by the 2 researchers and themes of responses were identified. These themes were then discussed and agreed by way of cross checking.	parents time. Conversely consultants thought it **more difficult when there was poor planning, lack of time, interruptions and when there was disagreement with parents. (*consultants*)** Consultants had much to say when asked "what makes talking (*around the time of child's death*) to parents go well?". Responses: **-Planning before discussion (consultant):** **-Manner and conduct of discussion (consultant):** **-Stage management of discussion (consultant):** **Keep perspectives/know limitations/honesty:** -"*To know my limitations-i do not and cannot know everything (consultant)"* -*"We are not superhuman and it is OK to share this with families and the rest of the team (consultant)"* -*"We all make mistakes (consultant)"* -*"The more I know the more I know I don't know (consultant)"*	citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			Compassion and humanity (around the time of a child's death): -"*The need for compassion and humanity not to be just a technician (consultant)"* -"*If you do not have empathy, e.g. shed tears or reflect on these issues, it is time to retire (consultant)"* *Sensitive to differences: "Families manage death and react to this in different ways and we need to be sensitive to this." (consultant)* *"It's never the same twice, what works for one may not work for another so be flexible." (consultant)* **Communication and document well:** **Death happens:** -"*Death is a reality and in many cases cannot be predicted or prevented (consultant)"* -"*There is such a thing as a good death experience" (consultant)* **Do not rush/time** **Learn to recognise grief:**	

Study details	Participants	Methods	Findings/results	Comments
			-"*Staff often need support for months after a particular situation (consultant)*" -"*I have learnt to deal with anger and aggression as a symptom of distress*" (consultant)	
Full citation Branchett, Kate, Stretton, Jackie, Neonatal palliative and end of life care: What parents want from professionals, Journal of Neonatal Nursing, 18, 40-44, 2012 **Ref Id** 349972 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims** To determine what parents had actually experienced relating to neonatal palliative and end of life care	**Sample size** N=57 (54 mothers and 3 fathers) **Characteristics** Respondents were parents who had lost a child in the neonatal period. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** A neonatal palliative care project (SWMNN,2011) initiated by the combined Midlands Newborn Networks. The project included a Newborn Network Board Parent Representative, who attended all Project Board Meetings and was charged with the task of scoping parents' viewpoints and experiences in relation to neonatal palliative and end of care episodes.	**Themes/categories** **Empathy:** Parents longed for understanding: "[My baby] had been in NICU for nearly 3 weeks and **it helped that the nurses that had cared for him in that time came and said goodbye to him. It showed me that he was not just another statistic, he was my baby."** **Time and Space:** Parents were struggling to comprehend their loss and make sense of of their feelings. Their shock meant that thinking straight was almost impossible; apparently simple discussions or events became impossible or insurmountable:	**Limitations** **Aim(s): Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was not clearly reported. The relationship between the researcher and the respondents not clearly reported; unsure about the relationship between the researcher and the "parent representative" who posted the questions on website to elicit answers from parents **Data collection:** Data collection relied on the answers parents responded to the questions posted on website, no any discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail, no description of how

Study details	Participants	Methods	Findings/results	Comments
and determine how this knowledge could be used to improve experiences for families in future. **Study dates** 2011 **Source of funding** Department of Health, UK		**Data collection** Data were collected through response to a few simple questions initially posted on a parent's support website. Responses were overwhelming and consequently led to a larger study with more formal processing and presentation of the data. **Data analysis** A thematic approach was applied to the analysis as "in vivo" quotations were collated and organized by similarities and relevance.	*"I had questions after question fired at me what felt like minutes after [my baby] was born. It was just too much for me to handle, as it just seemed like minutes since my darling baby boy had been alive with us, but everyone else wanted to simply move on..." (parent)* *"...I think the most important thing to me was that i got to hold him and sit with him in a private room and I wasn't rushed into anything." (Parent)*	"themes" were arrived at; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Low **Other information**
Full citation Byrne, Mary, Tresgallo, Mary, Saroyan, John, Granowetter, Linda, Valoy, Glenny, Schechter, William,	**Sample size** N=43 initial consults led by 32 different physicians	**Setting** One integrated palliative care service during its	**Themes/categories** **Perspectives of parents, which were commented by**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate

Study details	Participants	Methods	Findings/results	Comments
Qualitative Analysis of Consults by a Pediatric Advanced Care Team During Its First Year of Service, American Journal of Hospice & Palliative Medicine, 28, 109-118, 2011 **Ref Id** 361938 **Country/ies where the study was carried out** US **Study type** Qualitative study (descriptive phenomenology) **Aims** To develop awareness of the consult reality from family, referring, and provider participant perspectives. **Study dates** Not reported **Source of funding** Not reported	**Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Not reported	1st year of service; **Data collection** Consult reports were chosen as the data; **Data analysis** A specific analytic method was used, which took 3 steps: -discriminating units of meaning from the presenting objects, articulating insight for each meaning unit, and then synthesizing all units into a cohesive statement that describes the experience from the participants' perspective. -conceptual and interpretive validity were confirmed at different points during study design and	**researchers, in the context of transition from pediatric advanced care to** **Negative parent affects within a comforting milieu:** **anger, fears, and sadness** pervaded the presenting or underlying affect of parents as they participated in consults. There emotions were expressed openly or kept covert and made apparent through silences, body language, and brief remarks. The parents were noted to appear sad much of the time, and the mother spoke about the possibility of intraoperative mortality, and anticipated this by exploring funeral planning. **HCPs frustration, fear (during transition):** When the goals of a medical team with an intense curative focus did not align an integrated palliative care focus, the consulting team needed	for answering the research question **Sample selection:** Sample selection procedure was clearly reported (convenience sampling). The relationship between the researcher and the respondents clearly reported (physicians who were consulted); **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		implementation. The final report was reviewed and its interpretations validated by the 3 physicians who had primary role in chairing and narrating the summaries for any of the consults used in the study.	to defer while also advocating for their view of the family's and child's best interests. This role exposed the PACT team to its own frustrations, anger, and sadness, and the need to channel these appropriately to continue to work well with both the families and providers. **-respect family wishes based on the understanding of the family background and characteristics;** **-provide additional support for the family as they face difficult decisions ahead.** -**Grave underlying fear of abandonment; prior experiences and relationships of parents;** There was a parallel often unspoken fear that decisions made by parents or providers would amount to an abandonment of their child and also fear their	

Study details	Participants	Methods	Findings/results	Comments
			abandonment by the health care system. The ways in which parents and other family members receive information and use it within the initial consult is *influenced by their prior experience and relationships.* "up against this dilemma, they (parents) felt no matter what they decide the net result would be an abandonment of the child they loved". "…*with the marriage under enormous stress*…" and the realization the treatment options were exhausted, the mother …"*equates transfer to a palliative care program with "abandonment..*" -**Parents' characteristics regarding resolution to diagnosis**: Some parents had come to grips with the actuality of their child's diagnosis whereas the other remained essentially unresolved to this basic reality: Resolved parents still experienced	

Study details	Participants	Methods	Findings/results	Comments
			sadness, doubt, and fear but were better able to listen during the consult and to utilise supports offered. Unresolved parents who questioned the diagnosis or were unrealistic about its implications remained ambivalent about any decisions to be made as well.	
Full citation Caeymaex, L., Speranza, M., Vasilescu, C., Danan, C., Bourrat, M. M., Garel, M., Jousselme, C., Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU, PLoS ONE [Electronic Resource], 6, e28633, 2011 **Ref Id** 334375 **Country/ies where the study was carried out** France **Study type** Qualitative study	**Sample size** N=80 families out of 217 eligible families (37%) contacted consented to participate, which included 86 individual parents; **Characteristics** Mean age of participants: 33.9 (SD: 4.6) Most were women (63%), and European (81%), with a minority of African parents. **Inclusion criteria** Not reported **Exclusion criteria**	**Setting** 4 NICUs in different areas in France **Data collection** -In-depth face-to-face interviews lasted an average of 100 minutes. They were based on a thematic guide derived from a review of existing studies and three pilot interviews (not included in the final sample). -Telephone interviews were	**Themes/categories** **Development of a trusting relationship: Kind, non-judgemental involvement (communication in the context of decision making); (parents)** The parents felt comforted in a protective, sympathetic and communicative ambience: "*They even asked me if I was hungry*". They appreciated dealing with the same caregivers the whole time: *"All 10 days, this paediatrician was there. She was really a person with whom we made decisions, choices, and*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:**

Study details	Participants	Methods	Findings/results	Comments
Aims To explore parents' experience of the EOL decision making process for their child in the NICU. **Study dates** Not reported **Source of funding** Not reported	Parents were excluded if they: -did not speak French; -Lived more than 100 km away from the interview site or if the child's physician objected to this contact (in most cases where civil or criminal legal proceedings were underway or when a parent had had a psychiatric disease requiring hospitalisation (major depressive disorder, bipolar disorder, psychoses, drug addiction) before the child's birth;	less structured and limited to topics spontaneously chosen by the parents. **Data analysis** Discourse analysis: -to take into account the subjective perspective of the qualitative method used in the study, the researchers disclosed a priori opinions about the themes of interest, which varied from "p0arents should decide with the staff" to "parent should not be included bbecause this would generate guilt feelings afterwards". -attention was paid to the emergence of new themes, surprising findings, and contradictory results. Data	*she was there for us in the last seconds (…) She shared everything with us*". **Individual preference for doctors' involvement in the decision making process:** Parental desire for guidance in the DM varied amongst participants. More than half of the participants stated that the medical staff should express their opinions overtly and directively. These parents reported that they had felt overwhelmed by the situation (emergency, discovery of an unexpected malformation, or extreme prematurity) or by the exhaustion due to the baby's long hospital stay. Some mothers related this to their own weak health status in the post-partum. Other parents (approximately a quarter of the participants) preferred that the staff reveal its preference non-directively. Finally, a	The analytical process was described in detail; researchers did not critically review their own roles in the process; saturation in terms of data analysis was reached; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		collection was discontinued when *saturation* occurred.	small minority reported that they did not need the staff opinion to decide. **An interpersonal dialogue about the decision was praised; (parents)** conversations with the doctor between humans on an equal footing made it possible to imagine the overall reasonableness of the choices. *"He explained that it was …I remember he said something: this isn't reasonable"* (f20). The family context and the realities of life had to be taken into account. "*The doctor left me the choice. He explained to me the risks of these choices. He told me, you already have a three-year-old daughter. He stayed in the context of our little family: for the child, for me, for my family. If something happens to you, who will take care of him? Very concrete questions.*" **Respectful language toward the child and the**	

Study details	Participants	Methods	Findings/results	Comments
			parents left a memory of the doctor's positive intentions: **(parents)** "*Doctor A always called the baby by her name: 'Lena has very serious sequelae'. She was a person, not an ordinary case*"**.** Inversely, a disagreeable, barely involved attitude encouraged subsequent questions about the decision taken: "*This doctor, I don't ever want to see him again. When he told us that it was no longer legitimate to continue the resuscitation, he said it to us casually, without emotion, as if that happened to him every day. He was not warm. So, was he telling us the truth? That's a question*" **An expert medical explanation, transmitted frankly, not necessarily in detail,** allowed the parent to understand the situation: **(parents)** "*The doctor had explained the severity of the sequelae to us. He said to us, do you*	

Study details	Participants	Methods	Findings/results	Comments
			understand what that means? But obviously we did not know what that meant" (m20). The doctor should translate, repeat and refine the medical data without creating false hopes or using incomprehensible metaphors. Consistency among the professionals was reassuring.	
Full citation Contra, N., Sourkes, B. M., Opportunities for quality improvement in bereavement care at a children's hospital: Assessment of interdisciplinary staff perspectives, Journal of Palliative Care, 28, 28-35, 2012 **Ref Id** 361998 **Country/ies where the study was carried out** US **Study type** Qualitative study	**Sample size** N=60 staff members from multiple disciplines participated **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** a university-based children's hospital **Data collection** -a semi-structured interview protocol was developed based on findings from the authors' previous studies, and on the existing literature. -2 social workers with extensive clinical experience in bereavement conducted the interviews	**Themes/categories** Perspectives of HCPs: **Logistic barrier to honor parents wishes around the child's death:** **"***I recently worked with a Jewish family who wanted to remain with the body over night. I did everything I could to honour the family's important wish because I knew it was what they needed. However, finding space for this to happen took a miracle. I should have been doing others for the family but spent most of my time on this one issue" (social worker)*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents clearly reported (unknown to each other besides one family); **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; no discussion on whether saturation has been reached in terms of data analysis;

Study details	Participants	Methods	Findings/results	Comments
Aims To examine the current state of bereavement care at a university-based children's hospital from the perspective of the interdisciplinary staff. **Study dates** Not reported **Source of funding** Not reported		-the disciplines participants represented included: medicine, nursing, social work, chaplaincy, child life, psychology, interpreter services, etc. -about 1/3 of the participants were re-contacted to add or clarify information **Data analysis** Content analysis: One social worker and one psychologists independently conducted a content analysis of the interviews and identified emergent themes.	**Anticipatory guidance, timing of talking about imminent death:** *"The timing of our interventions is usually too late…Sometimes we got called to work with a sibling right when the child is dying…that is way too late and way too awkward…" (child-life specialist)* *"The problem is we still have trouble with addressing palliative issues in a timely manner…" (nurse)* *"The problem is we still have trouble with addressing palliative issues in a timely manner…" (nurse)* **Helpful:** **Staff communication, cooperation, and care coordination when the child's death is imminent:** Staff identified many obstacles to providing optimal end-of-life care. These included difficulties in getting all team members on the same page when the child's death was imminent and in communicating with	researchers did not critically review their own roles in the process; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			colleagues and agencies beyond the hospital. "There are large gaps in communication...we need to figure out who needs to be involved and how to get everyone informed" (nurse) "Sometimes community physicians are totally left out the loop when a patient dies" (physician) **Unhelpful:** **Staff suffering:** Staff expressed their suffering regularly and vehemently. They recounted experiences that haunted them and voiced their concerns about the cumulative impact of losses over time. Many remarked that as the pace and intensity of their work increased, it was even harder to pause - or stop- around the time of a child's death. *"One surgeon confessed after a patient died that he wasn't sure he could do this work anymore. I inquired about how he was doing and he was very grateful. 'No one ever asked about me,' he*	

Study details	Participants	Methods	Findings/results	Comments
			said. 'No one asks about how I am doing.'" (social worker) *"One of our fellows was so overcome that he sat in the corner of the room when the child died and cried. He felt bad that he wasn't more able to do something and sated, 'I was speechless.' The mother reported to me that this display of emotion meant more to her than any words ever could." (social worker)*	
Full citation Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H., Family perspectives on the quality of pediatric palliative care, Archives of Pediatrics & Adolescent Medicine, 156, 14-9, 2002 **Ref Id** 334430 **Country/ies where the study was carried out** US	**Sample size** N= 68 (a letter was mailed to 156 families. A total of 68 participants, representing 44 families, were interviewed) **Characteristics** **Child's diagnosis:** Oncologic: 28/44 (64%) Cardiac: 4/44 (9%) Premature: 4/44 (9%) Other: 8/44 (18%) **Child's age at the time of death:**	**Setting** Lucile Salter Packard Children's Hospital (LSPCH), Calif, **Data collection** Interviews: Interviews with parents were conducted by a panel of 5 interviewers comprising social workers and	**Themes/categories** Parents' perspectives: **compassion and care, using straightforward nontechnical language, allow for hope:** Participants also emphasized that difficult news should be conveyed with compassion and care, using straightforward	**Limitations** **Aim(s):**Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents clearly reported (unknown to each other besides one family); **Data collection:** Data collection process clearly reported; no discussion on

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative study **Aims** To obtain personal accounts of families' experiences to learn ways to improve care for pediatric patients and their families. **Study dates** 1996-1997 **Source of funding** Part by the estate of Yvonne Conover, part of the Charter Auxiliary benefiting Lucile Salter Packard Children's Hospital (LSPCH)	hours or days to > 15 yrs **Inclusion criteria** English- and Spanish-speaking family members of deceased children who received treatment at Lucile Salter Packard Children's Hospital (LSPCH), Calif, were recruited. **Exclusion criteria** Not reported	clinical psychologists (with the exception of one family, the interviewers were unknown to the participants); Pilot interviews were conducted, and final revisions were made; The interview began with demographic questions. Participants were encouraged to elaborate, especially concerning areas needing improvement, and to bring up any issues or suggestions that were not directly addressed in the interview. **Data analysis** The interview group first identified as many themes as possible and computed	nontechnical language. Above all, family members recommended giving difficult news directly and honestly while still allowing for hope. Parents also mentioned they would have appreciated better preparation that bad news was coming. Doctors need to relay medical facts honestly but always **allow for a glimmer of hope**, even if only for a miracle. The doctors who best connected with S always had hope. Be sensitive, honest, cautious about word choice. It should come from someone the parent already has a relationship with. **Language barrier and cultural differences:** The lack of a common language compromised parents' ability to acquire complete information and to fully understand their	whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		frequencies as a guide to identify themes that occured more (or less) often. The collection of themes were then collapsed into categories.	child's medical condition, treatment, and prognosis. In addition, cultural differences could be detrimental to care. For example, if the Spanish-speaking parents' expectations that physicians show their child affectionate attention were not met, this became a barrier to trust and confidence in the medical team. These families reported feeling isolated, confused, and distrustful of the hospital system. *"No one ever told me the baby could die. I never understood what was happening medically. The doctor came out during the operation and asked my wife if they should stop or continue the operation. I didn't understand that the baby would die either way at that point. No interpreter came during this conversation."*	

Study details	Participants	Methods	Findings/results	Comments
Full citation Contro, N. A., Larson, J., Scofield, S., Sourkes, B., Cohen, H. J., Hospital staff and family perspectives regarding quality of pediatric palliative care, Pediatrics, 114, 1248-52, 2004 **Ref Id** 334432 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To obtain personal accounts of HCPs and families' experiences to learn ways to improve care for pediatric patients and their families. **Study dates** 2006-2007	**Sample size** n= 446 HCPs + 68 families members **Characteristics** HCPs: HCPs included 110 attending physicians, 48 residents, 191 nurses, 17 social workers, 21 psycho-social support member, and 42 ancillary support staff members. Families: a total of 68 family members of 44 deceased children were interviewed **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Lucile Salter Packard Children's Hospital (LSPCH), Calif, **Data collection** Staff survey: qualitative data from staff were collected by open-ended questions (regarding the most difficult experience when a paediatric patient died) were included in the survey Family interviews: in individual interviews, the family members described their expeirneces regarding the treatment and death their child.	**Themes/categories** HCPs perspectives: **feeling inexperienced, distressed and inadequate in communication with patients and families:** *"I didn't know how to comfort the family. I also had trouble with feeling that maybe I could have done things differently that somehow might have c hanged the outcome. I doubted my decisions (medically) and wondered if we had done everything possible. "* (HCPs) ***Unfamiliar with cultural differences:*** *I personally was prepared for the family's reaction. They knew their child was going to die but when it happened, their response made me uneasy. They 'wailed' as part of their culture. I was unfamiliar with their culture so I was caught-off guard. I would like to know more about*	**Limitations** **Aim(s): Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents was not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Low

Study details	Participants	Methods	Findings/results	Comments
Source of funding Part by the estate of Yvonne Conover, part of the Charter Auxiliary benefiting Lucile Salter Packard Children's Hospital (LSPCH)		**Data analysis** Staff survey: two clinical social workers and 1 psychologist reviewed the response to the open-ended question and identified recurrent themes. Two independent raters coded the responses according to these themes; Family interviews: five interviewers reviewed the family responses and discussed what appeared to be the most salient themes. Themes that appeared to occur frequently were grouped into categories, including interactions with hospital staff members.	*cultural differences with dying patients. (HCPs)* **Careless and insensitive remarks** caused families lasting pain and complicated their grief: *"I know we had to ask if we didn't want our son resuscitated. It's just they way he did it. It was very cold. He was saying 'if he has to be resuscitated, this is what's going to happen...' It was very negative talk about our son dying.* **Early communication of pain:** *"I wish they had communicated to us sooner that there were pain here that maybe we could have brought in. They couldn't find the right combination to put her on."*	**Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Davies, B., Connaughty, S., Pediatric end-of-life care: lessons learned from parents, Journal of Nursing Administration, 32, 5-6, 2002 **Ref Id** 357766 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To provide insights into the meaning of optimal paediatric end-of-life care. **Study dates** Not reported **Source of funding** Not reported	**Sample size** Not reported **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** A regional children's hospital **Data collection** Not reported **Data analysis** Not reported	**Themes/categories** **Perspectives of parents:** **Facilitators:** **Communicate on an individual basis:** Staff gently ask as to the information parents might want; Staff assess parents' desire on an individual basis to talk about sensitive topics, such as the child's impending death, funeral plans, and bereavement issues; **Consistent information from same staff member (s):** 1 or 2 members following the family throughout the course from diagnosis to death so consistency of service could be achieved; **Time (at child's death) and privacy:** At the time of death, parents want staff to allow them as much time as they need with the child, without being rushed or criticised for "taking so	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was not reported. The relationship between the researcher and the respondents not clearly reported ; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not reported; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Low **Other information**

Study details	Participants	Methods	Findings/results	Comments
			long". Appreciated privacy; **Small acts of human kindness, compassion; take time to listen, and respect families' wishes** "Small acts of human kindness", human qualities of compassion, gentle concern, and a sense of humor; **Staff's communication skills and level of comfort or discomfort with death:** Staff must first become comfortable with death itself; **Barriers:** **Lack of emotional support from staff:** Staff lacked knowledge about how to provide **emotional support** when the child died; **Lack of compassion from staff:** Staff lacked compassion and just focused on cure and treatment; Not received adequate information so didn't know what question to	

Study details	Participants	Methods	Findings/results	Comments
			ask; Not knowing what was happening; **Staff's fear of death:** HCPs' personal fear of death	
Full citation Davies, B., Contro, N., Larson, J., Widger, K., Culturally-sensitive information-sharing in pediatric palliative care, Pediatrics, 125, e859-65, 2010 **Ref Id** 348236 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To learn about experiences of Mexican American and Chinese American families who require paediatric palliative care. This article describes parents' perceptions of information sharing by health care	**Sample size** N=36 parents from 28 families **Characteristics** Parents: mean age: 34.4 years (range: 18-64) **Inclusion criteria** Participants were included when 1) their child died from a life-limiting illness and was treated at either site; 2) their child died 6 months to 5 years before the study; 3) they spoke English, Spanish, Cantonese, or Mandarin; and 4) a parent or a grandparent was born in Mexico or China. **Exclusion criteria** Not reported	**Setting** Paediatric palliative care centre, CA, US **Data collection** -Semi-structured interviews, averaging 2 hours long each. **Data analysis** -Constant comparative procedures was used to identify themes. Themes were coded and sorted into categories. Ongoing analysis focused on linking categories, testing them against data, and revising categories until	**Themes/categories** **Perspectives of parents:** **Attention to the cultural and religious background of the family:** Some physicians incorporated the family's culture and religion when providing information. One mother reflected, *"the doctor would do everything he could, he didn't give us much hope." Knowing this family's strong religious belief, the physician said, "the one up above will have the last word. I will put myself in His hands, and I will do my best.".* In contrast, a Chinese mother was angry when a physician did not consider the cultural importance of family involvement. An intern "impolitely" asked	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
providers during their child's hospitalisations and at their child's death. **Study dates** Not reported **Source of funding** National Institute of Nursing Research, US		overall conceptualisations were created by using techniques for meeting standards.	the family to leave the room so that he could talk to the patient alone. The mother queried, *"how could the patient talk to him? The patient was very sick. He needed family to stay.."* The mother described the intern as "mean," stating, *"He never considered our feelings."*	**Other information**
Full citation Davies, R., Davis, B., Sibert, J., Parents' stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child, Child: Care, Health and Development, 29, 77-82, 2003 **Ref Id** 362039 **Country/ies where the study was carried out** UK	**Sample size** The sample included 23 married couples and 7 single parents Participants were identified by professional colleagues of the authors and invited to take part by letter. **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria**	**Setting** South GLamorgan and West Midlands **Data collection** In-depth interviews were carried out in parents' homes. **Data analysis** Interviews and filed notes were audio taped and transcribed verbatim. Through interpretative data analysis, assisted	**Themes/categories** **Sensitive paediatricians: respond parents' concerns with human sympathy and understanding; sensitive to parents' needs as a parent and a family;** Paediatricians who listened to parents, took their concerns seriously and were able to respond with human sympathy and understanding. They were technically competent too and expedited investigations or referrals to other consultants.	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process was not clearly reported (only reported in-depth interview was conducted); no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative study **Aims** This study explored parents' experiences of care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. **Study dates** Not reported **Source of funding** Wales Office of Research and Development	Not reported	by NU*DIST software.	*Mother: He said he would look into it and sent her for a C.A.T Scan and there was this build up for Christmas and we got the results back on the 22nd of December about the brain scan R: They were normal? Mother: No, they came back abnormal there was a great big matter over the brain and he said like it was the 22nd of December. He said, 'Go home and have the best Christmas you can.' and he phoned us up over Christmas, he was really nice and then he got her booked in for the Thursday after Christmas to have a lumbar puncture done and some more blood tests and things. and that was the actual thing that diagnosed it and we we retold like it was the new year and we're told on the second of January. R: How did he handle that do you think? Mother: He was really good wasn't he? (to father) Father: Very well, as best as you can in handling that sort of situation we couldn't*	detail; researchers did not critically review their own roles in the process; no discussion on whether saturation in terms of analysis has been reached **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Low **Other information**

Study details	Participants	Methods	Findings/results	Comments
			*have asked for better. Even now if M goes into hospital even though she's not under him he will always come and see her (**parents of child diagnosed with Metabolic Leukodystrophy)** **Acknowledge and respect parental knowledge and willing to work in equal partnership with them:** *The first time we went to see him after she was diagnosed was the only time she was with him longer than two minutes and he had the cheek to say 'Yes, you could see she was classic MPS.' That made me so angry **(mother of daughter diagnosed with Sanfillipo Syndrome).*** None of those responsible for delayed diagnosis apologised to parents. Reflecting their insensitivity these seemed oblivious to the serious consequences this had had upon the child, the parents or family as a whole. Even after correct diagnosis	

Study details	Participants	Methods	Findings/results	Comments
			they persisted in treating parents in a dismissive and off-hand manner. It is hard not to conclude that this authoritarian manner acted as a smokescreen for the less knowledgeable to hide behind and that this was recognized by parents themselves hence their immediate decision to transfer elsewhere. Sensitive paediatricians not only acknowledged but respected parental knowledge and were willing to work in equal partnership with them as exemplified here.	
Full citation de Sa Franca, Jael Rubia Figueiredo, da Costa, Solange Fatima Geraldo, Lopes, Maria Emilia Limeira, da Nobrega, Maria Miriam Lima, de Franca, Inacia Satiro Xavier, The importance of communication in pediatric oncology palliative care: Focus on humanistic nursing theory, Revista Latino-Americana de Enfermagem, 21, 780-786, 2013 **Ref Id**	**Sample size** N=10 nurses **Characteristics** Not reported **Inclusion criteria** -nurses having worked for at least one year in this unit, being active during the data collection period,	**Setting** A public hospital based i Joao Pessoa, Brazil, which is a reference unit in this state for the treatment of cancer for children and adolescents. **Data collection**	**Themes/categories** Perspectives of HCPs: **verbal and non-verbal communication:** ...that both verbal and non-verbal communication established with the child experiencing the process of terminal illness, is considered to be the	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents was not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation

Study details	Participants	Methods	Findings/results	Comments
362048 **Country/ies where the study was carried out** Brazil **Study type** Qualitative study **Aims** To investigate and analyse communication in palliative care in paediatric oncology from the viewpoint of nurses, based on Humanistic Nursing Theory. **Study dates** 2010 **Source of funding** Not reported	and being available to participate in the study. **Exclusion criteria** Not reported	Semi-structured interviews using a recording system, with questions relevant to the proposed objective: what do you think of communication as an instrument to assist children with cancer who are in the terminal phase? How do you use communication to assist children with cancer in the terminal phase? **Data analysis** -Data were qualitatively analysed according to Humanistic Nursing Theory and based on the five phases of Phenomenological Nursing, which were: researcher's preparation to know herself; the researcher	basis of a good interpersonal relationship, intended to enable *being-better*, as the following testimonies show: *Communication is very important in palliative care. [...]. Children, sometimes, during the initial phase of the disease, do not communicate with words, but communicate with their gaze, with touch. You have to understand that! It is a call that the child is presenting to us. [...], Communication is not only with words: it's a gesture, it's eye contact, it's a way of waking up, it's a good day s/he gives you. It's a smile she transmits you; it is knowing how to recognize these signs* (Nurse). *In communication with children, we have to pay attention to all the communication channels (verbal and non-verbal). So, we need to learn to read the children's sixth sense. [...]. In this sense, if she is in the terminal*	has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		scientifically knows the other person; the researcher complementarily synthesise the realities that became known	*phase, she realizes it's changing, permits other things. [...]. If you get there with a serious look on your face, she already knows something that will cause suffering is coming; you have to transmit joy (*Nurse*).* The researcher commented that: the two analysed categories show that this form of providing care indicates a need to promote a human and holistic practice of care, developed through cuddling, gazes, words and listening to, to meet the patient's needs because s/he is considered unique based on the I-You relationship. **Ties of trust established between nurse and child** Communication is a process of involvement that is established,	

Study details	Participants	Methods	Findings/results	Comments
			among other ways, through a dialogue between people. It is an active process, of attention and active listening. This aspect is referred to by nurses and refers to the establishment of bonds with a child, as expressed below: *This communication issue, I always try to, like, reassure, especially in relation to pain. I try to talk to her, to address her [...] you look into that child's eyes, she is looking at you, she'll trust you. [...], it is a touch, a gaze; you have to show confidence* (Nurse). *When I communicate with a child, I try to become as close as possible, because we know that children are afraid, when they see us wearing white, they don't want to talk. [...]. So, when you reassure the child a little, play, and step out of your routine for a while, you have some time. [...]. Correct*	

Study details	Participants	Methods	Findings/results	Comments
			communication is when the child (who is already fragile due to the disease) trusts you in the development of the care relationship. So, you have to know what you're going to say. (Nurse) Authentic communication focusing on care to enable well-being and better-being.	
Full citation Forbes, T., Goeman, E., Stark, Z., Hynson, J., Forrester, M., Discussing withdrawing and withholding of life-sustaining medical treatment in a tertiary paediatric hospital: a survey of clinician attitudes and practices, Journal of Paediatrics & Child Health, 44, 392-8, 2008 **Ref Id** 357795	**Sample size** N=162 respondents (out of 385 clinicians contacted), of which 81 were juniors and 81 were seniors. **Characteristics** Female respondents accounted for 72.8% of the junior and 40.7% of the seniors.	**Setting** Survey carried out by open-ended questionnaires to clinicians working at RCH, Australia **Data collection** -Online survey with open-ended questions. A	**Themes/categories** **Perspectives from HCPs:** **Barriers perceived by HCPs:** -Family disagreement with the treating team regarding the child's prognosis; -Concerns that family was not ready for a discussion about withdrawing or	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported;

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out Australia **Study type** Mixed-methods study (qualitative and descriptive quantitative); **Aims** To learn about doctor's current attitudes and practices relating to discussions concerning withdrawing or withholding life sustaining equipment (WWLSMT) in the paediatric setting. In particular, the study sought to understand: -what the potential barriers to communication are; -whether discussion guidelines regarding WWLSMT and a structured form for documenting the outcomes of these discussions would be helpful; **Study dates** Not reported **Source of funding** Not reported	**Inclusion criteria** paediatricians, surgeones and junior doctors at the RCH **Exclusion criteria** Not reported	specially convened working group comprising junior and senior medical staff, a clinical ethicist and a medical education officer determined the structure and content of the survey. **Data analysis** Not reported	withholding life-sustaining medical treatment; -Junior doctors also identified prognostic uncertainty, uncertainty about how to structure the discussion and concerns about dealing with requests from families for treatment that did not appear to be in the child's best interest. -Differences of opinions between treating units; -Poor ward set-up; -Poor documentation of previous discussion; -"*Personal inability*" to deal with the emotion involved in these discussions because of exhaustion" -"*Fear*" of dealing with these discussions; -Difficulties in acknowledging that the patient cannot recover;	**Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process; no discussion on whether saturation has been reached in terms of data analysis; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Low **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Gaab, E. M., Glynn Owens, R., MacLeod, R. D., The voices of young new zealanders involved in pediatric palliative care, Journal of Palliative Care, 29, 186-192, 2013 **Ref Id** 362149 **Country/ies where the study was carried out** New Zealand **Study type** Qualitative study **Aims** To describe self-identified factors that affect 9-to-18-year-old paediatric palliative care (PPC) patients and their siblings during the process of receiving PPC. (**Study dates** Feb 2010 to Aug 2011	**Sample size** N= 16 young people (including 7 patients, 3 brothers, and 6 sisters from 8 families) **Characteristics** The participants identified as New Zealand European, Maori, other European, or Pacific Islander. **Inclusion criteria** Most of the families were recruited through the PPC team, whose members identified potential participants as English-speaking, within the designated age range, and with the cognitive ability to verbalise their perspectives. **Exclusion criteria** Not reported	**Setting** Paediatric Palliative Care, New Zealand **Data collection** -Participants were encouraged to express their feelings about the changes in their lives; no attempt was made to persuade them to feel other than they way they did. -Willing participants received participant information sheets and their preferred recording medium (a blank 100-page journal on audio recorder). Caregivers were informed that the recorders were for the children's use only.	**Themes/categories** Perspectives of young people involved in pediatric palliative care: The researchers commented that: care should be taken when approaching families to talk about a child's mortality, as each family member may feel differently about it. The them of being understood and communicating one's feelings and perceptions to others highlights that some young people wanted to have their situation acknowledged. **Being understood and understanding others; Difficulties recognised and appreciated:** **"**_The main thing [friends] have done is like...respecting that I have tumor and like can't do as many things cause of my tumor..I just think that they understand my tumor and..that they acknowledge about the tumor._**"**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; no discussion on whether saturation has been reached in terms of data analysis; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers'

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported		-The participants held diaries for one to four weeks. After data were collected, the recordings were only viewed by the researcher and confederates at the university. **Data analysis** Thematic analysis: -the principal investigator transferred each of the diaries and recordings into an electronic format. -the transcripts were stored in NVIVO 9 qualitative data analysis software. -all the condensed statements were analysed thematically. Repeating codes were grouped together. The coding procedure was intended to identify the sub-	Patients usually wanted their difficulties recognised and appreciated. A couple of siblings expressed the desire to have their hardships acknowledged as well. Some sought the empathy of others who were in similar situations. **Concerns about Mortality (described by young people):** *"The thing I worry most is the, um, dying bit. That's what I don't like. The doctors tell you but..you want to know the truth, but in a way, you don't. Like stuff like that, you don't want to know that truth. Like, I don't. But in a way, you do..but year" (young people);*	roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		themes specific to each data set, and frequencies were noted. -two collaborating PHD candidates at the University of Auckland performed the cross-validation of the themes.		
Full citation Gordon, C., Barton, E., Meert, K. L., Eggly, S., Pollacks, M., Zimmerman, J., Anand, K. J., Carcillo, J., Newth, C. J., Dean, J. M., Willson, D. F., Nicholson, C., Accounting for medical communication: parents' perceptions of communicative roles and responsibilities in the pediatric intensive care unit, Communication & Medicine, 6, 177-188, 2009 **Ref Id** 344478 **Country/ies where the study was carried out** US **Study type**	**Sample size** N=51 interviews with parents **Characteristics** **Inclusion criteria** Not included **Exclusion criteria** Not included	**Setting** Paediatric hospitals' PICU **Data collection** Interviews **Data analysis** -Discourse analysis consisted of parents' narratives and descriptions of medical communication;	**Themes/categories** **Understanding the complexity and uncertainty of medical communication on the part of parents (parents)** *"They answered you know everything that you know everything that I needed to know that I knew that they could answer. I'm a fairly logical person. And I understand that they don't necessarily have all the answers and a lot of times the answers that people do have are not the answers that I really want." (Parents)* **For professionals: Communicating professionally in their**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was not clearly reported. The relationship between the researcher and the respondents was not clearly reported (unknown to each other besides one family); **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process

Study details	Participants	Methods	Findings/results	Comments
Qualitative study **Aims** To examine parents' perceptions of good and poor medical communication with the team who cared for their child prior to his or her death in the PICU. **Study dates** Not reported **Source of funding** Not reported			**roles as clinician (parents)** *".. .[W]hy would the doctor tell me that if - if [Jamal] - if most parents - if most - if most - if most parents see their kids sink like that they'd have gone ahead and let them die. That's not professional for a doctor to say to a parent." (Parents)* ***Request for organ donation at the wrong time: (parents)*** In another example, a parent told a narrative of a request for organ donation and criticized the clinician's professionalism: "I remember when he was telling us my son was brain dead in the same sentence he was asking us to donate his organs. *And I feel that was inappropriate at the time*." ▪ **Managing parents' hope without creating false hope,**	**Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			balance between hope and realism (*parents)* *"I mean when I asked questions, um, they were explaining things. But, you know, many times they came in during the day and, uh, there were things just - and then they walked out. And, kind of ignored us a little bit. And I realize now when I look back that - that the doctors realized certain things where we had still this glimmer of hope. And, um, but they had seen - have so much experience they do know and understands the signs. And, um, I don't know if they really wanted to tell us more about it. And, take this glimmer away"* Three parents in six accounts held clinicians directly responsible for creating or maintaining false hope as the death of their child approached: *"They seen it [child's death] coming and I could tell by their actions after the fact that they seen it coming and it's - it seems*	

Study details	Participants	Methods	Findings/results	Comments
			like they led us on for a little, little longer than they should." *"And how much was I supposed to take when I sit there and I'm thinking that all my hope is you're telling me that OK she's gonna be OK. And that's all I'm hearing and I know that, I don't know if that's their job. 'Cause I would have much better they told me her chances were slim or her chances was nil or something. But she's not gonna be OK. And I got mad at them because they told me she was gonna be OK if she wasn't."* *"Remember when you're on that floor there's kids they can't help"* **Not just take the child as a patient:** Parents criticized clinicians who failed to fulfill their responsibility of viewing their patient as a child: "*Um, just the way he presented the information in such a cold matter of fact tone. Without any real consideration for*	

Study details	Participants	Methods	Findings/results	Comments
			what he was really talking about. It was like he didn't have a concept that he was talking about a human being."	
Full citation Hendricks-Ferguson, V. L., Parental perspectives of initial end-of-life care communication, International Journal of Palliative Nursing, 13, 522-31, 2007 **Ref Id** 334667 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To examine parents' perspectives of: 1) the timing and method used by HPCs to introduce EOL options for their child, and 2) what their preference would have been	**Sample size** a convenience sample of 28 parents (19 mothers and 9 fathers) **Characteristics** In the sample of the parent participants, 26 were Caucasian and two were African-American. The majority of parents were married (80%). **Inclusion criteria** -mother, father, or legal guardian of a child who died between 6 months and four years before and who received care this programme; -parents who were with the child during the last week of the child's life; (brain tumour was the primary diagnosis of the participants children) -parents who understand and speak English; and -parents who had access to a telephone	**Setting** The paediatric Wings Hospice Programme at Barnes-Jewish Hospital in St Louis, MO, USA, telephone interview **Data collection** Data were collected via audio-taped telephone interviews with parents using open-ended questions focused on parents' perspectives of their child's EOL experience. **Data analysis**	**Themes/categories** **Parents perspectives (in the context of initial end-of-life care communication)** **Positive memories:** **HCPs spend time to explain the consequences of receiving EOL care at home to their teenager (Parent)** The mother felt reassured that the hospice nurses would provide comfort measures for her daughter during EOL. Another mother shared her memory of the ICU when her 17-year-old daughter wanted to stop treatment and go home: *"The health care team spent time to make sure my daughter understood the consequences of her decision to receive EOL care at home. The*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported (convenience sampling). The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process was not clearly reported no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; no discussion on whether saturation in terms of analysis has been reached **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the

Study details	Participants	Methods	Findings/results	Comments
regarding the selected time and method to introduce EOL options. **Study dates** Not reported **Source of funding** Oncology Nursing Society Foundation Research Fellowship Award	**Exclusion criteria** Not reported	Data were analysed using content analysis methodology.	*hospital social worker presented the Wings programme to me"* **Compassionate and caring when discussing EOL options: give options, give opinions, and focus on what's the best for the child (parents)** The physician indicated that the time had come for the family to consider two options because the current treatment was not helping her daughter. One option was to continue more treatments which would require unpredictable hosopitalisation, but they physician believed more treatments would not help the child. The 2nd option was to focus on comfort measures that could be provided in the home. *"He encouraged us to consider where our daughter would be most comfortable and where we would want her remaining time to be spent, in an out of the*	researchers' roles and potential influences in the analytical process not critically reviewed Overall quality: moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			hospital or at home with us." The mother was grateful for how well the physician communicated the issue and helped the parents in making the best decision for their daughter and accepting her death. **Sensitive and supportive communication by HCPs related to hospice care recommendation for child (parents)** *"It's my job to make sure of EOL discussions sensitive and supportive your child goes peacefully communication by HCP and I take that job related to hospice care very seriously' recommendation for child"* *"Let the hospice staff come and talk to you and see what you think, they are very good"* *"They were sensitive when they told us but they told us outright"* *"there is a hospice programme here' 'He was very kind about it and*	

Study details	Participants	Methods	Findings/results	Comments
			matter of fact when he said, 'You will need help"	
Full citation Hsiao, J. L., Evan, E. E., Zeltzer, L. K., Parent and child perspectives on physician communication in pediatric palliative care, Palliative & Supportive Care, 5, 355-65, 2007 **Ref Id** 334694 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** The purpose of the study was to identify the aspects of physician communication that children with life-limiting illnesses and their parents perceived to be facilitative or	**Sample size** -20 parent and child pairs of pediatric oncology and cardiology patients (child and parent) -Potential participants were identified from referrals by health care providers affiliated with these institutions . -Response rate for invited subjects for this study was 57%. **Characteristics** **Children: Age in years, mean (range):** 14.25 (9-21) **Child diagnosis, n (%):** oncology: 10 (50) Cardiology: 10 (50) **Parent respondent's relationship to child** Mother: 17 (85) Father: 1 (5) Legal guardian: 2 (10) **Inclusion criteria** -parent and child pair of pediatric oncology and cardiology patients with a poor prognosis (physician	**Setting** Two children's hospital and one pediatric hospice in LA, California, USA **Data collection** -Two psychologists and one doctoral level nurse administered questionnaire and interviewed parents and their children, aged 7-22 years. -Interview prompts (questions) were used to elicit elaborations (questions reported) -two research assistants and the project coordinator	**Themes/categories** **Perspectives from both parents and child:** • **Relationship building:** **Helpful:** **-Develop a personal relationship with child and family;** **-provides emotional support (provides assurance, compassion, caring, consideration, hope);** **-Respect parents and children (cares about what parents and children think, listens to opinion even if disagrees with it);** **-Believes the patient, is on the "same side" as patient;** **-Relates to child well;**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed

Study details	Participants	Methods	Findings/results	Comments
obstructive in pediatric palliative care. **Study dates** **Source of funding**	reported likely < 20% chance of survival beyond 3 years) **Exclusion criteria** -children and parents who were unable to speak English fluently enough to participate and parents who were not mentally competent.	individually analysed the interview data, identified preliminary list of themes, grouped into codes using code book and checked discrepancies and reached consensus if there was any **Data analysis** -all interviews were audiotaped and videotaped, there were then transcribed verbatim -transcripts were then analysed for themes using grounded theory approach, which allows concepts and theories to emerge from the data itself-tw-t-	**-Friendly (personable, polite, happy);** **-Responsible and reliable;** **-Not judgmental about patient's lifestyle or beliefs, is understanding** **-Honest** **-Admits when s/he does not know something;** **Unhelpful:** **-Doctors has a bad attitude (arrogant, disrespectful, or harsh)** **-argue with parents in front of child;** **-Breaks trust** **-Unfamiliar with family** **-No follow-through with services** Children and parents appreciated doctors who took the time to get to know the patients as individuals and develop a friendship with the patients. Respect was also mentioned by both parents and children. *"It's not really a doctor-patient kind of thing...it's more just-I would say a friendship. ... It helped me deal with my pain, you know, when we talk to each other."* ***(Child)***	**Other information** -Self-selection of bias may also have been a factor because those subjects who chose to participate may be more open to communicating with unfamiliar people than those who refused to be contacted. -Another limitation was the recruitment of patients through health care providers who may have differing opinions on whether a patient fits the prognosis criteria, especially given the difficulty in predicting length of life

Study details	Participants	Methods	Findings/results	Comments
			"The doctors, the way they speak to her, it's like they are on ..friend level. They have this friendship and...she said they feel like...family to her" ***(parent)*** Children also emphasized the importance of doctors believing the children's words, reporting that they could tell when the physicians did not believe what the child was saying. *"They are comfortable..talking to patients and their parents. Starting the conversation of with, "How's high school? ...Just people skills and just the general love for the profession (child)* *"Well, she believes me, when I'm talking about pain, she believes me, basically" (child)* **Demonstration of effort and competence: determination to help and knowledge and capacity to do so** *"They really have a visible care for the patients..a determination*	

Study details	Participants	Methods	Findings/results	Comments
			and..doggedness to help them in any way to go past the call (of duty)" (child) - **Information exchange:** Many parents reported being devastated when physicians broke bad news in an insensitive manner or when they believed that the physicians hid information about the child's treatment, leaving parents unprepared for the outcome. *"He did a great job of giving me the information...I think he was very clear about what expectations...Tell me, what am I going to see? I want to know what I'm going to see. I don't want to be surprised. I hate surprises" (parent)* **-Helpful:** **-Really listens to child or parent**	

Study details	Participants	Methods	Findings/results	Comments
			-talks in a way that child and parent understand (limits medical jargon) **-Unhelpful:** **-breaks bad news in insensitive manner** **-does not prepare parents for treatment effects or hides information** **Level of child and parent involvement** Parents and their child do not always agree on the level of knowledge and involvement in the child's care *"You [the parent] need to talk to your child from the very beginning about what his or her condition is...Never underestimate something or oh this won't hurt...And don't deceive them, and I'll say the same for clinicians and physicians." (Parent); However,* *"Do not talk in front of Maryly, and any information that was gonna happen that day, like if any new things were going to change for Marly,...I want to know about it and I was going*	

Study details	Participants	Methods	Findings/results	Comments
			to tell her..of any change. Because the way I was going to tell would be a little different than perhaps someone else communicating that information" (parent) **Helpful:** **-includes parents in decision making;** **-consults with parents before talking directly with child in certain situations;** **Unhelpful:** **-talks as though child not in the room** **-does not explain why there is a change in treatment course, does not prepare child and family for the change;** - **Coordination of care: information continuity among health care providers** "*And actually it was clear to me that, that people were reporting just about everything that I'd said to each other so everybody*	

Study details	Participants	Methods	Findings/results	Comments
			on the same page" (parent) **Helpful:** **-good communication within health care team** **unhelpful:** **-disagrees with other health care team members or gives different advice without resolving confusion** **Obstacles to children directly communicating information to physicians:** *"I guess like they [physicians] overwhelm me sometimes I feel easier having mom tell them...He's the only one that could get them [the physicians] to* ***listen to me"*** *(Child)* **- Perceives parents as individual who knows more;** **-Perceives parents as the better communicator;** **-Believes physicians will only take parent seriously;** **-Scared that physician will give them bad news;**	

Study details	Participants	Methods	Findings/results	Comments
			-Hides emotions for different reasons (e.g. to protect parents, not be a burden or disappoint parents) **-Lacks ability to communicate because of cognitive deficits;** **-Lacks verbal abilities;**	
Full citation Lundqvist, Anita, Nilstun, Tore, Dykes, Anna-Karin, Both empowered and powerless: Mothers' experiences of professional care when their newborn dies, Birth: Issues in Perinatal Care, 29, 192-199, 2002 **Ref Id** 362440 **Country/ies where the study was carried out** Sweden **Study type** Qualitative study **Aims**	**Sample size** N=16 mothers **Characteristics** All mothers were Swedish citizens and spoke fluent Swedish. Their ages varied between 20 and 37 years. **Inclusion criteria** Mothers who gave birth to a baby who died within 2 weeks of delivery at any of 3 hospitals in the south of Sweden during 1997 and 1998 were eligible for the study **Exclusion criteria** Not reported	**Setting** 3 hospitals in the south of Sweden **Data collection** Interviews: The first author (AL) interviewed the mothers for a period of 60 to 90 minutes between 14 and 32 months (mean 22 months) after the death of their baby. The interviews were audiotaped either in the mother's home (6 mothers), in a secluded room in one of the hospitals (1 mother), or at the	**Themes/categories** **Different opinions regarding withdrawal of life support caused by information not delivered: (parents)** One mother had not been informed about withdrawal of life support and was *"accused"* of not being cooperative in the decision concerning the time for withdrawal. *As I see it, the physician who was responsible for the care of our baby was much too interested in the machines. And he made decisions that I now know he had no right to force us to follow. He had no right to force me to withdraw the ventilator… I felt that I had no say in*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported; **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; no discussion on whether saturation has been reached regarding data analysis;

Study details	Participants	Methods	Findings/results	Comments
To examine and illuminate mothers' experiences and perceptions of the care given to them at neonatal clinics while facing the threat and the reality of losing their baby. **Study dates** Not reported **Source of funding** Not reported		department of nursing (9 mothers), all according to the respective mother's wish **Data analysis** All interviews were transcribed verbatim and analyzed to identify their meaning. -to gain a complete sense of the proceedings, each author read all of the interviews. The first author (AL) analyzed each single sentence by asking: what does this sentence reveal about the experience(s) being described? Significant statements were clarified and organized into broad topical areas. the next step was a process called	*the matter concerning my baby. (Mother)* **Empathy-supporting comfort:** **Sensitivity towards mothers' needs and wishes, give mother time to stay with the baby when the baby dies:** *"Our baby wouldn't survive…. Often they [the babies] would fall asleep with the mother or father [the physician had said]. My first reaction was, Ican't go through with this. But then, Ithought he would recognize my heartbeats. Of course he will be in my arms…. We had to give him a name. We didn't want to baptize…. Ihad not wanted my baby to have a borrowed christening robe [crying]. The nurse had prepared a small bunch of flowers that we have dried and now keep in a book. She hadn't lit the candles, but we had candles. They had taken away almost all [the equipment from the baby's body]. My*	**Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		‘‘free writing,’’ responding to the question: what is it that the mothers want others to know about their experiences? The purpose was to permit the emergence of themes more sensitive to their experiences. In this way clusters of themes were identified.	*husband and Inamed him, and then we withdrew the ventilator. First the nurse put him beside his twin sister [to say good-bye] and then directly in my arms. There he quickly fell asleep. After a while we felt that we had said good-bye to him. Later on we heard that the reflective breathing had gone on for a long while, and the nurse had had him in her arms, which was so good to hear [crying]. Then, the day after they asked if we wanted to look at him again." (Mother)* **Information withheld, feeling not taken into account: (parents)** A feeling of not being taken into account and the lack of confidence in the health care professionals was experienced. For instance, one mother noted that information about the state of her baby was withheld from her. Another mother, who had not been informed, felt violated when she	

Study details	Participants	Methods	Findings/results	Comments
			overheard nurses talking to each other, saying that their baby was brain dead. **Insensitive remarks (made by HCPs): (parents)** Being congratulated by the nurse for having given birth to such a fine baby was painful under the circumstances. Still, the mothers were understanding about such behavior. I don’t think you can congratulate, even more, ask, ‘‘How are you?’’ or ‘‘Look here!’’…It was almost as if it was thrown at me what is she saying? Don’t congratulate me! He was lying there. Only by looking at him you would have understood that congratulations were not appropriate. However, she [the nurse] didn’t mean to be unkind. It was certainly just thoughtlessness. (M.12) **Misunderstanding cause by medical terms: (parents)** **A**fter consenting to an autopsy, one mother misunderstood the	

Study details	Participants	Methods	Findings/results	Comments
			expression *“pathology ward.”* She thought that they brought the baby to the cold storage room, but the staff referred to the place where the autopsies were performed. The mother could not, to her great regret, see her baby anymore. **Mention of autopsy or organ donation soon after the baby's death: (parents)** Despondency was experienced in some situations: for example, when the question of an autopsy or organ donation was raised only a short while after the baby’s death. Still, the mothers generally had a tolerant attitude toward the health care professionals. "*Our last wishes were that we would be left alone when the ventilator was withdrawn. … But the physician came and asked, with a smile on his lips, about an organ donation. It was frustrating. … Our last moments together with*	

Study details	Participants	Methods	Findings/results	Comments
			the baby, and he could not wait. … Ithink that he was nervous about asking us, and people who are nervous often smile when they find the situation unpleasant". (Mother) **Lack of connection with the HCPs: (parents)** The mothers kept their thoughts to themselves when they felt disconnected from the staff. During the interview the mothers often said that they had wanted to be more ‘‘*guided.”* "*The staff told me to ask them when I wanted to hold them [the twins], then they would help me, as there were many wires and tubes. … But even if they said I could. …it is very seldom (crying) one asks for it. I know that they don't mean to be unkind. They believe that the mother will ask for help, but you don't ask because you don't want to disturb the staff. (Mother)"* **Confirmation and guidance from staff: (parents)**	

Study details	Participants	Methods	Findings/results	Comments
			The feeling of disconnection caused the mothers to feel insecure because they were worried about their lack of concern for their baby. They needed confirmation from the health care professionals that they met the staff's unexpressed expectations, but at the same time did not want the staff to decide for them. "*I had bad feelings or a bad conscience the whole time, when I left the baby and went home. The gnawing anxiety was always there. But no one understood…. Maybe they did not want to say yes or no. They always said, ''do what you feel is right.''…But I didn't want them to say that I should have stayed in the hospital all the time (laughing), but be a little more definite— ''of course you shall go home if you want to.'' (Mother)* **Support to parents as well during critical time (parent):**	

Study details	Participants	Methods	Findings/results	Comments
			Sometimes attention was given only to the critically ill baby, and the mothers were left feeling ignored. The mothers also had problems in handling their grief later, when some felt that they had received too little information about the treatment that had been given to their baby. They would have liked someone from the staff to sit down with them afterward and explain the medical details and nursing care reports to them. "*I only remember that there were a lot of doctors and other staff, almost ten persons in the room who all at once fell upon him. And we felt a little outside; we didn't know what was happening…. There was no one to talk to us. Some support would have been comforting, just at that moment. Only being there." (Mother)*	

Study details	Participants	Methods	Findings/results	Comments
Full citation Meert, K. L., Eggly, S., Pollack, M., Anand, K. J., Zimmerman, J., Carcillo, J., Newth, C. J., Dean, J. M., Willson, D. F., Nicholson, C., National Institute of Child, Health, Human Development Collaborative Pediatric Critical Care Research, Network, Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit, Pediatric Critical Care Medicine, 9, 2-7, 2008 **Ref Id** 350113 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the paediatric intensive care unit (PICU).	**Sample size** N=58 parents of 48 children who died in the PICU 3-12 months before the study parents of 161 deceased children were contacted, 56 parents of 48 children were interviewed; **Characteristics** of the 56 parents interviewed: 37 (66%) were mothers; 42 (75%) were white mean age 36 yrs (range 22-57 years) **Inclusion criteria** Not reported **Exclusion criteria** Parents who do not speak English or Spanish	**Setting** 6 children's hospitals in the CPCCRN research network **Data collection** -semi-structured audio recorded telephone interviews were conducted by research coordinators from the clinical centre where the child died. Each audio recording was monitored by one of two investigators who provided feedback to the interviewers to ensure quality and consistency across sites. -all comments made by parents regarding communication were spontaneous. The interview question that prompted most spontaneous	**Themes/categories** **Affect** Parents emphasized that complete and candid information must be expressed with a caring emotional tone. Parents described a caring tone as "*compassionate"* , "*kind"* , "*consoling" , and "supportive*". **One parent described the physicians' warm display of emotion at the time of her child's death: *"I remember after we had our quiet time with S- after she passed, the doctors were all outside the door. And they were very kind and some of the young doctors were in tears. And it was very moving to see all these emotions because they had watched her fight for days."*** In contrast, some parents described the pain encountered when honest information was expressed with a callous emotional tone. Parents described a callous tone as "*cold*" and causing the	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported (unknown to each other besides one family); **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
Study dates Jan 2006 to May 2006 **Source of funding** the National Institute of Child Health and Human Development Collaborative Paediatric Critical Care Research Network (CPCCRN)		disclosures regarding physician-parent communication was as follows: "What are some of the things that you would want to talk about with the intensive care doctor?" **Data analysis** -Content analysis, two investigators, a paediatric intensive care physician and a behavioral scientist performed the data analysis	parent to "*feel more like a number*". One parent described the insensitive way that a physician informed him of his child's fatal diagnosis, *"He came across very cold almost like he was trying to impress the residents that he was with. That was a horrible incident especially for my wife, well for me too. Just the way he presented the information in such a matter-of-fact tone. Without any real consideration for what he was really talking about. It's like he did not have a concept that he was talking about a human being" . (parent)* **Withholding Information and Providing False Hope** Parents often felt that physicians withheld information, especially concerning their child's prognosis. Parents described a sense that physicians were *"beating around the bush"* . Parents also described that withholding their	

Study details	Participants	Methods	Findings/results	Comments
			child's prognosis kept them *"in the blind"* *and made them feel "led on" when they "deserved to know" and "wished someone would have told".* Some parents considered the possibility that physicians intentionally withheld prognostic information as a way of protecting parents' optimism and reducing their suffering. As one parent explained, *"I would like to know why, when there were so many physical signs that led us to believe that it was a very, very serious situation, why didn't they say that? One time, during a conference, I asked the doctor directly if it was serious, and that was the only time he said 'yes.' … And I realize now when I look back that the doctors realized certain things where we had still this glimmer of hope. But they had seen and had so much experience. They do know and understand the signs and I don't know if they really wanted*	

Study details	Participants	Methods	Findings/results	Comments
			to tell us about it, and take that glimmer away. I truly do not know." Regarding communication of an overly optimistic prognosis, another parent said, *"I wonder why he told me that, maybe it's because he was just trying to help me out."* ▪ **Vocabulary (medical terms) and pace:** Several parents commented on the complexity of language used by physicians when communicating about their child's condition. Parents wanted information provided in "*layman's terms*" or "*English terms*"rather than "*doctor talk*" . One parent described her inability to understand the treatment that was planned for her child "*I kept asking, 'What is this? What are you telling me you are going to do for her?' They gave me*	

Study details	Participants	Methods	Findings/results	Comments
			answers in medical terminology. This is what I kept getting, and I'm like, 'Could you explain that?' No one really explained it to my satisfaction because I did not and still do not understand. And I would like to understand it in layman's terms. It was what you were gonna do for her". Additionally, parents wanted information provided at a rate in accordance with their ability to comprehend. Parents advised that when giving bad news, physicians might need to let parents "*chew on it for a little while*" and allow "*time to set in*" because "*you can only take so much information at once*" . When information was provided too quickly, some parents perceived the communication as callous. One parent said, "*And I remember when he was telling us our son was brain dead and in the same sentence he's asking us to donate his organs*". Excessive use of	

Study details	Participants	Methods	Findings/results	Comments
			medical terms and too rapid rate of communication caused some parents to feel overwhelmed. ▪ **Body Language:** In addition to the content and style of physicians' speech, parents commented on physicians' nonverbal behaviors when giving bad news. Physicians' body language led some parents to suspect the physicians were "*guilty*" or had "*done something*". One parent described the physician's lack of eye contact, "*I wanted to ask the doctor, after he came out and talked to me after her procedure, why didn't he look me in my face, he kept his head down to the ground talking to me. Then when he lift his head up he turned the other way but he never*	

Study details	Participants	Methods	Findings/results	Comments
			looked me in my eyes. What went wrong?"	
Full citation Meyer, E. C., Ritholz, M. D., Burns, J. P., Truog, R. D., Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations, Pediatrics, 117, 649-57, 2006 **Ref Id** 334888 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aims** To present the parents' own words about what was most and least helpful at their child's end of life, ways to enhance communcation, and advice ab out how to improve care.	**Sample size** N=56 parents from 56 households out of 96 households eligible **Characteristics** Mean age of parents: 42.3 (±8.4) 91% of parents were white, 50% were Catholic **Inclusion criteria** Parents whose children had died after the foregoing of life-sustaining treatment were eligible to participate. **Exclusion criteria** Not reported	**Setting** Children's Hospital Boston; Massachusetts General Hospital; Tufts New England Hospital **Data collection** -Self-administered, anonymous questionnaires were mailed to household of 96 children who had died; -Open questions in the parental Perspectives Questionnaires was designed to elicit parent responses. **Data analysis** -Content analysis was conducted on	**Themes/categories** **Communication and Care Coordination:** Some parents preferred a single familiar figure (or few) to serve as spokesperson who was capable of lessening the confusion and offering understanding, whereas others preferred to hear all of the viewpoints. *"[There were]…too many doctors explaining things, there really should be just a few. It is too confusing."* *"There were many different MDs involved in my child's care. This became difficult when information was given to me. They sometimes had very different opinions and ways of dealing with the critical illness of my child. If there was a way of meeting together with all of them and myself it would have been very helpful."*	**Limitations** **Other information**

Study details	Participants	Methods	Findings/results	Comments
Study dates Not reported **Source of funding** Nathan Cummings Foundation		the parental responses to the open-ended questions by marking and categorizing key words and phrases to identify topics and issues of relevance to the parents.	*"Share with us the dilemmas the medical staff may be facing, what bias the doctors and nurses may have to stop or keep going." (parents)* **Emotional Expression and Support by Staff** Parents strongly endorsed staff members' *genuine expression of kindness and compassion.* Staff emotional expression occurred both verbally and behaviorally and was generally perceived as authentic and reflecting care beyond that embedded in the professional role. Some parents encouraged staff to *"be real people"* and to allow themselves to express real feelings. Staff members who were perceived as aloof, detached, or unexpressive were described as *"stone-faced"* and viewed as less empathic. *"Be compassionate and ask how parents are. Don't fall into that detached type of working.*	

Study details	Participants	Methods	Findings/results	Comments
			Parents need to feel that people really care, not that it's just a job. The people at the hospital who allowed themselves to have genuine feelings helped me the most." *"[The staff] ...stood there with us and shared our grief. How can you improve on that? They communicated volumes with that simple act."* *"Communicate honestly, false hope in this situation is unfair. I can appreciate detachment by the staff who go through these situations on a regular basis. However, that personal touch becomes so important to people who are functioning at a low level. The staff becomes the only link between you and the unknown." (parents)* **Preservation of the Integrity of the Parent-Child Relationship: to be recognized for their vital role, responsibility, and contribution to the child's care** Many parents emphasized the sanctity	

Study details	Participants	Methods	Findings/results	Comments
			of the parent child relationship and fulfillment of parental duties. In general, parents wanted to be recognized for their vital role, responsibility, and contribution to the child's care. Parents valued being listened to, respected, not judged, and included in the decision-making process. ***"Listen to what the parents have to say. Show more sincere compassion for the parents' and the child's needs. In the long run, the parents do know what is best for their child." "When I would read my child's chart and see "impaired coping" written, there was nothing more disrespectful. I'd like to see some of these people "cope" with the same situation and have to read that someone thinks they're 'impaired.' I personally saw to it that one nurse who wrote that in the chart not take care of my son again."*** *(parents)*	

Study details	Participants	Methods	Findings/results	Comments
			Privacy and time (not to be rushed) with the baby: **Privacy was highly valued during the final hours and days together.** Some parents described **“*quiet time*”** as moments of peacefulness when they could “*reach out and touch him” or “go and see him at all hours of the night*.” **It was essential that parents not be rushed or intruded on during these special moments. Several parents emphasized the importance of being with their child throughout hospitalization, including after death. For many, there was a wish to focus intensely on the time to “***say goodbye.*” “*The nurse who took care of my infant was so kind and compassionate. She stayed in the room with us but also gave us our space, which was really good. They let us take as much time as we needed*	

Study details	Participants	Methods	Findings/results	Comments
			to say good-bye." "[Being able] to sleep with my son one final time." (parents)	
Full citation Midson, R., Carter, B., Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences, Journal of Child Health Care, 14, 52-66, 2010 **Ref Id** 334894 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims** To explore the experiences of parents within one tertiary centre, the trigger that stimulated the need to survey their experiences, how practice was developed after the first survey and the challenges that still lie ahead in	**Sample size** N=55 (28 in 2006/07, 27 in 2008) [a total of 110 families (58 in 2006/07 and 52 in 2008) were invited, and 55 participants agreed to participate.] **Characteristics** Location of the child's death was: Cardiac critical care, N=21 PICU: N=19; NICE: N=9; Other wards: n=6 Age range: 3 days to 17 years; **Inclusion criteria** The target population for the survey was 20% of all the in-house deaths in a one-year period. Families who had made formal complaints or were undergoing legal disputes with the hospital were identified but not excluded from the target population; Families whose child died between 18 months and one year; Families of children aged 0-17 years who had experienced either "acute" deaths	**Setting** Great Ormond Street Hospital which is a tertiary treatment centre receiving referrals across UK. Most of the children who died in the hospital are admitted or transferred to the intensive care areas. **Data collection** Families were approached by letter for interview. The interview was conducted by phone, home visit or at the hospital in a room away from the main building. The interview used scripted questions, developed by the End of Life Care	**Themes/categories** **Barriers that need to be overcome:** **Fear of reactions:** not knowing how a family, or child, might respond or how staff themselves might feel if **asked to discuss death and dying can lead to staff avoiding the issue**. This may lead to blocking the "cues" that children or families might use to try and ask about possible outcomes. Other avoidance tactics might include diverting the issue by focusing on "what is happening" and avoiding exploring too far ahead (researchers' comments). **Ownership of who should hold these conversations (lack of plan or discussion):** Although it is often junior staff who are at the bedside listening to children and families it	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; however no reporting on how different data collection methods (telephone interview, face-to-face interview etc) may impact on data collection and how researchers undertook them to control for possible biases in data collection process; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process; data saturation

Study details	Participants	Methods	Findings/results	Comments
changing the barriers, attitudes, and culture that impede some aspects of end of life care. 2006-2007 survey: to find out from parents whose child had died, their views about the care ans support they and their dying child had received. 2008 survey: the same was subsequently repeated, with another cohort of parents, in 2008 to ascertain any differences following the introduction of some strategies in End of Life care. **Study dates** 2006-2007 (first survey); 2008 (second survey) **Source of funding** Not reported	or deaths that had been anticipated; **Exclusion criteria** Not reported	Group and additional comments from parents were encouraged; The process continued until the target for each survey of 25% of bereaved families had been achieve. **Data analysis** The data from both surveys were collated and analysed using descriptive statistics and thematic analysis.	can be difficult for them to respond to the direct question "Am I going to die?", this is especially so if the Consultant has not agreed a plan or discussions have not been held. (researchers' comments)	reached or not was not clearly reported; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Low **Other information**
Full citation Pearson, Helen Nina, "You've only got one chance to get it right": Children's cancer nurses' experiences of providing palliative care in the acute hospital setting, Issues in Comprehensive Pediatric Nursing, 36, 188-211, 2013 **Ref Id**	**Sample size** N= 7 nurses out of 12 invited across the four sites contacted with the assistance of ward managers. **Characteristics** The 7 participants were all female, aged between 22 to 25 years.	**Setting** -Non probability sampling was used which allowed the researcher to target a specific population. Participant were recruited with the assistance of ward managers. Four sites were	**Themes/categories** **Knowing what to say: anxieties (among novice nurses)** Anxieties around communication and feeling participants did not have the words to support the child or family was paramount. Words somehow did not seem enough which left the	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was clearly reported. The relationship between the researcher and the respondents was clearly reported;

Study details	Participants	Methods	Findings/results	Comments
362616 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims** To understand children's cancer nurses experiences of providing palliative care in the acute hospital setting. **Study dates** Oct 2011- Feb 2012 **Source of funding** Not reported	**Inclusion criteria** Registered children's nurses; children's nurses qualified within the last 2 years; Novice children's nurses with no previous palliative care experience outside of the oncology setting; participants who volunteered freely; **Exclusion criteria** Not reported	contacted and ward managers at each site gave participants information packs to those members of staff which fitted the inclusion criteria. **Data collection** Semi-structured interviews were used to collect data; each interview runs between 45 and 60 minutes and were audio-taped **Data analysis** Data were analysed using Strauss and Corbin method. Categories were explored from transcripts of interviews. Emergent categories were coded to devise meaning from the data *until data*	participants distressed and not knowing what to say. "*I didn't feel like I had the words to support them (the parents0, I didn't know what to say to to them..." (novice nurse)* *"We just spoke t o them and...it sounds silly but but something it's the hardest thing to do" (novice nurse)* **Identifying what the family wants:** Clinical care, providing support, and meeting the family's religious beliefs were important to understand by participants. "*We knew the patient quite well from previous admissions, parents made the decision from the start they they wanted to be in hospital. And it was getting to know what they [parents] wanted, they were quite good at setting out a plan and informing us that they wanted nurses that knew the patient to look after her and when they wanted things done*	**Data collection:** Data collection methods clearly reported; data saturation during collection was achieved; **Data analysis:** The analytical process was not described in detail; researchers critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Moderate Other information **Other information**

Study details	Participants	Methods	Findings/results	Comments
		saturation was reached. Coded data were then merged into themes and concepts. Reflexivity: The researcher used a reflexive diary which provided a consistent and systematic documented account of the participants' interview. The use of reflexivity was important to consider as the researcher came to the phenomenon with a set of preconceptions and experiences that could have influenced the way the experience was described by the participant and the way the data was collected, interpreted and analysed.	*they'd let us know" (novice nurse)*. "*They [the parents] all have different cultural and religious beliefs, so a lot of them led from their different cultural and religious beliefs"*	

Study details	Participants	Methods	Findings/results	Comments
Full citation Price, J., Jordan, J., Prior, L., A consensus for change: parent and professional perspectives on care for children at the end-of-life, Issues in Comprehensive Pediatric Nursing, 36, 70-87, 2013 **Ref Id** 335000 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims** To investigate health and social care professionals' perspectives on developing services for children with life limiting conditions at the end-of-life using issues identified by bereaved parents as priorities. **Study dates** 2008-2009	**Sample size** 35 health care professionals **Characteristics** Not reported **Inclusion criteria** Professionals with over 2 years' experience were recruited from a regional children's cancer unit and a children's hospice in one region of the UK **Exclusion criteria** Not reported	**Setting** Regional children's cancer unit and a children's hospice, UK **Data collection** -Participants were identified by an intermediary nurse, they subsequently received a written invitation and information leaflet. -5 focus groups were conducted with 35 HCPs, each lasting between 90 to 120 mins. Each focus group consisted of 6 to 9 participants experienced within children's palliative care. Although known to most participants, the researcher has no managerial or other responsibility over participants, thereby reducing the potential for researcher bias.	**Themes/categories** Challenges: **Divergence, even discord, between professional and parent approaches regarding whether to deliver the "truth (about death)" to the child. (HCPs)** HCPs explaining that many **parents sought to hide the "truth" of likely impending death** in an effort to protect their child from further suffering, participants were unequivocal that the most appropriate strategy was to tell the child the "truth."Reasons given included that being kept informed helped to alleviate *any worries a child might have and that, typically, children possessed a deeper understanding of their probable outcome than parents appreciated.* ...Disparity between professional and parental approaches was considered to create an underlying tension between the two, resulting in additional	**Limitations** **Aim(s):** **Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents clearly reported (researcher had no managerial or other responsibility over participants); **Data collection:** Data collection process clearly reported (measures to avoid dis-appropriated contribution based on those who made their views during group discussions were taken) ; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in

Study details	Participants	Methods	Findings/results	Comments
Source of funding Sandra Ryan Internal Fellowship School of Nursing, Queen's University Belfast		-This was further reduced through the highly structured nature of the States of Nominal Group Techniques (NGT) process, which provides a structured process for obtaining qualitative information and avoided one of the biggest pitfalls of group interviews, namely, disproportionate contribution based on participants make their views and experiences known. In this study, equality of expression was encouraged and the confidential nature of the focus group was ensured. -A 2nd researcher, completely unknown to all participants, was present to take notes and to assist as required.	stress felt by participants as they strove to uphold a partnership approach to care. (HCPs) **Anger, stress of the parents and HCPs being the target of those anger and stress: (HCPs)** Occasional problematic interaction between parents and professionals. Some spoke of open conflict and also of how they found themselves being the "target" of parents anger and stress, particularly during the period immediately leading up to their child's death. At least some **degree of discord was associated with a wide range of issues, including: talking about death to children, whether or not to resuscitate, addressing sibling need, location of care, securing services, withdrawal of treatment/food/fluids, and parental denial.** **Personal emotional impact: (HCPs)**	the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		--Discussions were recorded with consent, using a digi-recorder **Data analysis** -Data analysis took the form of a basic thematic analysis, whereby recurrent or common elements of participants' discussions were identified. -In order to enhance analysis rigor, primary analysis was undertaken by one researcher, who then discussed her emerging analytical framework with another. Where appropriate, modifications to the framework were made on the basis of discussion.	Although participants gained considerable fulfillment from their work, emotional impact was most frequently discussed in negative terms. This included strong **feelings of inadequacy, frustration, and sadness arising from the complex, intense, and often protracted nature of professional engagement with dying children**, their parents and wider family. (HCPs) **Balance between "personal" and "professional" involvement; lack of training and guidance on maintaining appropriate professional "distance" and formal support on how to cope with their own distress (HCPs)** Because of the typically extended nature of the relationships, profound dilemmas arose around trying to **successfully balance "personal" and "professional" involvement**. Participants were acutely	

Study details	Participants	Methods	Findings/results	Comments
			aware of the likelihood and associated risks of becoming "overly" or inappropriately involved with a child and wider family, including in terms of coming to be seen by parents as a "friend" rather than professional carer. Further, participants talked about the need to remain emotionally robust to enable them to cope with a child's death, parent/family distress and continuing of care for the "next one" (dying child). A perceived lack of formal support, particularly in relation to training and guidance in, for example, maintaining appropriate professional "distance" and developing coping skills, as well as reactive support when personal distress became problematic, was endemic to participants discussions of this issue. **Siblings: therapy, storytelling, and simple explanations to promote sibling inclusion; provide**	

Study details	Participants	Methods	Findings/results	Comments
			advice and support to parents (HCPs) Participants struggled over how best to help siblings both before and after the child's death. They described measures employed to promote sibling inclusion, such as are therapy, storytelling, and provision of (often) simple explanation concerning ongoing circumstances. Participants' role in providing advice/support to parents who themselves felt guilty about the lack of attention they were able to give siblings was discussed.	
Full citation Robert, R., Zhukovsky, D. S., Mauricio, R., Gilmore, K., Morrison, S., Palos, G. R., Bereaved parents' perspectives on pediatric palliative care, Journal Of Social Work In End-Of-Life & Palliative Care, 8, 316-38, 2012 **Ref Id** 335027	**Sample size** N=14 parents (whose children were age 10 years and older at the time of death) 14 parents from 9 families out of the 47 families contacted consented to participate; **Characteristics** Mean age of parents: 51 years (±6);	**Setting** A tertiary children's hospital **Data collection** -by three focus group sessions: the study investigators, including a palliative care	**Themes/categories** **Perspectives of parents:** **Trusted relationship and care providers near the end of child's life:** Parents valued trusting relationships with provider. Care was considered optimal when the provider and patient had grown to know one another. Intimacy was	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Study type** Qualitative study **Aims** To describe and begin to understand the experience of bereaved parents whose deceased child had received paediatric oncology services at a tertiary comprehensive cancer centre. **Study dates** May 2008 to June 2009 **Source of funding** MD Anderson Cancer Cantre Children's Art Project	Mean age of deceased children at the time of death: 15 (±3) Ethnicity: n/N Hispanic: 3/14 Non-Hispanic white: 10/14 Other: 1/14 **Inclusion criteria** Eligible focus group participants were parents of children who had been treated at a tertiary comprehensive cancer centre and were at least 10 years old at the time of death, and had died at least 1 year prior to the study. **Exclusion criteria** Not reported	physician, a paediatric psychologist, and a social worker with expertise in focus group research, served as content experts in developing an interview script. Content domains were derived from a literature review. -following well-established qualitative focus group methods, GRP trained the other investigators to record detailed field notes and behavioural observations during the sessions. -During focus group sessions, following an introductory explanation, sequences of open-ended, semi-structured questions were posed by the facilitators that addressed the	highly valued at the child's end of life. Trusted others were increasingly relied upon, and parents limited their child's interactions to persons well known to the family. *"If somebody wasn't there throughout the whole ordeal, I wasn't interested in talking to them.....It's pretty hard to open to with somebody you don't know at that point in time in your life....I go back to the relationship and trust." (parent)* Time, interest, care, sensitivity, empathy, consideration, and love from the treatment providers was highly valued. **Personalised accommodation:** Parents believed that every child was unique, as was their diagnosis, and both required creative and personalised solutions and a dynamic work environment: *"the less rules, the better. What was perfect for [one patient] was totally*	discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		topics of communication, emotional care, treatment decision making, spiritual care, and symptom management. **Data analysis** -content analysis: group discussions were transcribed verbatim and provided the basis for the content analysis. - six-member research team (three investigators, two advanced practice nurses, and one research coordinator) participated in an exploratory analysis of the textual content to identify codes for all three focus group transcripts. Major themes evolved by grouping textual	*different for [our son]..Ask the ki*d." **Emotional care (based on individual needs):** Parents described the child's ambivalence to talk about death and the importance of child having control regarding end-of-life discussions: *"Our daughter wanted to talk about [terminal cancer], then didn't...[a doctor asked her], "What are you afraid of?...Dying?..Why?...That made it easier for her to talk to us,...to be in control...she could plan for her funeral."* Participants also described the importance of providers' skill in talking about death. Parents believed that some providers had avoided talking about death or relied on a set method or technique for having an end-of-life discussion. Both avoidance and rote methods for talking about death were troubling. Parents suggested the	

Study details	Participants	Methods	Findings/results	Comments
		codes similar in content together. Disagreements over themes were resolved by consensus.	importance of **tailoring end-of-life discussions according to the needs of those participating.** **Sensitive and caring staff:** *"Near the end of his life, [my son] was in pain, the doctor came with a student, and asked, "When do you think we should should give him this amount or the other?" I was very disappointed. You have to consider that this child is in pain. If you want to ask this question [of the student], get out. I should be you and a doctor." (parent)* *"...Be sensitive. Trust comes from time and relationship. It was difficult when doctors that I have never seen come in at the end of. [They weren't going to] make his life more comfortable. They were researching, and were trying to participate, but once we cross that line, it was time for us, not them".* **Being patient:**	

Study details	Participants	Methods	Findings/results	Comments
			"They took as long as it took. They were never in a hurry to leave our room. We learned to be patient because we knew that those doctors were with other parents and doing the same thing." **No false hope:** Our son's doctor did it well. We never had false hope. [The doctor said], *"This is what we can try. I'll tell you what we are accustomed to seeing, as far as [treatment] response..."* *"When the time comes, do you want your child to be in the conversation? No matter how hard it is, everybody wants the truth, but I don't think covering it over and over and over is helpful"* **Negativism:** There was a lot of negativism. *The doctors would say "He's not moving this. He's not having any kind of actions. We're not sure, what's going on...*" *He had just come out of a coma. We were*	

Study details	Participants	Methods	Findings/results	Comments
			communicating with him by eyelid, hand, and toe movements, which the doctors failed to acknowledge. **Communication, record keeping** was lacking between departments **Layman's terms** like *supportive care.* Speak English. I've already got this cancer word weighing me down. Keep it straight and simple.	
Full citation Steele, A. C., Kaal, J., Thompson, A. L., Barrera, M., Compas, B. E., Davies, B., Fairclough, D. L., Foster, T. L., Jo Gilmer, M., Hogan, N., Vannatta, K., Gerhardt, C. A., Bereaved parents and siblings offer advice to health care providers and researchers, Journal of Pediatric Hematology/Oncology, 35, 253-9, 2013 **Ref Id** 353876 **Country/ies where the study was carried out** US and Canada	**Sample size** N= 99 families members of children and young people died of cancer, including 36 mothers, 24 fathers, and 39 siblings from 40 families 41 families out of 60 eligible bereaved families contacted consented to participate, data missing from one family due to tape malfunction **Characteristics** Parents: Mothers averaged 40.5 years of age (SD=7.4), and 78% (n=28) were White;	**Setting** Participants enrolled by the child's oncologist in the US and Canada, interviews were held at families; **Data collection** -Individual interviews with open-ended questions were conducted one-to-one with each family member	**Themes/categories** **Mutual respect; respect parents' perspectives and knowledge: (parents)** Parents acknowledged the difficulty in communicating bad news but offered that they need to be heard and a delicate balance must be maintained. One mother felt information should be repeated to families to ensure their understanding: "*Keep on keeping on.. even when they (the family) just don't want to let the hospice*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process ; saturation was reported

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative study **Aims** To determine how to improve care for families by obtaining their advice to healthcare providers and researchers after a child's death from cancer. **Study dates** Not reported **Source of funding** National Institute of Health, US	Fathers averaged 43.9 years of age (SD=7.8), and 83% (n=20) were White; Most siblings were female (64%, n=25), White (72%, n=28), and an average of 12.3 years of age (SD=2.6) **Inclusion criteria** Eligible families: -had a bereaved sibling 8-17 years old -were fluent in English -lived within 100 miles of the hospital **Exclusion criteria** Not reported	after questionnaire were completed. Participant response were audio-taped for transcription and coding. Data for this paper were derived from answers to one of the interview questions: What advice, if any, do you have for us healthcare providers and researchers, who work with children and families? **Data analysis** Content analysis: -four researchers independently analysed the data through content analysis, a qualitative approach to analysing data from open-ended questions. (data saturation in terms of analysis was	*people step in the door..because we will eventually come around.*" Another mother suggested that parents' perspectives should be acknowledged: "I *want them (medical staff) to respect my point of view as much as I was respecting theirs. They were pressuring (me) to make decisions that I knew were not right at that time. We know that they've been taught. We are very grateful for what they are doing. They do their best, but there are those times that they have to listen to parents."* **Include siblings in a developmentally appropriate way (Siblings):** **S**iblings provided advice about how medical teams could communicate more effectively with them and noted the need to be included in a developmentally appropriate manner. One 17-year-old sibling stated, *"The doctors, they mostly just talked to my parents, but it might have been*	to be achieved in terms of data analysis **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		achieved in this study)	*nice to have been included in stuff like that."* Similarly a 14- year-old sibling added, *"They (doctors) talked to me, but they kinda talked down to me like I was stupid, "cause I'm younger." "Some people change depending on the situation they're around. Some people get more sophisticated than other kids. So they have more of an adult mind*," added a 13-year-old sibling. **Compassionate care, treat the dying child as an individual:(parents)** Family members offered advice to health care professionals about their need to feel supported and cared for throughout the child's illness. A father encouraged health care providers to *"realize that (these) are special people that ya'll work with."* A mother added, "T*hese kids are dying, and they know they are dying. Some of them (health care providers) need to be more compassionate."* A father stated, *"You don't want to*	

Study details	Participants	Methods	Findings/results	Comments
			think that your child is just a patient at a hospital. Treat them more as an individual rather than just a patient on a clipboard.” Another father added that *“during some of the more stressful times the (health care providers) were ya little less than compassionate, more of a matter of fact of business. I understand they can’t make promises, but I didn’t want promises that everything would be okay. But at the same time, I want their promise that we would get through it.”* Siblings also echoed the statement that their brothers and sisters want to be treated like normal kids. One 16-year-old sibling said, *“Treat them (patients) like human beings not like they’re sick.”*	
Full citation Stenekes, J., Ens, D. L., Harlos, Michael, Chochinov, Harvey Max, Mytopher, Kristine, A Descriptive	**Sample size** N= 29 HCPs (out of about 850 eligible staff).	**Setting** 3 tertiary care hospitals in Canada	**Themes/categories** Perspectives of HCPs: **Comprehensive care plan with clear goals**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate

Study details	Participants	Methods	Findings/results	Comments
Study Evaluating Perinatal Healthcare Providers' Perspectives of Palliative Programming in 3 Canadian Institutions, Journal of Perinatal & Neonatal Nursing, 28, 280-290, 2014 **Ref Id** 362804 **Country/ies where the study was carried out** Canada **Study type** Qualitative study **Aims** To examine the views of HCPs involved in perinatal palliative c are in 3 tertiary care hospitals in Canada. Developing an understanding of their perspectives of care provision, as well as the interactions that took place with families and other teams while providing perinatal palliative care, was of interest. **Study dates** June 2010 to June 2011	**Characteristics** The majority of participants were over 31 years old (93.1%); The majority of them (75.9%) have cared for a fetus or child with a life-limiting illness and their family more than 10 times ; **Inclusion criteria** All staff of the 3 sites that provided direct patient care in any capacity to pregnant mothers or infants were eligible to participate. This included physicians, nurses, respiratory therapist, midwives, social workers, chaplains, etc. **Exclusion criteria** Not reported	**Data collection** -Purposive sampling was used to obtain a representative sample; -Data were collected by focus group and 1-to-1 interviews: -four focus groups were the primary method of data collection. a question guide, developed by the research team to elicit the perspectives of the HCPs regarding the delivery of PPC services, was used for all focus groups and interviews. Probing questions were used to obtain further detail on comments provided by participants. Focus groups lasted from 48 to 100 minutes in length.	**and roles of involved HCPs:** Respondents frequently cited "*communication*" as the most crucial element in providing perinatal palliative care. When communication between teams was weak, the development of a comprehensive care plan was affected, which resulted in unclear goals. *"When things go poorly, to me the first thing that goes wrong is communication....Another element that trends to fall apart is confusion about roles of the health care team. So we find on some occasions that it's not clear to the family or to the healthcare providers who is attending to what with regards to the baby's needs, and who is primarily responsible and accountable for the needs of the babay and the family" (HCPs)* **Protected time and dedicated space, sensitive to the needs of families:**	for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; no discussion on data saturation has been reached; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported		-five individual interviews were conducted by a member of the research team, 4 took place by phone and 1 was in person. Interviews were recorded and lasted 17 to 31 minutes in length. **Data analysis** Content analysis: -content analysis was undertaken, which allowed for the development of a thematic summary, while maintaining the essence of participants' views and language. -the qualitative data were analysed thematically, which involves an ongoing search for patterns within the data toward the	Participants clearly felt this change had resulted in better overall care: *"We did all the stillbirths or perinatal losses on Labor and Development...And we often had a real lack of privacy. ... But then we would be sometimes in a room where in the next room you would hear a baby being born and the baby's crying, and this mother knows her baby is not going to cry. It was very hard and it was kind of like, you know what, we have KDPR there, the rooms are very private...it just makes so much sense." (HCPs)* **Flexibility and formality:** Several participants identified the needs for flexibility in the midst of unknown outcomes: *"It is not always set out in stone. It can be very complicated at times. I know recently we had a situation where there was a plan that palliative care was involved, but there was confusion as to*	**Other information**

Study details	Participants	Methods	Findings/results	Comments
		formation of themes. -transcripts were then coded by the primary author according to the themes and models	*whether we would call neonatology or the resusc team.....the team was not exactly sure why they should be present, if the baby would be palliative. S there was kind of like flip-flop as to who would be caring for this child. So I think sometimes it's not always set in stone what's going to be done."*	
Full citation Weidner, J., Cameron, Marcella, Lee, C., McBride, Judy, Mathias, J., Byczkowski, L., End-of-life care for the dying child: what matters most to parents, Journal of Palliative Care, 27, 279-287, 2011 **Ref Id** 345189 **Country/ies where the study was carried out** US **Study type** Qualitative study	**Sample size** N=29 parents in 20 families (out of 99 families contacted) **Characteristics** 28 parents were White and 2 were African American **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** A large paediatric hospital located in the Midwestern United States. **Data collection** Initial contact to parents was sent by the physician who had maintained the most consistent relationship with the family during the child's illness; Semi-structured interviews and	**Themes/categories** Perspectives of parents: **Compassionate and sensitive in terms of timing of delivering the information of imminent death:** Many parents felt that the delivery of information and the timing of delivery should be sensitive and compassionate. Health care providers should know what to tell parents and **ascertain when they are ready to accept information related to their child's death.** *"All of the doctors and nurses came over and*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not

Study details	Participants	Methods	Findings/results	Comments
Aims To identify and define the dimensions of paediatric end-of-life (EOL) care that are important to parents. **Study dates** 2006-2007 **Source of funding** StarShine Hospice and Palliative Care; Cincinnati Children's Hospital Medical Centre;		focus group were conducted **Data analysis** Content analysis: team members first reviewed each transcript independently, coding portions of the text and identifying emerging themes. The team then met to review the transcripts and reach consensus on the major themes used to define dimensions of EOL care that were important to parents. After reaching consensus, team members returned to the coded transcripts to define each dimension using the parents' words.	*started doing the drill of "it's very bad," which I wasn't prepared for...a little overwhelming. I would just say it's really important for folks to realise people handle this kind of stuff differently. "* As the child approached death, it was important to parents to be told what to expect so they could **prepare themselves for physical changes they would see in their child.** They depended on health care providers to explain what was going to happen next in the death process. "*There are certain things that happen to a dying child that somebody who is not and an RN or somebody who is not medically qualified would not know about...more emphasis should be put on that. People should be prepared to know what's [going to] happen when, and what their child is going to look like. Things they can do. Just the overall picture"*	critically review their own roles in the process; unclear how themes were derived; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** moderate **Other information** 20 out of 90 families contacted consented to participate;

Study details	Participants	Methods	Findings/results	Comments
			-reassurance from HCPs that they've made the right decision (parents) Parents talked about the conflict they felt over whether they had made the best decisions for their child; due to this, they appreciated the reassurance they received from health care providers. *"That's probably the only thing I walked away from the hospital feeling conflicted about...Did they fully understand who she was and whether this was right? Should I really have taken her off the ventilation? Was it the right decision?..Knowing that I was dealing with people didn't necessarily know her, so they might not know the nuances, even though they know their crafty very well" (Mother)* *-View the child as an individual not as an illness* *Many parents spoke of the importance of having health care providers view their child*	

Study details	Participants	Methods	Findings/results	Comments
			not as an illness but as a unique individual who lives within their family. *"The feeling that you are there with your daughter and not just with somebody with an interesting malformation or some new science. but this is just this kind that you really love" (parent)* *"They treated his body part or whatever it was at that time and he wan#t a whole child" (parent)*	
Full citation Wood, F., Simpson, S., Barnes, E., Hain, R., Disease trajectories and ACT/RCPCH categories in paediatric palliative care, Palliative Medicine, 24, 796-806, 2010 **Ref Id** 358396 **Country/ies where the study was carried out** UK **Study type** Qualitative study	**Sample size** 30 families (30 out of 76 families contacted agreed to participate); Health care professionals who had an interest in the care of children living with LLCs; **Characteristics** Families with children with LLCs, further details not reported **Inclusion criteria** Patients were purposively selected from the clinical records of the Symptom Care Team in order, as	**Setting** South Wales **Data collection** -Four focus groups were held with HCPs in order to develop interview schedule for use with families; each focus group lasted about 2 hours; -Semi-structured interviews with families who consented to participate, based	**Themes/categories** Interactions with professionals: Hope: It was reported in the study that parents often challenged professionals by attempting to re-define the professional's criteria of their child's quality of life. Mother: "*I mean what we've been through over the years with [daughter's] consultant in [local hospital] who I find is a very grey man with a very grey aura who gives you no hope and I could, i*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was clearly reported; unsure about the relationship between the researcher and the families interviewed; **Data collection:** No discussion on whether saturation has been reached for the relevant themes reported **Data analysis:** The analytical process was not described in detail, no description

Study details	Participants	Methods	Findings/results	Comments
Aims To collect qualitative experiential data and use it to identify major themes and what events- in health, social and education domains- were considered to be "milestones" by families and professionals caring for children with LLCs. **Study dates** Not reported **Source of funding** Wales Office of Research and Development for Health and Social Care, Research Funding Scheme	far as possible, to encompass all four Association for Children's Palliative Care (ACT) categories (including cancer, cardiac anomalies; cystic fibrosis, muscular dystrophy, HIV/AIDS with anti-retroviral treatment; Batten's disease; Severe cerebral palsy). **Exclusion criteria** Those who did not speak English well enough to give valid consent to participate, or who were bereaved within a year of the study's commencement.	on the interview schedule developed using data collected from the focus groups with HCPs. -The interviews were "iterative": as new, interesting themes emerged, they were further explored in subsequent interviews and focus groups **Data analysis** -Data were analysed using thematic content analysis; -Standard thematic analysis techniques were used, in which transcripts were closely examined to identify themes and categories. Codes were applied to the broad themes, which were then broken down	*just feel like screaming at him and saying "do you not understand, I have to deal with this every single day of my life why can't give me a glimmer of hope?" The same as the consultants in [regional hospital] when she was ill last year, they don't know her they don't know, it's like 'oh she's got no quality of life, don't extend her'. And you are thinking no hang on a minute she's changed more lives than anybody I know in this world, in my world, and how dare you assume that she lives a vegetative existence (mother of a girl with cerebral palsy)*.	of how "themes" were arrived at; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality: Moderate** **Other information**

Study details	Participants	Methods	Findings/results	Comments
		further into sub-themes.		
Full citation Woolley, H., Stein, A., Forrest, G. C., Baum, J. D., Imparting the diagnosis of life threatening illness in children, BMJ, 298, 1623-6, 1989 **Ref Id** 357981 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aims** To explore parents' experiences of the way in which they were told the diagnosis of life-limiting conditions of their child. **Study dates** Not reported	**Sample size** N=45 families **Characteristics** Children's age ranged from 1-17 years (mean 7.5 yrs), and the length of illness ranged from 6 months to 10 years (mean five years). **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Helen House, UK, the first Hospice in Europe caring for children suffering from chronic life threatening conditions. **Data collection** The data were collected during a study of the effects on the family of chronic life threatening illness in children. The main study was carried out with 24 families with children who had been referred but had not yet attended Helen House and 21 families whose children were being cared for within the health service.	**Themes/categories** **When the diagnosis of life threatening disease of the child is delivered:** Overall: among the families interviewed, the satisfied families cited the doctor's openness, directness, and sympathetic understanding in presenting the findings. The word "*trust*" was repeated used, and if the doctor looked at them and greeted and addressed them by name this helped in generating both trust and a feeling of being respected at a time when they were feeling vulnerable. **One father's description illustrate the best features of the initial communication:** **"***Following investigation the doctor gave us a frank open explanation of the diagnosis: he gave us time and took us on board as parent...He was*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was not clearly reported. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not reported; researchers did not critically review their own roles in the process; whether saturation in terms of analysis reached or not was not reported; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported		**Data analysis** Not reported	*the one who always gave us the worst news and we were upset, but the stress is much less if you know the worst: it is more if you feel the truth is being hidden. If the doctor seems able to cope with the incurable bit you feel safe and trust are essential if you are going to be able to take the news on board and accept it*." **(parent)** **Pacing and reactions of parents:** Parents said that their immediate shocked reactions affected their ability to hear and take in what was being said. Many reported that it was essential to be given sufficient time. Most parents appreciated being given time together in private to take the news in and to share their feelings. **Who attended the interview and where it took place:** Privacy: in private, uninterrupted, unhurried,	the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			both parents being present All parents wanted the interview to be held in private where they would be neither overheard nor interrupted. **How parents wish to be told the diagnosis:** **Setting**: in private, uninterrupted, unhurried, both parents present if possible; **Manner:** establish initial contact; show to respect to family (they are vulnerable); call family by name; do not avoid looking at them; be direct, open, sympathetic; **Information**: (flexibility is essential): pace rather than protect from bad news; name illness; describe symptoms relevant to child's condition; discuss aetiology-parents will usually want to know; Be prepared to tolerate their reactions of shock, especially anger and weeping; **Prognosis**: listen to parents' concerns about time, place, and nature of	

Study details	Participants	Methods	Findings/results	Comments
			death; outline available support throughout illness and death; elicit what parents have understood; clarify and repeat; If parents are ready, mention symptoms the child might experience during deterioration; **Follow-up**: acknowledge that it may be difficult for parents to absorb all information; offer early follow-up; mention sources of support; if available give telephone numbers; give address of self help agency; ensure adequate communication of content of interview to general practitioner and health visitor and (if at tertiary centre) to referring paediatrician; perhaps suggest to families that they write down questions in preparation for next appointment.	

G.2 Review question: Information provision

What information and information types (written or verbal) is perceived as helpful and supportive by the family or carer before and after an infant, child or young person dies including managing practical arrangements, and care of the body?

Study details	Participants	Methods	Findings/results	Comments
Full citation Branchett, Kate, Stretton, Jackie, Neonatal palliative and end of life care: What parents want from professionals, Journal of Neonatal Nursing, 18, 40-44, 2012 **Ref Id** 349972 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim(s)** To determine what parents had actually experienced relating to neonatal palliative and end of life care and determine how this knowledge could be used to	**Sample size** N=57 (54 mothers and 3 fathers) **Characteristics** Respondents were parents who had lost a child in the neonatal period. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** A neonatal palliative care project (SWMNN,2011) initiated by the combined Midlands Newborn Networks. The project included a Newborn Network Board Parent Representative, who attended all Project Board Meetings and was charged with the task of scoping parents' viewpoints and experiences in relation to neonatal palliative and end of care episodes. **Data collection** Data were collected through response to a few simple questions initially posted on a parent's support website. Responses were overwhelming and consequently led to a larger study with more formal processing and presentation of the data. **Data analysis** A thematic approach was applied to the analysis as "in vivo" quotations were collated and organized by similarities and relevance.	**Themes/categories** **Forthcoming and timely information:** *"Please keep parents informed. It seems a constant uphill struggle to obtain information...particularly in the hours immediately after delivery of transfer"* **Honest information:** **"***Be honest with parents and don't be scared of telling the truth. People cope- they don't have a choice"* **Accurate information and information shared among relevant health care professions during transition:** Parents disliked having to correct information or inform health professionals of previous events. They wanted to be able to rely on their care providers **"***Please record what happens in the delivery room and afterwards accurately. Having to correct notes or even worse, discover what they have been lost, causes untold misery and hurt..."* *"Please inform all relevant people of what happened. One of the monitoring hospitals wasn't informed and we got chaser letters-very upsetting and totally unnecessary"*	**Limitations** **Aim(s):** **Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was not clearly reported. The relationship between the researcher and the respondents not clearly reported; unsure about the relationship between the researcher and the "parent representative" who posted the questions on website to elicit answers from parents **Data collection:** Data collection relied on the answers parents responded to the questions posted on website, no any discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail, no description of how "themes" were arrived at; researchers did not critically

Study details	Participants	Methods	Findings/results	Comments
improve experiences for families in future. **Study dates** 2011 **Source of funding** Department of Health				review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Low **Other information** The study was undertaken by a lone researcher as part of a scoping exercise within a bigger project therefore may lack some of the formal research rigour.
Full citation Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H., Family perspectives on the quality of pediatric palliative care, Archives of Pediatrics & Adolescent Medicine, 156, 14-9, 2002 **Ref Id** 334430	**Sample size** N= 68 (a letter was mailed to 156 families. A total of 68 participants, representing 44 families, were interviewed) **Characteristics** **Child's diagnosis:** Oncologic: 28/44 (64%) Cardiac: 4/44 (9%) Premature: 4/44 (9%) Other: 8/44 (18%)	**Setting** Lucile Salter Packard Children's Hospital (LSPCH), Calif, **Data collection** Interviews: Interviews with parents were conducted by a panel of 5 interviewers comprising social workers and clinical psychologists (with the exception of one family, the interviewers were unknown to the participants);	**Themes/categories** **Honest information with clinical accuracy:** "*...And they were honest about not knowing how it was going to go, but they would do everything they could to keep her within the comfort zone. That was so important to me. And the fact that acknowledged that this is a situation that is not going to have a good outcome*" **Straightforward non-technical language:**	**Limitations** **Aim(s):** **Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents clearly reported (unknown to each other besides one family);

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Study type** Qualitative study **Aim(s)** To obtain personal accounts of families' experiences to learn ways to improve care for pediatric patients and their families. **Study dates** 1996-1997 **Source of funding** Part by the estate of Yvonne Conover, part of the Charter Auxiliary benefiting Lucile Salter Packard Children's Hospital (LSPCH)	**Child's age at the time of death:** hours or days to > 15 yrs **Inclusion criteria** English- and Spanish-speaking family members of deceased children who received treatment at Lucile Salter Packard Children's Hospital (LSPCH), Calif, were recruited. **Exclusion criteria** Not reported	Pilot interviews were conducted, and final revisions were made; The interview began with demographic questions. Participants were encouraged to elaborate, especially concerning areas needing improvement, and to bring up any issues or suggestions that were not directly addressed in the interview. **Data analysis** The interview group first identified as many themes as possible and computed frequencies as a guide to identify themes that occured more (or less) often. The collection of themes were then collapsed into categories.	Above all, families recommended giving difficult news directly and honestly while still allowing for hope. Parents also mentioned they would have appreciated better preparation that bad news was coming (*no direct quotes)*. **Consistent information give by different staff:** Mixed messages resulted in confusion and emotional turmoil, and added an additional layer of stress for families: "*The morning nurse said ,' he had a great day', then she leaned over and told the doctor, 'his "sats" went down.' I felt they weren't being honest with me. Just tell me! Sometimes I felt like they were telling me what they thought I wanted to hear*."	**Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**
Full citation deJong-Berg, M. A., Kane, L., Bereavement care for families part 2: Evaluation of a paediatric follow-up programme, International	**Sample size** N=29 (of the 82 families eligible to take part in the programme, 81 were sent the survey material, 8 were returned because families	**Setting** -Strollery hospital, Alberta, Canada, a 133-bed quaternary care facility, offering family-centred care. After establishing a paediatric palliative care team, a	**Themes/categories** **Information from faith community: Parents who were part of faith community indicated this a strong source of information and support;**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question

Study details	Participants	Methods	Findings/results	Comments
Journal of Palliative Nursing, 12, 484-94, 2006 **Ref Id** 349258 **Country/ies where the study was carried out** Canada **Study type** Qualitative **Aim(s)** To evaluate a programme providing standard bereavement follow-up service after its three years' delivery. **Study dates** 2005 **Source of funding** Not reported	have moved. 29 surveys were returned completed. They represent 29 parents of 21 families) **Characteristics** **Gender: n(%)** Male: 10 (34.5) Female: 19 (65.5) (8 couples included in above) **Age of child:** Birth to 1 to 11-16 years; **Age of parents:** 25-35 years to 45 years and over **Inclusion criteria** -Families had experienced the death of a child at the hospital or at home and were served by Children's Services Homecare; -Families had completed the 1-year follow-up programme between 2002 and 2004; -Families that agreed to receive the questionnaire after being reached by the introduction phone call about the study; **Exclusion criteria** Not reported;	bereavement follow-up programme for the entire hospital started in 2002 and was evaluated 3 years later; -The completed bereavement follow-up programme consists of memory creation at the time of death, a sympathy card, five mailings of letters/cards and handouts, and at least one phone call from palliative care staff. **Data collection** Survey by a questionnaire containing 17 closed questions, 3 questions with a mixed format (a yes/no answer and an open question allowing for further elaboration) **Data analysis** -Answers to open ended questions were grouped by the co-investigator on a question-by-question basis and added to the reporting of results. The data analysis process included several readings of the transcripts by each individual investigator to obtain an understanding of the general themes; followed by initial coding and categorizing. The investigators discussed the categories and themes together until agreement was reached; -Quotations were selected to strengthen the reporting of these	**Information from private counselors and psychologist**: were also reported as helpful; **Information in different forms concerning bereavement support:** Parents found books, music, poetry, and websites, as well as grief seminars, to be useful aids in their grieving**.** **Unmet needs: Information on things you should not to say but could be passed out to family and friends:** *"Sometimes I felt that there should be booklet of things you should not say- that you could pass out to family members and friends"* **Information on access to grief expert seminars:** *"Try to channel people into (grief expert) seminars if this is possible;* **Information (in the form of stories) to younger children** *"Providing stories for younger children (2-4 years)"* **Timely infomation about funeral arrangement:** *"There was very good information provided re funeral arrangements that I wasn't able to read until after the funeral...would have appreciated a one page sheet at the hospital with key information (like taking a lock of hair")* **Information with spiritual perspective/direct experiences:** *"Include more of a spiritual perspective/direct experiences should include more heart/soul rather than mind/intellectual anecdotal"* **Medical record of the child (after the child died):** *"I have felt the need to possess and someday read my daughter's medical*	**Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process (by open questions in questionnaire) clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; data were collected by open questions in surveys, implications of that to data collection and analysis not reported; researchers did not critically review their own roles in the process; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		themes and to link the data with the themes; -The participants, owing to the anonymity of the question, did not review the data;	*records. While I cannot read them now, I know I will feel better knowing I have a copy of them when I am ready. I hope you will help me obtain them. "*	
Full citation Hsiao, J. L., Evan, E. E., Zeltzer, L. K., Parent and child perspectives on physician communication in pediatric palliative care, Palliative & Supportive Care, 5, 355-65, 2007 **Ref Id** 334694 **Country/ies where the study was carried out** US (perspective from child and parents) **Study type** Qualitative study **Aim(s)** To identify the aspects of physician communication that children with life-limiting illnesses and their parents perceived to be facilitative or	**Sample size** -20 parent and child pairs of pediatric oncology and cardiology patients (child and parent) -Potential participants were identified from referrals by health care providers affiliated with these institutions . -Response rate for invited subjects for this study was 57%. **Characteristics** **Children:** **Age in years, mean (range):** 14.25 (9-21) **Child diagnosis, n (%):** oncology: 10 (50) Cardiology: 10 (50) **Parent respondent's relationship to child** Mother: 17 (85) Father: 1 (5) Legal guardian: 2 (10) **Inclusion criteria**	**Setting** Two children's hospital and one pediatric hospice in LA, California, USA **Data collection** -Two psychologists and one doctoral level nurse administered questionnaire and interviewed parents and their children, aged 7-22 years. -Interview prompts (questions) were used to elicit elaborations (questions reported) -two research assistants and the project coordinator individually analysed the interview data, identified preliminary list of themes, grouped into codes using code book and checked discrepancies and reached consensus if there was any **Data analysis** -all interviews were audiotaped and videotaped, there were then transcribed verbatim	**Themes/categories** **Information provision helpful or unhelpful identified by children and parents:** **Helpful information:** Information that prepares parents for bad news or consequences of treatment; Talks in a way that child or parent understand (limits medical jargon); Talks in straightforward way; Lets child know what s/he can still do in spite of illness; Appropriate level of child and parent involvement: recognition and accommodation of desired level of child and parent involvement in communicating with physicians and participating in child's care (parents and their children did not always agree on the level of knowledge and involvement in the child's care). **Unhelpful information provision:** Break bad news in insensitive manner; Does not prepare parents for treatment effects or hides information; Overwhelms child with too many restrictions; Does not explain why there is a change in treatment course; does not prepare child and family for the change**;**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality: Moderate**

Study details	Participants	Methods	Findings/results	Comments
obstructive in pediatric palliative care. **Study dates** Not reported **Source of funding** Elizabeth Glase: Paediatric Research Network	-parent and child pair of pediatric oncology and cardiology patients with a poor prognosis (physician reported likely < 20% chance of survival beyond 3 years) **Exclusion criteria** -children and parents who were unable to speak English fluently enough to participate and parents who were not mentally competent.	-transcripts were then analysed for themes using grounded theory approach, which allows concepts and theories to emerge from the data itself-tw-t-	Information giving in relation to coordination of care: lack of Information continuity among health care providers Disagree with other health care team members; different advice without resolving confusion	**Other information** -Self-selection of bias may also have been a factor because those subjects who chose to participate may be more open to communicating with unfamiliar people than those who refused to be contacted. -Another limitation was the recruitment of patients through health care providers who may have differing opinions on whether a patient fits the prognosis criteria, especially given the difficulty in predicting length of life
Full citation James, L., Johnson, B., The needs of parents of pediatric oncology patients during the palliative care phase, Journal of Pediatric Oncology Nursing, 14, 83-95, 1997 **Ref Id** 334714 **Country/ies where the study was carried out** Canada **Study type** Qualitative study	**Sample size** N=12 parents (of 8 children) (46 families met the inclusion criteria. The physician eliminated 19 families for various reasons, 27 letters were sent out and 12 parents of 8 deceased children consisted the sample) **Characteristics** **Parents:** **Age range**: 35-54 years **Education**: 10 parents had a college or university education	**Setting** Parents of paediatric oncology patients who died 1 to 3 years ago were contacted and interviewed at home **Data collection** -semi-structured, open-ended interview -all interviews were conducted at the parents' homes, The interviews were tape recorded. Field notes were written by the primary investigator after the interview was completed. -The interviews were transcribed verbatim by the primary investigator alone.	**Themes/categories** **Un-overwhelming information: Denial of/or lack of full information about anticipated physical changes surrounding the impending death as something that facilitated their ability to promote a more normal lifestyle for the entire family:** **"***Perhaps the fact that we didn't have as much information in way was kind of good for trying to carry on and be normal…if we were probably aware of all thing things that might have happened. We might not have decided that was good thing to do."* *"perhaps the fact that we didn't have as much information in a way was kind of good for trying to carry on and be normal..."*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported; physicians selected participants; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process reported; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers'

Study details	Participants	Methods	Findings/results	Comments
Aim(s) To identify parents' perceptions of their needs while their child was dying of cancer. **Study dates** Not reported **Source of funding** Not reported	**Inclusion criteria** -parents whose child died of various types of cancer 1 to 3 years ago -parents who resided in the Greater Metropolitan Toronto area -they spoke and understood English **Exclusion criteria** -families with psychiatric difficulty/emotional instability; -marital discord -unable to locate -unable to identify attending physician -dissatisfaction with health care system	**Data analysis** -The analysis involved multiple readings of the transcripts for the purpose of identifying significant statements, phrases, and sentences within each transcript and commonalities among transcripts. -Tentative themes were identified based on these commonalities. -The co-investigator for this study was given two complete transcripts to analyse according to the above process. This analysis was compared with the primary investigator's findings. Differences between them were discussed and clarified. -The first two families who participated in the study were contacted by telephone to request feedback on patterns, interpretations and conclusions identified by the researchers (member checking).	**Information provision in relation to enhance parents' abilities to guide their children:** **quality and quantity of information they had about how to manage their child's physical care as well as information they received about *community resources*. Specifically, the amount of information they received about physical changes to anticipate as their child approached death influenced their ability to care for their child.** **"***I feel I needed more information about what to expect" "There was lots of little things like that I found that weren't actually explained…a lot of trials and error of finding out things***"**	own input distinguished); the researchers' roles and potential influences in the analytical process was reviewed **Overall quality**:Moderate **Other information** -re-call bias from respondents as the child's death had occurred 1 to 3 years before the study; -one investigator was employed at the study setting and remembered the deceased children, although recollection of the parents was limited. This could have helped build up the rapport with the parents, however if the parents had had negative experiences, they have been reluctant to state their true feelings to the investigator -the method of sample selection may have created a biased sample. Those families the physicians felt they should not be contacted may be the very parents with the strongest needs during their child's palliative care phase
Full citation Jones, B. L., Companionship, control, and compassion: a social work perspective on the needs of children with cancer and their families at the end of life, Journal of	**Sample size** N=131 (social workers of a national voluntary membership organisation) A survey was mailed to all 260 members of the	**Setting** Survey questionnaire with both quantitative and qualitative/open-ended questions	**Themes/categories** (from social workers' perspective) **Relevant medical information and coordination of and transition to palliative care services:** "*Families need to have the information necessary to make appropriate*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly

Study details	Participants	Methods	Findings/results	Comments
Palliative Medicine, 9, 774-88, 2006 **Ref Id** 353605 **Country/ies where the study was carried out** US **Study type** Quantitative and qualitative **Aim(s)** to identify the social workers' perspectives regarding the psychosocial needs of children with cancer at the end of life and their families. **Study dates** Not reported **Source of funding** Not reported	association. Non-respondents received a second mailing to improve the response rate. The two mailings yielded a sample of 131 self-selected participants, a 50% response rate. **Characteristics** of the 131 respondents, 92% had a master's or higher degree; 68% had 4 or more years of experience in pediatric oncology; 80% practiced in a hospital setting; 91% were women, and 90% were between 26 and 55 years old. **Inclusion criteria** Members of the national voluntary organisation (APOSW) **Exclusion criteria** Not reported	**Data collection** -Focus groups with members of the social workers voluntary organisation were conducted to guide the subsequent design of a survey instrument containing Likert-type scales and open-ended questions. **Data analysis** -during analysis of the survey data, a template analysis of the qualitative data preceded a principal components analysis of the quantitative data; -the qualitative data, consisting of the social workers' written responses to the open-ended questions, were examined using template analysis. -template analysis was used because the first level codes in the study were decided a prior by the topics posed in the questions. Other codes were added during the data analysis to accomodate emerging patterns. -coding was done with Atlas. Ti, a qualitative data analysis software package, which is based on grounded theory methodology -2nd level codes were developed using a constant comparative analysis of the data to elicit themes -coding decisions were verified and checked with an experienced qualitative methodologist and peer debriefer.	*decisions. For those families wanting to have their child's care in the home there needs to be better pediatric palliative hospice services. Specifically those who can deal with children and families*" (information and option needs to be realistic) **Honest information on disease progression, symptom options and end-of-life issues/choices:** "Families need open discussion of disease...progression, symptom options and end-of-life issues/choices.." **Developmentally appropriate information** The social workers identified that adolescents need to have medical information, autonomy, and empowerment for personal control over life and end-of-life decision-making. According to those surveyed, even young children need to have developmentally appropriate information and the opportunity to participate in decision-making. **Clear and consistent information:** The social worker in the study also indicated that families also need to have clear and consistent information to make the best decisions with an for their child	reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: moderate **Other information** -only social workers were recruited in this study (no voice of other professionals). However, it is clear that social workers' views of children and families needs can be influenced by their professional training and perspectives. -the survey used in the study was not previously validated through formal testing

Study details	Participants	Methods	Findings/results	Comments
Full citation Kavanaugh,K., Moro,T.T., Savage,T.A., How nurses assist parents regarding life support decisions for extremely premature infants, JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing, 39, 147-158, 2010 **Ref Id** 307116 **Country/ies where the study was carried out** US **Study type** Qualitative, longitudinal, collective case study **Aim(s)** To describe nurse behaviors that assisted parents to make life support decisions for an extremely premature infant before and after the infant's death.	**Sample size** N= 40 cases (which involved 40 mothers, 14 fathers, 42 physicians, 17 obstetric nurses, 6 neonatal nurses, and 6 neonatal nurse practitioners) **Characteristics** **Inclusion criteria** -Parents were at least 18 years of age, English speaking, and had participated in a prenatal discussion with a physician regarding treatment decisions for their infant due to threatened preterm delivery; -physicians and nurses were those identified by parents who had spoken to them about life support treatment decisions for the infant (all expectant mothers were hospitalised at the time of recruitment) **Exclusion criteria** Not reported	**Setting** three hospitals that provided high risk perinatal care. interviews were conducted face-to-face in a private room in the hospital, in the mother's home, or over the telephone. **Data collection** -a semi-structured interview guide was used; a total of 203 interviews were conducted (137 prenatal, 51 postnatal, and 15 end-of-life). For this analysis, all interviews were transcribed verbatim, checked for accuracy, and coded. Data related to the nurse's role were analyzed and summarized. - **Data analysis** -This study was guided by the Ottawa Decision Support Framework. This study focused on the first phase of the framework, assessing determinants of decisions, which included: perceptions of the decisions (e.g. knowledge of the health care condition; information that was given/explained); personal and external resources used to make the decision (e.g. information, advice, emotional, instrumental,	**Themes/categories** **For the article, findings related to the nurse behaviors that assisted parents to make life support decisions for their extremely premature infant:** **-Information from multiple medical professionals (given by supporting medical staff such as nurses besides the physician):** The majority of parents felt that nurses assisted them by giving them information. Nurses give info by 1) helping parents to understand the prognostic and other health information that the physician had given (translating the medical information so parents can understand better); 2) answering questions, 3) explaining the care that the mother and infant were receiving or expected to receive, and 4) providing information on the NICU or other resources; **-Personalised information about their baby:** Parents appreciated when nurses gave personalised information about their baby, such as comments about the infant's unique behaviour. -**Information given from other methods/sources:** In addition to directly providing information, several mothers reported that nurses gave them a tour of the NICU or booklets related to prematurity.	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
Study dates Not reported **Source of funding** National Institute of Health		and financial support from others to make the decisions; skills and advice for others) -Life support treatment decisions were defined as prenatal decisions regarding pregnancy management, delivery, and immediate care of the infant, and postnatal decisions for life support for the infant, including the decision to withdraw life-sustaining treatment; -Two investigators independently reviewed all coded data related to the nurse code. These coded data were reviewed to identify and describe patterns in the data, noting the source of the data (parent, physician, nurse) and frequency of occurrence. The final description of the categories of nursing role was prepared after consensus was reached between the two researchers.		
Full citation Laakso, H., Paunonen-Ilmonen, M., Mothers' grief following the death of a child, Journal of Advanced Nursing, 36, 69-77, 2001 **Ref Id** 357861 **Country/ies where the study was carried out** Finland	**Sample size** N=50 (174 mothers were contacted, 91 returned the survey questionnaire. 52 mothers volunteered to participate interviews) **Characteristics** Mothers whose child died under the age of 7 years because of illness (75% of children were under 1 year),	**Setting** Interviews of mothers whose child died under the age of 7 in a Finnish hospital district between 1990 and 1994 **Data collection** -First survey, then interviews were conducted with those who were willing to be interviewed (reading mothers' responses provided the researcher with a great deal of additional information on the topic).	**Themes/categories** **Honest information:** Mothers wanted honest information about the illness; **Hindrance: Insufficient information and offensive way of delivering information;** Carers/families' opinion on caring of the child not respected while insufficient information was given by the medical staff ; Information given in an offensive way	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative study **Aim(s)** To analyse the mother's grief and coping with grief following the death of a child under the age of 7 years. **Study dates** 1990-1994 **Source of funding** Not reported	at least 1 year ago. Age range: 20-49 years **Inclusion criteria** Not reported **Exclusion criteria** Not reported	-Thematic interviews: which is semi-structured interviews suitable for exploring emotionally sensitive topics or f or studying a phenomenon that the interviewers are not used to discussing on a daily basis. **Data analysis** -Interview data were analysed using inductive content analysis drawing on qualitative material, which involves a process of identifying, recording and classifying data. In a data-based analysis, models, themes and classes emerge from research data through the process of data reduction, grouping and conceptualisation.		**Data analysis:** The analytical process was described in detail; unclear whether there was saturation of analysis concerning information provision; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: moderate **Other information**
Full citation Laakso, H., Paunonen-Ilmonen, M., Mothers' experience of social support following the death of a child, Journal of Clinical Nursing, 11, 176-85, 2002 **Ref Id** 353655 **Country/ies where the study was carried out**	**Sample size** N=50 for interview (91 mothers responded to the survey, a response rate of 54%, among them, 52 (57%) were willing to participate the interview) **Characteristics** Not reported	**Setting** Interviews **Data collection** -thematic, semi-structured interviews, were conducted to deepen the survey data. These are suited for research purposes when the study topic is sensitive or when studying phenomenon that is unfamiliar to interviewers. -interview themes were as follows: time before the child's death;	**Themes/categories** **Information about purchasing a coffin, organizing the funeral and buying funeral flowers** Informational support from those close to the mother mainly consisted of positive advice from the mother's own mothers, discussing with friends, and receiving consolation and caring. Informational support consisted of advice, and assistance in funeral arrangements. (***no quotes from respondents***)	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation

Study details	Participants	Methods	Findings/results	Comments
Finland **Study type** Combined quantitative and qualitative study **Aim(s)** To describe the grief and coping of mothers whose child had died under the age of 7 years. The paper describes the social support received as experienced by mothers. **Study dates** 1995 (mothers who child died between 1990 and 1994 were invited to take part in the study) **Source of funding** Not reported	**Inclusion criteria** Mother whose child died between 1990 and 1994 **Exclusion criteria** Not reported	child's death and related events; time after the child's death; and the present moment and the future. **Data analysis** -Interview data were analysed using qualitative content analysis, which is a process for identifying, coding and classifying data. -inductive analysis was employed, in which models, themes and classes are formed by reducing, grouping and conceptualizing the data. -reduced expressions were first formed from the interview material using questions derived from the interview themes. A word, a pair or a group of words was chosen as the unit of analysis; -the reduced expressions were recorded as precisely as possible using the terms found in the interview material. -the reduced expressions were grouped by combining expressions with similar content into one category and naming the category with a label describing its content.	**Information on the child's illness, its gravity, causes, prognosis, and death**. They wanted to realistic, honest, and accurate information, but reported both an adequate supply of information and the absence of information (***no quotes from respondents***)	has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process; no reporting of how categories/themes were developed; **Findings/results:** Results were not presented clearly (e.g., citation/data and the researchers' own input not distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: low **Other information**
Full citation Meert, Kathleen L., Eggly, Susan, Pollack, Murray, Anand, K., Zimmerman, Jerry, Carcillo, Joseph, Newth, Christopher J., Dean, J., Willson, Douglas F.,	**Sample size** N=56 (56 parents of 48 children) Recruitment: parents were contacted consecutively beginning with those whose	**Setting** Six clinical centers and a data coordinating centre included in the Collaborative Pediatric Critical Care Research Network (CPCCRN) established by the	**Themes/categories** **Information on:** **Cronology of events leading to PICU admission and death** *"I would just like to clarify what happened. J- was in a regular room and she kind of crashed. By the time I got back to*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly

Study details	Participants	Methods	Findings/results	Comments
Nicholson, Carol, Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit, The Journal of Pediatrics, 151, 50-55, 2007 **Ref Id** 350114 **Country/ies where the study was carried out** US **Study type** Qualitative **Aim(s)** To investigate parents' perspectives on the desirability, content and conditions of a physician-parent conference after their child's death in the pediatric intensive care unit (PICU) **Study dates** 2006 **Source of funding**	child died 12 months earlier. Initial contact occurred via a mailed letter that originated from the hospital where the child died. The letter asked parents to participate in a research interview. Parents were telephoned two weeks later to explain the details of the study and schedule interviews. If both parents of one child agreed to participate, separate interviews were scheduled. **Characteristics** **Parents, n(%)**: Mother: 37 (66) Father: 17 (30) **Age in years, median (range):** 36 (22-57) **Education, n (%):** Elementary school: 2 (4) High school: 16 (28) College: 29 (52) Post-graduate: 4 (7) Other: 5 (9) **Deceased child:** **Male sex,** n (%): 26 (54) **Age in years, median (range)**: 1.6 (0.0-20.8) **Trajectory of death, n (%):** Sudden, unexpected:16 (33) Lethal congenital anomaly:4 (8)	National Institute of Child Health and Human Development **Data collection** -A committee of CPCCRN investigators developed an interview guide to elicit parents' experiences with and perceptions about meeting with their child's intensive care physician after their child's death. -The interview guide was based on the bereavement literature and the clinical experience of the investigators. -To standardize interview procedures, interviewers participated in training sessions that included didactics, modeling of interview techniques, role-playing and feedback -All interviews were monitored by one of two investigators who provided feedback to the interviewer or maintain standardization and quality **Data analysis** -Analysis was ongoing during data collection and interviews were conducted until saturation was reached. Two investigators, a	*the hospital, she went from being in a regular room to being in ICU and everything was just horrid. At that point, there really wasn't a chance to go, 'What happened?'"* **Cause of death** *"Nobody ever really told me what was wrong with him. It was some different things that they had said could be but nothing was a fact. I just want to know why he died."* **Treatment** *"I want to know about her medicines and the different beds they had her in and what role they played and what were they hoping to accomplish by putting her in those beds and with the machines that they used on her."* **Autopsy** *"We had issues about the autopsy which I would have liked to have explained a little bit more."* **Genetic risk** *"Is it something genetic? Is it something to look for in my other children?"* **Medical documents** *"The only question that we really had was on his death certificate. It was marked cerebral edema and we're curious as to why that was, rather than marked as actually SIDS. Cause, they said that's exactly what SIDS is, when they quit breathing."* **Limitation/withdrawal of life support** *"What I'd like to ask is the whole difference between critical care and comfort care. You know we talked about it with the doctor in the conference room, when we made that decision, but that would probably be the topic that I'd want to talk about."*	reported. The relationship between the researcher and the respondents not clearly reported but measures were taken regarding how to collect data; **Data collection:** Data collection process clearly reported; how data saturation was reached was reported **Data analysis:** The analytical process was reported; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: moderate **Other information** Limitations of this study include the large number of parents who could not be contacted and the predominance of mothers among participants. Differences in parents' views based on demographics, the trajectory of death or mode of death could not be evaluated due to the small sample size.

Study details	Participants	Methods	Findings/results	Comments
The study was funded by cooperative agreements from the National Institute of Child Health and Human Development and the Department of Health and Human Service	Chronic potentially curable disease:8 (17) Chronic progressive condition with intermittent crisis:20 (42) **Mode of death, n(%)** Limitation of therapy:7 (15) Withdrawal of therapy:22 (46) Brain death:6 (12) Failed resuscitation:13 (27 **Inclusion criteria** Parents or legal guardians were eligible to participate if their child died in the PICU at one of the CPCCRN sites between 3 and 12 months prior to the start of the study. **Exclusion criteria** Parents who did not speak English or Spainish	pediatric intensive care physician (KM) and a behavioral scientist with expertise in health communication (SE), analyzed the interviews -Discrepancies between investigators were resolved by listening to the audio recording together and reaching consensus. A member of the data coordinating center reviewed 20% of the interviews with representation from each site to confirm the accuracy of the data set -The data set was imported into a qualitative analysis software program to facilitate data management. The two investigators used an iterative process to identify themes pertaining to the content and conditions of the physician-parent conference. -This process included independent reading of the data set to identify themes; comparison of themes between investigators; re-reading of the data set and discussion to refine themes and reach consensus on their meaning. - To enhance the validity of the thematic analysis, two bereaved parents reviewed the manuscript to provide their opinions as to whether parents' views were appropriately represented.	**Ways to help others** *"My only thing now, is there anything I could do in terms of being there for other parents or helping them in that respect?"* **Bereavement support** *"Maybe talk to them about where you can get help…I think it would be important if they think about telling you what you could do and where you could go."* **What to tell other family members** *"After the fact, we had a lot of questions asked to us, by our own family. Everybody. We tried answering the best we could but when everything is going on it's really hard to communicate to the rest of the family all the details and everything."* **Unhelpful information provision:** **Withholding prognosis**: *"It was apparent they knew my baby was dying but none of them quite came out and said 'your baby's gonna die'…So they knew and that irritated me that they didn't come out and say it."*	

Study details	Participants	Methods	Findings/results	Comments
			Use of medical jargon: *“The head of PICU was very helpful in explaining everything in layman's terms.”* **Conflicting information**: *“I talked to one doctor and he told me not to have this procedure done this way. And I turned around and the intensive care doctor was doing the procedure that way…I think the doctors need to talk to one another.”*	
Full citation Michelson, K. N., Patel, R., Haber-Barker, N., Emanuel, L., Frader, J., End-of-life care decisions in the PICU: roles professionals play, Pediatric Critical Care Medicine, 14, e34-44, 2013 **Ref Id** 334893	**Sample size** Sampling: purposeful sampling: firstly, in a pilot phase, the hospital bereavement coordinator identified parents based on her perception of the parent's readiness to participate. Subsequently, the researchers identified and invited participation from all parents of children who died	**Setting** University based tertiary care children's hospital **Data collection** -In depth, semi-structured focus groups (with HCPs) and one-on-one interviews (with parents) designed to explore experiences in end-of-life care decision making.	**Themes/categories** **HCPS**: **Keep parents updated about the medical situation, describe changes and prognosticates** **“***That if the team feels like things are headed in a bad direction. I think it’s inappropriate for there to be a lag time between them feeling that or seeing that. If diagnosing that and it being communicated to the family (Nurse)”* *“I’ve seen some, some excellent examples of, of communication by a*	**Limitations** **Aim(s): Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; how

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Study type** retrospective qualitative study **Aim(s)** To describe the roles and respective responsibilities of pediatric intensive care unit (PICU) health care professionals (HCPs) in end-of-life care decisions faced by PICU parents. **Study dates** 2007-2009 **Source of funding** NICHD grant	in the PICU between 2007 and 2009. Parents: n=18 HCPs: Not clearly reported (data collection involved in 9 focus groups and two nurse interviews involving 48 clinicians) **Characteristics** Parents: age in years: mean (sd) 35 (6.6) cause of child's death: n(%) neoplasm: 7 (54) Heart disease: 3 (23) Bowel perforation: 1 (8) Sepsis: 1 (8) Trauma: 1 (8) **HCPs:** Position: n(%) attending physician: 7 (15) chaplain: 4 (8) child-life specialist: 1 (2) fellow physician: 6 (13) nurse (bedside): 20 (42) social worker: 6 (13) case manager: 1 (2) **Inclusion criteria** Not reported **Exclusion criteria**	-Researchers continued parent data collection until reaching data "saturation." This was determined by study team consensus that parents were not describing new concepts. -A physician or a social worker conducted the parent interviews. Neither interviewer provided clinical care to the children whose parents were interviewed. -A social worker conducted all clinician focus groups and interviews. Interviewers/moderators used an interview guide intended to encourage discussion about issues important in PICU end-of-life care decision making and considerations. Interview guides were modified based on ongoing data analysis, an iterative approach to data collection typical of qualitative research. **Data analysis** Methods not clearly reported; quotations and "themes" reported	*couple of our fellows with regards to updating families on where things are at and that in a sensing saying things are not looking good and this is what we've done (Nurse)"* **Parents:** **Present decisions to parents; describe available options; give recommendations:** **"***Before the surgical team was doing their rounds…we asked what the options were for continuing treatment and, you know, they talked about our, our options. That if she went into arrest, you know, they could try the compressions or the, the, you know, other attempts to revive her. (Parent)"* **Clarify parents understanding by repeating information or answering questions:** **"***So they did explain to us everything that was going and you know and they allowed us to participate in the rounds in the morning and ask questions when they were done (Parent)"*	"saturation" of data was reached during data collection was reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: low **Other information**

Study details	Participants	Methods	Findings/results	Comments
	-less than 18 yrs old; -unable to communicate fluently in English; -had a child admitted with known or suspected non-accidental trauma; -were parents of a child >=8 years old; -were without available contact information			
Full citation Midson, R., Carter, B., Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences, Journal of Child Health Care, 14, 52-66, 2010 **Ref Id** 334894 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim(s)** To explore the experiences of parents within one tertiary	**Sample size** N=55 (28 in 2006/07, 27 in 2008) [a total of 110 families (58 in 2006/07 and 52 in 2008) were invited, and 55 participants agreed to participate.] **Characteristics** Location of the child's death was: Cardiac critical care, N=21 PICU: N=19; NICE: N=9; Other wards: n=6 Age range: 3 days to 17 years; **Inclusion criteria** The target population for the survey was 20% of all the in-house deaths in a one-year period. Families who had made formal complaints or	**Setting** Great Ormond Street Hospital which is a tertiary treatment centre receiving referrals across UK. Most of the children who died in the hospital are admitted or transferred to the intensive care areas. **Data collection** Families were approached by letter for interview. The interview was conducted by phone, home visit or at the hospital in a room away from the main building. The interview used scripted questions, developed by the End of Life Care Group and additional comments from parents were encouraged; The process continued until the target for each survey of 25% of bereaved families had been achieve.	**Themes/categories** **Early or timely information which could prepare parents earlier for the possible outcome (early information helped being prepared)/;** One parent explained tha**t** **"**sharing thoughts about a possible diagnosis earlier on, would not have affected the outcome but at least we would have been better prepared**.** Another parent also stated they would have appreciated "*more preparation and the mention of death as a possibility. Nobody uses the word terminal but a clearer more consistent picture would have been nice***"** **Info given in anticipatory guidance (info of what to anticipate):** However, some parents were still not being given adequate anticipatory guidance. **Need for info: Info that prepares parents for the eventuality that their child might die or will die is one of the clearest lessons learned/Info that helped parents for the eventuality even all other aspects of care are good:**	**Limitations** **Aim(s):** **Clearly reported** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; however no reporting on how different data collection methods (telephone interview, face-to-face interview etc) may impact on data collection and how researchers undertook them to control for possible biases in data collection process; no discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings/results	Comments
centre, the trigger that stimulated the need to survey their experiences, how practice was developed after the first survey and the challenges that still like ahead in changing the barriers, attitudes, and culture that impede some aspects of end of life care. 2006-2007 survey: to find out from parents whose child had died, their views about the care ans support they and their dying child had received. 2008 survey: the same was subsequently repeated, with another cohort of parents, in 2008 to ascertain any differences following the introduction of some strategies in End of Life care. **Study dates** 2006-2007 (first survey); 2008 (second survey) **Source of funding** Not reported	were undergoing legal disputes with the hospital were identified but not excluded from the target population; Families whose child died between 18 months and one year; Families of children aged 0-17 years who had experienced either "acute" deaths or deaths that had been anticipated; **Exclusion criteria** Not reported	**Data analysis** The data from both surveys were collated and analysed using descriptive statistics and thematic analysis.	"I didn't realise until afterwards that I didn't know what was going on. I didn't even consider she would die". Another explained "I had to keep asking, I needed to feel informed". This need for information is an overriding concern, even when all other aspects of care are good. **Information about prognosis and change:** One of the parents explained that "*care was great but I needed to be more informed. Things kept changing. I didn't have time to prepare*". **Information about choices and options: (so preparation, planning could be made)/implication of information provision in planning** Another parent said "*I wasn't given any options-and choices were not mentioned until we met again after her death*" **Information of realistic options:** There is not an equitable provision of community services across the UK. It is important that the options parents are offered are realistic. If, for example, a family wishes to take their home to die the GP and Community Children's service would need to be able to offer support out of hours. **Hindrance: unease/unwillingness of the clinicians to acknowledge the likelihood of death as an outcome:** Even when families suspect their child may die it can be difficult to voice this concern. Professionals may also collude with families to conceal information from children themselves.	**Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Low **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Monterosso, L., Kristjanson, L. J., Aoun, S., Phillips, M. B., Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service, Palliative Medicine, 21, 689-96, 2007 **Ref Id** 334905 **Country/ies where the study was carried out** Australia **Study type** a two-phase combined quantitative and qualitative study **Aim(s)** To obtain feedback from families of children receiving palliative and supportive care about their care needs in hospital and in community settings; to elicit views of parents and service providers to better understand the needs of such families and	**Sample size** For the qualitative part of the study: N= 38 parents + 20 service providers Those parents who agreed to be contacted regarding participation in phase 2 were approached by the research assistant via telephone. A total of 38 face-to-face or telephone semi-structured interviews were undertaken involving both cancer and non-cancer groups. **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Western Australia **Data collection** -6 questionnaires were administered either by phone or face-to-face were used to collect quantitative data in the first phase; -those parents and service providers who agreed to participate the 2nd phase were interviewed either by telephone or face-to-face; -each interview was audio-taped and transcribed. **Data analysis** -Transcriptions were analysed using the technique of content analysis. Open coding was used to identify common themes.	**Themes/categories** **Adequate and timely information on the non-cancer child's diagnosis, changes in condition, and longer term prognosis (parents):** Many parents from the non-cancer group whose child required complex care were concerned about their child's future and felt their physician's explanation of longer term prognosis was inadequate; Parents in the non-cancer group required clear information about their child's diagnosis, changes in condition and treatments, however, many physicians seemed to fail to provided this information in an effective and timely manner **Lack of central service point (service providers):** Service providers consistently expressed concern with existing community-based disability services in terms of lack of palliative support for children and a central information point.	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** low **Other information**

Study details	Participants	Methods	Findings/results	Comments
the barriers and facilitating factors associated with supportive and palliative care. **Study dates** 2003-2005 **Source of funding** Not reported				
Full citation Nolbris, M., Hellström, A., Siblings' needs and issues when a brother or sister dies of cancer, Journal of Pediatric Oncology Nursing, 22, 227-234, 2005 **Ref Id** 359462 **Country/ies where the study was carried out** Sweden **Study type** Qualitative study	**Sample size** N=10 (siblings whose brothers and sisters died of cancer) -participants were recruited from the oncology unit where their siblings died. They were selected by the first author with regard to age and gender for the purpose of heterogeneity. **Characteristics** **Age of healthy siblings**: mean (range) 21.5 (10 to 30) **Inclusion criteria** Not reported	**Setting** Oncology unit at Queen Silvia Children's Hospital, Goteborg, Sweden **Data collection** -interviews were conducted at the hospital, in the participants' homes, or at their place of work, from 1.5 to 6 years after the cancer patients' deaths. **Data analysis** -content analysis was performed in steps. The purpose was to find patterns and categories in the interviews related to the phenomenon of investigation. -the data were transcribed verbatim following each interview,	**Themes/categories** **Unhelpful: Lack of information from the medical staff** (information giving was taken as a kind of support or need for support, informational support) Healthy siblings felt insufficiently informed about the prognosis of the disease. They had been informed mostly by their parents. "It would have been easier of a doctor had talked to me about what happened; I didn't know anything about the side-effects". *"My mother informed us; no doctor talked to us". "Information from doctors and nurses about the disease was lacking." "Offered support-no."* **Lack of understanding about the implications of the disease due to the lack of information** Some of the siblings were not prepared that the sick child would die. *"I was not prepared," "I didn't know what was going on." "I was not prepared for what was going to happen, but it was really*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; however no discussion on whether saturation has been reached for any of the themes reported; **Data analysis:** The analytical process was not described in detail; how categories emerged from the data not clearly reported; researchers did not critically review their own roles in the process

Study details	Participants	Methods	Findings/results	Comments
Aim(s) To explore siblings' needs and issues when a brother or sister dies of cancer, interviews were conducted with 10 surviving children and young adults. Of particular interest was their individual participation in and experience of the period of disease, dying and mourning. **Study dates** 1998-1999 **Source of funding** Vastra Gotaland Foundation in Sweden	**Exclusion criteria** Not reported	and the text was read in its entirety several times by both authors to obtain meanings -emerged categories were re-organised and refined through discussion between the two authors until agreement was reached to ensure reliability	*good to be a part of things, to be allowed to participate."* **Lack of information about how to go through the process, guidelines, literature, contact with other siblings who had the same experiences:** The siblings were in shock at the time of the funeral, and it was not easy for them to express any of their requests, but no one asked them either. "*To meet others in the same situation and who have experienced the same thing could be helpful." "a network for siblings," and "special literature about siblings' thoughts when a child had caner and dies".* However, the siblings did not notice or believe that there were any guidelines or routines for how they should be treated. "*I wish that different things would be available, for example, contact with siblings or literature"*	**Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** low **Other information** a limitation of the study may be the time interval that elapsed from the events surrounding the death of the sibling to the time the study was conducted.
Full citation Price, J., Jordan, J., Prior, L., Parkes, J., Living through the death of a child: a qualitative study of bereaved parents' experiences, International Journal of Nursing Studies, 48, 1384-92, 2011 **Ref Id** 353800	**Sample size** N= 25 parents (16 of 24 families agreed to participate and the stories of 16 children were assimilated, told by 16 mothers and 9 fathers) (bereavement parents who had lost a child with a life limiting condition between 6 and 24 months earlier) -stratified sampling enabled comparisons to be made across particular subgroups.	**Setting** Potential participants were identified through the children's hospital and children's hospice which serve that region. Typically, interviews were conducted in parents' homes, on the grounds that familarity was likely to encourage participants to feel more at ease. **Data collection**	**Themes/categories** **Information that allowed parents to pilot/navigate their way through the process:** Information provision allowing parents to be involved in complex decision making and *navigate* their way through the multiple shifting challenges of carrying for their child and their child's subsequent death, while attempting, all the whilst to retain a sense of control amidst perceived chaos; **"***But we were still willing to hear even it meant losing his eye or something if it*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out UK **Study type** Qualitative study **Aim(s)** To redress the gaps in knowledge by exploring, retrospectively, parents' experiences of caring for children with both malignant and non-malignant conditions throughout the entire trajectory of their child's illness and subsequent death. **Study dates** Not reported **Source of funding** School of Nursing and Midwifery, Queens University Belfast Sandra Ryan Fellowship	**Characteristics** **Diagnosis of child:** Non-malignant: 10 Cancer: 6 **Inclusion criteria** Parents who had lost a child with a life limiting condition between 6 and 24 months earlier. **Exclusion criteria** Not reported -	-an in-depth interview with bereaved parents. All interviews were digitally recorded, with permission. -a semi-structured interview guide, containing a number of general questions as well as possible prompts and cues, acted as an "aide memior." -data was collected by the first author, an experienced children's nurse with no affiliation to participants. -themes arose inductively from the data **Data analysis** -the analytical framework was developed on the basis of a comprehensive treatment of all data, involving constant comparison both within and across parents' accounts, identification of deviant cases and memo writing. -in addition, a selection of interview transcripts was shared across all members of the research team in order to promote the full possibilities for analytical insight. -a data management package, NVIVI, facilitated the more practical and procedural aspects of developing the eventual analytical framework.	*would save his life we were still wiling to consider any option you know but em we knew to when it got to that stage that it was too late anyway***"** It was in the context of supporting or facilitating this involvement (through, for example, provision of relevant information) that the role of health care professions becomes particularly important. That is, **giving parents adequate information and/or communicating with them more generally about their child's care is not a purely utilitarian issue.**	has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; unclear how "themes" arose from content of accounts; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** moderate **Other information** -the sample consisted primarily of parents employed in what are typically regarded as "middle class" occupations. The importance of social class in mediating experience of illness has been highlighted previously.
Full citation	**Sample size**	**Setting**	**Themes/categories**	**Limitations**

Study details	Participants	Methods	Findings/results	Comments
Redmond, Bairbre, Richardson, Victoria, Just Getting on with it: Exploring the Service Needs of Mothers Who Care for Young Children with Severe/Profound and Life-Threatening Intellectual Disability, Journal of Applied Research in Intellectual Disabilities, 16, 205-218, 2003 **Ref Id** 351486 **Country/ies where the study was carried out** Ireland **Study type** Qualitative study **Aim(s)** To explore the mothers' views of the usefulness of the financial, practical and emotional supports being offered to them and their suggestions for service improvements. **Study dates** Not reported	n=17 (mothers of children aged 4 years and under/with severe/profound intellectual disability, some with attendant complex medical, life-limiting conditions). **Characteristics** **Mothers:** **age in years, mean (range):** 32 (29-45) **Diagnoses of children** ranged from significant birth trauma to serious metabolic disorders to complex congenital abnormalities **Inclusion criteria** Not reported **Exclusion criteria** Not reported	Not clearly reported, just mentioned interviews were conducted at homes; **Data collection** -semi-structured interviews with a topic guide -all interviews were taped and transcribed **Data analysis** -the data were analysed using a content analysis approach seeking out common issues and themes shared by the wider group	**Lack of comprehensive information available to mothers to help them avail of potentially useful and even essential services.** Mothers frequently referred to the process of gaining useful information as "*haphazard*", typically involving asking the same question to several different sources, only to be given conflicting answers. Mothers reported a distinct of **clear, correct and comprehensive information** relating to available services for children with intellectual disability. "*When we...went looking for information, it wasn't there....you're fishing around in different areas, there is not one place for it.*" (Mother of a girl aged 3 years) Mothers cited the **need for comprehensive, reliable information on practical medical and paramedical services specifically designed to meet the needs of this group of fragile children with severe intellectual disability**: "*a school or something that had all the services, swimming pool and everything that would be good for him, I'd love it. Someplace where he'd enjoy it, with plenty of nurses and help, physios to stimulate him-just to keep him happy*" (a mother of a boy aged 2.5 years) Many mothers commented the **establishment of a central service, advocacy officer or even a telephone advice line whereby families can access the information** which they need to avail of essential services:	**Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was not reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: low **Other information**

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported			"*someone should be responsible for co-ordinating the services and calling to the person and saying A, B and C is available to you, and bringing the information." (mother of a boy aged 3.5 years)* *"a liaison officer or somewhere where all this information is gathered and when there is a child born with a disability or a particular syndrome, there is somebody responsible for passing on this information to the parents or family" (a mother of a boy aged 3.5 years)*	
Full citation Rini, A., Loriz, L., Anticipatory mourning in parents with a child who dies while hospitalized, Journal of Pediatric Nursing, 22, 272-82, 2007 **Ref Id** 335026 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aim(s)**	**Sample size** N=11 parents (9 females and 2 male) from a sample of 14 parents contacted **Characteristics** **Causes of death of children:** 8 of the parents' children died in the paediatric intensive care unit (PICU)m, two in the nionatal intensive care unit (NICU), and on at a general pediatric floor. **Age of deceased children:** ranged from 10 days to 20 years; **Inclusion criteria** Not included	**Setting** University of North Florida, US **Data collection** -a descriptive design, using focused, guided, semi-structured, in-depth interviews, was used to collect data; -a set of open-ended questions, developed from a review of the literature and from the researcher's own personal experience in this field, was used to guide the interviews. -a purposeive sampling technique was used to recruit 11 parents who sustained the death of a child during the child's hospitalisation, thus comprising a homogeneous subgroup.	**Themes/categories** **Sufficient information on prognosis and cause of death:** Information, particularly **detailed information explaining why a child is not expected to survive**, is critical in helping parents prepare for the death of their child; **Information on prognosis, outlooks (e.g. death) helped parents to get prepared;**Parents' desire for detailed information explaining why a child is not expected to survive (Insufficient information); "*I think they knew more than they wanted to tell me. Like the last day, I think they knew, and they weren't..they just didn't want to I guess...but sometimes they need to prepare that person...*" **Information about process of burial** one parent suggested that the hospital have an information packet available to parents that will help them with the process of burial for their child. Knowing	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the one of the researchers and the respondents reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the

Study details	Participants	Methods	Findings/results	Comments
To describe the presence (or the absence) and the role of anticipatory mourning in parents who recently experienced the death of a hospitalised child and to determine if there were consistent factors that they described as helpful or detrimental to them during this process. **Study dates** 2001-2002 **Source of funding** Not reported	**Exclusion criteria** Not reported	**Data analysis** -The researchers conducted the interviews; field notes were taken during the interview -All interviews were tape-recorded and transcribed by an independent hired transcriptionist. -The researchers performed transcribed text analysis, followed by repetitive examination of transcripts fro the emergence of themes and subsequent coding or thematic content. -After repeated analysis, collapsed themes encompassed broader categories -To assure trustworthiness, content analysis was performed by the researchers and a secondary reviewer. The secondary reviewer who recorded the data and confirmed thematic content, possessed knowledge of the content area and was familiar with qualitative data analysis. -Lastly, upon completion of the study, two study parents were randomly selected to review the results, and both confirmed thematic content and conclusions.	what to expect, who to call for burial information and services, what costs to expect, and how to make funeral plans was described as very important and something that was not available.	researchers' roles and potential influences in the analytical process not critically reviewed; validation of results was conducted by randomly selecting two mothers review the themes. **Overall quality**: Moderate **Other information** All parents who consented to the interviews were Caucasian.
Full citation Sullivan, J., Monagle, P., Gillam, L., What parents want from doctors in end-of-life decision-making for children,	**Sample size** N=25 (bereaved parents) -with the approval of the Human Research Ethics Committee of the Royal Children's Hospital, an invitational notice to	**Setting** Royal Children's Hospital, Melbourne, Australia **Data collection**	**Themes/categories** **Supportive information that helped parents to be the ultimate decision maker for their child:** Actions by doctors which assisted parents to fulfil this decision-making role were positively appraised;	**Limitations** ***Aim(s):*** *Aim of the study clearly reported, research method was appropriate for answering the research question*

Study details	Participants	Methods	Findings/results	Comments
Archives of Disease in Childhood, 99, 216-20, 2014 **Ref Id** 358348 **Country/ies where the study was carried out** Australia **Study type** Qualitative study with a semi-structured interview design **Aim(s)** To examine parents' views and experiences of end-of-life decision-making. **Study dates** Not reported **Source of funding** Not reported	participate in the research was placed in the bereavement support newsletters of three organisations **Characteristics** **Inclusion criteria** -Parents whose child had a life-limiting condition; -their child was aged between 3 months and 12 years at the time of death -the parents had discussed en-of-life decision and the care for the child **Exclusion criteria** Not reported	-semi-structured interviews with questions covering relevant areas for end-of-life decision making **Data analysis** -Interviews were audio-recorded, transcribed and thematically analysed by the PR using a four-stage thematic analysis method -a checklist for good thematic analysis was used as an aid to the process -to promote accuracy in coding, several early coded transcripts were reviewed by one of the co-authors	**Factual information in oral or written form about the child's condition and its course** **Factual information in conjunction with the doctor's opinions or recommendation about what to do:** Additionally, most parents expressed the view that his factual information should be given in conjunction with the doctors' opinion or recommendation about what to do; "*so we had a view and (name of the neurologist) gave us a view and were aware if was up to us...*"	***Sample selection:*** *Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported;* ***Data collection:*** *Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported* ***Data analysis:*** *The analytical process was reported; researchers did not critically review their own roles in the process* ***Findings/results:*** *Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed* **Overall quality:** moderate **Other information**
Full citation Yuen, W. Y., Duipmans, J. C., Jonkman, M. F., The needs of parents with	**Sample size** N=16 parents A total of 25 parents were eligible for the study, 16	**Setting** A national referral centre for EB, the Netherlands	**Themes/categories** **Honest information about the diagnosis and lethal prognosis**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was

Study details	Participants	Methods	Findings/results	Comments
children suffering from lethal epidermolysis bullosa, British Journal of Dermatology, 167, 613-8, 2012 **Ref Id** 348459 **Country/ies where the study was carried out** The Netherlands **Study type** Qualitative study **Aim(s)** To identify the needs of parents of parents who have lost their child to lethal epidermolysis bullosa **Study dates** Not reported **Source of funding** Not reported	independent parents were willing to participate. **Characteristics** Not reported **Inclusion criteria** All parents who had lost their child to lethal EB 1 year prior to the start of the study **Exclusion criteria** Not reported	**Data collection** -telephone interviews conducted by the primary investigator. -the interviews were semi-structured and open-ended, in which the investigator invited parents to narrate their experiences and thoughts about their child's illness; **Data analysis** -the interviews were recorded on tape and transcribed verbatim by the primary investigator. The transcripts were analysed by multiple line by line readings. Significant statements, phrases and sentences were identified and used to distill common themes.	Although parents thought it was hard to hear the news, they were all glad they were informed honestly. Parents indicated that important factors in the conversations in which the **news was delivered with ....visual aids and written brochures.** "*He could not make it better than it was. It was very hard to hear it, but on the other side, he couldn't have told it in a different way. I wouldn't want that*" *"If you are not honest with people, then they keep hope...That will give problems, as you will give them more [treatment]. That should not happen"*	appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** low **Other information**
Full citation	**Sample size**	**Setting**	**Themes/categories**	**Limitations**

Study details	Participants	Methods	Findings/results	Comments
Wocial, L. D., Life support decisions involving imperiled infants, Journal of Perinatal & Neonatal Nursing, 14, 73-86, 2000 **Ref Id** 360102 **Country/ies where the study was carried out** US **Study type** Qualitative **Aim(s)** To understand better parent perceptions of the decision making process by making the following determinations including: what information was important to parents in reaching a decision about withholding and/or withdrawing treatment from their infants. **Study dates** Not reported **Source of funding**	N=20 parents whose infants received treatment in a single NICU, located in a single metropolitan area. (31 families were eligible to participate in this study. 8 families were unable to be located, 5 families declined. 5 families were interviewed as part of a pilot to refine the interview tool. 12 families participated in the interview that resulted in the data reported) **Characteristics** **Informants:** age: 19 to 40 years; most of them were white (97%), had at least some college education (67%), and had health insurance (92%) **Inclusion criteria** -the infant must have been admitted to and received treatment in the NICU -parent informants must have participated with health care providers in a discussion to consider withholding and/or withdrawing treatment from their infants -the infant must have died	interviews with families (2/3 of the interviews were completed by phone) **Data collection** -open-ended interviews were used to collect data -all interviews were audiotape recorded and transcribed verbatim. Immediately after the interview, the researcher recorded notes relevant to the affect of subjects, the atmosphere where the interview took place, and impressions of the interview process -Interview styles and techniques were developed using feedback from a mental health professional skilled in conducing qualitative research and relevant literature -the decision to close data collection was made in consultation with a panel of expert researchers once it was determined phenomenal ***saturation*** had been reached **Data analysis** -Content analysis techniques which included the steps of (transcribe each interview, write a summary abstract of each interview, extract the relevant fact to create an event history, develop a story line and topics using study aims, review each transcript for significant themes, determine relevance of	Clear, accurate and timely exchange of information contribute to parents' positive retrospective perceptions of their experience; **Needs for updated information:** **Needs:** parents were looking for any information that would help them interpret their infants' condition. "*I think them most important thing to us, or the most helpful thing to us to be frequently updated, to be constantly updated*" **Comprehension and things help them to understand their infant's test results:** parents appreciated information that was easy to understand; "*I was digging at the questions, at trying to understand*". Parents also mentioned how helpful it was to see x-rays or CAT scans of "normal" babies next to their infant's test results. "*Give that that knowledge you know, educate us so we can have some answers. We had to ask for his CAT scans...Obviously we are not medical students and a lot of the stuff may be you know a little though to understand, but it can be broken down. We will comprehend it if you just lay it out there"* **Accessible information when needed:** Parents wanted and appreciated information that was readily available to them. "*I want to be able to ask questions, because this was complicated, you know, this was hard...and several times, you know we had them call the specialist so we could ask them questions and stuff...They*	**Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality**: moderate **Other information** Informants of this study were a fairly homogeneous group.

Study details	Participants	Methods	Findings/results	Comments
National Institutes of Health	**Exclusion criteria** -inability to comprehend and speak English	themes to study aims, develop codes and definitions for themes) -to ***verify the credibility*** of the results, a clinical expert in neonatal nursing reviewed the results following completion of data collection	*said, 'no, no problem, just give me a second and I will call them page them and have them come here and talk to you*" **Direct information:** When parents received direct information that was "up front" and not "sugar coated" they perceived it as truthful	
Full citation Hunt, A., Coad, J., West, E., Hex, N., Staniszewska, S., Hacking, S., Farman, M., Brown, E., Owens, C., Ashley, N., Kaur, J., May, K., Chandler, V., Barron, D., Wik, A., Magee, H., Lowson, K., Wright, D., Gunn, K., Kelly, K., Woodhead, S., Together for Short Lives, The Big Study for Life-limited Children and their Families – Final research report , 2013 **Ref Id** 360103 **Country/ies where the study was carried out** UK **Study type** Qualitative study	**Sample size** N=59(41 parent(s)/family carers + 18 children and young people) (66 families were approached and of them, 51 participants in the study which included 59 individuals (41 adult parents/carers and 18 children and young people aged 5-18) **Characteristics** **Adult parents/carers:** 74% of adult participants were mothers and 13% were fathers; **Diagnoses of children and young people:** Static encephalopathy and congenital and chromosomal group**: 21%** Neuromuscular group**: 19%** **Age of children and young people:** 5-10 years: 36%	**Setting** Interviews in which locations were chosen by the participants **Data collection** -In-depth interviews and arts-based focus groups were conducted using an Appreciative Inquiry (AI) approach. Fundamental to this approach is the desire to discover "what works well" and "why it works well." -Participants were asked using arts-based tools what was good about services or met needs, what could be better about services or unmet needs and what the ideal future for services would look like. **Data analysis** -Open ended questions from the questionnaire were analysed thematically.	**Themes/categories** **Information given either in patronising ways, or conversely, in medical jargon; information about the child's illness in different forms:** Despite parents' wealth of experience regarding practical care (including complex medical procedures), there were numerous reports that hospital nurses and consultants addressed parents in either patronising ways, or conversely, they spoke in medical jargon which was difficult to parents to understand. (***no quotes***) **information about the child's illness in different forms:** On two occasions it was reported that a hospital doctor failed to give the parent any explanation about the child's illness and just handed the mother a leaflet (***no quotes***). **Lack of information about services the child and family entitled to (e.g., directory for services):**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed

Study details	Participants	Methods	Findings/results	Comments
Aim(s) To under the met and unmet needs of children with life-limiting conditions and families (*Strand 2 of The Big Study for life-limited children and their families*) **Study dates** 2011-2013 **Source of funding** The Big Lottery Fund	11-15 years: 15% **Inclusion criteria** -50-80 families using West Midlands Children's Services -families living in one of the five West Midlands NHS clusters and Gloucestershire NHS Cluster (n=6) -Children with a diagnosis of a life-limiting or life-threatening condition and their families that are receiving children's palliative care services **Exclusion criteria** -families not using the services of West Midlands Children's Services -families not living in West Midlands NHS clusters and Gloucestershire NHS Cluster -young adults not in receipt of children's palliative care services	-principles of *framework analysis* were used to analyse data. Once all data sets were coded, initial categories were refined and sorted into the three main sub-categories within the themes of met needs, unmet needs and implications for future needs.	The availability of information was very varied and easily accessible information was the exception rather than the rule. "*It is a minefield finding out what you are entitled to. Most of the things we have found out by accident. There are all those services out there but they should make it more transparent-a directory or something" (parent)* *"I mean the care is out there for you, you just have to find out. If somebody sat me down and told me all this someday, nobody told me we has to find out ourselves"* **Explanation of about the child's illness, diagnosis, research in the area:** "*Then the paediatrician phone one evening when my husband was out and said [the child] has got spinal muscular atrophy, if you wnat to look it up on the internet you can find out all about it. I remember thinking it was quite callous. It was shocking..." (parent)* *"The way we were given the diagnosis wasn't the best-it was in a normal clinical appointment. The doctor was looking at his watch at one point. I asked what sort of research was going on [to help] and the doctor said, 'don't worry about that, just love him' " (parent)* **Lack of information about voluntary services and support groups:** There appears to be a lack of centralised information about voluntary services and support groups which is early accessible to families **(no quotes)**;	**Overall quality**: moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			Conflicting advice/information given by different professionals: Parents and carers mentioned occasions when different professionals gave them conflicting advice and this was particularly disconcerting when parents were learning new complex medical procedures or when parents had to hand over the administering of medicines to their child. **Information on how to use equipment (practical information):** There also appeared to be a problem in relation to the information or advice given to parents and carers regarding how to us equipment that a child or young person requires;	

G.3 Review question: Advanced Care Planning

What are the barriers and facilitators to the infant, child or young person, the family and the multidisciplinary team in being involved in decision making to inform the development, assessment and reviews of personalised, parallel and advanced care planning (including if appropriate decisions about continuing or stopping life-sustaining treatment and attempting cardiopulmonary resuscitation?

Study details	Participants	Methods	Themes/ categories	Comments
Full citation El Sayed, M. F., Chan, M., McAllister, M.,	**Sample size** N=12 postgraduate physician trainees in neonatology	**Details** SAMPLE SELECTION 25 trainees were invited to participate. Each trainee	**Results** **HEALTHCARE PROFESSIONALS’ PERPECTIVE**	**Limitations** **Aim:** The aim is broadly described. The chosen research

Study details	Participants	Methods	Themes/ categories	Comments
Hellmann, J., End-of-life care in Toronto neonatal intensive care units: challenges for physician trainees, Archives of Disease in Childhood Fetal & Neonatal Edition, 98, F528-33, 2013 **Ref Id** 334536 **Country/ies where the study was carried out** Canada **Study type** Qualitative (semi-structured interview) **Aim of the study** To explore the	**Characteristics** All participants were neonatal subspecialty trainees at the University of Toronto. The majority of the participants were female, married, between the ages of 31 and 40 years; eight have children. 11 stated that they had a moderate level of intrinsic religiosity. Eight had previous clinical experience in neonatology prior to joining the fellowship programme in Toronto, and of these three worked in a religious healthcare centre during those years. To the authors' knowledge, these participants had not previously been part of a palliative care team. **Inclusion criteria** Trainees were eligible to participate if they had been in their Clinical Fellowship for at least 9 months in the hospitals provide neonatal care affiliated with the University of Toronto	received a letter describing the study, which included a separate consent form ensuring confidentiality to participate in the study. SETTING Hospitals that provide neonatal care affiliated with the University of Toronto DATA COLLECTION The authors used an in-depth, semi-structured interview guide developed specifically for the study The interview questions addressed trainees' beliefs, attitudes, preferences and expectations regarding discussions of EOL neonatal care. Interviews were audio-taped and conducted in a private room DATA ANALYSIS Audio-recorded interviews were transcribed verbatim Content analysis was undertaken, including concept saturation and theme generation. The text about the participants' experiences	**Withdrawal of life-sustaining (WLST) treatment based on poor outcome** Within this theme, three related categories were identified: <u>Infant's best interest</u> Trainees reported that quality of life is hard to define since it is different for each person and each family. Forming an opinion that serves the best interests of the infant while taking into consideration parents' coping skills and acceptance is described as a major challenge. *"What I might interpret as bad or poor quality of life may not be the family's opinion…When they make the decision to continue treatment that personally this is a baby that I would withdraw on, I do feel bad about the situation thinking that this baby is going to continue really suffering, having pain. The family can't see it the way I'm seeing it." (trainee)* <u>Consensus decision making</u> Consensus decision-making was appreciated as a process that sought agreement of participants and the resolution or mitigation of minority objections. *"In the end, no one should feel like he/she made the decision. It is a shared decision". When there is divergence of opinion, it leads to trainee anxiety and they often had trouble going forward with the proposed plan as this trainee shared, It is only when I'm able to establish consensus from my whole team that I will go ahead. Then…I know that I am not the only one, the whole team has decided. I am a representative of the team and…I establish some balance of dealing with this issue, so I do not get into that kind of distress which I used to get." (trainee)* <u>Therapeutic options available</u> Trainees also expressed that the process of WLST was very different when compared to their home countries, and initially it may be distressing They did not encounter the same types of scenarios that occur in Canada. They felt that families in Toronto tended to accept transition from life-extending care	method is adequate for answering the research question. **Sample selection:** The procedure for sample selection was vaguely reported, as it is not clear if all trainees were contacted. The response rate is low (< 50%), and it is not clear if those who did not took part differ from those who accepted. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. **Data analysis:** The data analysis was reported; and thematic analysis is also described. However, researchers did not critically review their

Study details	Participants	Methods	Themes/ categories	Comments
challenges for trainees when EOL decisions are undertaken and to encourage them to reflect on how they might influence such decision making. **Study dates** January to December 2009 **Source of funding** Not reported	**Exclusion criteria** Not reported	was then extracted and combined into one text, which constituted the unit of analysis. The text was divided into meaning units that were condensed; the condensed meaning units were abstracted and labelled with a code. The whole context was considered when condensing and labelling meaning units with codes. The various codes were compared based on differences and similarities and sorted into subcategories and categories These categories were discussed and revised by two study researchers The content of the categories was formulated into a theme. Rigour of emerging themes was achieved through thick description in which adequate reference to quotes in the text demonstrated the presence of an emerging theme.	to palliative care only after using all technological intervention, making the whole process much longer. *"Here, they use all the technology they have. Once they reach the last end, they start discussing withdrawal…. It is totally different from back home where we didn't have the option to keep on supporting to the last minute. Here it is a longer process." (trainee)* When addressing specific options of therapy available in EOL care, many trainees commented that withdrawal of nutrition and hydration was the hardest for them: *"The nutrition thing I'm not comfortable with at all. I have been here for two years and I've heard a lot about it. Now I can hear…but I'm still not comfortable doing it and I don't think I'll be doing it. I'm not at that stage yet." (trainee)* **Explaining 'no resuscitation options' to parents** Trainees felt responsible for making parents aware of 'DNR' as an option when cure is no longer a realistic goal. However, they expressed they did not always have the answers, especially when talking with families about predictions of morbidity and mortality. Their ability improved with time, and generally towards the end of their training, they felt more comfortable discussing 'DNR' options with parents. *"I used to have that kind of hesitation earlier, but now I do my homework, i.e. I read a lot and I should be in my mind sure and comfortable that that's an option which is fine." (trainee)* *"I'm more comfortable now. Definitely, became more comfortable over the years. I didn't know what to say. I wasn't sure. Usually the decision not to resuscitate is taken for cases where you shouldn't resuscitate. I'm comfortable with that." (trainee)* **Clarifying do not resuscitate orders (DNR)** 'DNR' orders can include a range of different yet related options from withdrawal or withholding life-sustaining treatment to not escalating current treatment or no CPR in	own roles in the process. **Findings/results:** The results were presented clearly using relevant quotes from participants and are applicable to the aims of the study. **Overall quality:** moderate risk of bias **Other information** The authors report there is no conflict of interest International trainees The study focuses only in the views of trainees and how this influences EOC decision making Response rate: 12/ 25

Study details	Participants	Methods	Themes/ categories	Comments
			the event of cardiac or respiratory arrest. The process of WLST can be confusing for families if not done with extreme skill, care and sensitivity. *"Do Not Resuscitate" orders"…every time we do it, it is left to the interpretation of the people of how to do it." (trainee)* **Empowering families with knowledge and explaining their role in a shared decision-making process** Communicating and collaborating with parents was generally seen a *'positive thing'*; but they suggested that a degree of provider recommendation and parental guidance would be helpful without necessarily shielding parents from any unpleasant information or taking over their decisions. *"I think sometimes we can be a little bit more definite in our guidance because that is a big decision for parents to actually make and to feel like they have to make. I don't think that is something I could ever decide to do. I don't even have kids and I can't imagine being told "Go home and think about it. Come and tell us what your decision is." (trainee)* **Dealing with different cultures** It was recognised that there is important to learn about cultural expectations at the time of EOL discussions, as well as how to best support the cultural and religious needs of various families. *"You will find people from every part of the world in Toronto so that makes it enriching for us as physicians, but sometimes difficult because you have to individualize each case according to the understanding which you grasp from the first meeting with parents. Difference would be the culture." (trainee)* Some parents may believe that withholding or withdrawing treatment is not acceptable in their cultural/religious practices. Some trainees found this uncomfortable, whereas others thought it is useful:	

Study details	Participants	Methods	Themes/ categories	Comments
			"I try to avoid the babies whose parents have very strong religious beliefs because I don't know how to properly talk to them." (trainee) *"Many people think that if you involve God in this decision, then you might find it difficult… but if these parents have a strong belief in God or whatever that is then I think it is important to appreciate and to understand it." (trainee)* **Managing personal internal conflict** Some trainees learned to separate their personal beliefs when making a decision with parents. *"It is something I have to deal with. I've learned to actually withdraw my own personal religion from whatever decision that is made. I've had to."* Others decided that the rules of their faith cannot be considered when dealing with EOL situations. *"I put it in the back burner. I say: 'This is the way I am going to deal with it and hopefully I'll be forgiven in whatever decision it will have to be."* **Implications for fellowship training in neonatology** Most trainees in this study believed it is very important to receive formal training in EOL care. *"There should be more training, more mock cases, more sessions on how to manage end-of-life, which is not easy and we encounter every single day."*	
Full citation Hammes, B. J., Klevan, J., Kempf, M., Williams, M. S., Pediatric advance care planning, Journal of Palliative	**Sample size** N=12 families (13 interviews done, as 1 father and mother were interviewed separately) 5 families refused to participate **Characteristics**	**Details** SAMPLE SELECTION All paediatric patients with advanced directives starting in 1986 were identified. Parents or carers were sent an invitation letter, with a consent form. Parents were contacted	**Results** **PARENTS' PERSPECTIVE** **<u>Benefits of having and advance directive</u>** **Ensuring the best care** Twelve parents expressed that the planning process worked to preserve the current and individual quality of life for the child. For example, one mother in the study explained that even though her son had compromised health, he still had	**Limitations** **Aim:** The aim is clearly reported and the chosen research method is adequate for answering the research question. **Sample selection:** The procedure for

Study details	Participants	Methods	Themes/ categories	Comments
Medicine, 8, 766-73, 2005 **Ref Id** 344504 **Country/ies where the study was carried out** USA **Study type** Qualitative study (interview) **Aim of the study** To describe the process and population involved in pediatric advanced care planning and to discuss the parents' perceptions of the planning process. **Study dates** Not reported	Age at signing of AD (median/ range): 4.89 (2 days to 12 years old) Gender (M/F): 8 and 9 Diagnosis: c Living/ deceased (N): 8 and 9 Age at death (median/ range): 4.6 (2 months to 12 years old) Six children had a secondary diagnosis of cerebral palsy **Inclusion criteria** Paediatric patients with advanced directives Children born between 1983 and 2003 **Exclusion criteria** Not reported	within a week to determine interest and to arrange a time for the interview. SETTING Department of Paediatrics, Gundersen Lutheran Centre, La Crosse, Wisconsin DATA COLLECTION The interview conducted on the phone or in person at the hospital (at mutual agreement). The conversations were audiotaped and transcribed for accurate documentation of responses. The interview included questions about who initiated and was included in the advance care planning conversations, the reasons for having and advance directive, the benefits and disadvantages of advance care planning and problems that arose during the process. DATA ANALYSIS	activities he enjoyed. Parents also agreed that the best care for the child meant avoiding unnecessary suffering. **Providing time and information to make decisions** Eleven parents found that the information given during the discussions and the time allowed to think about the decisions was useful. Having the opportunity to ask questions and discuss thoughts and preferences before an actual emergency was helpful for parents because they knew the decisions were made in a clear frame of mind and not during the stressful situation. **Helping to communicate desired care** Eight parents talked about the difficulties they had with the many care providers. They explained that having and advance directive avoided confusion and conflicts. They also noted that they helped them avoid continuously re-explaining their preferences. **Having peace of mind** Eight parents found beneficial having an advanced directive, as it provided a clear direction and gave them a sense of control. It also allowed for preferences to be made known without a sense of confrontation. All these benefits provided "*peace of mind*". **Problems encountered with the advance directives/barriers** **School** Four parents reported the school district had difficulty agreeing to follow the advance directive because many of the policies of the school require all life-saving treatments to be done for the child on school grounds. One family removed the child from school after being told the school could not honour the plan. In another case the school created a special document for the child. **Emergency medical technicians**	sample selection procedure was clearly reported. The most relevant limitation is that it was limited to children who had an advance directive. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. **Data analysis:** The data analysis was reported; and thematic analysis is also described. However, researchers did not critically review their own roles in the process. **Findings/results:** The results were presented clearly and are applicable to the aims of the study. **Overall quality:** moderate risk of bias

Study details	Participants	Methods	Themes/ categories	Comments
Source of funding Not reported		A form of content analysis was used to analyse the interviews. Three of the authors completed an independent, in-depth study of the transcripts and created a list of themes. These initial lists were compared, discussed, and refined. Through this process dominant themes were identified.	Two parents reported that some community emergency medical technicians had difficulty honouring the advance directives because it was for a child. **Community** Two parents expressed concerns that community and family members at times did not support the idea of a child having an advance directive. One mother stated that the community thought she and her husband were "*choosing whether the child lives or dies*". **Legal** One child's advance directive was legally challenged by a county attorney, by the judge ruled in favour of the legal guardian.	**Other information** Children with neuro-degenerative conditions only Patients were identified by the existence of an advanced directive, and it is not known how many parents may have declined to consider and advance directive Retrospective study Small sample 1/3 of the parents/ guardians did not participate in the study
Full citation Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., Furman, W. L., End-of-life care preferences of pediatric patients with cancer, Journal of Clinical Oncology, 23,	**Sample size** n= 20 patients n=19 parents (1 patient refuse the parent to participate) n=16 physicians (two had multiple participating patients) There were 36 potentially eligible patients. 4 parents of patients declined permission: 3 declined because their child had not been involved in the decision	**Details** SAMPLE SELECTION Patients were screened for eligibility daily during rounds of each clinical team. After the physician confirmed patient eligibility, an interviewer approached the parent and described the study in detail. With the parent's permission, the patient was then invited to participate. SETTING	**Results** **PARENTS' PERSPECTIVE** **Deciding as my child prefers.** Choosing as the patient would want or as the patient previously directed the parent to choose (n=18) *"I talked with my child about what to do if we ever faced that decision, and I knew ahead of time what she wanted me to do, and that helped. I know I was doing what she would have wanted."* Mother of a 12-year-old girl with a brain tumour **Trusting staff and being supported by them.** Believing in the expertise of the treating clinicians and feeling recognized by the clinicians as contributing most significantly to their child's welfare (n=16) *"Nobody on the staff there is going to think that I made the wrong decision. They always made me feel like I did the right*	**Limitations** **Aim:** The aim is clearly reported and the chosen research method is adequate for answering the research question. **Sample selection:** Sample selection is clearly described, but it is unclear whether the patients who responded differed to those who were contacted but did not

Study details	Participants	Methods	Themes/ categories	Comments
9146-54, 2005 **Ref Id** 348284 **Country/ies where the study was carried out** USA and Australia **Study type** Qualitative (interview) **Aim of the study** To identify the preferences of children and adolescents with advanced cancer about their end-of-life care and the factors that influenced their decisions. **Study dates** 22-month study period	1 declined because the child was too ill to participate 12 patients declined: 5 patients at St Jude and 7 patients at Sydney Children's Hospital Reasons: "don't want to talk about it" (n=5), "no time to participate" (n=4), and "feel good about it and have nothing more to say" (n =3) Gender (M/F): 7 and 5 Ethnic group: 4 black and 12 white A phase I trial was under consideration for 3 patients who declined, DNR status was adopted for 5patients, and terminal care was initiated for 4 patients. **Characteristics** Patients Mean age (range):17 years and 4 months (10 years 0 months to 20 years 9 months) Gender (M/F): 6 and 16 Ethnic group: 17 white patients Setting: St Jude n=14 Sydney Children's Hospital n=6	Paediatric oncology centre of St Jude Children's Research Hospital in Memphis, TN, and Sydney Children's Hospital in Sydney, Australia. DATA COLLECTION The patient, parent, and physician were interviewed separately Authors used the descriptive decision–theoretic decision analysis model. They developed and tested open-ended questions about the decision, possible choices, anticipated outcomes, and influencing factors for use in interviews. Interviewers were retrained throughout the study period. The same three interviewers completed all interviews, which were initiated only after the end-of-life treatment decision had been made and documented in the medical record. All interviews were conducted face to face, tape recorded with the permission of	*thing for my child."* Father of a 13-year-old boy with leukaemia **Deciding as a good parent would.** Considering the facts, explanations, opinions, and preferences of experts and others (eg, family members, ill child, and other bereaved parents) and then choosing the option most consonant with an internal definition of a caring, competent protector of their child (n=16) *"The doctor gave us the facts and told us how serious this is, and we told our daughter. But the choice part has not been difficult for us. …it's never been a question for us because she has plans, and we are going to do everything we can to see that those plans are able to be made and, if not, then she knows and we know that we have done everything we can."* Father of a 10-year-old female with leukaemia **Avoiding negative outcomes.** Choosing an option that prevents or reduces the risk of adverse effects on the child and family (n=13) *"This would have meant extra days in the hospital…injections at home…probably less time off between treatments. He might not get the time to recuperate in between."* Mother of a 14-year-old male with a solid tumour **Being helped by my faith.** Believing in a Greater Being and in the strength that comes from spiritual beliefs and practices (n=13) *"I don't care what you want to call it, my belief had a lot to do with believing that there is something better out there for her."* Mother of a 15-year-old girl with leukaemia **Nothing more to do.** Parents conclude that no acceptable curative or life-prolonging option exists (n=12) **Still trying for cure or longer life.**	participate. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. **Data analysis:** The data analysis was reported; and thematic analysis is also described. **Findings/results:** The results were presented clearly and are applicable to the aims of the study. **Overall quality:** Low risk of bias **Other information** The authors indicated no potential conflicts of interest oncology patients only

Study details	Participants	Methods	Themes/ categories	Comments
Dates not reported **Source of funding** Not reported	Diagnoses: solid tumour (n=12) brain tumour (n=4) leukaemia (n=4) <u>Parents</u> 13 mothers and 6 fathers No other demographic data about parents or physicians were collected <u>Physicians</u> Gender (M/F): 12 and 4 No other demographic data about parents or physicians were collected **Inclusion criteria** Eligible patients had parent and physician approval to participate and were English speaking, between age 10 and 20 years, and directly involved in one of three end-of-life decisions (enrolment onto a phase I trial, adoption of DNR status, or aggressive symptom management only [terminal care]). Parent and physician inclusion criteria included the following: English speaking,	participants, and transcribed by a trained medical transcriptionist. DATA ANALYSIS The accuracy of the transcripts was verified by two members of the team. Validated interview data were entered into the ETHNOGRAPH software program (Qualis Research, Colorado Springs, CO). Each phrase was analysed for meaning. Two members of the team jointly reviewed the first three interviews and, using standard qualitative methods, applied labels (first-level codes) to key phrases to capture their meaning. The same team members developed a code dictionary for each group of participants that comprised all first-level codes identified. Four other team members then used the group-specific code dictionary to complete a semantic content analysis of each group's interview data. Inter-rater reliability	Parents make a choice in the hopes of keeping their child alive (n=11) *"I am…prolonging the inevitable until a cure comes along…I want her to be healed. I keep telling her to hold on…"* Mother of a 14-year-old girl with a brain tumour **Wanting time left to be good.** Parents desire to focus on the quality of their child's remaining days of life (n=8) *"I have very strong convictions about quantity versus quality. Deciding to go home—I'm just tickled…She is a whole different person."* Mother of a 15-year-old girl with leukaemia **Wanting to help others.** Parents' decision making is influenced by a desire to benefit current or future patients (n=5) *"What my daughter goes through would be very important to another child. It's not just to save her but children in the near future that could possibly come down with this particular type of cancer…"* Mother of a 17-year-old girl with a solid tumour *"Hopefully and in someway, we will be able to get through all this and go on with our life, but if it does not work out, well I want someone else to benefit."* Mother of a 17-year-old girl with a brain tumour **CHILDREN'S PERSPECTIVE** **Thinking about my relationships with others.** Decision making affected by caring for others (family, staff, future patients), preferences of others, and the desire to benefit others (n=19) *"If I can help someone else, that's wonderful, I think."* 14-year-old girl with a brain tumour **Avoiding adverse events.** Deciding against the risk of pain, nausea, likelihood of hospitalization, or the negative effects on family (n=14) *"I knew it would make me a little bit sick and that I would be in the hospital for a few days each time. I could also have*	

Study details	Participants	Methods	Themes/ categories	Comments
	directly involved in the end-of-life decision, and consent to participate. **Exclusion criteria** Not reported	estimates (% agreement) for each code ranged from 50% to 100% within and across all interviews. After the first-level codes were applied to all interviews, team members independently identified codes that consistently occurred together and had overlapping meaning. These codes were grouped into broader categories of response. The frequency of each category of response was calculated. Three to four members of the study team analysed each interview; and inter-rater reliability was estimated after each of the first 10 interviews and subsequently after every third interview. Reliability estimates for each category ranged from 88% to 100% within and across all interviews.	*tried vincristine, but I had that before and I didn't think my body could get through that."* 18-year-old male with a solid tumour *"It was explained to me that every new patient would get a stronger dose, every time. Mine would be the highest dose, and I could get all the symptoms the first day that others got on the 10th or 11th day."* 18-year-old female with a solid tumour **Wanting no more therapy.** Choosing to end therapeutic efforts even if such efforts might extend life (n=13) *"We decided not to go with chemo because I don't want to be sick the rest of my days, and it's not like it is going to cure me, so I just said, 'we'll go home and take it from there.' "* 15-year-old girl with acute lymphoblastic leukaemia *"I want to die. I just want to get it over with…it feels like I'm being tortured, not tortured, not forced, they are not purposely doing this, but they might as well just chain me up to the wall and put needles in my arms."* 18-year-old with a solid tumour **Ready to die and go to heaven.** A certainty of living an afterlife that will be better than current life circumstances (n=10) **Seeing others die.** Having observed or learned about others who were supported on a mechanical ventilator and concluding that this prolongation of life is to be avoided (n=10) *"Why would I want a tube in my throat? I saw two other patients like that—I don't want that. I wouldn't be able to talk with my family or hold my Mom's hand. That is not living."* 15-year-old girl with acute lymphoblastic leukaemia *"Seeing other members of my family on tubes. You just lay there. I don't like it. I wouldn't want it for me. I don't want to be kept alive like that. If someone is ready to die, I say 'let*	

Study details	Participants	Methods	Themes/ categories	Comments
			them die,' you know? 15-year-old with acute myeloid leukaemia **Believing treatment now is futile.** Concluding that no remaining option is likely to affect the cancer, at least not without a serious adverse effect (n=6) *"If anything was going to work, it would have done it before now."* 16-year-old boy with a solid tumour *"We've been through the main steps…if it was going to work, probably it already would have worked. Stuff like the radiation, the chemo stuff, and then the experimental chemo, and we have been through several chemos and stuff, so I figured if it was going to slow it down or stop it, you know, it would have done it by now. And, if it hadn't done it by now, it's just going to grow, so I may as well be at home having fun."* 17-year-old boy with a solid tumour **Seeing a chance for cure.** Considering cure unlikely but aware that a parent or sibling still believes in that possibility (n=4) *"My mom told me they were getting very good results with this drug."* 16-year-old boy with a solid tumour *"We were kind of really happy that they had chemotherapy, something else that we could try."* 15-year-old girl with a solid tumour **PHYSICIANS' PERSPECTIVE** **Being influenced by patient and family preferences.** Particular consideration is given to the expressed wishes of the terminally ill child and the parents (n=14) *"…the father identified that it was important that they try everything that was a potential benefit. That was important for both the son and the father, but especially the father."* **Considering the prognosis and comorbid conditions.** Concluding that survival was unlikely or impossible given the patient's medical status (n=14)	

Study details	Participants	Methods	Themes/ categories	Comments
			"This was her second relapse. She had relapsed a year earlier with spinal cord disease, and it was a matter of time before she had recurrence elsewhere in the supratentorial region, and she was having moderate pain." **Wanting to benefit my patient and others.** Considering potential positive outcomes that could result from certain decisions (n=13) *"In terms of what was available, this would be the one that could give him some potential help in controlling his tumor and pain relief…."* **Wanting to avoid harm.** Considering the negative outcomes of a decision option for the patient and the family (n=11) *"She would have an easier death than if we had done a lot of manipulation with machines."* **Patient/family understand and accept.** Parent and ill child's grasp of the seriousness of the clinical situation facilitates efforts to assist them with end-of-life decision making (n=8) *"He has been very realistic about his situation, and that has helped me with this."* **Having no other option.** Recognizing that all therapeutic possibilities had been pursued but without lasting benefit (n=8) *"We had exhausted all of the conventionally useful drugs and experimental drugs."*	
Full citation Hinds, P. S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E.,	**Sample size** N=43 parents **Characteristics** Parents' ages (range): 23 to 59	**Details** SAMPLE SELECTION Eligible participants were identified sequentially during staff meetings or through daily records review as having made a	**Results** **GROUP 2: PARENTS' PERSPECTIVE** **Factors parents thought when making their decision** **Fighting for life.** Parents indicate that as long as any hope remains, efforts to cure the child must continue (n=6)	**Limitations** **Aim:** The aim is clearly reported and the chosen research method is adequate for answering the research question.

Study details	Participants	Methods	Themes/ categories	Comments
Gattuso, J., Martinson, I., Yi, K. H., Drew, D., An international feasibility study of parental decision making in pediatric oncology, Oncology Nursing Forum, 27, 1233-43, 2000 **Ref Id** 348285 **Country/ies where the study was carried out** Australia, China and USA **Study type** Qualitative (interview) **Aim of the study** To describe parenteral decision	Parent's gender: 5 fathers and 38 mothers Children's ages (range): 1 year 8 months to 19 years 11 months **Inclusion criteria** Parents were eligible to participate at one of the following time points: Group 1. (not relevant for our review) Group 2. While enrolled in a frontline therapeutic child has experienced documented and confirmed disease progression during the previous 4 to 6 weeks that necessitated changing therapeutic protocols or treatment plans. Group 3. The child had experienced a 1st or 2nd disease recurrence. (text not legible) Group 4. The child's disease had progressed to the terminal stage and end-of-life decision such as DNR or withdrawal of life support had been made within the prior 24 hours to 3 weeks. **Exclusion criteria**	treatment related decision. Four groups of parents were included (see inclusion criteria), each group was making decisions at a specific time point during the child's treatment for cancer. SETTING A paediatric research centre in the South-Eastern United States A children's large hospital in a large Australian city A children's hospital in Honk Kong DATA COLLECTION Parents were interviewed privately and their answers to 6 open-ended questions were audiotaped. The interview questions were derived from the descriptive decision-making theoretical model and have been used previously in two studies. The taped interviews on non-English speakers were translated and transcribed. The transcriptions were entered in Ethnograph software.	**Not having a real choice.** Although 2 or more treatment options were offered, only one option seemed acceptable and viable (n=6) **Considering likely adverse events of treatment.** Parents contemplate the potential negative effects of treatment of their child (n=3) **Wanting quality of life.** Parents desire a normal lifestyle for their child (n=3) **Being helped by religious beliefs.** Parents describe being assisted in decision making by trust in a greater being and by being able to pray (n=3) **Choosing good science.** Parents chose the option that seemed most logical, sound and promising (n=2) **What did your doctor, nurse, social worker or chaplain at the hospital say that helped you with the decision?** **Trusting staff.** Parents express strong faith in the HC team's ability to provide the best care for their child, have their child's interest in mind, and guide them in decision making (n=6) **Getting information from the HC team.** Parents report finding facts and explanations from doctors and other professionals about certain symptoms or behaviours or updates and progress reports quite useful in understanding their child's changing situation (n=2) **Being supported by staff (n=2)** **What did your doctor, nurse, social worker or chaplain at the hospital say that did not help you with the decision?** **None** **GROUP 3: PARENTS' PERSPECTIVE** **Factors parents thought when making their decision** **Doing what we must.** Parents opt for additional treatment if any hope exists to be certain that all options have been attempted or because not doing so in unacceptable (n=8)	**Sample selection:** Sample selection is clearly described, but it is unclear how many participants agreed to participate. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. **Data analysis:** The data analysis was reported; and thematic analysis is also described. Themes are very similar across the groups, although it is expected that the parents raise different issues depending on the stage of the disease. **Findings/results:** The results were presented clearly and are applicable to the aims of the study. However it could have been very illustrative

Study details	Participants	Methods	Themes/ categories	Comments
making about treatment options for children with cancer and determine the feasibility of a similar but larger international study. **Study dates** Not reported 12-month period **Source of funding** Not reported	Not reported	**Data analysis** Coding dictionaries were generated at each site in an effort to capture the site-specific factors of the decision-making process; when codes were identified, the same labels and definitions were used for information from all 3 sites. Each site coordinator reviewed the lists generated at all 3 sites for overlapping meaning. 3 or 4 members of the team coded all interviews independently. A 90% agreement criterion across codes was maintained. Frequencies of codes were determined across sites. Strategies proposed by Krippendorf.	**Not having a real choice.** Although 2 or more treatment options were offered, only one option seemed acceptable and viable (n=7) **Considering likely adverse effects of treatment.** Parents contemplate the potential negative effects of treatment of their child (n=5) **Knowing my child's preference.** Their child's statement about fears or desires related to treatment influence parents (n=3) **Out of love for my child.** Parents describe being influences by great affection for and loyaly to their child (n=3) **What did your doctor, nurse, social worker or chaplain at the hospital say that helped you with the decision** **Getting information from the HC team**. Parents report finding facts and explanations from doctors and other professionals about certain symptoms or behaviours or updates and progress reports quite useful in understanding their child's changing situation (n=8) **Being supported by staff.** Parent report that staff listened to their or their child's concerns and responded to them, explained situations or conditions in a compassionate and easy-to-understand way, or made efforts to secure the needed information (n=3) **Trusting staff.** Parents express strong faith in the HC team's ability to provide the best care for their child, have their child's interest in mind, and guide them in decision making (n=4) **Sensing staff commitment.** Parents report feelings sustained by the healthcare team's obvious concerns for their child and by the team's continuous efforts to cure their child's disease (n=2) **Sensing hope in staff.** Parents felt encouraged by the positive attitude of the healthcare team toward a treatment option (n=2) **What did your doctor, nurse, social worker or chaplain at the hospital say that did not help you with the decision?**	to have quotes from the participants. **Overall quality:** Moderate risk of bias **Other information** International study Children's ages (range): 1 year 8 months to 19 years 11 months Oncology patients only Study included a group of parents whose child had had a first treatment without disease progression of recurrence. These data has not been considered Evidence from group 2 considered as indirect

Study details	Participants	Methods	Themes/ categories	Comments
			Fearing disagreement with staff. Parents want to avoid displeasing the healthcare team and losing its support (n=2) **Disliking style and urgency.** Parents report reacting negatively to the way in which options were offered or the abbreviated time frame in which the decision needed to be made (n=2) **GROUP 4: PARENTS' PERSPECTIVE** **Factors parents thought when making their decision** **Wanting to minimize suffering.** Parents desire to avoid or reduce pain, fear or other negative experiences for their child (n=4) **Considering likely adverse effects of treatment.** Parents contemplate the potentially negative impact of certain drugs or therapies on their child (n=6) **Nothing more left to do.** Parents acknowledge that all possible curative or supportive care efforts have been attempted with their child to no avail (n=6) **Believing that my child could not survive.** Parents conclude that their child cannot continue to live (n=4) **Feeling that we did all we could.** Parents find comfort in determining that everything that good, caring parents could do has been done for their child (n=6) **Knowing my child's preference.** Their child's statements about fears or desires related to treatment influence parents (n=3) **What did your doctor, nurse, social worker or chaplain at the hospital say that helped you with the decision?** **Getting information from the healthcare team.** Parents report finding facts and explanations from doctors and other professionals about certain symptoms or behaviours or updates and progress reports quite useful in understanding their child's changing situation (n=6) **Being supported by staff.** Parent report that staff listened to their or their child's concerns and responded to them, explained situations or conditions in a compassionate and	

Study details	Participants	Methods	Themes/ categories	Comments
			easy-to-understand way, or made efforts to secure the needed information (n=6) **Trusting staff.** Parents express strong faith in the HC team's ability to provide the best care for their child, have their child's interest in mind, and guide them in decision making (n=5) **What did your doctor, nurse, social worker or chaplain at the hospital say that did not help you with the decision?** **Fearing forced.** Parents describe being made to choose a treatment option when they did not want to make the decision (n=5) **Caring involvement interferes.** Parents described being hampered in decision making by the fondest staff members have for their child and concern about how their child's death will affect staff (n=1)	
Full citation Lotz, J. D., Jox, R. J., Borasio, G. D., Fuhrer, M., Pediatric advance care planning from the perspective of health care professionals: A qualitative interview study, Palliative Medicine, 29, 212-222, 2015 **Ref Id**	**Sample size** N=17 healthcare professionals **Characteristics** Age (Mean/SD): 46 (14.4) Gender (M/F): 6 and 11 Professional experience, years (Mean/ SD): 21 (9.5) Care setting: outpatient care n=8 hospital care n=7 care facility n=4 Professional groups Physicians n=9 Nurses n=6 Social professionals n=2 **Inclusion criteria**	**Details** SAMPLE SELECTION Purposeful sampling. Sampling decisions were made a priori based on reasonable criteria rather than theoretical saturation At least one representative for each selected profession, discipline, and care setting was included SETTING Paediatric palliative care DATA COLLECTION Individual interviews were conducted by a psychologist and CYP	**Results** **HEALTH PROFESSIONALS PERSPECTIVE** **<u>Benefits of paediatric advance care planning</u>** **Sense of security and control.** Thirteen HCPs raised that pACP gives both HCPs and parents peace of mind. It provides a clear direction in case of emergency procedures in a written document. It is also mentally prepares parents for difficult situations: *"So, that they then know exactly what has been discussed, what was decided. To have it in black and white […] it also conveys, I believe, additional security, so you know: It is all right if I do NOT dial the emergency/critical care number now so somebody gets here because it's getting critical. It's all right the way it is."* (Nurse in a special nursing facility); *"It's important to establish at least a little bit of clarity for the staff, for the parents, just what common goal is pursued and also which measures ARE taken and which are simply omitted. Insofar, I just think it is really IMPORTANT and makes a whole lot of sense for everyone involved with the child.*	**Limitations** **Aim:** The aim is clearly reported and the chosen research method was appropriate for answering the research question. **Sample selection:** The procedure for sample selection procedure was clearly reported. Sample decisions were made a priori based on reasonable criteria rather than theoretical saturation (selective sampling)

Study details	Participants	Methods	Themes/ categories	Comments
362434 **Country/ies where the study was carried out** Germany **Study type** Qualitative (interview) **Aim of the study** To investigate the attitudes, barriers, and benefits as well as requirements for paediatric advance care planning (pACP) from the view of health care professionals (HCPs) and to generate hypotheses on pACP that can be tested in a larger cohort. **Study dates** April 2012 to April 2013	HCPs representative of one of the defined professional groups, disciplines, and care settings HCP in a leading position with major responsibilities (e.g. senior physician, medical director, head of department, division manager); HCps with a special interest in the research question **Exclusion criteria** No interest in the research question Insufficient German language skills	trainee psychotherapist, following a semi-structured interview guide. The interviewer was trained to conduct interviews in a working group on qualitative research methods and received an additional training from a psychotherapist experienced in palliative care research and interviewing. Interviews were audiotaped and transcribed verbatim. Words or phrases stressed by the interviewees were transcribed in capital letters. The transcripts were not returned to the participants in order to avoid censoring and corrections for reasons of social desirability. At the beginning of each interview, the concept of paediatric advanced care planning (pACP) was explained to the participant. Then they were asked three open questions: (1) What are your experiences with	*Therapists included, doctors, nurses, parents. Just to always provide clarity and to just fix one GUIDELINE. Otherwise everyone is always very INSECURE in their doing and acting, and this just provides clarity and thus security."* (Nurse in a special nursing facility) **Improving quality of care.** Four physicians and two nurses said that pACP could help reducing unnecessary suffering for the child. pACP discussions and documents could lead to a fewer number of emergency and intensive care interventions in CYP with a LLC. *"I rather see the realistic situation in a way that you have a patient in the critical care unit where you have to painfully realize: this was somehow wrong, this won't work, ok? And THEN you say: Ok, now he is already here but we tie our own hands and say this and that we WILL NOT DO anymore."* (Intensive care physician) **Ensuring respect of patients' and parents' wishes.** Two physicians and one nurse indicaed that pACP makes parents feel that they are being taken seriously and ensures that their own or their child's wishes are respected in situations when they are not present: *"I think it can take the burden off the parents to a certain degree, and this having-to-be present all the time as well. This family for example would really love to go on vacation for a week. But then they say, in fact they don't dare to, because surely he will be hospitalized then […] So there is this fear: the moment I turn my back on the nurses, they do what in fact we don't want."* (Primary care physician) **<u>Barriers to paediatric advance care planning</u>** **Fear and discomfort regarding pACP documents.** HCPs raised that they lack the competence to make EOL decisions in children and showed concern about making wrong decisions based on a child's AD. For example	**Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. **Data analysis:** The data analysis was reported; and thematic analysis is also described. Researchers' role in the process was also described. **Findings/results:** The results were presented clearly and are applicable to the aims of the study. **Overall quality:** low risk of bias **Other information** The interview questions were developed and structured according to the recommendations by Helfferich (2005). The resulting interview guide was discussed in

Study details	Participants	Methods	Themes/ categories	Comments
Source of funding This work was supported by the "Stifterverband für die Deutsche Wissenschaft" (grant number: 401.20112934).		any forms of ACP for severely ill children and adolescents? (2) What are your experiences with written ADs that patients/parents bring with them and that have been completed prior to your first encounter with the patient? and (3) How should an approach to pACP ideally look like? At the end of the interview, participants could add anything else they found important relating to pACP. **Data analysis** Interview transcripts were analysed using qualitative content analysis and the software MAXQDA-10. Information was summarized into categories, checking back with the original data. Resulting categories were then organized into 3 main categories (benefits, barriers, requirements of pACP). For each category, content, coding rules, and prototype examples	psychosocial professionals do not feel competent to assess the child's medical condition, and in a crisis they would prefer to call an emergency physician to decide whether the child's AD applies. Emergency physicians feel uncomfortable too with making EOL decisions for a child they do not know, and without having the time to evaluate the situation, as they fear later accusations or legal consequences: *"And then, our practice is that we have to say: […] in such a case, we call the emergency physician and we can give this letter to him, ok? And then, it is again the physician's decision"*. (Social worker in a non-medical care facility) *"When the emergency physician comes, he will always do everything. […] You can't call him and present him a piece of paper and tell him: "don't do anything," ok?"* (Intensive care physician) **Uncertain prognosis.** HCPs are afraid of making false-negative predictions and prefer refraining from initiating pACP discussions with the children or parents before the prognosis is certain: *"On the other side, it is the experience that one can also misassess the situation, also in the negative sense. So, the situations where one would have thought, based on experience, that this cannot turn out well, they have stabilized once again […] Therefore, one is very cautious. You first have to come to the point for yourself when you say: o.k., I really don't see, to the very best of my knowledge and belief, any chances left."* (Intensive care physician) **Physicians' difficulty in initiating pACP** Physicians and nurses expressed their own reluctance to address EOL issues with the patient/parents because they tend to *"close their eyes to the facts and don't want to picture the worst case scenario"* (Intensive care physician). Also there are perceived taboos in other cultures. **Difficulties in identifying the child's wishes.**	various research groups with clinical and bioethics expertise and was piloted with an assistant physician of the paediatric palliative care team, resulting in no major revisions. Conflict of interest: none declared 100% response rate Participants with no interest in the topic were excluded, which may bias the results

Study details	Participants	Methods	Themes/ categories	Comments
		were defined to increase transparency and reliability. Authors first performed a case-by-case analysis and then compared and summarized the results across all interviews. The resulting categories and coding were reviewed, discussed. This resulted in the merging of a few sub-categories.	All HCPs were worried about not acting according to the child's wishes, as they feel the child's will is often unknown. **Burden for parents.** Physicians are afraid that ACP takes away hope, and they showed concern about forcing and overburdening children and parents, as this can result in destroying the trusting relationship with the family. Also it is a responsibility for parents when they sign the AD for their child. **Limitations of pACP documents.** Physicians raised limited applicability of the pACD document and the parents' right to revoke an AD. **Lack of coordinated communication.** All professional groups mentioned that there is insufficient information-sharing between HCPs, lack of round tables and lack of a continuous contact person. **Insufficient implementation in health care system.** All professional groups raised that there is neglect of pACD in current practice, with shortage of time and lack of funds for pACD. **<u>Requirements for pACP</u>** **Time points/ reasons for initiating pACP.** Most participants called for early initiation of pACP shortly after diagnosing an incurable condition, but considered this unrealistic in many cases, because the parents often need more time to process the bad news. Therefore, they gave priority to the family's readiness for pACP discussions when deciding about when to initiate pACP. Some also focused on important occasions for initiating pACP in the course of the disease, such as discharge at home or a severe deterioration of the child's condition. **Process characteristics.**	

Study details	Participants	Methods	Themes/ categories	Comments
			Once initiated, pACP should be conceived as an ongoing process, adapted to the individual family. Decisions should be made known in the community and be regularly reviewed. Written documents should also be distributed to emergency services and local hospitals to prepare them for potential emergency situations. Besides concrete emergency planning, HCPs working in outpatient care or non-medical care facilities stressed the need to discuss daily life issues and plan for the EOL. This included planning of future support options in everyday life, dying, and bereavement. **Participants is pACP.** Most HCPS thought pACP should be a multidisciplinary process that should include all relevant HCPs in the community. The relevant people will depend on the child the family and may become relevant at different time points throughout the pACP process. Cooperation and information-sharing between the different care providers was also viewed as key. Most participants thought that any child able to communicate should be involved in pACP, regardless of its age, as children should be given the opportunity to discuss their fears, EOL needs, and treatment preferences themselves with an HCP. They stressed the importance to use child-appropriate communication (e.g. using children stories). *"If the patient himself says he wants this and this and that, no matter how old the child or adolescent is, when he can express it I think it has to be considered."* (Outpatient nurse). The interviewees disagreed on whether the parents should always sign an AD or whether they should only be given the option to do so (given the high burden of responsibility). **Professional education.** All HCPs asked for education that covers both medical and non-medical issues, such as legal situation and communication.	
Full citation	**Sample size**	**Details**	**Results**	**Limitations**

Study details	Participants	Methods	Themes/ categories	Comments
McHaffie, H. E., Lyon, A. J., Hume, R., Deciding on treatment limitation for neonates: the parents' perspective, European Journal of Pediatrics, 160, 339-44, 2001 **Ref Id** 351959 **Country/ies where the study was carried out** UK **Study type** Qualitative (interview) **Aim of the study** To explore parent's perceptions of treatment withdrawal/ withholding, their	N=108 parents (59 families, 62 babies) participated at 3 months **Characteristics** Age (range): Age: 60% of mothers were 30 years or older; 8% in their teens 67% of of parents were 30 years or older For 38% of mothers this was the 1st pregnancy 61% had 1 to 5 previous pregnancies 41% had suffered previous obstetric loss 8 of the pregnancies were multiple Mean gestation was 32 weeks, 9 babies were born < 24 weeks Time of death: 61% died in the 1st week of life 10% lived > 3 months 1 survived almost 9 months **Inclusion criteria** Previous discussion with parents about treatment limitations. Babies with a medical prognosis of either early death or impairment	SAMPLE SELECTION The stated policy within each unit was to recall parents at approximately 6 weeks after the death of a child. Respondent parents were recruited at this first follow-up appointment with a neonatologist. SETTING Three Regional Neonatal Centres in the East of Scotland. DATA COLLECTION Face-to-face tape-recorded interviews at 3 and 13 months after the baby's death. The 1st interview lasted 2h and 45 mins on average (1h to 5h 15 min). Second interviews lasted from 30 min to 4h 30 min (mean 2h). The two semi-structure interviews schedules designed specifically for the study were based on the literature and on clinical experience. **Data analysis** Data were entered onto a computer under pre-determined variable	**<u>PARENTS PERSPECTIVE</u>** **Who made the decision?** 56% (n=60) of parents fell they took responsibility for decision making, and 45 felt it was their decision alone; 15 parents felt they took a joint decision with the doctors; 4 sets of parents subsequently wished that they had taken responsibility for the decision at least in part parents referred differences between the units some neonatologists made the decision seem to be exclusively a parental responsibility, but parents also describe them as guiding and supporting others neonatologists almost always kept in the medical domain, although these parents felt them to be listening carefully about parents views **Did the right people decide?** 83% or parents felt the right person had decided; 12% were unsure - in one case the baby experienced a very distressing death witch upset them and made them question their role in the decision 5% felt in retrospect that the wrong person had decided **Factors that helped parents to decide** There were 4 factors which helped parents decide that withholding treatment was best for the baby: Visible deterioration The prospect of suffering Clear information about the poor condition of the child Bleak prognosis **Involvement in decision making** The majority of parents would want to be involved, but it is important also to take into account those who do not want. The staff at the NICU should be sensitive to parent's preferences. **Evidence of a poor prognosis**	**Aim:** The aim is broadly described. The chosen research method is adequate for answering the research question. **Sample selection:** The procedure for sample selection was vaguely reported, as it is not clear if all parents who lost a child were contacted. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is vaguely reported. The researchers do not discuss saturation of data. **Data analysis:** It is unclear why interview data was only analysed as frequency numbers or rates when a thematic analysis would have been more appropriate. **Findings/results:** The results are very vague and do not fully respond to the

Study details	Participants	Methods	Themes/ categories	Comments
experience and their opinions. **Study dates** Not reported **Source of funding** The study was funded by The Scottish Executive.	severe enough to seriously limit potential quality of life. Three main categories: preterm delivery, congenital abnormalities and asphyxia. **Exclusion criteria** Not reported	names, with scope for unlimited values to accommodate the full range of responses. SPSS was used to analyze the high volume of information. 22% of the interviews were independently checked by two other people for both accuracy of coding and the interpretation of content.	Parents are able to tolerate a degree of uncertainty and they demonstrate trust in the expertise of senior clinicians. Some parents also showed doubts (after child passing away). One of the main reasons is the lack of concrete evidence of a bleak outcome. If parents can be shown abnormal scan results... the accuracy of medical assessment is reinforced.	objectives of the study. **Overall quality:** high risk of bias **Other information** UK based (Scotland) (+) Large N Interview about retrospective information, possible recall bias Results are mostly descriptive, and there is just some insight in the discussion section, but this is more related to authors' interpretation of the results than the parents actual responses
Full citation Mitchell, S., Dale, J., Advance Care Planning in palliative care: A qualitative investigation into the perspective of Paediatric	**Sample size** N=14 **Characteristics** Consultants and senior nursing staff (including matrons, and those with leadership and managerial roles within PICU) were invited to participate in the study. **Inclusion criteria**	**Details** SAMPLE SELECTION Local admission criteria define that admission to the Neonatal Intensive Care Unit (NICU) occurs from labour ward or a postnatal ward only. Otherwise, all critically unwell neonates and children are admitted to the PICU. SETTING	**Results** **<u>HCP's PERSPECTIVE</u>** **Recognition of a life-limiting illness trajectory** Lack of diagnostic precision provides an <u>obstacle</u> to undertaking ACP, as having clear diagnoses are not always possible when working with paediatric population. Participants described recognition of the child's illness trajectory as a key <u>barrier</u> to initiating ACP, and described the need for earlier recognition of the LLC to be able to have earlier ACP, rather than waiting until all therapeutic options had been exhausted:	**Limitations** **Aim:** The aim is clearly reported and the chosen research method was appropriate for answering the research question. **Sample selection:** The procedure for sample selection

Study details	Participants	Methods	Themes/ categories	Comments
Intensive Care Unit staff, Palliative Medicine, 29, 371-379, 2015 **Ref Id** 366039 **Country/ies where the study was carried out** UK **Study type** Qualitative (semi-structured interviews) **Aim of the study** To explore the experiences of senior medical and nursing staff regarding the challenges associated with Advance Care Planning (ACP) in	Not reported **Exclusion criteria** Not reported	the PICU of a tertiary referral centre children's hospital in the UK (Birmingham Children's Hospital) DATA COLLECTION Semi-structured interview, which comprised open questions and a series of prompts to guide the interview. All interviews were conducted in a quiet room. The interview was informed by the literature and was subsequently modified according to emerging findings, throughout the interview process. Interviews were conducted until data saturation was achieved around the main themes. Interviews were transcribed verbatim and anonymised. DATA ANALYSIS The main author carried out a familiarisation process with the data, and the identification of summary statements (open codes) that	*"it's almost like relapsing remitting MS [multiple sclerosis], they get relapsing remitting ICU and their relapses occur more frequently and last longer."* (D1) Participants described experiences where gaining consensus among the healthcare professionals involved had been a significant barrier to the ACP process: *"we can be a lot more proactive given the opportunity, but often we're just trying to, er, persuade our colleagues who are providing care at the time, long before I see admission [to PICU], to raise the point."* (D4) *"before you can convince any parents, you have to convince the other specialties. You have to bring them on board. If they're not on board, you have no chance, or your chances with the family are much much less."* (D7) Nursing staff were described as most frequently being the ones who identified the deterioration in a child's condition, although sometimes it was parents who raised the issue of end of life care: *"often the nurses are way ahead of us, often the nurses are the people who suggest it … And sometimes it's us who realise. Sometimes it's the specialty consultants realise enough is enough. It's rare for the families to suggest it, but I have had families suggest it to me."* (D1) *"parents who have seen their children having very umm, frightening events, life threatening events, cardiac arrest, the parents that have witnessed a number of cardiopulmonary resuscitations, they'll get to a point where they can't watch it anymore."* (D2) **ACP as a multi-disciplinary, structured process** ACP was considered to be a 'good idea' or 'essential' by all participants, and they all emphasized its multidisciplinary nature. A number of barriers were also identified, such time constraints, conflicting clinical demands and lack of formal	procedure was clearly reported. **Data collection:** The data collection process is clearly reported. Interviews were conducted until data saturation was reached. **Data analysis:** The data analysis was reported; and thematic analysis is also described. Researchers' role in the process was also described. **Findings/results:** The results were presented clearly and are applicable to the aims of the study. **Overall quality:** low risk of bias **Other information** UK-based study Includes both medical and nursing staff Conducted in just in PICU setting, limiting the generability of

Study details	Participants	Methods	Themes/ categories	Comments
relation to children and young people (CYP) with life-limiting illnesses in the Paediatric Intensive Care Unit (PICU) environment and opportunities for improvement. **Study dates** August 2011 to October 2011 **Source of funding** This study was carried out with the support of a Practitioner’s Allowance Grant from the Royal College of General Practitioners Clinical Innovation and Research		described every element of the interviews. Emerging themes from this list of open codes were divided into overarching categories, and a final coding framework was developed. The transcripts were reviewed and every section of each interview colour coded to an allocated category, to produce an organised dataset (Gill 2008). All this process was conducted manually. A percentage of transcripts were independently reviewed and coded. The coding frameworks from these analyses were compared, allowing further development of categories and themes and a plan to present the themes in a systematic way to reflect phases of illness towards the end of life.	training in communication skills. A lack of established rapport with the family before having to raise the issue of end-of-life care for the first time during acute situations, including resuscitation, was identified as causing particular difficulty: *"it’s very difficult for us, because it is usually in the acute settings, unusual that we even get an opportunity to speak to them before the breathing tube goes down."* (D5) *"It [ACP] should have happened before they came to ICU, for a lot of children. And I know the challenge is that we never know when that end is going to be, but if the families have had no preparation that this is likely to take place, it’s even harder."* (N3) *"worst case scenario … would be [discussing end-of-life] right in the arrest situation … then you try to give parents the heads up about that, actually this is not really going to be a successful resuscitation, and to try to prepare them … in a very short space of time. Umm, depending on the parents that might be with them watching at the bedside."* (D2) It was felt that these discussions should occur before admission to PICU, with clinicians who are known to the family. However, PICU staff can make useful contributions to these discussions by explaining the implications of a PICU admission and the potential burden of intensive therapies: *I think it’s the person who knows the family best. They are the people who should do that, whether it’s the community nurse, whether it’s their GP, or whether it’s their general paediatrician. Whoever knows them best and has the best relationship, is the person who should initiate that conversation."* (N3) *we get called in as intensive care doctors to help, er, the people who are managing the case long before a critical episode long before a critical episode to talk through what a resuscitation would involve and what the treatment we provide involves. And that, um, … parents will often agree in that situation that what we’re contemplating doing is abhorrent in some way; you know it’s just a step too far."* (D4)	results to other settings or other PICU settings

Study details	Participants	Methods	Themes/ categories	Comments
Centre (SFB-2011–2024).			The use of a formal document in ACP was seen as positive, as it provides a framework for discussions, and empowers both HCP and parents to agree a care plan which reflects the family's wishes: *I'm going to see somebody on the ward that's collapsed and you're considering whether they need ICU, you know, to look in their medical records, you see the [ACP], and you can quickly identify rather than going through tons of medical notes to find out what's happening.* (N5) **The value of ACP** Medical staff considered important to allow plans to be made in anticipation of different clinical scenarios, whereas nursing staff gave more emphasis to offering choice in terms of place of death, and the opportunity to carry out pre-bereavement work, as well as the introduction of other healthcare teams including hospice and community teams and the chaplaincy team when cultural and religious concerns were a priority: *"Sometimes they have quite specific needs that they, or specific wants, they want to, and you can't always facilitate them if you don't … know in advance."* (N5) *"if we want to get this child home, you know, we bring the community teams in, meet the teams. If you want to take your child afterwards to a hospice, let's go … let's go to the hospice, let's go and see the bedroom, let's go and … it's just all about preparing them and getting the, to … just so that they're not frightened by – you know, new faces or different people."* (N6) An important issue for both medical and nursing participants was the need for ACP in order to make best interest decisions: *"I have seen however many mothers here as well, who have never even held their baby, and the baby's stuck here with their chest open for three weeks, and then we finally withdraw care and they still haven't even held their baby."* (D5)	

Study details	Participants	Methods	Themes/ categories	Comments
			"I don't think the meaning of life sustaining treatment is always explained very well. How invasive it is and how uncomfortable, and how it takes you away from your normal environment, it takes you away from family interaction … lots of things we do carry significant risk of complications, and you should only really do them if, at the end of it, it is going to improve someone's quality of life." (D8) HCPs were all able to recall situations where ACP discussions had resulted in achieving a peaceful terminal phase of illness and death in a preferred place of care. Positive feedback had been given by parents at subsequent bereavement meetings: *"I do believe it's helping. Well I know it is because I've seen parents coming back to us and talking about it, and saying how they feel it's, it's helped them."* (N2) *"When he died I think it was all as sort of planned and predicted and … Yeah, the family were grateful, which is usually a good sign."* (D3) It was recognised, however, that acute clinical deteriorations often cause a crisis where even the most detailed ACP does not prevent a last-minute deviation from the plan: *"if they make an ACP they may still change their mind right at the very end, um … But at least they will have had the opportunity to sit down and seriously think about what they want for their child."* (N3) **Adverse consequences of inadequate ACP** Participants described situations where the admission of a critically unwell child with life-limiting illness to PICU had led to distressing consequences for the patient, their family and the staff involved in their care: *"We definitely get exposed to when that whole process has gone wrong because children come here to die you know. Or come here with a life-threatening, you know, a development in their illness that could have been anticipated better and planned for in a different way." (D8)*	

Study details	Participants	Methods	Themes/ categories	Comments
			"I know the challenge is that we never know when that end is going to be, but if the families have had no preparation that this is likely to take place, it's even harder." (N3) *"So I think there are many examples in my head and in my career where we have over-medicalised the end-of-life and families have clung on to the medical management rather than the holistic palliative care management of children, such that they feel that they're failing their child if they don't ask for everything."(D1)* Participants described the moral and emotional distress associated with the provision of care and interventions that were not felt to be in the best interests of the patient or their family: *"we get faced with decisions that are out of our control, someone else has decided actually, either between the family and the team, the medical team, the nursing team, they have decided that this child needs to come to ICU, and it is taken out of our hands." (D8)* The number of deaths in the PICU (the setting for this study) was 73 in 2010, equating to one or two deaths per week (the expected number for a PICU of this size when adjusted for the severity of illness38). The emotional impact of witnessing death so frequently on staff was described, but was more widely recognised and managed by nursing staff compared to their medical colleagues: *"death is difficult and it is emotive and upsetting but at the same time, it is unavoidable, we have to deal with it." (D8) #* *"when I was a registrar it was easier for me because I had to just sit and have a debrief with my … consultant, as I love to cry. But now, I have to be this brave person and it's very … very difficult." (D6)* *"It's not real life what's going on in there, it's just so horrendous what is happening every single day … so 'No, you're not doing it today. You've done it a couple of times recently and that is enough'. Because if you do it too often you have to leave. You have to protect yourself." (N2)*	

Study details	Participants	Methods	Themes/ categories	Comments
			Emergent themes- transitions An additional theme regarding transitions in care emerged during some of the later interviews. The challenges associated with managing CYP at 'transition' stages – babies moving from neonatal ICU to PICU, and those who make the transition to adult palliative care services – were described: *"These teenagers that are the cross over … I don't think paediatric and adults viewpoints on who they admit to ITU necessarily match at the moment."* (N5)	
Full citation Dunsmore, J, Information, Support, and Decision-Making Needs and Preferences of Adolescents with Cancer: Implications for Health Professionals, Journal of Psychosocial Oncology, 13, 39-56, 1996 **Ref Id** 372826 **Country/ies where the study was carried out** Australia	**Sample size** N = 51 young people with cancer **Characteristics** Age (mean, range): 18 (15 to 24) years old Gender (M/F): 27 and 24 **Inclusion criteria** Young cancer patients who attended the 1992 session of the camp of the National Australian Teenage Cancer Patients Team, a national peer-support group for cancer patients aged 12 to 24 years and their teenage siblings. **Exclusion criteria** Not reported.	**Details** SAMPLE SELECTION See inclusion criteria. DATA COLLECTION Focus groups and a detailed literature search were used to develop a 42-item, self-administered questionnaire. The questionnaire consisted of open and closed questions and sought demographic data, disease characteristics, and data on the adolescents' information and psychosocial needs and preferences, their coping strategies, support mechanisms, and self-perceptions of differences between themselves and their "healthy" peers.	**Results** **<u>CHILDREN'S PERSPECTIVE</u>** **When asked about who should make the decisions:** in general they believe that they should not make the decisions on their own; more than half (n=24) of the respondents preferred illness-discussions with health professionals to be conducted when parents are present; whereas some (n=10) wanted to limit the discussion to physicians and themselves; only a few (n=6) believed that they should make the decisions themselves (4 of these respondents had relapsed); and only a few (n=5) indicated that they did not want to be involved **When asked who made such decisions and how they felt about it:** Many respondents indicated that *they were not consulted of that the decision was out of their control.* Almost half said the physician made the decision about treatment, one fifth reported it was their parents and only a few (n=3) said physicians, parents and themselves discussed about it; Although the majority would have preferred to be more involved in decision making, most did not complain too strongly. Most were philosophical in their reactions: "doctors know best", "no problem, I trust him", "fine" "ok";	**Limitations** **Aim**: The aim is clearly reported and the chosen research method is adequate for answering the research question. **Sample selection:** The procedure for sample selection procedure was clearly reported. The most relevant limitation is that it was limited to adolescents attending a summer camp. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not

Study details	Participants	Methods	Themes/ categories	Comments
Study type Qualitative study (self-administered questionnaire with close and open-ended items) **Aim of the study** To identify the information, support and decision making needs and preferences of young people with cancer, the extent to which those needs were being met, and the implications for health professionals. **Study dates** 1992 **Source of funding** Not reported.		The obtained data consisted of a mixture of retrospective and current-day responses. DATA ANALYSIS Responses to open-ended questions were content analysed and coding categories were developed. An independent researcher reached a high level of agreement of the categories developed. Frequency counts of responses to open- and close-ended meetings were then tallied. Testing for significance was applied to results obtained from questions that permitted only one response.	some however felt it was "OK" at the time of diagnosis because they had been too young, whereas "now" would be different; about one forth were dissatisfied *"I feel angry and frustrated I wasn't involved", "left-out", "not in control", "fed up and upset sometimes"* **Choices about treatment:** some (n=13) said they had thought about giving up treatment; but 4 responded that they felt they had an option, it was either "treatment or death"; and 5 said they had no say either through physicians or their parents, they were simply told their treatment should continue **Other issues:** Privacy: 46% reported that they would like this discussions with their physician were conducted in private, rather than during public ward rounds. Many respondents commented about this large public ward rounds, which made them feel stupid and invaded their privacy. **Facilitators to communication regarding decision making:** Interactional communication: the ability and allow and encourage feedback and questions; Professional friendship: expressions of genuine concern for the patient as an individual, not just as disease, a sense of humour and certain level of personal disclosure; Knowledge and professional expertise: the basis for confidence in health professional's skills and ability to make the "right" decision on the patient's behalf; Honesty and straight-forward approach: provision of all cancer information, including sensitive topics as the ability to have children… **Barriers to communication about decision making:**	discuss saturation of data. **Data analysis:** The data analysis is just briefly; and thematic analysis is no done. The researchers did not critically review their own roles in the process. **Findings/results:** The results were are vaguely presented, just in a descriptive manner. Thematic analysis would have been more appropriate. **Overall quality**: high risk of bias **Other information** Aims to include siblings (although it's not clear if they have actually included any) Does not only focus on planning Population might not be representative Mixed population, 12 to 24 years old. Data cannot be extracted

Study details	Participants	Methods	Themes/ categories	Comments
			An impersonal, detached or professional manner: which could be viewed as uncaring and intimidating; The use of jargon and high-powered authoritarian behaviour: particularly the use of medical terminology, which respondents viewed as an attempt to keep the powerless, and large groups of professionals on ward rounds; Lack of time and haste; The generation gap: perceived discomfort of some health professionals when dealing with young people, especially regarding sensitive topics: eg. "too clinical", "too text-bookie", "humourless", "ancient", "stuffy"	separately for each age group Limited to cancer patients only
Full citation Erby, L. H., Rushton, C., Geller, G., "My son is still walking": stages of receptivity to discussions of advance care planning among parents of sons with Duchenne muscular dystrophy, Seminars in Pediatric Neurology, 13, 132-40, 2006 **Ref Id** 372827	**Sample size** N = 19 parents of children and adolescents with Duchenne Muscular Dystrophy (DMD) **Characteristics** Children's age (range): 8 to 37 Parents' age (range): 34 to 64 **Inclusion criteria** Parents of children with Duchenne Muscular Dystrophy **Exclusion criteria** Parents whose children had Becker muscular dystrophy (a milder form). Parents whose sons had not yet reached the age of 7, as the developmental capacity	**Details** SAMPLE SELECTION The sample of parents was recruited by sending invitation letters to families who were members of the Parent Project for children with DMD and families from the Muscular Dystrophy Association (MDA). A recruitment survey included with the invitation letter asked parents about the ages and health status of their children and whether the parent(s) would be willing to participate in an in-depth interview. DATA COLLECTION 1-hour interviews were conducted in person by one of the co-investigators (LE) who has prior training. an interview guide was	**Results** **<u>PARENT'S PERSPECTIVE</u>** **<u>ACP Communication</u>** Many parents said that they had not heard about "advance care planning" before, and they had not discussed the concept with HCPs. Although many thought that these discussions could be important, they preferred to delay this process until consideration seemed more urgent. *". . . and I guess, in this household, it is always we will cross that bridge when we come to it. Yeah, the disease is progressing and he is not as strong as he once was, but he is still okay. . . . so if I don't have to deal with it, then why deal with it."* (mother of a 16 year old) *"I am very vague on what an advance directive is . . . I think it has to do with like a DNR? I have not discussed that with him because we're not there yet. We are not even close to being there."* (mother of an 18 year old) Although none of the parents felt ready to discuss EOL medical decisions or care plans, they expressed a need for services that would allow them respite from their duties as caregivers. *"I would prefer to go out on a vacation for two to three days and just like sleep. Not doing anything. Just go to Hawaii and*	**Limitations** **Aim:** The aim is reported and the chosen research method is adequate for answering the research question. However the aims are too wide. **Sample selection:** The procedure for sample selection procedure was clearly reported, and the population is relevant for the aim of the study. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is reported,

Study details	Participants	Methods	Themes/ categories	Comments
Country/ies where the study was carried out USA **Study type** Qualitative (interview) **Aim of the study** To explore the level of participation of children and adolescents in decision making and the parents' feelings about including their children in such discussions. **Study dates** Not reported **Source of funding** Not reported.	of children under the age of 7 would preclude them from active participation in most medical decisions.	developed to prompt discussion Parents were given $25. The interviews were audiotaped. The interviews included questions about the following: (1) the understanding of the child with DMD about his medical condition, (2) parents' feelings about when information about the condition should be or should have been revealed to their sons, (3) parents' feelings about and experiences of communication with health care professionals, (4) parents' feelings about and experiences, with planning for and talking about their sons' futures, (5) parents' knowledge of ACP, and (6) parents' feelings and experiences related to ACP. DATA ANALYSIS Two co-investigators developed a list of themes through an iterative process The software QSR NUD*IST was used to assist in coding the	*just stay in the hotel and sleep all day."* (mother of a 9 year old) Carers focussed a considerable amount of the conversation about their sons' futures in terms of education, career, and need for independence in the face of increasing disability. For example they talked about making plans for college and trying to decide about the appropriateness of semi-independent living away from home. *"Well mainly, when he is 18 of course, we will have college and if he goes to college, will he stay at home or will he live there. There are some schools now that offer residential service for kids like him that need nursing care, which he may or may not need at that point."* (mother of a 14 year old) *"We have talked about, 'You will go to college and grow up while you are at college' . . . this is a right of passage . . . We are focusing now on things that he is good at and how could he make a living that will not be affected by his muscular dystrophy."* (father of a 16 year old) When talking about the future, some parents also mentioned "long-term care planning." To most parents, this meant planning for their sons' financial futures in the event that they were unable to care for their sons any longer. However, parents did not talk about medical planning when talking generally about planning for the future. *"I try not to think too far into the future. I mean you have to plan some things out. Um, long term care issues. Obviously, if we . . . something happened to us, we would need to have a plan in place. We don't have a plan in place but we should."* (mother of a 14 year old) *"We have to be prepared and we have to establish a trust for our son, a trust so that when we are not here, he is okay."* (mother of an 8 year old) **<u>Factors That Influence ACP Communication</u>**	but it's not clear if it's done according to a theoretical framework. The researchers do not discuss saturation of data and their role in the process is not described either. **Data analysis:** The data analysis is described; and data is presented to support the findings, but it is not clear is saturation has been achieved. The researchers did not critically review their own roles in the process. **Findings/results:** It's a hypothesis generating model. Results are described, and are clearly presented. **Overall quality:** moderate risk of bias **Other information** (This sample includes CYP between 7 to 37 years old. Where possible data has been extracted for parents of children

Study details	Participants	Methods	Themes/ categories	Comments
		interview transcripts. This software allows to mark sections of text that are to be assigned a particular thematic code and subsequently to retrieve all text related to a specific code for further analysis.	**Competing Demands** The demanding nature of being a parent of a son with DMD lead parents to delay consideration of ACP: *“Basically, I have tried to educate myself to be his primary care physician and then just trying to find a doctor that I can call up and say, ‘I need a referral. Sign this. I need a prescription for this.’ I need a doctor that will just give me a signature, because when I left things up to the medical people out there, they have never done their job. It is okay if I’m reading medical journals because if [they] are not going to get the information, then I will.”* (mother of an 18 year old) **Families Need to Distance Themselves at Times From Muscular Dystrophy** Although having contact with other families whose children also have DMD was found helpful, parents also felt they have to distance themselves from muscular dystrophy sometimes. Parents also felt that the children themselves often showed when they needed to separate themselves from the MD community. *“Now, he got to a point where he said, ‘I don’t want to go to camp anymore.’ So I said, ‘Well, can you tell me why.’ So he just said, ‘I just don’t want to be with other children that have the same thing as me.’ ”* (mother of an 8 year old) *“I mean he is very low key about his role as it related to the MDA and I think he had the opportunity to [play a prominent role], but he said, ‘No, let somebody else do it. I want to get back to being with my buddies and my family again.’ So . . . he is very cognizant of how others feel about him . . . perceive him; and, I think in two ways, the disease and then the notoriety that goes along with him having already played a prominent role.”* (father of a 16 year old) This distancing may diminish opportunities for families to discuss issues relevant to planning for future quality of life. **Stages of Receptivity: Nodal Moments in the Life Experience of Muscular Dystrophy**	up to 18. However it has to be looked at as indirect evidence. The paper does not really focus on end of life care planning, it's follows a more general approach on understanding the disease.

Study details	Participants	Methods	Themes/ categories	Comments
			The life experience played a role in parents' views of their sons' readiness to discuss ACP. *"He is aware because a lot of the people that we know who have Duchenne's that are in our age group are getting tracheotomies, have nighttime breathing machines. So we do know that this is possibly in our future . . . when he is at that point, I'm sure we will have discussions on those topics and give him time to make a decision on how he wants it . . . I want him to be more involved. I think the awareness is there. The involvement is really not."* (mother of an 18 year old) Several specific life events, including "transitioning to a wheelchair," "getting a feeding tube," and "seeing other kids die" were seen as particularly salient in terms of the timing of such discussions. *"In our community, people always ask, 'is he still walking?' I mean that is the BIG question . . . because a lot of your issues medically that come up occur after the walking stops. I remember when he was really young, I would think to myself, 'well, let's see, one down, so we probably have about another four years before he stops walking.' " (mother of a 14 year old)* *"He was only 8 when this 13 year old boy died . . . he wanted assurance that when he got to 13 that wasn't going to happen. So I think as he's going past 13 . . . he's realized that it is very different for different people . . . I mean this particular boy stopped walking at 9. And he knows that that is a big thing, a big benchmark for him . . . as long as he is walking, he doesn't worry too much. (same mother of 14 year old)* In some cases, the death of a close family member or friend also opened up an opportunity for discussions about the end of life. However, none of the interviewed parents had taken this discussion beyond generalities. After having to make the decision to take a grandparent off a respirator, 1 mother mentioned having a brief discussion with her son.	

Study details	Participants	Methods	Themes/ categories	Comments
Full citation Parker, D., Maddocks, I., Stern, L. M., The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy, Journal of Paediatrics & Child Health, 35, 245-50, 1999 **Ref Id** 334958 **Country/ies where the study was carried out** Australia **Study type** Qualitative (interview with semi-structure and open-ended questions) **Aim of the study** To examine the potential role for palliative care	**Sample size** N=13 There were 21 potential participants: 5 could not be contacted 2 declined to participate 1 agreed, but due to unexpected death of the son, the interview was not conducted **Characteristics** 9 bereaved families and 4 current families 6 interviews were conducted with both parents, 4 with the mother only, and 2 with the wives of individuals Age of children at death (range): 8 to 31 years Age of the children that were still cared for at the time of the interview (range): 17 to 21 years **Inclusion criteria** Families of children and young adults who had either died of Duchenne muscular dystrophy, Becker muscular dystrophy or spinal muscular atrophy over the previous 7 year period	**Details** SAMPLE SELECTION Due to the small number of affected individuals, a convenience sample was used. The Muscular dystrophy association and the Crippled Children's Association were asked to identify the parents based on the inclusion criteria. Contact was made with potential candidates via letter with a letter of introduction and information sheet. SETTING Palliative care, Women's and Children's hospital, North Adelaide DATA COLLECTION The interviews were semi-structured and open-ended. Interview questions were developed by members of the research team in collaboration with representatives from the MDA. Questions addressed issues such as: the experience of caring (formal and informal);	**Results** **<u>PARENTS' PERSPECTIVE</u>** **Ventilatory support issues** HC Individual choice. Families interviewed that were currently caring for their sons did not like to discuss issues concerning ventilatory support with them. The parents indicate they have been made aware, by health professionals, of the available choices in ventilatory support. It appeared to be an individual matter whether discussions about end-of-life care and decisions were encouraged within a family. How they were approach by the HC professional. The way in which issues such as ventilatory support were approached by professionals was important. *One parent commented that when their son had been seen by a respiratory specialist regarding breathing difficulties and options of care had been discusses, the specialists had been very blunt. Later, seeing another specialist that was much more gentle and less confronting, she felt her son was able to understand and make informed decisions regarding his future management.* **Advance directives** Implementation problems: one family went to casualties with their son and the mother overheard doctor's questioning why the family had come to emergency if they didn't want treatment for their son. Not having a formal AD document: of other two children who had died, there was no AD, but they had discussions about resuscitation Reluctance to talk about end of life issues: *"live for the moment"* Dead of another child: this facilitates discussions, to understand what the other child wants Wanting whatever treatment that is available: both parents and children	**Limitations** **Aim:** The aim is broadly described. The chosen research method is adequate for answering the research question. **Sample selection:** The procedure for sample selection was adequately reported, but the authors do not report the response rate, and whether those who agreed to participate differ to those who refused. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is vaguely reported, with just a brief description of the questions used in the interview. The researchers do not discuss saturation of data. **Data analysis:** It is unclear why interview data was only

Study details	Participants	Methods	Themes/ categories	Comments
services in the care of individuals with muscular dystrophy and spinal muscular atrophy. **Study dates** Not reported **Source of funding** The study was funded by a Crippled Children's Association Research and Development Grant.	Families currently caring for individuals with these conditions **Exclusion criteria** Not reported	support that had been available; discussions regarding ventilatory support; recall of the terminal period of care; support during care and in bereavement; the appropriateness of PC services; and recommendations for further support. The interviews were tape-recorded and transcribed verbatim. DATA ANALYSIS Transcripts were entered into the NUDIST version 3 software program and analysed for recurrent themes.	Difficult to start conversations with the children: Parents found difficult to initiate discussions concerning emergency care and treatment decisions with their sons. Parents' difficulty in discussing issues of emergency treatment were interpreted as an implicit rejection of the use of advance directives. As one father commented: *"we never talk much about the future, especially with him, he never asks for it. Sometimes I probe a little but he really doesn't really want to, so it is an unwritten law: we never talk about it. I am quite sure he knows what is happening, but we never talk about it and I believe in that"*.	analysed in a narrative manner, when a thematic analysis would have been more appropriate. **Findings/results:** The results are very vague and the potential influences in the analytical process not critically reviewed **Overall quality:** high risk of bias **Other information** Includes mixed population, regarding age (8 to 31 years) - very indirect The main aim of this review is not planning - indirect
Full citation Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., Bensing, J. M., Young patients',	**Sample size** N patients = 7 (22.6%) N parents = 11 (17.7%) **Characteristics** **<u>Children</u>** Age - mean (range): 11.6 (8–16) Age at diagnosis - mean (range) 10.4 (8–15)	**Details** **Setting** Department of Paediatric Oncology, University Medical Centre Groningen **Sample selection** Recruitment was carried out differently in the two oncological wards, and were identified by a	**Results** **<u>CHILDREN AND PARENTS VIEW</u>** **Preferences concerning participation in the decision making process:** Most parents and HCP preferred <u>decisions to be made in collaboration</u> between patients, parents, and health care providers. This preference concerned major decisions about the execution of treatments as well as decisions concerning procedures surrounding treatment	**Limitations** **Aim:** The aim is clearly described and the chosen research method is adequate for answering the research question. **Sample selection:** The procedure for sample selection was

Study details	Participants	Methods	Themes/ categories	Comments
parents', and survivors' communication preferences in paediatric oncology: results of online focus groups, BMC Pediatrics, 7, 35, 2007 **Ref Id** 372829 **Country/ies where the study was carried out** Netherlands **Study type** Qualitative (focus groups) **Aim of the study** To gain insight into the interpersonal, informational, and decisional preferences of participants involved in	Gender, male - % (N): 42.9% (3) Diagnosis - % (N) Leukaemia 42.9% (3) Brain tumour 28.6% (2) Lymphoma 14.3% (1) Soft tissue sarcoma 14.3% (1) **Parents** Age - mean (range): 45.9 (37–72) Gender, male - % (N): 45.5% (5) **Inclusion criteria** Eligible participants were selected by consecutive inclusion in two Dutch university oncological wards, and asked to participate in separate focus groups. The first group (referred to as 'patients') consisted of children and adolescents (8 to 17 years old), who had been diagnosed with childhood cancer 6 weeks to 1 year ago, and who were currently in active treatment. Separate focus groups were organised for children (aged 8 to 11 years) and adolescents (aged 12 to 17 years).	nurse (ward 1) or using electronic records (ward 2). Candidates were informed about the study and asked to participate by a letter, and received a reminder two weeks after the initial letter. Family members were able to individually choose to participate Participants were given individual login names and passwords to ensure anonymous access to the Internet focus, and were asked not to mention their own names, addresses or health care providers. On the third day, participants who had not yet responded received a remainder to invite them to respond. **Data collection** The online focus groups were conducted in an asynchronous form (i.e. participants could read others' comments and could respond at any time, not necessarily when anyone else was participating). This allowed participants to	and examinations, such as the timing of appointments and the use of sedatives. Two children (both aged 10) showed a preference for a passive role in making major decisions on treatment. The two patients, however, did want to take part in less important decisions. Although parents could be of assistance in reaching a decision, and, in doing so, could affect the decision-making process, survivors and adolescent patients emphasized that they should be the ones to make the final decision. **Reasons for preventing participation in decision making:** Some participants said that characteristics of the situation sometimes prevented them from being actively involved in deciding about treatment. In some cases they felt they did not have a choice, as the patient's only chance of getting better was to be treated, and there was a prescribed treatment protocol. Lack of sufficient knowledge of the illness and treatment or trust in the physician's expertise Practical circumstances The patient being too ill or depressed to decide.	well reported. The response rate is low (< 25%), although there were no differences regarding demographic characteristics. The relationship between the researcher and the respondents is not indicated. **Data collection:** The data collection process is clearly reported, but the researchers do not discuss saturation of data. Authors used an online focus groups, using a recommended approach by a previous research group. **Data analysis:** The data analysis was reported; and thematic analysis is also described. However, researchers did not critically review their own roles in the process. **Findings/results:** The results were presented using

Study details	Participants	Methods	Themes/ categories	Comments
paediatric oncology. **Study dates** February 2006 **Source of funding** This study was financially supported by the Dutch Cancer Society (Grant number: NIVEL 2004-3192)	Parents of patients were asked to participate in a separate focus group. **Exclusion criteria** Insufficient mastery of the Dutch language, a lag in development, treatment for secondary tumours, and being in a palliative phase of care (oncologists' evaluations) were used as exclusion criteria.	respond from their home and at any time convenient to them. A new question was asked on the first five days, starting with a concrete question about their experiences with the diagnostic consultation, before turning to more general and abstract, such as preferences regarding participation in decision making. Questions of the previous days remained open for responses during the whole week, but on days 6-7 participants were offered to introduce new issues they considered relevant. Topics were derived from the literature and were the same for all groups. Questions were comparable in content, but the wording was adapted to the age range of the participants. **Data analysis** Two authors read the transcripts independently and constructed a preliminary thematic coding scheme.		relevant quotes from participants and are applicable to the aims of the study, but a higher number of quotes would have been more useful to reflect the views of the participants in the different groups. **Overall quality:** moderate risk of bias **Other information** Paediatric oncology only Very low response rate for both parents and children Mixed population, that also includes survivors of childhood cancer - this data has not been taken into account if possible Children who are in active treatment for childhood cancer but not receiving palliative care (very indirect evidence) Mainly focuses in communication preferences

Study details	Participants	Methods	Themes/ categories	Comments
		Disagreements during this process were discussed until consensus was achieved.		

G.4 Review question: Preferred place of care and place of death

What preferences do children and young people with a life-limiting condition and their family members or carers (as appropriate) have for place of care and for place of death, and what determines those preferences?

Study details	Participants	Methods	Outcome(s)	Quality assessment
Full citation Hechler, T., Blankenburg, M., Friedrichsdorf, S. J., Garske, D., Hubner, B., Menke, A., Wamsler, C., Wolfe, J., Zernikow, B., Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer, Klinische Padiatrie, 220, 166-74, 2008 **Ref Id** 334664 **Setting** Children who had died of cancer were identified at 6	**Sample** Bereaved parents of 48 children who died of cancer from 1999-2000 (11 fathers and 45 mothers). **Inclusion criteria** -All families who had lost their child to cancer in 1999 and 2000 as identified in 6 of 19 specialist centres; -Parents were contacted by the specialist centers and invited for an interview. Only those who gave written informed consent to participate were included. **Exclusion criteria** -Not reported	**Description** Interviews were conducted by trained interviewers (paediatric oncologist or specialised nurse) who were not involved in the child's treatment. The interviews were divided into 5 topics (as described in the aims) and each topic was further subdivided into subsections. However, the questions are not explicitly described. Forty interviews were conducted with one parent only, and eight with couples. If couples disagreed on an item the answer of the parent who spent most of the time with the child in the end-of-life care period was recorded. Interviews took place according to the preferences of the parent/s. Forty-sex parents wanted to be interviewed in person; of those, 44 wanted to be interviewed at home and 2 at a neutral place (in a café). Two parents wanted to	**Description** Preference: 88% of parents in retrospect preferred home as the locale of death most appropriate for their child. Congruence between actual and preferred place of death: 48% of children died at died at home even though 88% chose 'at home' in hindsight as the most appropriate locale of death. Information provided in relation to preferred place of death: It is stated that almost half of the parents reported to have been informed on the possibility of palliative home care for their child.	**Aims** Only broadly described. **Sample selection** Sample selection is clearly described, but it is unclear whether parents who responded differed to those who were contacted but did not participate. **Data collection** Not very clearly described only broad categories provided.

Study details	Participants	Methods	Outcome(s)	Quality assessment
of 19 specialised departments for paediatric oncology and parents were invited to participate in the study. Interviews were conducted in a location according to the preference of the parent/s. Study conducted in Germany **Study type** Qualitative study (utilizing validated semi-structured interviews) **Aim(s)** To investigate parent's perspective on the following topics: 1) symptoms and quality of life in the end of life care period; 2) characteristics of the child's death (this included a question on preferred place of death); 3) anticipation of their child death and care delivery; 4) end of life decision; 5) impact of the child's death on the parents and perceived social support by the health care team		be interviewed over the phone. Interviews lasted on average 136 minutes (range: 50 to 210 minutes).		**Data analysis** It is unclear why interview data was only analysed as frequency numbers or rates when presumably a thematic analysis would have been more appropriate. **Results / findings** Some of the findings are not very clearly presented and rather than exploring a perspective it provides purely descriptive findings.
Full citation	**Sample**	**Description**	**Description**	**Aims**

Study details	Participants	Methods	Outcome(s)	Quality assessment
Kassam, A., Skiadaresis, J., Alexander, S., Wolfe, J., Parent and clinician preferences for location of end-of-life care: home, hospital or freestanding hospice?, Pediatric Blood & Cancer, 61, 859-64, 2014 **Ref Id** 334740 **Setting** Hospital for Sick Children, Toronto Canada **Study type** Survey design **Aim(s)** To determine bereaved parent and clinician preferences for location to EOL care and death	Parents of children who died of cancer between 2005 and 2011 (N=75). The survey respondents were mostly mothers (81.3%) who were white (81.3%) and 48% had a university education. **Inclusion criteria** Parents resided in North America, were English speaking, their child died at least 6 months before enrolment, and their child's primary oncologist permitted contact with the family. **Exclusion criteria** Children who died within 4 weeks of their cancer diagnosis	Administered questionnaires to 140 parents of children who died of cancer between 2005 and 2011.Seventy-five parents agreed to participate giving a response rate of 75/140 (54%). Parents and clinicians views on location of end of life care and death was assessed using a clinical vignette. The clinical vignette described a child with widely metastatic cancer and no realistic chance of cure and descriptions of 3 options for possible locations of end of life care: home, free standing hospice and inpatient ward was provided. The care provided in the three settings was described in the vignette. Parents and clinicians were asked to rank order their preference for the location of end of life care and death (1=most ideal and 3= least ideal). Parents and clinicians were also asked to rank order their preference a second time with the additional assumption that the free standing paediatric hospice was affiliated with the main children's hospital. A multivariable analysis was carried out to identify independent characteristics that help or hinder a child dying in the preferred location. This used child characteristics (type of malignancy, age), family characteristics (income, race, distance from hospital, siblings, marital status) and treatment characteristics (involvement of a palliative care team, cancer directed therapy during the last month of life, stem cell transplant)	**Preferred location of death for the case described in the vignette based on rank ordering** Home was the preferred location for death for 70.8% (51/72) of parents. Hospital was the preferred location for death for 23.9% (17/71) of parents. The free standing hospice was the preferred location for death 5.7% (4/71) of parents. **Preferred location of care for the case described in the vignette based on rank ordering** Home was the preferred location for care 57/72 (79.1%) of parents ranked home as their first choice, 11/72 (15.2%) ranked hospital as their first choice of care and 5/72 (6.9%) hospice. **Congruence between preferred place of death and the place where the respondents child had died** Of 51 parents who had indicated home as the preferred place of death 39 children (76.1%) had died at home, 16/17 (94.1%) of those who preferred hospital had died at hospital and none 0/4 of those who had indicated a preference for free standing hospices had died at this location. **Congruence between preferred place of care and**	Clearly stated aim, but the ranking of preference based on a hypothetical case may not be the best design to address this question. **Sample selection** The sample seemed to have been systematically selected, but response rate was low and it is therefore unclear whether this is a representative subsample of all parents identified. **Data collection** The full vignette that was presented to the parents was reproduced in the report as well as the description of the care provided in each setting. However the instructions and procedure for rank ordering the preference is unclear. Retrospective design is sensitive to recollection biases. **Data analysis** Some of the data tables are not very clearly presented and therefore the analysis is a bit

Study details	Participants	Methods	Outcome(s)	Quality assessment
			the place where the respondents child had died Of 51 parents who had indicated home as the preferred place of care 48/57 children (84.2%) had been care for at home, 7/11 (63.3%) of those who preferred hospital had been care for at hospital and none 0/5 of those who had indicated a preference for free standing hospices had been care for at this location. <u>Factors associated with congruence between actual and preferred location of death:</u> Two variables were independently associated with whether or not a child was likely to have died at the parents' preferred place of death. Fewer children with haematologic malignancy died in the preferred location and more children died in the preferred location when a palliative care team was involved in the treatment of the child. <u>Factors associated with congruence between actual and preferred location of care:</u> There was only one variable with a trend to be independently associated with whether or not a child was likely to have been cared for at the parents' preferred place of care. When a palliative care team was involved in the treatment of the child they were	difficult to follow. Multivariable results are not presented in the tables which only features the univariate analysis (only provided in the body of the text). **Results / findings** All findings are based on the clinical vignette and it is unclear whether the parents were made aware that this would then be related to where their own child had died.

Study details	Participants	Methods	Outcome(s)	Quality assessment
			more likely to be cared for at their parents' preferred place of care.	
Full citation Vickers, J., Thompson, A., Collins, G. S., Childs, M., Hain, R., Place and provision of palliative care for children with progressive cancer: A study by the paediatric oncology nurses' forum/United Kingdom children's cancer study group palliative care working group, Journal of Clinical Oncology, 25, 4472-4476, 2007 **Ref Id** 345166 **Setting** Children and their families were identified prospectively in 22 UK oncology centres **Study type** Survey design **Aim(s)**	**Sample** All children registered over a 7 month period through the United Kingdom Children's Cancer Study Group (UKCCSG) for whom in the view of the treating oncologist a cure was no longer possible because of recurrence /progression despite maximal therapy. (N=185 of which data could be analysed from N=164 children and their families). Children's median age: 8.7 years Range 0.3-19 years53.7% boys, 46.3% girls. The most common tumour type was CNS/brain tumour (36%) followed by leukaemia (22.6%) **Inclusion criteria** Treating oncologist view of child for whom cure was no longer possible because of recurrence/progression despite maximal therapy **Exclusion criteria** Not reported	**Description** Over 7 months 185 children from 22 UK oncology centres were recruited to participate. Every month until death or a maximum of 20 months, questionnaire data were collected by clinical staff and coordinated by an identified person at each centre. 21 children remained alive at end of study and were excluded leaving an analytic sample of 164 children (88.6% response rate). Families completed two or more questionnaires.	**Description** Preferred place of death: Home was the preferred place of death for 98/164 (68%) at baseline. Change in preference over time: The initial preference for a death at home at study entry was 68% but it rose to 132/164 (80.5%) in last month of life. Congruence between preferred and actual place of death: Eighty-six percent of children for whom a preference for home death was recorded at any point (120 of 140) actually died at home.	**Aims** Aims are clearly stated but do not fully match the protocol. The focus was the effectiveness of an outreach team model of palliative care to enable children to die at the preferred place of death. **Sample selection** Sample systematically and prospectively collected **Data collection** It was described where the questionnaire was developed and that it was piloted but it is unclear what specific questions were posed. **Data analysis** Only descriptive data were reported no analysis was carried out.

Study details	Participants	Methods	Outcome(s)	Quality assessment
To describe and show effectiveness of the outreach team model of palliative care in allowing home death for children with incurable cancer.				**Results / findings** Children were recruited but results were only described as results for families. It would have been nice to separate the responses of children from those of the rest of their families.

G.5 Review question: Organ donation

What aspects of communication and information provision facilitate or hinder discussions between children and young people with a life limiting illness and their family members or carers (as appropriate) with healthcare professionals to make decisions on organ or tissue donation?

Study details	Participants	Methods	Findings/results	Comments
Full citation Hoover, S. M., Bratton, S. L., Roach, E., Olson, L. M., Parental experiences and recommendations in donation after circulatory determination of death, Pediatric Critical Care Medicine, 15, 105-11, 2014 **Ref Id** 334687	**Sample size** N=13 parents (representing 11 out 32 invited families who consented to donate their child's organ; predominantly European American and Christina) **Characteristics** Ethnicity: n/N	**Setting** ICU of a single children's hospital located in the Western US **Data collection** Interviews: -an interview guide was developed on experiences of the local organ procurement organisation social worker,	**Themes/categories** **Factors contributing to parental decision making:** **Wanting to making something good out of the tragedy of their child's death:** In deciding to donate, many parents explained hoe donating meant helping others and creating something positive out of their child's death. "*I mean she meant a great deal to us, and I loved her with everything in me,*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported (purposeful selection in a single children's hospital in

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Study type** Qualitative study **Aims** To describe parents' experience of organ donation decision making in the case of donation after circulatory determination of death. **Study dates** Not reported **Source of funding** Not reported	European American: 11/13 Hispanic American: 2/13 Religious identity: Christian: 9/13 None: 3/13 Other: 1/13 **Inclusion criteria** Not reported **Exclusion criteria** Not reported	physician liaison, and a literature review; -Based on review of the pilot interviews, the interview guide was modified by three authors -all interviews were conducted by the same author, audio recorded, and transcribed. **Data analysis** Thematic analysis: -the coding process for transcription was consistent with constant comparison, which requires sorting and comparisons to discern key themes. -first, open codes were developed that represented key concepts that closely matched participants' language, such as "glad to help people, but still not easy that my child isn't here"; -next, in comparing codes between transcripts, focused codes were identified that represented the concept evidence across transcripts; -these focused codes were examined to develop emerging themes that represented the most salient	*but I wanted her to be able to make more of an impact on somebody else's life by being able to donate, something that we would save somebody, you know?"* Similarly, another consented parent explained, "*That was largely my reasoning for organ donation, because I was going to make sure that something good could come out of a tragedy."* **Wanting to honour their child's preferences:** In addition to parental desire to help others, many believed that their child would have wanted to help others. Consented parent 2 shared, "*I think this is what she had wanted me to do for her."* For those whose children were adolescents, 2 out of 3 parents reported knowing their child's stated preference and fulfilling their preference to donate. In the other consented adolescent case, consented parent 5 was uncertain about donation. However, she remembered thinking, *"I know what I need to do. I've had this conversation with my son. I know what needs to be done.'...If he were able to talk, then he would have totally said, 'take everything.' I know that."* In the decision to consent to donate, their child's stated preferences were honoured. **Confusion about viability of organs:** Several families had some difficulty understanding whether or not their child could donate certain organs due to the trauma they had suffered. On one hand,	the Western US). The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
		aspects of the decision making process for the participants collectively.	consented parent 8 assumed that her child's heart was not viable: *"And it went over across our mind a little bit such trauma that I don't think that it would have been good at that point, you know, because they had to do CPR on her several times, I just didn't feel that that was the way to go, but I wanted to do her kidneys and her liver."* In contrast, some parents assumed that donation was medically viable and then learned that it was not. Consented parent 3 explained, "I *mean [age] healthy younger girl, I mean you'd think after, you know, if someone needed a heart that that wouldn't-but I guess it has to be pretty, those things have to be pretty, they have to pretty careful."* Consented parent 4 expressed her distress about learning that some organs could not be donated for transplantation. "*I only thing I remember is that doctor...had told me that her body went without oxygen for so long that they would be afraid that they were too tainted to put into somebody else and so that they couldn't use her organs, and I remember that upset me, and I started crying."* **Wanting to protect their child's body;** Another factor that influenced parental decision making was the desire to protect their child's body. As consented parent 1 stated the reason not donating: "*Because she she'd be through too much*." Consented parent 8 explained, "*When you're in this situation you're*	The study was conducted in one site; the majority of participants were American Europeans;

Study details	Participants	Methods	Findings/results	Comments
			thinking, 'okay, she's going to have this casket and she's going to be in there, and I want her to be as pretty as she can for as broken and bruised as she is." Parents' desire to protect their child's body also influenced parents to limit specific organ donation. Many parents wanted their child's dead body to be *"whole."* **Wanting to help their child die peacefully:** Parent decision making was motivated by parents' desire to help their child die and be at peace. This influenced how long parents were willing to maintain life support. in considering how to donate, some parents had discomfort regarding prolonging dying while seeking potential recipients. For example, consented parent 7 remembered "*just trying to get it done quick. We just didn't want to drag it out*." Understanding how donation would impact the time of death was important. **Shock and difficulty coping with the sudden unexpected death of the child:** The factors that influenced the decision-making process revolved around the child's unexpected and sudden death. Parents emphasized their shock and difficulty coping with the sudden unexpected death of their child. *"partially you never really think you kids are going to go before you. So you never think about it."* Thus, parents' decision making carried the weight of accepting that their	

Study details	Participants	Methods	Findings/results	Comments
			child is dying. As another example, *when asked about the most difficult part of the decision to donate, consented parent 9 stated "letting her go." Similarly, consented parent 4 shared, "The negative part is just your kid in the hospital period. Nothing to do with the organ donation."* **Donation as meaningful contribution** Donation provided the opportunity for families to help others. Consented parent 9 stated that "She's living on in somebody else." Some parents remembered having negative feelings when they learned about the recipient. Consented parent 2 explained, "I would hope that it would like, you know, a 30-year-old or something, not a 60 or 70-year-old people. And that's what kind of hurt me, but I mean it helped their life but I understand that." Consented parent 1 explained how donation to research was less satisfying: "I would definitely rather it goes to somebody than [be] used for research. But they also need research to make things better and to help somebody else.. [but], when it's used for research, it's done." **Connecting with others (in the grief process):** In the grief process, many families shared the importance of connecting with others who have experienced	

Study details	Participants	Methods	Findings/results	Comments
			death, especially death their own child. Contact from organ procurement organisation facilitated this connection for some participants. This contact, including newsletters and letters, provided a connection with other families also affected by death and donation. Consented parent 9 shared, "*We didn't expect all the outreach that was offered to us when we decided to do it. That's a good program to have...You know, maybe somebody we might do that [participate in a memorial hosted by OPO]. You know, as part of a way to remember her.*" **Parent recommendations regarding donation:** **Overall recommendations**: **Informed by positive experiences**: Accommodate requests, such as spending time with deceased child after donation procedure **Informed by improvable experiences**: Be sensitive to parents' distress and provide privacy at the time of death **Recommendations for hospital staff**: **Informed by positive experiences**: spending time with parents and show compassion; allow parent to stay with their child throughout hospital experience; **Informed by improvable experiences**: approach as early as possible to allow time to consider donation	

Study details	Participants	Methods	Findings/results	Comments
			Recommendations for organ procurement organisation (OPO) coordinator: **Informed by positive experiences**: appreciate parents' preferences about organ donation; provide relevant information and updates, not providing irrelevant information; communicate honestly; **Informed by improvable experiences**: Communicate clearly; provide information about unknown time to complete donation match; follow-up to see if parent want to make changes about donation preferences after parents provide initial consent **Recommendations for OPO education**: **Informed by positive experiences**: None reported **Informed by improvable experiences**: provide information about success rates and need for organ donation online; provide information about what kind of research is conducted with donated organs	

G.6 Review question: MDT

Not applicable to this review

G.7 Review question: Day and night end of life care

Not applicable to this review

G.8 Review question: Rapid transfer service delivery

Not applicable to this review

G.9 Review question: Care based in the child or young person's home

What is the clinical and cost effectiveness of a home-based programme of care, compared with care in other settings?

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Arland, L. C., Hendricks-Ferguson, V. L., Pearson, J., Foreman, N. K., Madden, J. R., Development of an in-home standardized end-of-life treatment program for pediatric patients dying of brain tumors, Journal for Specialists in Paediatric	**Sample size** N=166 children **Characteristics** All paediatric patients dying of a brain tumour at the Children's Hospital Colorado for the period 1900 to 2005. **Inclusion criteria** - Deceased paediatric patients	**Interventions** - Group 1 or control group (n=22): patients who died between 1990-1995, before the EOL programme was implemented. - Group 2 (n=92): patients who died between 1996 and 2005, after the EOL programme was implemented.	**Details** SAMPLE SELECTION Children with admission for paediatric brain tumours between 1990 and 2005 DATA COLLECTION - Retrospective review of the patient's medical records. - Accessible hospice or home-care charts were also reviewed for data for a subset of patients whose	**Results** Results are presented group 1 vs group 2 **Unplanned/ precipitous admissions to hospital (pre-post EOL programme)** - Number of patients admitted to hospital: 54% (12) vs. 29% (27); p<0.05 - Total number of admissions: 20 vs. 38	**Limitations** **Appendix D. NICE checklist Cohort studies** A. Selection bias (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Nursing: JSPN, 18, 144-57, 2013 **Ref Id** 348188 **Country/ies where the study was carried out** USA **Study type** Observational retrospective study, using a retrospective chart review **Aim of the study** To evaluate an in-home end-of-life (EOL) programme for paediatric patients dying of brain tumours. **Study dates** 1990 to 2005 **Source of funding** ARTMA Foundation for paediatric brain tumour research.	diagnosed with a brain tumour. - Age: 1 month to 19 years old. - Documentation of the child's place of death. - Documentation of the reasons for child hospitalization. **Exclusion criteria** - Having any gaps in chart documentation. - Lack of any specified information related to the inclusion criteria.	<u>Details of the in-home end-of-life (EOL) programme</u> - Comprehensive EOL discussion - Medications for symptoms control - Primary family liaison: a specific healthcare provider to be the contact person for the family and for the hospice or home-care agency. - Home visits: to assess the patient's symptoms by one or two healthcare providers from the team.	clinic or inpatient charts were lacking needed information. DATA ANALYSIS - Descriptive statistics - Chi Square for comparisons	- Average length of stay (days): 4.05 vs. 3.03 **Family or caregiver stress and distress (pre-post EOL programme)** Not reported **ICYP satisfaction/ control (pre-post EOL programme)** Not reported **Parent/ carer satisfaction/ control (pre-post EOL programme)** Not reported **Control of symptoms (pre-post EOL programme)** Not reported **Health related QoL (pre-post EOL programme)** Not reported	A3. The groups were comparable at baseline, including all major confounding and prognostic factors: yes (not reported, but the control group was smaller, and were treated 5 years earlier) Level of risk: HIGH RISK OF BIAS <u>B. Performance bias</u> (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: yes (not reported, but the control group was treated 5 years earlier) B2. Participants receiving care were kept 'blind' to treatment allocation: no (not possible due to the nature of the intervention) B3. Individuals administering care were kept 'blind' to treatment allocation: NA Level of risk: HIGH RISK OF BIAS <u>C. Attrition bias</u> (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? NA

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? NA C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: UNCLEAR <u>D. Detection bias</u> (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: yes D2. The study used a precise definition of outcome: yes D3. A valid and reliable method was used to determine the outcome: unclear (it is not clear how accurate medical records are) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: UNCLEAR **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					• Conflict of interest: none • Group 1: as no formal neuro-oncology programme existed before 1995, the data from the control group was limited by the quality of data collected prior to 1995. This group is smaller in size and they were treated 5 years before. • Limited to children with brain tumours. • Authors did not perform an analysis to control for other factors. • Convenience sample. • Mixture of hospice and care, not only home care.
Full citation Groh, G., Borasio, G. D., Nickolay, C., Bender, H. U., von Luttichau, I., Fuhrer, M., Specialized pediatric palliative home care: a prospective	**Sample size** N=40 families (3 were excluded because of parents refusal) **Characteristics** • Age, median: 6 years old (1 month to 18 years)	**Interventions** • Before implementation: usual palliative care • After implementation: paediatric palliative home care (PPCH) Details of PPCH programme:	**Details** SAMPLE SELECTION All primary caregivers of critically ill-children who were receiving for the first time palliative home care through the PPHC between 2011 and 2012 in Munich. DATA COLLECTION	**Results** Results are presented before and after the intervention (PPCH) was implemented: **Unplanned/ precipitous admissions to hospital** Not reported	**Limitations** **Appendix D. NICE checklist Cohort studies** A. Selection bias (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
evaluation, Journal of Palliative Medicine, 16, 1588-94, 2013 **Ref Id** 334633 **Country/ies where the study was carried out** Germany **Study type** Observational, before-after implementation study **Aim of the study** To evaluate the acceptance and effectiveness of Pediatric Palliative Home Care (PPHC) as perceived by the parents. **Study dates** April 2011 to June 2012 **Source of funding**	• Diagnosis: ○ non-malignant (75%): neurological 33%; congenital 20%; metabolic 18%; cardiovascular 5% ○ cancer: 25% • Religious beliefs ○ 88% Christians ○ 12% Muslims • Median period of PPCH: 11.8 weeks (0.5 to 58) **Inclusion criteria** • All primary caregivers of severely ill children receiving specialized palliative home care through the PPCH team.	• 3 paediatricians, 2 nurses, a social worker and a chaplain, all with special training in palliative care. • The main task of the team were the provision of palliative medical and nursing care, including 24/7 on-call service, as well as psychosocial support and coordination of professional assistance in cooperation with the local Health Care Professionals. • The participants had no additional support service added to their care during PPCH involvement that was not a direct result of the PPHC team's work.	• Assessment of care: two questionnaires were developed for the children's primary caregivers based on clinical practice and validated questionnaires. • The first assessment took place during the first 6 weeks of involvement of PPCH team. The second assessment was scheduled during the following 6 months. Both questionnaires were completed in dialogue form by a trained psychologist. • Caregivers' QoL: Quality of Life in Threatening Illness, family version (QOLFTI-F) • Caregivers' anxiety and depression: Hospital Anxiety and Depression Scale (HADS)	**Family or caregiver stress and distress** • Subjective burden due to patient's disease (NRS): median (IQR): 10.0 (2) vs. 7.0 (3); p<0.001 • Burden relief for caregivers (NRS): median (IQR): 2.0 (3) vs. 9.0 (3); p<0.001 • Caregiver stress and burden (HADS): median (IQR): 28.0 (8.5) vs. 19.0 (6); p<0.001 **ICYP satisfaction/ control** Not reported **Parent/ carer satisfaction/ control** Not reported **Control of symptoms** • Symptom control (NRS): median (IQR): 5.0 (3) vs. 9.0 (2); p<0.001 **Health related QoL**	to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS B. Performance bias (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: yes B2. Participants receiving care were kept 'blind' to treatment allocation: no (not possible due to the nature of the intervention) B3. Individuals administering care were kept 'blind' to treatment allocation: NA Level of risk: HIGH RISK OF BIAS C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
The study was funded by the Deutsche Kreshilfe (German Cancer Aid, Grant-Nr. 107627.	**Exclusion criteria** - Caregiver's inadequate German language proficiency - Caregiver's inadequate intellectual ability to understand the questionnaire		DATA ANALYSIS - Wilcoxon test for non-parametric data	- Patients' QoL (NRS): median (IQR): 2.5 (2) vs. 4.0 (4); p<0.001 - Caregivers' QoL (QOLLTI-F): median (IQR): 5.8 (1) vs. 7.1 (1.3); p<0.001 *NRS: numeric rating scale *HADS: hospital anxiety and depression scale *QOLLTI-F: quality of life in life threatening illness - family carer version	C2a. How many participants did not complete treatment in each group? NA C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? 0 C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: LOW RISK OF BIAS D. Detection bias (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: yes D2. The study used a precise definition of outcome: yes D3. A valid and reliable method was used to determine the outcome: unclear (a questionnaire was developed based on validated scales, but it's not clear whether this new questionnaire has been validated) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: HIGH RISK OF BIAS **Other information** • The funding body was not involved in the conduct of the study • High response rate • The interviewer was not blind to the responses • Participant's responses subjected to social desirability bias • Small number of families • No control group • No estimation of the sample size made • Participants are not comparable before and after the intervention was introduced, as the condition deteriorates
Full citation Postier, Andrea, Chrastek, Jody, Nugent, Sean, Osenga, Kaci, Friedrichsdorf,	**Sample size** 425 children **Characteristics**	**Interventions** • Before implementation: usual palliative care	**Details** SAMPLE SELECTION Home/ hospice patients aged 1 to 21 years that had initiated treatment between 2000 and 2010	**Results** Results are presented before and after the intervention (PPC) was implemented:	**Limitations** **Appendix D. NICE checklist Cohort studies** A. Selection bias (systematic differences between the comparison groups)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
J., Exposure to Home-Based Pediatric Palliative and Hospice Care and Its Impact on Hospital and Emergency Care Charges at a Single Institution, Journal of Palliative Medicine, 17, 183-189, 2014 **Ref Id** 351461 **Country/ies where the study was carried out** USA **Study type** Observational before-after implementation study (using retrospective administrative data analysis) **Aim of the study** To compare paediatric	- Age: 1 to 21 years old - Diagnosis: ○ non-malignant (n=225): respiratory 61.3%: neurologic 60%; genetic 29.3%; cardiac 17.8%; metabolic 7.6% ○ malignant (n=200) - Length of palliative exposure **Inclusion criteria** - Patients initiated treatment between 2000 and 2010 **Exclusion criteria** - Infants < 1 year old (as data would not be available for the previous 12 months)	- After implementation: home-based paediatric palliative care and hospice care (PPC) Details of the PPC programme: Palliative hospice/ home services emphasized 24/7 access and care coordination through home-based visits by nurses, social workers, child life specialist, chaplains, music, massage therapists, physicians and volunteers	DATA COLECTION - Administrative data. For patients with more than 1 admission to the PPC/ hospice program, only the 1st admission data was used. DATA ANALYSIS - Bivariate analysis using Wilcoxon test were conducted for hospital admission. - Multivariable analysis were conducted to adjust for patient level variables.	**Unplanned/ precipitous admissions to hospital** - Number of hospital admissions: 3.09±3.6 vs. 3.18±4.3; p=0.538 - Length of hospital stay (days): 20.97±43.3 vs. 10.91±21.3; p<0.001 **Family or caregiver stress and distress** Not reported. **ICYP satisfaction/ control** Not reported. **Parent/ carer satisfaction/ control** Not reported. **Control of symptoms** Not reported. **Health related QoL** Not reported.	A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS B. Performance bias (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: yes B2. Participants receiving care were kept 'blind' to treatment allocation: no (not possible due to the nature of the intervention) B3. Individuals administering care were kept 'blind' to treatment allocation: no Level of risk: HIGH RISK OF BIAS C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
hospital care resource utilization before and after enrolment in a home PPC/ hospice program. **Study dates** 2000 to 2010 **Source of funding** No financial support was provided for this study.					C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): yes C2a. How many participants did not complete treatment in each group? 0 C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? 0 C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: LOW RISK OF BIAS <u>D. Detection bias</u> (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: yes D2. The study used a precise definition of outcome: yes D3. A valid and reliable method was used to determine the outcome: yes D4. Investigators were kept 'blind' to participants' exposure to the intervention: no

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: LOW RISK OF BIAS **Other information** • Conflict of interest: no financial conflict of interest. • Indirect population: children included in this study have life expectancy over 2 months • Authors only had access to a single institution records, and it's possible that the participants were admitted elsewhere • Some children had more than 1 access to the PPC/ hospice services (only first admission data was used) • Additional services may have been in place that were not accounted for • Participants' responses may be biased due to recall bias and desirability bias • No control group • Low internal valididy inherent to BA study design, as it is expected

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					that the participants condition will change over time
Full citation Friedrichsdorf, Stefan J., Postier, Andrea, Dreyfus, Jill, Osenga, Kaci, Sencer, Susan, Wolfe, Joanne, Improved quality of life at end of life related to home-based palliative care in children with cancer, Journal of Palliative Medicine, 18, 143-150, 2015 **Ref Id** 442746 **Country/ies where the study was carried out** USA **Study type** Before and after implementation study (by means of a retrospective survey)	**Sample size** 60 bereaved parents (79,6% response rate) • PCC/Oncology (n = 30) • Oncology (n = 30) **Characteristics** Data is presented PPC/ oncology vs usual care/ oncology <u>Children</u> • Female sex, n (%): 17 (57) vs 10 (37); p=0.07 • Age at diagnosis (years), mean (SD): 8.1 (7.3) vs 7.3 (5.8); p=0.58 • Duration of disease (years), mean (SD): 2.0 (1.5) vs 2.8 (4.2); p=0.34	**Interventions** All 60 children had received medical care throughout their illness at CHC, 30 (50%) of whom were also enrolled in CHC's home PPC and hospice care program.	**Details** SAMPLE SELECTION • Parents of children who died while receiving cancer care at CHC between 2002 and 2008 were identified through administrative data review, and were invited to complete the ''Survey About Caring for Children with Cancer (SCCC).'' DATA COLLECTION • Firstly, an invitation letter, consent form, survey booklet, and postage-paid return envelope were mail, and a reminder/thank-you letter was mailed 2 weeks after the initial mailing, followed by a reminder call 2 weeks later.	**Results** Results are presented PPC/ oncology vs usual care/ oncology: **Unplanned/ precipitous admissions to hospital** Not reported **Family or caregiver stress and distress** Not reported. **ICYP satisfaction/ control** Not reported. **Parent/ carer satisfaction/ control** Not reported. **Control of symptoms** Not reported. **Health related QoL** • Amount of fun, great deal/ a lot/ some (n = 59): 21 (70.0%) vs 13 (44.8%); adj p value = 0,03	**Limitations** **Appendix D. NICE checklist Cohort studies** <u>A. Selection bias</u> (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: yes A3. The groups were comparable at baseline, including all major confounding and prognostic factors: there were significant differences in relation to the type of cancer Level of risk: MODERATE RISK OF BIAS <u>B. Performance bias</u> (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: unclear B2. Participants receiving care were kept 'blind' to treatment allocation:

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study To evaluate the distress and quality of life of a group of children who received end-of-life care from a oncology paediatric palliative care programme (PPC) with those who received usual care. **Study dates** 2002 to 2008 **Source of funding** CHC's internal Research Grant Programme	• Age at death (years),mean (SD): 10.1 (5.8) vs 10.1 (6.8); p=0.98 • Cancer type, n (%); p=0.01 ○ Leukaemia or lymphoma: 6 (20) vs 17 (57) ○ Brain tumour: 15 (50) vs 8 (27) ○ Other solid tumours: 9 (30) vs 5 (17) Bereaved caregivers • Female sex, n (%):22 (76) vs 26 (87); p=0.33 • Age at time of survey (years), mean (SD):44.4 (7.1) vs 42.8 (8.3); p=0.44		• A second survey packet was mailed 6 weeks later and a final call attempt was made those parents who had expressed an interest in participating, but never returned a survey packet. • Parents were given the option to complete the survey over the phone or face-to-face with a trained research team member. Surveys were mostly completed at home by parents, and one parent asked for phone-based assistance • Other diagnostic and service related data was obtained through retrospective chart review. • The SCCC, containing 211 items, is a validated bereaved	• Felt peaceful/ calm, great deal/ a lot/ some (n = 52): 15 (51.7%) vs 14 (60.9%); adj p value = 0,63 • Feeling afraid, all the time/most of time (n = 60): 13 (43.3%) vs 8 (26.7%); adj p value = 0,15 • Experiencing events adding meaning to life: (88.9%) vs 19 (63.3%); adj p value = 0,02 • Adjusted p value: from multivariate logistic regression analysis models that adjusted for age at death and cancer diagnosis	no (not possible due to the nature of the intervention) B3. Individuals administering care were kept 'blind' to treatment allocation: NA Level of risk: HIGH RISK OF BIAS C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? NA C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? 0 C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: UNCLEAR

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	• White race, n (%): 28 (100) vs 28 (100) • Education level (% bachelor's degree or higher), n (%): 15 (52) vs 12 (40); p=0.89 • Time since child's death (years), mean (SD): 4.5 (2.2) vs 4.7 (2.1); p=0.71 • No. of living children, mean (SD): 1.9 (1.0) vs 1.7 (1.1); p=0.47 **Inclusion criteria** Parents were eligible if: • Had a child with a primary diagnosis of cancer who was 0 to 17 years at the time of diagnosis • Spoke English **Exclusion criteria**		parent survey that has been used extensively to evaluate EOLC domains. Specific domains reported in this analysis include symptoms and their treatment (example item: ''Did your child receive treatment specifically for sleep disturbance?''), quality of life (example item: ''How much fun did your child have during his/her last month of life?''), and parent sociodemographic characteristics (e.g., current marital status). • Survey completion took approximately 90 minutes. DATA ANALYSIS • Summary statistics were calculated as means (standard deviation, SD) for continuous variables		D. Detection bias (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: NA D2. The study used a precise definition of outcome: unclear D3. A valid and reliable method was used to determine the outcome: yes D4. Investigators were kept 'blind' to participants' exposure to the intervention: no D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: HIGH RISK OF BIAS **Other information** • Adjusted results • Retrospective study • The study includes children with cancer only

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	Not reported		or proportions (%) for categorical variables. • t-test was used to test for differences between treatment group • v2 or Fisher's exact test was used for proportions • Questionnaire data was dichotomized • Missing answers to individual questions were left as missing and excluded from analyses • v2 was used for unadjusted results was used to compare symptom distress and management, participation in EOL planning, and QOL outcomes • Multivariate logistic regression was used to adjust each comparison for age at		

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
			death (years) and cancer type (haematological malignancy, brain tumour, or other solid tumours) • Analyses were conducted using SPSS20 • Significance level was set at $p < 0.05$.		

G.10 Review question: Emotional and psychological support

Are psychological interventions (including short term bereavement therapies) effective for family members and carers of infants, children and young people and what factors influences their attitudes about those interventions before and after the death of an infant, child or young person with a life-limiting condition?

Psychological interventions for parents/carers, qualitative

Study details	Participants	Methods	Findings/results	Comments
Full citation Jennings, V., Nicholl, H., Bereavement support used by mothers in Ireland following the	**Sample size** N=10 mothers whose child died of LLCs.	**Setting** Unstructured interviews with mothers at their home;	**Themes/categories** Mothers' perceptions on attending accessing formal sources of bereavement support	**Limitations** **Aim(s):**

Study details	Participants	Methods	Findings/results	Comments
death of their child from a life-limiting condition, International Journal of Palliative Nursing, 20, 173-8, 2014 **Ref Id** 353596 **Study type** Qualitative study **Aims** To examine ten mothers' experiences of bereavement following the death of their child from a life-limiting condition in Ireland. The objectives were to: explore mothers' experiences of bereavement support following the death of their child from a life-limiting condition; explicate supports that were helpful or unhelpful to mothers following the death of their child; uncover additional issues or coping strategies used by mothers following their child's death. **Study dates** 2012;	**Characteristics** Four of the deceased children had died from a malignant condition; the remaining six children died from non-malignant conditions including rare congenital and genetic conditions; Age of the deceased children ranged from 2 months to 11 years; **Inclusion criteria** Mothers who: have had a child died from a LLCs; have had a child aged from birth to 12 years at the time of death; experienced the death of their child 1-5 years before the date of the interview; **Exclusion criteria** Mothers whose child had died less than 1 year ago at the time of sample recruitment; were unable	(mothers reported that they relied on a combination of informal and formal bereavement support following the death of their child. Formal sources of support included professional counsellors, professional organisations specializing in bereavement support) **Data collection** A national parent bereavement support organisation acted as a gatekeeper for the recruitment of the sample; Unstructured interview: data were collected by the lead researcher using a single unstructured interview with each mother in their home; **Data analysis** Content analysis: all of the interview transcripts were coded. The data were organised into text groups and then meanings were assigned. Open coding was used, involving line-by-line analysis and allowing the	(sources of group support included hospital organised bereavement group meetings, bereavement days, and voluntary organisations). The mothers felt supported by attending group meetings, through meeting other parents who had also experienced the death of their child: **Companionship and being understood:** *" It was good hearing other people's stories and they had the same kind of feelings...I don't know, it's kind of a general companionship or something being with other people that you don't feel like you are the only one"*	Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was reported (by a bereavement charity acting as a gatekeeper). The relationship between the researcher and the respondents not clearly reported; **Data collection:** No any discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail, no description of how "themes" were arrived at; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the

Study details	Participants	Methods	Findings/results	Comments
Source of funding No external source of funding;	to speak English; did not give written consent.	data to be "opened up or fractured."		analytical process not critically reviewed **Overall quality:** Low **Other information**

G.11 Review question: Social and practical support

What factors of social and practical support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

Study details	Participants	Methods	Findings/results	Comments
Full citation Remedios, C., Willenberg, L., Zordan, R., Murphy, A., Hessel, G., Philip, J., A pre-test and post-test study of the physical and psychological effects of out-of-	**Sample size** • N=77 carers ○ N=58 pre-respite ○ N=39 pre-respite and post-respite **Characteristics** • Gender: N=25 M; N=33 F	**Setting** • Very Special Kids (VSK) is located in Melbourne, Australia, and supports families	**Themes/categories** **Income and financial pressure** Free-text qualitative data revealed that financial costs of caring, coupled with an inability to work, posed a major difficulty for some families: *“Taken on an extra job (started a business) for extra income as my financial situation is becoming dire. My daughter who attends VSK is having more seizures, waking at night and becoming heavier and taller. My*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the

Study details	Participants	Methods	Findings/results	Comments
home respite care on caregivers of children with life-threatening conditions, Palliative Medicine, 29, 223-30, 2015 **Ref Id** 351495 **Country/ies where the study was carried out** Australia **Study type** Mixed-methods research study design using both qualitative and quantitative methods (pre-test and post-test study) **Aim(s)** To determine the impact of out-of home respite care on levels of	- Relationship to child: N=23 Father; N=32 Mother; N=3 adoptive parents **Inclusion criteria** Not reported **Exclusion criteria** Not reported	who are caring for children with life-threatening conditions. This includes the provision of out-of home respite at 'The House', a purpose-built children's hospice **Data collection** Questionnaires including: standardised psychometric measures open-ended questions (about perceptions of respite and other VSK services)	*home is not equipped properly for her condition and I cannot afford a larger more equipped house." (ID: 052)* **Reasons for respite (benefits for respite):** the main reason for utilising respite at The House was to havetemporary relief from caregiving: *"For a break as I do most of [my child's] personal care myself and only get a break while she is in respite." (ID: 009)* Other reasons for respite were to spend time with other family members, to attend an important occasion, to go on holiday, to have an operation or to attend a work function. (Authors quote)	researcher and the respondents was reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information** Data analysis methods reported

Study details	Participants	Methods	Findings/results	Comments
fatigue, psychological adjustment, quality of life and relationship satisfaction among caregivers of children with life-threatening conditions **Study dates** December 2011 - April 2012 **Source of funding** This work was supported by the Medical Research Foundation for Women and Babies.		Participants completed surveys at two time points: 2 weeks prior to respite admission (Time 1) and approximately 1 week after discharge (Time 2). **Data analysis** • Descriptive statistical analysis was used to describe and profile this caregiver population. • Qualitative responses were analysed by two authors using conceptual and relational content analysis.		

Study details	Participants	Methods	Findings/results	Comments
Full citation Jennings, V., Nicholl, H., Bereavement support used by mothers in Ireland following the death of their child from a life-limiting condition, International Journal of Palliative Nursing, 20, 173-8, 2014 **Ref Id** 353596 **Country/ies where the study was carried out** Ireland **Study type** Qualitative study (this study has been included and reported in information provision review)	**Sample size** - 10 Mothers **Characteristics** - 9 mothers were in two-parent relationships, 1 mother was separated. - 9 mothers had other children **Inclusion criteria** Mothers who: - Have had a child who died from a life-limiting condition as outlined in the ACT (now Together for Short Lives) (2009) classification - Have had a child aged from birth to 12 years at the time of death - Experienced the death of their child 1–5 years before the date of the interview. **Exclusion criteria** Mothers who: - Their child had died less than 1 year ago at the time of sample recruitment	Setting Ireland Data collection Unstructured individual interviews Data analysis Conventional content analysis Each interview was transcribed verbatim and imported into NVivo 9 (QSR International) Data analysis was guided by Creswell's (2009) framework The interview transcripts were coded.	**Themes/categories** **Keeping the memory of the deceased child alive:** *"He'll never be gone from my memory. He will always be there and I think that's really important." (Participant 7)* It was also achieved by attending their (mothers) deceased child's grave on their own, which was important to their adjustment to bereavement: *'I would go to the grave twice a day; it was like it was her school, it was her time ... It was almost like a ritual. I went up in the morning and again in the afternoon.' (Participant 3)* *"Bar his bed clothes nothing has changed in his room ... He's not in the house but he's everywhere ... I sleep with Tom's pyjamas under my pillow. Every night I take them out." (Participant 10)* *"I have a massive memory box with all her stuff. And her first tooth ... I have her lock of hair and bits and pieces ... videos we had taken of her. I have all that upstairs and I think that will all just stay." (Participant 6)* *"Yeah that is Tom's shelf up there. People have given me these things. That's his urn, there's a box of letters from his school friends, various photos, and his communion class photo. And I keep it all here." (Participant 2)* **Informal source of help:** Some mothers said that family and friends were hugely supportive and helpful: *"I think friends and family are the main ... my friends, that's what got me through ... friends*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents was discussed **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
Aim(s) To report on a research that examined mothers' experiences of bereavement support following the death of their child from a life-limiting condition. **Study dates** 2012 **Source of funding** This work had no external sources of funding	- were unable to speak English - did not give written consent	The data were organised into text groups and then meanings were assigned.	*and neighbours. 'Cos they're there, not the milestone moments, just the normal moments." (Participant 7)* Others mentioned that websites or online chat rooms were supportive, especially in early bereavement. *"When I went back to work ... no one asked me anything. Nothing. No conversations about her with anyone at all. They didn't say anything." (Participant 6)* The mothers felt supported by attending group meetings, through meeting other parents who had also experienced the death of their child: *"It was good hearing other people's stories and they had the same kind of feelings ... I don't know, it's kind of a general companionship or something being with other people that you don't feel like you're the only one." (Participant 1)* **Formal sources of support: (covered by information review)**	**Other information** Data analysis methods reported (The study has been included and reported in information provision review)
Full citation Price, J., Jordan, J., Prior, L., A consensus for change: parent and professional perspectives on care for children at the end-of-life, Issues in Comprehensive	**Sample size** - N=35 health and social care professionals **Characteristics** - N=3: Drs (Hospital) - N=24: Nurses - N=3: Health care assistants	Setting Professionals with over 2 years' experience were recruited from a regional children's cancer unit and a children's hospice	**Themes/categories** **Structured bereavement support** "Participants ranked structured bereavement support for families as the most important priority for service development … Significant professional and personal dilemmas arose when families expected bereavement support to be provided, often over the long term, by those previously involved in care. These dilemmas included: feelings of guilt at not being able to provide	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection clearly reported. The relationship between the researcher and the

Study details	Participants	Methods	Findings/results	Comments
Pediatric Nursing, 36, 70-87, 2013 **Ref Id** 335000 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim(s)** To investigate health and social care professionals' perspectives on developing services for children with life limiting conditions at the end-of-life using issues identified by bereaved parents as priorities **Study dates**	- N=3: Play specialist/Nursery Nurse - N=1: School Teacher Physio **Inclusion criteria** Professionals with over 2 years' experience with a regional children's cancer unit and a children's hospice in UK **Exclusion criteria** Not reported	in one region of the United Kingdom Data collection focus groups (using the nominal group technique) Data analysis thematic content analysis primary analysis was undertaken by one researcher, who then discussed her emerging analytical framework with another.	the support required; ‘‘burn-out’’ and consequent diminution in the ability to provide effective nursing care; and the potential for families' ‘‘recovery’’ through bereavement to be jeopardized through an over-dependency on individual care team members" (Authors quote) **Increase sibling support (**no quotes**)** **More family support in home (**no quotes) **Out of hours required** (no quotes) **More emphasises on making** memories (no quotes) **Community support/home care** (no quotes)	respondents was unclearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were not presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Data analysis methods reported

Study details	Participants	Methods	Findings/results	Comments
November 2008 - January 2009 **Source of funding** Sandra Ryan Internal Fellowship School of Nursing, Queen's University Belfast				
Full citation Robert, R., Zhukovsky, D. S., Mauricio, R., Gilmore, K., Morrison, S., Palos, G. R., Bereaved parents' perspectives on pediatric palliative care, Journal Of Social Work In End-Of-Life & Palliative Care, 8, 316-38, 2012 **Ref Id** 335027	**Sample size** N= 14 parents from 9 families (out of 25 families who responded to contact attempts). **Characteristics** Not reported **Inclusion criteria** Participants were parents of children who had been treated at a tertiary comprehensive cancer centre and were at least 10 years old at the time of death and died a minimum of 1 year prior to the study. **Exclusion criteria**	**Setting** A tertiary comprehensive cancer centre **Data collection** Focus group method was used to gather information and minimize the potential for participant distress. And exploratory group interview methods were used during the focus group sessions.	**Themes/categories** **Social support: (Parents' perspective)** The need to maintain social relationships and connections with local community members: "*He wanted to be with his friends and in classes as much as possible...I would wheel him out and put him in the care - literally pick him up and put him in the driver's seat, put the wheelchair in the back. He would drive to school, call his buddies from class and say, "hey, I'm in the parking lot. Can you come get me?"...Tons of support in every teacher, principal and student."* Parents emphasized the importance of discussing social support needs with providers and maximizing social connections in the treatment plan.	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Study type** qualitative study **Aim(s)** To describe and being to understand the experience of bereaved parents whose deceased child had received pediatric oncology services at a tertiary comprehensive cancer centre. **Study dates** 2008-2009 **Source of funding** Not reported	Not reported	**Data analysis** The group discussions were transcribed verbatim and provided the basis for the content analysis. ATLAS was used to organise and analyse qualitative data. A six-number research team participated in an exploratory analysis of the textual content to identify codes for all three focus group transcripts. Major themes evolved by grouping textual by consensus.		critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information** Small size but acceptable for qualitative study; Possible selection bias of participants; Participants may be subject to recall bias but how this was affected by their emotions couldn't be assessed.

Study details	Participants	Methods	Findings/results	Comments
Full citation Contro, N., Sourkes, B. M., Opportunities for quality improvement in bereavement care at a children's hospital: assessment of interdisciplinary staff perspectives, Journal of Palliative Care, 28, 28-35, 2012 **Ref Id** 334431 **Country/ies where the study was carried out** US **Study type** Qualitative study **Aim(s)**	**Sample size** N = 60 staff members from multiple disciplines **Characteristics** Disciplines represented were: medicine, nursing, social work, chaplaincy, child life, psychology/psychiatry, respiratory therapy, interpreter services, education, and family - centred care. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Lucile Packard Children's Hospital, a tertiary and quaternary care hospital **Data collection** Semi-structured interviews: protocol based on findings from previous studies and on the existing literature. The protocol was pilot tested. Two social workers with extensive clinical experience in bereavement conducted the interviews, which last a mean duration of 45 minutes. **Data analysis** One social worker and one psychologist independently	**Themes/categories** **Language and culture during bereavement follow - up: (HCPs' perspective)** Concern for the care of non-English speaking families, particularly in bereavement follow - up, was frequently expressed. There is a descending level of care depending on the language of the family: English-speaking families receive the most care, followed by Spanish - speaking families (with the help of bilingual staff and interpreters). Families who speak languages other English or Spanish receive little or no bereavement follow-up. Several staff reported feeling helpless when trying to serve non-English speaking families, despite the fact that the hospital has an exceptional interpreter service. "*Many [non-English speaking] families don't understand what is going on and it is very difficult for them. Many things are lost in translation and staff feels particularly helpless when they don't speak the same language as the family." (child-life specialist)* *"The interpreters are very good, but it is very difficult to use interpreters when dealing with bereavement issues. Consequently, sometimes the follow-up for these families just doesn't happen" (social worker)* **Lack of systematic bereavement follow - up after the child passes away: (HCPs' perspective)**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was not clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed;

Study details	Participants	Methods	Findings/results	Comments
Study dates To examine the current state of bereavement care at a university-based children's hospital from the perspective of the interdisciplinary staff. **Source of funding** Katie and Paul Dougherty Family Foundation and the Project on Death in America: Social work leadership Development Award		conducted a content analysis of the interviews and identified emergent themes.	Several mentioned that they gave written information to families about the grieving process and provided contact information for any available community resources. However, not one person interviewed knew how often families followed up on these referrals. *"There is often little follow-up or information (on children who have gone home or been referred to hospice. Out of sight, out of mind - there is no mechanism to support the flow of information."* *"We just don't take good care of the whole family...after the patient passes away there is a huge hole, and many times they are left to deal with it on their own."* *"The gap in care is the follow - up. We do the immediate are but often don't have time to follow up with families. They physician should offer an appointment three months out to answer any questions a family might have. Parents could always decline it but at least they would have the opportunity."* *"There is a lack of organisation and systematic follow-up with families after the death of a child. There needs to be funding and hospital support for bereavement activities"* **Helpful for bereavement -(HCPs' perspective)-Continuity of relationship as vital to the bereavement process .** Although staff identified continuity of relationships as vital to the bereavement process for them and for the families, they could rarely maintain these connections. ...family members who felt alone and	**Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
			abandoned by their "hospital family" after the death of their child. *"We need continuing support for families so they don't feel forgotten. If you have the choice between more or less, more is better because parents can always decline. But i think reaching out to families is best so they feel they are still remembered."* *"Families often feel no one really understand their situation except people at the hospital - but then they are abruptly cut off from these very people they have come to rely on"* **Bereavement support and needs for siblings and grandparents -(HCPs' perspective)** Most of the interviewed expressed deep concern about the paucity of services offered to siblings prior to, at the time of, and after the death of the child. When siblings did receive help, it was often because parents had requested it. Staff also identified other close to the child, e.g. grandparents, who experience great distress and yet rarely received services. "*siblings get lost due to time and resource constraints and are only occasionally seen for follow -up."* *"Many sibs go through the experience without any intervention."* *"Grandparents grieve twice as much...they grieve for the loss of the child and they grieve for the loss their own child feels. We need to pay more attention to them"*	

Study details	Participants	Methods	Findings/results	Comments
Full citation Champagne, M., Mongeau, S., Effects of respite care services in a children's hospice: the parents' point of view, Journal of Palliative Care, 28, 245-51, 2012 **Ref Id** 425469 **Country/ies where the study was carried out** Canada **Study type** Qualitative study **Aim(s)** To analyse, from the parents' point of view, the effects of respite services offered at a children's hospice.	**Sample size** Purposive sample N= 25 families (25 mothers and 8 fathers) out of the 29 families contacted **Characteristics** 58% of the interviewed mothers had a post-secondary, college, or university education, and 75% of the fathers. A majority of the mothers described themselves as stay-at-home parents. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Children's hospice **Data collection** Semi-structured interview, lasted about 1 hour long each. **Data analysis** All the interviews were transcribed and thematic analysis was conducted by a research professional, who followed the steps of coding, categorization, and creating interrelations.	**Themes/categories** **Effects of respite services on family members:** **Rest:** The mothers widely noted effect of the respite offered at the hospice was expressed very simply by several mothers: "*Rest, rest, for sure!"* *"The last time that i bought her to the lighthouse, i didn't do nothing that week. I let my friends cook for me...I went to their house. I did no cleaning, no nothing, and it was like: wow! i became more energized."* **Improved sleep:** *"While she was at the Lighthouse, i had a chance to catch up a bit more on my sleep. I went back to bed, and went back to sleep, and got some of my strength back."* **Feeling of liberation from the responsibility of caring for the sick child.** "*Just taking care of her takes a lot. Just travelling with her, with the wheelchair and the pump, dealing with all this stuff. Not to do that, it's respite in itself."* **Feeling of freedom:** Feeling free and being able to go out were invaluable effects of the respite days for parents. *"It gave me a chance to find myself...if i want to go and see and movie i can, i don't have to rush back by 8 o'clock. That's what's*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
Study dates 2007-2008 **Source of funding** University du Quebec a Montreal			*important when he's in respite. I don't have to stick to a schedule."* **Opportunity to take a vacation:** *"A two-week holiday is much better than just going out for supper!"* **Opportunity to spend time with their other children:** "*It also lets us make the best use of the time we spend with our younger son."*	**Other information** Only short-term effects of respite services were commented and described, unclear about long-term effects; Very homogeneous sample;
Full citation Cadell, S., Kennedy, K., Hemsworth, D., Informing social work practice through research with parent caregivers of a child with a life-limiting illness, Journal Of Social Work In End-Of-Life & Palliative Care, 8, 356-81, 2012 **Ref Id** 353429	**Sample size** N=35 individual and couple interviews (47 people) **Characteristics** Not reported for qualitative data findings **Inclusion criteria** - Carers who were caring for a child with a LLI **aged 19 or younger** - Carers who were **directly involved** in caring for a child with a LLI **Exclusion criteria**	**Setting** The study was mix-methods in two phases: - The first phase used quantitative methods and consisted of a questionnaire measuring personal resources, spirituality, stress and personal	**Themes/categories** **Connection with other parents by attending conferences, meeting other families in formal and informal settings.** "*They Do Not-They'll Never Understand. They Think It Is Something That Is Going To Be Cured Like In A Month Or Two, A Year, And It Is Gonna Be Over*" (Dad) "*No Matters How Many Times You Say It- That Is Why Going To The (MPS) Conference, It Is Like- Ahhhhh- I Am Like, You Do Not Have To Explain Anything, All These Parents Know It All. It Is Like A Family*" (Mom) Carers felt that connections with others did not have to be through face to face contact to be valued. Many connected with other parents through internet sites and blogs: "*Everything I've learnt I have learnt through there (Internet)…if eve I needed an information I go on to it and ask and you get lots of answers back. Most the same answers, but some different and it has just*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported and about the roles of the researchers **Data analysis:** Researchers did not clearly review their own roles in the analytical process while

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out Canada and United States **Study type** Mixed methods research using both quantitative and qualitative data (2 phases study: the second phase which is qualitative is the focus of this abstraction form) **Aim(s)** To explore the factors that allow parents who are caring for a child with a life-limiting illness to survive and to grow in the face of diversity **Study dates** 2012: publication date	People who were located in areas that were geographically accessible	growth of parents. - **The second phase used qualitative and is the focus of this abstraction form.** **Data collection** Semi-structured interviews **Data analysis** Content analysis was performed by reviewing the transcripts of the interviews.	*been the best thing for me. Like it is, you know, it is so sad to say, but it is nice to have somebody else exactly what you are going through*" (Mom) **Financial Stress And Burden** The financial struggles that families were confronted with were not solely related to their income: "*Everything is based on income, not based on how much money actually do you have. That might take at least half of it. Sometimes it is frustrating because our income may become higher than some other people, but that does not mean we are not needing it more…, like they do not take into consideration oh they are paying $500 a month in homecare and $200 a month for her feed, and you know, they make all this money they should be able to do without it*" (Mother) Carers spoke of the burden of major expenses such as costly renovations, having to buy a reliable vehicle to get a child to appointments, or moving to a different part of the province to be closer to the hospital: *"we've to refinance or home because of debt that was incurred because of going back and forth (to the hospital) and still having to go back and forth, you know, we are still having to rack up our credits cards again—sometimes extra costs, like the feeding, homecare, financial things. We'd like to expand our house, but whit the extra responsibility financially, well right now she is small it is not such a big deal, but as she grows…bigger changes."* (Mother)	it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed **Overall quality:** Moderate **Other information** Data analysis methods stated

Study details	Participants	Methods	Findings/results	Comments
Not reported: data collection **Source of funding** MOP-79526/Canadian Institutes of Health Research/Canada PET-69769/Canadian Institutes of Health Research/Canada			"*For many, the decision to continue working full-time or stay at home to care for their child came not easily: "I have my family behind me, you know, like telling me you have to be at home, "that's where you are needed right now," and "you shouldn't be working". But then' I know I have to work. It is not possible financially if I stop working, but at the same time you get to wonder, I do not know…. We are just At the point right now if I do not work it is going to be very bad".* (Mother) **Lack of reliable home care** Parent cited lack of reliable home care, in-home support, and respite services as common reasons for choosing to leave the workplace to care for their child full-time: "*And homecare was just a disaster. I was more stressed with homecare than I was with (our daughter)".* (Mom) "*Trying to get adequate staffing for him-we've had one or two girls that were more of a nightmare than something else and one girl was actually working out good, but she couldn't handle (our son) because he is high-maintenance and she just phoned one day and said "I am quitting". So, I said "Oh, so this is 2 weeks' notice. That is fine." "No, I am not just coming in"* (parent) **Lack of resource info related to the child** Parents spent substantial amount of time in searching for eligible funding subdues, grants, and tax credits related to their child. [..] Some mothers relinquished full-time positions in order to to have more time to	

Study details	Participants	Methods	Findings/results	Comments
			search and follow up on information that would benefit the family: "*Oh, the system gotta be a little more open for parents, families to help them to find more resources –to actually have people to stand up and say, "Hey you, we've something for you" rather than as a family having to actually track this stuff down because that is a big freakin' headache trying to track down services for your children. I can't think of anything that is any worse than the throughout this whole process*." (carer)	
Full citation Weidner, N. J., Cameron, M., Lee, R. C., McBride, J., Mathias, E. J., Byczkowski, T. L., End-of-life care for the dying child: what matters most to parents, Journal of Palliative Care, 27, 279-86, 2011 **Ref Id** 335206 **Country/ies where the study was carried out** US	**Sample size** N= 29 parents representing 20 families; **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Parents of children whose deaths were related to accident or injury were excluded from the study; Parents of children who died less than 6 months prior to the start of the study were excluded;	**Setting** A large paediatric hospital located in the Midwestern United States. **Data collection** Semi-structured interviews and focus groups; **Data analysis** The data analysis was an iterative multi-step process that involved both independent and	**Themes/categories** **Access to care and resources when the child is cared at home: (parents)** Many parents talked about the value of having their children at home at the EOL stage and stressed the importance of having enough resources to manage it. Some talked about the financial resources they required and the help they needed to fill out forms and file paperwork. Others talked about the equipment and training they needed to care for their child at home. They also indicated the importance of having help to coordinate these resources so that they could minimize the burden and maximize the time they spent with their child. "*There was on number to call when you have problems, and they contacted the person that you needed at that moment...It wasn't like you had 10 numbers...it made it a lot easier for us.*"	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical

Study details	Participants	Methods	Findings/results	Comments
Study type qualitative study **Aim(s)** To identify and define the dimensions of paediatric end-of-life care that are important to parents of children or infants who died either in hospital or at home under hospice care as a result of an illness, chronic condition, or birth defect. **Study dates** 2006-2007 **Source of funding** Starshine Hospice and Palliative Care, Cincinnati Children's Hospital Medical Center		collaborative efforts. Team members first reviewed each transcript independently, coding portions of the text and identifying emerging themes representative of important dimensions of ELOC care from the perspective of the parents interviewed. The team then met to review the transcripts and each consensus on the major themes used to define dimensions of ELOC car that were important to parents.	*"I guess they made you feel that our main concern is our child and being with our child...not coming up with the money for her to be here. They psychologist had contacted my insurance...she had already filled in my insurance company so i didn't have to reiterate the whole situation and try to figure how things were going to work out"* **Bereavement support: (parents)** First, almost all of the parents talked about the importance of bereavement support. Some indicated that this should take the form of helping parents to memorialize their child. Other talked about continued contact with health care providers, such as follow up call or a card sent on a significant date.	process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the analytical process not critically reviewed; **Overall quality:** Moderate **Other information** Small sample size from one site; Participants may be subject to recall bias due to bereavement emotions; No representative from the minority group in the recruited sample.

Study details	Participants	Methods	Findings/results	Comments
Full citation Grinyer, A., Payne, S., Barbarachild, Z., Issues of power, control and choice in children's hospice respite care services: a qualitative study, International Journal of Palliative Nursing, 16, 505-10, 2010 **Ref Id** 334631 **Country/ies where the study was carried out** UK **Study type** Qualitative study (descriptive phenomenology) **Aim(s)**	**Sample size** N=11 families -interviews (24 people interviewed) **Characteristics** people interviewed: 3 patients, 3 siblings, 10 mothers, 3 fathers, 2 grandmothers, 1 paid carer, 1 bereaved mother and 1 bereaved Sibling **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** - Families using a children's hospice in the north west of England. - This hospice provides inpatient beds, day care, bereavement support, and home care for children and young people from birth up to 30 years of age **Data collection** Semi-structured interviews	**Themes/categories** **Unmet Needs – Lack of choice regarding respite** "There seemed to be little choice about when, how often, and for how long respite care was offered. […] what was offered was gratefully accepted, but the timing and frequency of the respite did not always fit with the family's plans or preferences and they felt unable to articulate this for fear of appearing ungrateful." (authors quote) **Unmet Needs – Practical problems of access** The duration of the respite care was often very short and the complicated preparations necessary were thought by some to be disproportionate to the benefit *'[it's] very difficult packing everything up just for the day—almost not worth the bother'. (mother)* No offers of support with travel to the hospice were reported, and parents, particularly when on their own, could struggle with the practicalities of transporting a very disabled child along with heavy equipment and all their medications. *"It just would have been great if they could have offered a transport service to and from, that would make life easier ... On your own with him in the car ... if he was having a fit in the car or needing oxygen, I would be driving and I would have to pull over.'" (step mother)*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Clear sampling selection used. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process unclearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
To evaluate the views of 24 service users - parents, children and young people, siblings, guardians and family carers- on their experiences of respite care in the of a children's hospice in northern England. **Study dates** Not reported **Source of funding** This work was commissioned by the hospice (anonymous)		**Data analysis** - Data have been subjected to codification. Then they have been sorted and sifted in a manner that facilitates the identification of similar phrases, themes and patterns. - The three members of the team verified the interpretation through a process of continuing consultation	**Unmet Needs – Practical problems of access with respect to bureaucratic requirement** Although it was recognized that records need to be kept up to date, what was seen to be excessive and laborious form filling *"'More hassle than it's worth'. (mother)*	**Other information** Data analysis not stated
Full citation	**Sample size**	Setting	**Themes/categories**	**Limitations**

Study details	Participants	Methods	Findings/results	Comments
Einaudi, M. A., Le Coz, P., Malzac, P., Michel, F., D'Ercole, C., Gire, C., Parental experience following perinatal death: exploring the issues to make progress, European Journal of Obstetrics, Gynecology, & Reproductive Biology, 151, 143-8, 2010 **Ref Id** 334534 **Country/ies where the study was carried out** French **Study type** Qualitative study (descriptive Phenomology) **Aim(s)**	• 11 people interviewed (parents of deceased children) **Characteristics** • Type of pregnancy: 3 twin; 1 triple; 7 single • Relationship to child: 2 fathers; 9 mothers • Mode of response: 4 interview (face to face); 7 mail response **Inclusion criteria** Parents who had lost a child during the perinatal period in the study setting **Exclusion criteria** Not reported	Mother–infant department of the Centre Hospitalier Universitaire Nord in Marseille Data collection Questionnaire with open-ended response questions Semi-structured interviews (or face to face or by email) Data analysis Thematic analysis "Responses were analysed and grouped according to key themes: family circle (siblings, grandparents), announcing the seriousness of the diagnosis, time to say ‘‘goodbye,’’	**Timing of bereavement follow-up and support after child's death:** "Several mothers had visited the team on their own initiative, several months or even years after the death of their child. They described the need to return to the place where the events took place" (Authors quote) "The mothers thought booklets about the grieving process should be distributed 2 months or more after the death of the child, at a time when many families find themselves in a ‘‘social (or human) desert’’ after the support of the first few weeks has waned" (Authors quote)	**Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process and it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
To understand the parental response to perinatal death by describing the experiences of the families. The secondary objective was to understand, according to an ethical approach, parents' needs in an effort to improve interventions for bereaved families. **Study dates** Publication date: 2010 Data collection & analysis: not reported **Source of funding** not reported		parental feelings, and follow-up by the staff after the death." Ethical analysis "we examined whether certain ethical principles (i.e., the concepts of beneficence, nonmaleficence, autonomy, and justice) were encountered by the study participants"		**Other information** Data analysis methods stated
Full citation Steele, R., Derman, S., Cadell, S., Davies,	**Sample size**	Setting	**Themes/categories** **Understanding and information about respite care services provided by hospices: i.e. Viewing hospice as a**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for

Study details	Participants	Methods	Findings/results	Comments
B., Siden, H., Straatman, L., Families' transition to a Canadian paediatric hospice. Part two: results of a pilot study, International Journal of Palliative Nursing, 14, 287-95, 2008 **Ref Id** 345084 **Country/ies where the study was carried out** Canada **Study type** Qualitative study **Aim(s)** To describe the experiences of parents as their families transitioned in a Children' hospice in Canada	- 11 people interviewed (parents from 6 families) **Characteristics** - 6 mothers - 2 fathers - 2 siblings - 1 child with a life-threatening illness **Inclusion criteria** - Families who had recently been accepted into the study setting - And families who had their first on-site stay at the hospice. **Exclusion criteria** Not reported	Canuck Place Children's Hospice (CPHC) in Canada Data collection Semi-structured interviews Data analysis Thematic analysis (not explicitly stated): Average length of interview views was 60 minutes for adults and up to 30 minutes for ill children or siblings. All interview transcripts were coded for content separately for each participant. The coded content categories were	**possible resource for family (not only for end of life care):** *"That [end-of-life care] was what was deterring. Yeah, it was like, "Oh no! I don't want to…put my brain there! I don't want to think that we need that." I want to believe that my son's gonna live a long healthy life, right?'" (mother)* *"[I] never really paid much attention because we thought it was for end-of-life care. So I thought, well, if we reach that point with [child's name] we'll look into it then." (father)* Once parents became aware that the hospice provided respite as well as end-of-life care, they considered CPCH a possibility: *"I heard about it from a friend of mine ... and she said, Why don't you try that place?", but I think from what I knew I thought it was only end-of-life care. I didn't know that they provided respite care." (mother)* **Benefits of respite: acknowledged needs for respite from parents** **Benefits of respite: care and attention to all family members:** *"They're there to help you too, as opposed to just the child. They want your time to be relaxing and they do whatever they can to … make you feel content and happy about their care." (Parent)* **Benefits of respite: benefits for children receiving respite**	answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Method of data analysis not explicitly stated

Study details	Participants	Methods	Findings/results	Comments
Study dates 2008: publication date Not reported: data collection & analysis **Source of funding** Not reported		reviewed across all parental interviews to identify common, recurring themes and relational patterns within the data	"Parents were pleased with the individualized care and attention given to their child and they noted that CPCH was a better place for them compared with other respite services. They appreciated the support groups for the child, as well as the excellent professional services and available activities" (Authors quote) **Benefits of respite: benefits for families receiving respite** Respite allowed parents to rejuvenate and spend time with their other children while knowing they had not abandoned their ill child and that they were being safely cared for. *"'I can relax and not have to worry about everything and just pretend … I can just forget about my own worries for a bit." (Mother)* **Benefits of respite: dealing with future changes** "Parents saw benefits for the future as well. They felt more comfortable dealing with future changes, for example, if the child's health deteriorated and they required further medical interventions. Parents were less afraid about end-of-life care because they realized that CPCH manages more comprehensive care than they could provide at home on their own." (Authors quote)	
Full citation	**Sample size**	**Setting**	**Themes/categories**	**Limitations**

Study details	Participants	Methods	Findings/results	Comments
Malcolm, C., Forbat, L., Knighting, K., Kearney, N., Exploring the experiences and perspectives of families using a children's hospice and professionals providing hospice care to identify future research priorities for children's hospice care, Palliative Medicine, 22, 921-8, 2008 **Ref Id** 334843 **Country/ies where the study was carried out** UK (Scotland) **Study type** Qualitative study **Aim(s)**	Purposive sampling strategy; Families using hospice services, N=5; Hospice staff and volunteers, N=44; Professionals associated with the hospice, N=18 **Characteristics** Among the 5 families: new users n =2, using the hospice for 1 year or less; long-term users n =2, families using the hospice for 2 years or more; and a family being supported by the bereavement service, n=1. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	Semi-structured interviews in Delphi consensus survey **Data collection** Semi-structured interview and focus group schedules were developed by the research team to guide the data collection. Topics included: describing their experience of using the hospice and its services; experience of providing palliative care to children with life-limiting conditions and their families; face to face interviews with the 5 families, lasted between 32-51 minutes; Focus groups with 44 hospice staff and volunteers, lasted between 55 and 70 minutes; Telephone interview with 18	**Awareness of children's hospice care: (from the perspective of both professionals and families)** There was unanimous acknowledgement amongst participants that many myths and misconceptions concerning children's hospices continue to prevail amongst public and professionals alike. Recognition of the need to develop strategies that would promote a greater understanding of the hospice and assist to dispel existing misconceptions was made. It was felt very strongly across all of the participant groups that actively promoting the wide range of care and support provided by the hospice was necessary to increase awareness amongst the public and professionals and thus improve access to the service, tapping into unmet need: "*There is a big issue in terms of getting children and families across the threshold of a children's hospice, a) because of the terminology and b) because of professional misconceptions or lack of education and information that professionals have about what children's hospices do...." (Professional)* *"Well for everyone I would think the first priority is making the health professionals more aware of the service that the hospice offers." (Family)*	**Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** How the sample was selected was clearly reported. The relationship between the researcher and the respondents clearly reported; **Data collection:** Data collection methods clearly reported; whether data saturation was achieved was not reported; **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process; whether data saturation was achieved was not reported; **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
To generate a list of priority topics for children's hospice care research in Scotland from the perspective of its key stakeholders. **Study dates** 2007 **Source of funding** CHAS		professionals, lasted between 8 and 24 minutes. **Data analysis** Content and interpretive analysis of the transcripts was performed;		**Other information**
Full citation Forrester, L., Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child, International Journal of Palliative Nursing, 14, 578-85, 2008 **Ref Id** 353516	**Sample size** 16 families: - 6 families: receiving respite care at the hospice (hospice group) - 5 families: receiving respite care at home (home group) **Characteristics** - Place of death: ○ Home= 4 ○ Hospital= 1 ○ Study hospice= 10 ○ Other hospice= 1	Setting Children' hospice in the UK (no other details given) Data collection Retrospective cross-sectional survey using a postal questionnaire	Themes/categories **Support pre- and post-death of the child:** Continuity of care of personnel pre- and post-death was important for some, with respondents appreciating knowing who was caring for the child and eventually putting them in their coffin: *"They popped in and tucked * [in] at night and kept the music on for * and cared for **	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has

Study details	Participants	Methods	Findings/results	Comments

Country/ies where the study was carried out
UK
Study type
Qualitative study (retrospective cross-sectional survey using a postal questionnaire)
Aim(s)
To explore how bereaved families experience the child remaining in a cold bedroom following the child's death
Study dates
January 2002–March 2005
Source of funding
Not reported
	- Diagnosis:
	  - Malignant= 7
	  - Non-malignant= 9
	- Ethnicity:
	  - White= 15
	  - Mixed= 1
	Inclusion criteria
	Families of all the children in the study who had been cared for in the cold bedrooms in the period January 2002–March 2005
	Exclusion criteria
	Families no longer in contact with the hospice
		Data analysis
		Thematic analysis (not explicitly stated)
		Data was analysed by hand.
		The responses to each question from each respondent were considered to compile a framework of emerging themes and coded
		Each theme was then deconstructed into components, according to the researcher's interpretation.
			*physically … with grace and dignity as if * were their own child' (R 15).*
			Deterioration of the child's body:
			'*A slightly surreal experience'* (R 13)
			'I *found it very hard to be with * cold body'* (R 15).
			Opportunity to be close to the child – importance that the child was not taken away (cover by communication review)
			*" Easy access at all hours to go see, touch *, stroke * hair, talk to *" (R 9).*
			*"To have had * taken away would have been unbearable" (R 5)*
			*"We did not want to be parted from * until we had to" (R 14)*
			*"We could take * from the security of the hospice to the crematorium without being parted" (R 13).*
			"There are no memories of a death at home and the difficulties that accompany that" (R 14)
			"*I wanted * not to die at home so that there was not a room I did not want to go in*" (R 4).
				been reached for any of the themes reported; no details given about data saturation
				Data analysis: The analytical process was described in detail; researchers did not critically review their own roles in the process: no details given about analysis saturation
				Findings/results: Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed;
				Overall quality: Low
				Other information
				Data analysis methods not explicitly stated

Study details	**Participants**	**Methods**	**Findings/results**	**Comments**
			Care for the family The attention given to the families' physical needs (e.g. meals being provided). The importance of staying together as a family (e.g. the opportunity to have accommodation at the hospice): "Kept us together until we had to say goodbye" (R 13). **Arrangements around the cold bedroom** To choose whether to see or not the room before the child's death: "*It felt like we were being shown another room; the full impact of what it would mean didn't register; the rooms were not chilled at that point*" (R 10). The décor of the room was important for six families: "*The room was homely, peaceful, like a child's bedroom…we were told it could be kitted out…really to represent one's own home"* *"You could make the room into something your child would have loved…the room gave me comfort…"*	

Study details	Participants	Methods	Findings/results	Comments
			Care for the family around the cold room: e..g, provide family members with: warm jackets for parents to *wear,* *for family with another child, …"for the sibling to be able to go in and out of the room without restriction".* Comforting music **Help with funeral arrangement:** Respondents commented on how they valued help with making funeral arrangements; this included making appointments to register the death and with funeral directors. Ten respondents commented that the funeral directors visited them at the hospice. Five appreciated access to poetry/prose materials for use at the funeral service. *"We managed to organise what we wanted"*	
Full citation Eaton, N., 'I don't know how we coped before': a study of respite	**Sample size** 11 families: • 6 families: receiving respite care at the hospice (hospice group)	Setting This article is part of a larger study (which examined	Themes/categories Helpful or it would be helpful - **Regular sibling activity** day was deemed helpful:	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for

Study details	Participants	Methods	Findings/results	Comments
care for children in the home and hospice, Journal of Clinical Nursing, 17, 3196-3205, 2008 **Ref Id** 344379 **Country/ies where the study was carried out** UK **Study type** Qualitative study (descriptive phenomenology) **Aim(s)** To describe the experiences of families, whose children have life-limiting and life-threatening conditions and who have complex healthcare needs, of receiving respite	• 5 families: receiving respite care at home (home group) **Characteristics** **Characteristics** • **Hospice group** ○ 6 families with 7 children aged between 7–16 years whose medical conditions included epilepsy, cerebral palsy and complex special needs ○ One child lived with grandparents, the others lived within two parents in the family home and all except two children had well siblings ○ The families lived with 20 miles of the hospice • **Home group** ○ The medical conditions of the children (aged 3–15 years) of the 5 families in this group were very similar to those in the hospice group ○ 1 family was a single-parent family, all others two-parent families, one child was a twin and all	aspects of the quality of care for children in the community in Wales, UK) Data collection Semi-structured interviews. All families were interviewed in their homes, with interviews being tape-recorded (with their consent) and later transcribed verbatim. Data analysis The interviews were analysed based on the constant comparison method, with a second researcher undertaking analysis of a	"*You're always made to feel welcome"* (M8) Helpful or it would be helpful **- Flexible and suit the family needs:** "Hospice respite care during the school holidays was particularly helpful, especially when there were siblings." (Authors quote) Although both hospice and home respite services use a booking system for care, parents can find this too inflexible to meet their needs: "*When you have a crisis with a child like this, it's usually in the middle of the night, on a weekend, a bank holiday, when there's nobody around, or if they are there's a very limited service."* (M7) **Unmet needs – practical assistance when hospice/respite is available:** "*We have to trundle the equipment down*." (M1) "*We have to take his potty chair, medication, clothes, nappies, chocolate*." (M8) **Unmet needs – practical assistance when hospice/respite is available**: Although both hospice and home respite services use a booking system for care,	answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported; **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process were not critically reviewed; **Overall quality:** Moderate **Other information**

Study details	Participants	Methods	Findings/results	Comments
care at home or in a hospice. **Study dates** 1998 **Source of funding** The Wales Office of Research and Development.	but one child had siblings ○ The families were receiving respite care for two to six hours/week at home **Inclusion criteria** Convenience sampling. Selection was based on the families judgement regarding readiness and fitness (in terms of distress, stress, other pressing demands at home, etc.) to participate in the study. None **Exclusion criteria** None	portion of the data to check for coding agreement	parents can find this too inflexible to meet their needs: "*When you have a crisis with a child like this, it's usually in the middle of the night, on a weekend, a bank holiday, when there's nobody around, or if they are there's a very limited service*". (M7)	
Full citation Monterosso, L., Kristjanson, L. J., Aoun, S., Phillips, M. B., Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of	**Sample size** • 134 parents and 20 service providers. ○ Phase 1: 129 parents ○ Phase 2: 28 parents and 20 service providers. **Characteristics**	Setting This study was undertaken in Western Australia, and was undertaken in two phases: Phase 1 consisted of a series of surveys and Phase 2 consisted of	Themes/categories **Financial impact (lack of funding to purchase respite and other health care services):** "*Parents spoke frequently about difficulties in procuring funding for various forms of care and perceived a number of barriers and inequities to exist. Although adequate financial and practical assistance was central to care provision and contributed to the quality of life experienced by children*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Not clear sampling strategy used. The relationship between the researcher and the respondents was reported

Study details	Participants	Methods	Findings/results	Comments

a palliative care service, Palliative Medicine, 21, 689-96, 2007
Ref Id
334905
Country/ies where the study was carried out
Australia
Study type
Mix-methods design (Two-phase combined quantitative and qualitative study)
Aim(s)
To explore parents and service providers to better understand the needs of families of children receiving palliative and supportive care about their care needs in hospital and in
	- N=19: cancer group parents (parents in the cancer group were bereaved)
	  ○ In this group the most common condition of children was brain tumour (n=7)
	  ○ Age of child at diagnosis (year) = 6.00+/-4.54
	- N=110: non cancer group parents (not bereaved)
	  ○ In this group the most common condition of children was severe neurological (n=6)
	  ○ Age of child at diagnosis (year) = 1.80+/-2.96
	Inclusion criteria
	- Phase 1: Not clearly described
	- Phase 2: Those parents who, in Phase 1, agreed to be contacted regarding participation in Phase 2
	Exclusion criteria
	- Phase 1: not reported
	- Phase 2: not reported
		interviews with parents and service providers.
		Data collection
		Phase 1: 6 questionnaires administered either by telephone or face-to-face:
		18-item multi-level WeeFIM II
		124-items Multilevel Service and Educational Resource Utilization (SERU)
		16-item Patient Carer's Needs Survey (PCNS)
		14-item Hospital Anxiety and Depression Scale (HADS)
		17-item Family Inventory of Needs-
			and their parents, parents from the non-cancer group especially, articulated the burden they endured as a result of the lack of financial and practical assistance." (Authors quote)
			Skills of carers and environment (In-home hospice and familiarization):
			"Parents from the cancer group who used the services of community-based medical and nursing staff during the end-of-life phase of their child cited a lack of familiarity with the management of their child's medication (especially pain relief) and nutrition." (Authors quote)
			"Some parents of children with non-cancer diagnoses were concerned about the skills of the carers and reported that in-home respite or hospice may be useful as long as there was a long period of familiarization prior to use" (Authors quote)
			Access to and availability of services
			"Most parents from the non-cancer group used or attempted to access respite and felt this was crucial to the well-being of their children and other family members. However, many parents were hindered by lack of financial support and/or rigid criteria, which limited their access. In contrast,
				Data collection: Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported
				Data analysis: The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved
				Findings/results: Results were presented clearly. The researchers' roles and potential influences in the analytical process were not critically reviewed;
				Overall quality: Low
				Other information

Study details	Participants	Methods	Findings/results	Comments
community settings., the extent of service provision currently available to these families and the barriers and facilitating factors associated with supportive and palliative care. **Study dates** February 2003 - March 2005: data collection **Source of funding** Children's Hospice Association (Inc), the Department of Health and Ageing, Edith Cowan University, the National Medical and Health Research Council of Australia, and the Western Australian Department of Health through the Women and		Paediatric II (FIN-PED II) Phase 2: semi-structured interviews (either telephone or face-to-face) Data analysis Phase 1: Descriptive statistics Phase 2: Content analysis Each interview was audio-taped and transcribed. Transcriptions were analysed using the technique of content analysis. Open coding was used to identify common themes.	parents from the cancer group rarely felt the need to access respite." (Authors quote)	

Study details	Participants	Methods	Findings/results	Comments
Children's Health Service of Western Australia.				
Full citation Konrad, S. C., What parents of seriously ill children value: parent-to-parent connection and mentorship, Omega - Journal of Death & Dying, 55, 117-30, 2007 **Ref Id** 348316 **Country/ies where the study was carried out** US **Study type** qualitative study **Aim(s)** This article describes	**Sample size** Purposive and non-random sample N = 12 mother whose child was seriously ill or dying **Characteristics** Not reported **Inclusion criteria** Not reported **Exclusion criteria** Not reported	Setting Local paediatric palliative care programme Data collection The study utilised a psychological phenomenological design to gather information, detail of how data were collected were not clearly reported Data analysis Details of data analysis process not reported	Themes/categories **Social support -local parent-to parent organisations (peer group):** Mothers in this study strongly encouraged parents to seek out the support from other parents and take them as mentors and guides. Shared experience provided these mothers with both useful information and comforting reassurance that they could be competent in their child's care. "Try to talk to other people who are experiencing the same thing for two reasons: number one to get your hearts connected so that you know that you know, it, it's unbelievably helpful. And also to share the technical stuff or what's going on, um, physically with your kid." Mothers' s stories told comfort generated through informal connections with families who had similar journeys. "*one was a friend of a friend who knew that my son had [disease]..and then another one is someone who lives in town, um, that we were acquaintances with but they had heard*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection procedure was clearly reported. The relationship between the researcher and the respondents not reported **Data collection:** Data collection process not clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was not described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' roles and potential influences in the

Study details	Participants	Methods	Findings/results	Comments
unexpected findings from a qualitative study with mothers of seriously ill and dying children who support the value of parent-to-parent connection and mentorship. **Study dates** Not reported **Source of funding** Not reported			*our son had it. And I think parents do an incredible job supporting each other...I am not afraid to say to either one of these parties that I would ask a lot of questions...I would appreciate someone telling me what their experience was so i could at least get used to what we were dealing with."* Similarly helpful and comforting connections with local parent-parent-organisations were noted by a few of the mothers: *"There is some great resources out there aimed at educating parents of children with special needs. Find out who these people are and go to classes whatever the class is on. Just take the class. Meet other people. Ask some questions. The experts are right there. They will deal with your questions and answer it that night. I guarantee they'll take your name and they'll call you. "*	analytical process not critically reviewed; **Overall quality:** Low **Other information**
Full citation Brosig, C. L., Pierucci, R. L., Kupst, M. J., Leuthner, S. R.,	**Sample size** 19 deceased infants (interviews) **Characteristics**	**Setting** **Data collection**	**Themes/categories** **Environment** “Parents talked about many aspects of the environment in which their child died. For	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for

Study details	Participants	Methods	Findings/results	Comments
Infant end-of-life care: the parents' perspective, Journal of Perinatology, 27, 510-6, 2007 **Ref Id** 334363 **Country/ies where the study was carried out** USA **Study type** Qualitative study (descriptive phenomenology) **Aim(s)** The purpose of this study was to identify factors important to parents in their infant's end-of-life care. **Study dates**	11: both parents were present during the interview. 7: only the mother was present, 1:only an aunt who had been a caregiver. - 11 girls and 8 boys ranging in age at death from 1 day to 280 days (mean age of death was 62.89 days, s.d.=81.82 days). - The children's diagnoses included: hypoplastic left heart, other cardiac, metabolic disease, genetic syndrome with diaphragmatic hernia, central nervous system (CNS) anomaly, congenital myopathy, CNS injury hypoxic ischemic encephalopathy (HIE or meningitis), prematurity and necrotizing enterocolitis. - 18 died in the hospital (76% died in either the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU); only one infant died at home. - 8 out of the 19 families (42%) had hospice and/or palliative care team involvement **Inclusion criteria** parents whose infant (less than 1 year of age) had died not more than 2 years and not less than 6 months prior to the initiation of the study	- Revised Grief Experience Inventory (RGEI) - a 22-item Likert-type scale, yielding four principal factors: Existential Tension, Depression, Guilt and Physical Problems - semi-structured interviews **Data analysis** **RGEI:** The sample scores were compared with normative data from a sample that had lost a close family member or friend. **semi-structured interviews:**	those parents whose child died in the hospital, they spoke positively about things in the hospital that made their stay more comfortable, such as sleep rooms where they could rest, or family rooms in the intensive care units, where they could be with their child when the child died, without the lights and machines in the actual hospital room." (Author quote) Parents also described negative aspects of the hospital: *"It was an isolation room kind of very sterile, mask and everything...and you didn't feel very comfortable...I wish I had the chance to hold him more but he was hooked up to all those things." (Parent)* For those parents whose child died at home, they too reported mostly positive and negative experiences: *"She had really severe seizures and we weren't prepared for that...it was very frightening." (Parent)* **Family support** "Relying on family support was the most common way for parents to cope with their child's death. Parents indicated that it was helpful to them to be able to talk about their child with their extended family." (Authors quote) At times, parents felt that family members were not supportive and avoided talking about the deceased child: *"I try to give my mother a card on grandparents' day in honor of M. and it's like*	answering the research question **Sample selection:** Method of selection clearly defined. The relationship between the researcher and the respondents not clearly reported. **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported. **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information** Data analysis methods not explicitly stated

Study details	Participants	Methods	Findings/results	Comments
January 1994 - December 1997 **Source of funding** Not reported	**Exclusion criteria** Not reported	Interviews were audiotaped for later analysis. - The interviewer, the principal investigator and another co-investigator, and a psychologist, who participated in the interviews, each reviewed the tapes and rated the parents using the Post-Death Adaptation Scale (PDAS).	*just drop it, let's just forget it. She is dead, life goes on. But she is not dead in my eyes." (Parent)* **Bereavement support groups** "Most families had positive experiences in bereavement support groups. They indicated that it was helpful to be around people in which they could openly talk about their deceased child without feeling uncomfortable." (Authors quote) However, some parents indicated that they did not feel that other parents validated their loss, because their child was so young when he/she died: *"Most of the people in that group have lost older children, and somehow have the attitude that our loss as not as great as theirs." (Parent)*	
Full citation deCinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson,	**Sample size** N=24: Parent groups of 24 deceased children were approached to participate in the study	**Setting** - The bereavement program provided	**Themes/categories** **Hospital Bereavement Support (e.g. staff attending funeral)**	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for

Study details	Participants	Methods	Findings/results	Comments
R., Aoun, S., Bereavement support for families following the death of a child from cancer: experience of bereaved parents, Journal of Psychosocial Oncology, 24, 65-83, 2006 **Ref Id** 334482 **Country/ies where the study was carried out** Australia **Study type** Qualitative study (in-depth description of the experience relating to hospital-based bereavement support programmes) **Aim(s)**	N=9: parents (six mothers and three fathers) were analysed **Characteristics** - Parents resided in the metropolitan area of Perth (Western Australian) - Demographic and clinical details of deceased children varied: 4 children died at home, and 2 children died in hospital. **Inclusion criteria** - Parents whose child had died at the study setting during January 1997-December 1998. - Aged over 18 years - Able to understand and speak English. Parents who had at least one other living child. **Exclusion criteria** Not reported	by the Oncology Total Care Unit (OTCU) at Princess Margaret Hospital (PMH) in Perth, Western Australia - This study is part of a 3-stages research to determine the bereavement support needs of families whose child has died from cancer at PMH (This paper describes Phase 2 of the overall research) **Data collection**	Many parents felt that contact from oncology unit staff both during palliation and bereavement was important: *“But then it would have been nice if they (hospital staff) had said ‘Come for a check-up’ or-just don’t drop her like that. I think that’s the biggest mistake you can do.” (parent)* *“I thought that I’d have the phone call and they’d (hospital staff) say “how are you coping?” and that sort of thing. So it was very different to what I expected.” (parent)* **Information about death and bereavement (covered by information review)** Parents were not always open to discussion about this painful issue and in many ways wanted to maintain hope: *“The kids themselves would talk about dying. The parents didn’t want to accept that. We didn’t want to talk about it.” parent - father)* Many parents acknowledged they would have benefited from more information prior to the child’s death: *“I think if they (hospital staff) could get the parents on their own and explain to them the process of dying, the process of the actual cancer taking over and the reactions. I know it’s hard for them . . . I don’t know how they do it but I think I would have liked to have understood the process of the whole thing.” (parent)* **Contact with other bereaved parents (covered by information review):**	answering the research question **Sample selection:** Sample selection procedure was clearly reported but was unclear (for example about the selection criteria used to define the study sample). The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; discussion on saturation has been reached for any of the themes reported was mentioned **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process **Findings/results:** Results were presented clearly (e.g., citation/data and the researchers' own input distinguished); the researchers' potential influences in the analytical process we not addressed **Overall quality:** Moderate

Study details	Participants	Methods	Findings/results	Comments
To explore the experiences and needs of nine parents who had received hospital-based bereavement support following the death of their child from cancer, in Western Australia **Study dates** 2001-2002 **Source of funding** Oncology Total Care Unit at Princess Margaret Hospital		• Individual unstructured interviews • four open-ended questions was used the theoretical underpinning of bereavement services • interviews took place in the parents' home **Data analysis** • Narrative analysis was used • Polkinghorne's method of analysis was selected • Data were analysed by two of the study	*"Other parents from the bereavement group would come out and have a coffee or have a chat and reassure me. I found that was very, very helpful to know that I could talk to somebody else who had lost their child and had experienced losing a child. . . . You do hold back your feelings and you need somebody else that has been there." (parent)* Some parents felt the oncology unit should link them with other bereaved parents who could offer support: *"I think there should be someone tied up with the ward that has experienced it. I think at the end of the day it will help you cope with the situation better. There should be someone there who understands that it's a terrible thing to lose a child". (parent - mother)* **Community bereavement support:** *"And I also strongly recommend that they be very careful about the counsellors that they go to because there is a lot of counsellors out there but there's very few, very few who can really assist. And I mean in a concrete way with skills and, and in a way that they can ask questions that go down deeper than just the bereavement because the bereavement is the top layer." (parent)* *"Our parish priest was marvellous and Sister Margaret. They came down and helped organise the funeral and they knew what they were doing and that was a great help." (parent)*	**Other information**

Study details	Participants	Methods	Findings/results	Comments
		researchers.	**Unmet Needs - Respite and practical support during palliative phase:** *"It would have given me a break, I could have done things. I could have been stronger for her, I could have fought the battles." (parent)* **Unmet Needs – information to be extended family and friends on loss and grief (covered by information review):** *"I think my husband would have liked to be able to talk about it more to other people. Women talk a lot to each other. At work, he wouldn't really share too much, just the bare outline. And I think that he might have liked to have gone to a support group" (parent - mother)*	
Full citation Maynard, L., Rennie, T., Shirtliffe, J., Vickers, D., Seeking and using families' views to shape children's hospice services, International Journal of Palliative Nursing, 11, 624-30, 2005 **Ref Id**	**Sample size** 29 parents from 22 families (of whom 6 were bereaved) **Characteristics** • Source:7 participant (5 families) Quideham (Norfolk); 10 participants (8 families) Ipswich (Suffolk); 12 participant (9 families) Milton (Cambridge); • Relationship o child: 8 fathers; 21 mothers	Setting This study is part of a quality assurance initiative about EACH, an independent charitable organization which provides community-based children's palliative care and family support services	Themes/categories **Unmet needs – Aspects families don't like:** "The inflexibility of the booking system was a key area of dissatisfaction." (Authors quote)"Parents wanted more ability to negotiate when they could access(respite)care. They also told us that it was often difficult to raise concerns because care was usually so good and they were concerned that care staff might be offended" (Authors quote)	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has

Study details	Participants	Methods	Findings/results	Comments
334862 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim(s)** To describe a quality assurance initiative undertaken as one component of a clinical governance strategy. Service users participated in focus groups to discuss how staff communicated with them about their child's care, their family support needs, and how staff liaised with other professionals and organizations. **Study dates**	- Bereavement status: 6 out of the 22 families were bereaved. **Inclusion criteria** Not reported **Exclusion criteria** Not reported	throughout East Anglia, UK. Data collection Focus group interviews. Data analysis Thematic analysis: Discussion between group members facilitated the clarification and description of the abstract themes and categories within them. Verbatim quotations have been used to illustrate themes and pseudonyms have been used to maintain family confidentiality	**Unmet needs – information needs:** "They (the parents) wanted it (information about services, about what is available, and about those things which can help them make sense of their situation) at a time that was right for them. The overwhelming consensus was that parents wanted information about children's hospice services as soon as possible after diagnosis." (Authors quote)	been reached for any of the themes reported; no details given about data saturation **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process: no details given about analysis saturation **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information**

Study details	Participants	Methods	Findings/results	Comments
2004 **Source of funding** Not reported				
Full citation Davies, B., Steele, R., Collins, J. B., Cook, K., Smith, S., The impact on families of respite care in a children's hospice program, Journal of Palliative Care, 20, 277-86, 2004 **Ref Id** 334470 **Country/ies where the study was carried out** Canada **Study type** Qualitative Study **(**Participatory Action Research)	**Sample size** N=18 families (50 family members): face-to-face interviews N=70 families: mail-out surveys **Characteristics** Not reported **Inclusion criteria** All families (n=144) who had used the Canuck Place services during its 30 first months of operation **Exclusion criteria** Not reported	**Setting** Canuck Place children's hospice located in Vancouver, British Columbia, Canada, is the first free-standing children's hospice in North America **Data collection** • face-to-face interviews • mail-out surveys (questionnaire) The interview data guided the development of the mail-out survey.	**Themes/categories** **Respite care – benefit to the child (e.g. relaxation and enjoyment; learning and socialising)** It [Canuck Place children's hospice] was more comfortable than a hospital providing “less depressing”, surrounding and “better emotional” atmosphere, it was more “like home”: “ *I mean they are [the staff] always getting them involved …Today, she is going to walk down to the corner and watch some film that is being produced in the corner. Little things like that…they went out to the UBC [nearby university] sports facility—they had these off-road wheelchairs that they get to try out. So she had a good time on those. And trick-or-treating on Halloween, they went all over the place”*. (mother) “*For her, being at Canuck Place is a good memory. Every time she come back from Canuck Place …she says “Mommy, I made something for you.” She brings a lot of things home. She made a kite. And every time after that day—we came home and hung it in her room—and she remembers. “Oh, I made that at Canuck*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported and about the roles of the researchers **Data analysis:** Researchers did not clearly review their own roles in the analytical process while it was unclear whether saturation in terms of analysis has been achieved **Findings/results:** Results were presented clearly.

Study details	Participants	Methods	Findings/results	Comments
Aim(s) To evaluate the respite component of a broader project that examined the effect of the Canuck Place children's hospice program on the families it served during its first 30 months of operation. **Study dates** November 1995-July 2008: data collection **Source of funding** British Columbia Health Research Foundation – Community Grants Program for the full research study "An Evaluation of the Impact Of the		**Data analysis** Participatory Action Research: • 1 stage: development of an interview guide • 2 stage: face-to-face family interviews • 3 stage: development of a survey based on the findings from initial interviews. Patient respondents as well as ill children all completed questionnaires designed especially for them.	*Place" …I think for her is a good memory*". (mother) **Respite care – benefits to siblings** Because siblings could also attend school at Canuck Place and could stay overnight, all children in the family had time togheter away from parents, when they could about the illness and the ill child's prognosis. Parents believed such discussions benefited siblings/child relationship. (authors quote) **Respite care – Benefits to parents (e.g. getting a break; sense of freedom ; time for themselves and others)** *"When she is here, we can come and get her and take out to do stuff or we can just go and do what we want. I think it was more effective in that just had time to socialize with friends and be on my own so that I was a little sane. I found that when I was really stressed, I was obviously not very pleasant to be around. I mean, it is really to keep your cool when you Are going through all these different stresses and then you have teen agers that are on your case about nothing. Just everything happens at once. So you tend to snap a lot faster. So it really was important get away from it. And keep some sense of balance.""* (mother)	The researchers' roles and potential influences in the analytical process critically reviewed **Overall quality:** Moderate **Other information** Data analysis methods stated

Study details	Participants	Methods	Findings/results	Comments
Canuck Children's Hospice Program"				
Full citation Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H., Family perspectives on the quality of pediatric palliative care, Archives of Pediatrics & Adolescent Medicine, 156, 14-9, 2002 Ref Id 334430 Country/ies where the study was carried out US Study type	Sample size 68 people interviewed = family members (44 deceased children) Characteristics 68 people interviewed Sex= 23 M, 45 F Relationship to child= Mother: 36, Father: 21, Brother: 1, Sister: 1, Wife: 1, Foster mother 3, Uncle:1, Aunt: 2, Other 2 44 children Diagnosis= Oncologic: 28,Cardiac: 4, Premature 4, Other: 8 Inclusion criteria English- and Spanish-speaking family members of deceased children who	Setting Lucile Salter Packard Children's Hospital (LSPCH) - US Data collection Semi-structured interviews. Data analysis Thematic analysis (not explicitly stated) 5 interviewers conducted most of the interviews (4 clinical social workers and 1 clinical psychologist) reviewed the	Themes/categories **Bereavement Follow-up** Continued contact with hospital staff after their child's death was meaningful to the families who spent time at LSPCH. Follow-up by telephone, mail, and/or in person was desirable and appreciated: "*The phone calls are important. When her doctor called, I thought, "Wow, you're still thinking of us!" The nurse practitioner still calls periodically. When your child is sick like that, it becomes your life and the doctors and nurses become your extended family. If they can continue some kind of periodic contact, it's important. (Unclear quotation owner)*"	Limitations **Aim(s)**: Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection**: Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process.

Study details	Participants	Methods	Findings/results	Comments
Qualitative study (descriptive phenomenology) Aim(s) To analyse information from families about their experiences and their suggestions for improving the quality of end-of-life care, for developing a Paediatric Palliative Care Program Study dates September 1998-March 1999. Source of funding This study was supported in part	received treatment at Lucile Salter Packard Children's Hospital (LSPCH) Exclusion criteria geographic distance the cause of death was fetal demise	responses of the participants and discussed what appeared to be the most salient themes. The group first identified as many themes as possible and computed frequencies to use as a guide to identify theme		Findings/results: Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed **Overall quality**: Moderate Other information Data analysis methods not explicitly stated

Study details	Participants	Methods	Findings/results	Comments
by the estate of Yvonne Conover, and by the Charter Auxiliary benefiting Lucile Salter Packard Children's Hospital				
Full citation Davies, H., Living with dying: families coping with a child who has a neurodegenerative genetic disorder, AXON, 18, 38-44, 1996 Ref Id 353463 Country/ies where the study was carried out Canada	Sample size 15 families (convenience sample) Characteristics English- and French-speaking family members of deceased children who have diagnosed with neurodegenerative genetic disorder Inclusion criteria Not reported Exclusion criteria Not reported	Setting The Montreal Children’s Hospital which is a hospital that provides high quality healthcare to infants, children and teenagers. Data collection Structured questionnaire – 3 questions: 1) What are the unique features of the losses associated with a	Themes/categories **Community support groups** It was felt very important be actively sought out community support groups involving who had children with similar diagnoses: “It was important for us with parents who had children like us. We are able to share ideas, resources and frustrations” (unclear quote: not reported) “My family doesn’t understand what is like to live our son. We love him but it is not easy. It helps to talk with other parents” (unclear quote: not reported) **Respite care** Many Families felt that would not have been able to cope with their at home had it not been for respite care, outside their homes:	Limitations **Aim(s)**: Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents was reported **Data collection**: Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative study Aim(s) To explore factors and how families cope over time with a child who has a neurodegenerative genetic disorder. Study dates Not reported Source of funding Not reported		neurodegenerative genetic disorder? 2) What are the coping strategies that families employ to manage the losses associated with a child who has a neurodegenerative genetic disorder? 3) What support resources are required to better assist families to cope with a child who has a neurodegenerative genetic disorder? Data analysis Thematic analysis (not explicitly stated) Categories and themes emerged from the data	"*We would not have been able to care for her at home if we did not have respite care ate least once a month. Sometime even that was not enough. Life must go on despite her illness. We have regular problems like every other family. Without the short term respite we would have to look for an institution to care for her. We love her a great deal, but there were days when we were just surviving" (unclear quote: not reported)*	**Data analysis**: The analytical process was described in detail; researchers did critically review their own roles in the process while it was unclear whether saturation in terms of analysis has been achieved. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality**: Moderate Other information Data analysis methods not explicitly stated

Study details	Participants	Methods	Findings/results	Comments
		and the authors (who did not know the families) assessed the reliability of the coding system through categorizing instances into categories		

G.12 Review question: Spiritual and religious support

What factors of spiritual or religious support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

Study details	Participants	Methods	Findings	Comments
Full citation Boss,R.D., Hutton,N., Sulpar,L.J., West,A.M., Donohue,P.K., Values parents apply to decision-making regarding delivery room	**Sample size** 36 mothers **Inclusion criteria** Parents of infants who died between 1999 and 2005 as a result of extreme prematurity, defined as gestational age of 22 to 25 weeks, or a lethal congenital anomaly, such as	**Details** SAMPLE SELECTION Parents were contacted by mail at least 9 months after the infant's death. Parents who did not reject to participate were contacted by phone to participate in an interview. SETTING	**Themes/categories** **Hope** Regardless of medical information, parents maintained hope that everything would be fine, and this guided most parents' decision making. They were told by friends and family members to pray for miracles, and to trust that a miracle will happen. Some parents felt that they did not have to make a decision	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between

Study details	Participants	Methods	Findings	Comments
resuscitation for high-risk newborns, Pediatrics, 122, 583-589, 2008 **Ref Id** 116159 **Study type** Qualitative multicentre study **Aims** To characterize parental decision-making regarding delivery room resuscitation for infants born extremely prematurely or with potentially lethal congenital anomalies. **Country/ies where the study was carried out** US **Study dates** Data collection: 1999–2005 **Source of funding** The Bauernschmidt	severe congenital diaphragmatic hernia or hypoplastic left heart syndrome. **Exclusion criteria** Not reported **Characteristics** Diagnosis: Extremely premature = 13 Major anomaly =13 Maternal age: 1) <25 y = 7 2) 25–35 y = 11 3) >35 y = 8 Maternal race: 1) White = 16 2) Black/other = 10	This study was conducted at 2 urban, regional, referral centres and 1 suburban community hospital. DATA COLLECTION Semi-structured interview based on literature review and experts discussion 25 by telephone, and 1 hearing-impaired mother completed the interview via e-mail. Interviews were audiotaped DATA ANALYSIS Thematic analysis: Interviews were coded for content independently by the 3 reviewers Content codes were reviewed with the lead analyst, Discrepancies were resolved through repeated discussion Key themes were identified on the basis of the frequency with which they were raised in individual interviews.	regarding resuscitation in the delivery room, they wanted physicians to do everything they could, and the rest was in God's hands. *"I could not be the one to decide if God chooses to take the baby away at this time or just let it run its course" (mother of an infant diagnosed prenatally as having trisomy 18)* *"When they told me they thought she was not going to survive, I put it in God's hands. God had made her into a baby, and if I had made it that far [with the pregnancy], it was up to him"* *"You know everyone told me don't worry about what [the doctors] say, she will make it, she's a miracle. And so that's pretty much I heard" "There was a lady who said 'you know this child has all these problems, why are you going to bring him into the world? Are you looking for God to step in?' I said 'Well, as a matter of fact I am' If you think God is going to come in and perform a miracle, you have a right to do that."*	the researcher and the respondents not clearly reported **Data collection:** Data collection process and discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information** The study includes bereaved parents of neonates

Study details	Participants	Methods	Findings	Comments
Committee of the Eudowood Board, Johns Hopkins University School of Medicine.				
Full citation Forrester, L., Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child, International Journal of Palliative Nursing, 14, 578-85, 2008 **Ref Id** 353516 **Study type** Qualitative study (retrospective cross-sectional survey using a postal questionnaire) **Aims** To explore how bereaved families experience the child remaining in a cold bedroom following the child's death	**Sample size** 16 bereaved families whose experience the child remaining in a cold bedroom following the child's death (of 31 families contacted) **Inclusion criteria** Families of all the children in the study who had been cared for in the cold bedrooms in the period January 2002–March 2005 **Exclusion criteria** Families no longer in contact with the hospice. **Characteristics** Place of death: Home= 4 Hospital= 1 Study hospice= 10 Other hospice= 1 Diagnosis: Malignant= 7 Non-malignant= 9 Ethnicity: White= 15 Mixed= 1 Type mother = 13 grandmother 1	**Details** SAMPLE SELECTION Families were contacted by post and sent a study pack inviting them to participate. The contact was made in a very sensitive manner, so that parents who declined to participate did not have to read the full details of the study and/ or the questionnaire. Packages were sent being mindful of sensitive dates (birthdays,..) SETTING Children' hospice in the UK (no other details given) DATA COLLECTION Retrospective cross-sectional survey using a postal questionnaire The questionnaire was designed to collect data regarding: the decision to use a cold-room; the cold room itself, the positive and negative experiences, and what parents found helpful or unhelpful	**Themes/categories** **Religious/spiritual needs** Ten respondents felt that their religious needs were acknowledged/considered. One felt that these were not discussed. Three reported that they had no belief and two stated support was not required: *'I can pray anywhere and at any time' (R 10).* 'Candles were lit all through our stay' (R 16).	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported; no details given about data saturation **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out UK **Study dates** January 2002–March 2005: data collection **Source of funding** Not reported	father = 2 - Religion: Unknown = 3 Church of England = 9 Roman Catholics = 1 Christian = 3	DATA ANALYSIS Data was analysed by hand. The responses to each question from each respondent were considered to compile a framework of emerging themes and coded Each theme was then deconstructed into components, according to the researcher's interpretation.		process: no details given about analysis saturation **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Data analysis' methods not stated. The Authors were unable to establish contact with many eligible families. Retrospective survey
Full citation Forster, M., Windsor, Carol, Speaking to the deceased child: Australian health professional perspectives in paediatric end-of-life care, International Journal of Palliative Nursing, 20, 502-509, 2014	**Sample size** n=22 parents (n=12) health professionals (n=10) **Inclusion criteria** Parents: whose children had died within the confines of the paediatric tertiary hospital or had returned home and received outpatient care by paediatric tertiary hospital staff prior to the children dying.	**Details** SAMPLE SELECTION A search of deceased children was conducted at the hospital. Parents who had registered consent to be contacted in the future were sent an invite letter 12 weeks after the child's death. Those who showed interest in participating were contacted by phone. SETTING This paper draws on a larger Australian study of parent and	**Themes/categories** **Recognition of spiritual presence of the deceased child** Nurse participants reflected on the process of talking to a deceased child and how this was informed by a combination of the beliefs of parents, personal beliefs and respect for a child: "*I think it all depends on what you believe, I mean, some people think that, you know, once you're gone, you're gone. But I think mum was a lot happier with the idea that even though [child's] body was there, you know, his spirit was still there and it wasn't so*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection clearly reported. The relationship between the researcher and the

Study details	Participants	Methods	Findings	Comments
Ref Id 423625 **Study type** Qualitative study (descriptive phenomenology) **Aims** The focus of the paper is the practice of health professionals in speaking to a child after death to convey respect for the personhood of the deceased child, to recognise the presence of the deceased child, to model to parents who may be hesitant to be involved in post-mortem care and to de-medicalise the child's death. **Country/ies where the study was carried out** Australia **Study dates** data collection period: not stated	Health professionals: who had been involved in the care of a child and family around the time of the child's death. **Exclusion criteria** Not reported **Characteristics** n=12 bereaved parents whose children had died and received outpatient care by paediatric tertiary hospital staff prior to the children dying. n=10 nurses, doctors and social workers who had been involved in the care of a child and family around the time of the child's death.	health-professional constructions of meanings around postmortem care and communication where there has been a loss of a child. DATA COLLECTION Semi-structured individual interviews DATA ANALYSIS The transcribed interview data were subject to a process of data analysis according to social constructionism The analysis was inductive at the outset and became focused around significant conceptual ideas early on in the process. The analysis aimed to develop an analytical understanding of the ways in which health professionals negotiated and gave meaning to the death of a child as part of end-of-life care.	*much the body that I was talking to. It was the spirit or how she felt about it*." (RN 4) "*But yes, I think just personally treat the person like they're still there basically, or how I would want to be treated or how the parents want their child to be treated*." (RN 4) "*I think just a bit of respect for the family and for him. Like, it was only half an hour ago that he was still with us and now he's gone and I don't know. I guess we don't know where they've gone*."(RN 6)	respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers critically reviewed their own roles in the process but was unclear whether saturation in terms of analysis was achieved. **Findings/results:** Results were presented clearly. The researchers' potential influences in the analytical process were not clearly reviewed **Overall quality:** Moderate **Other information** No details provided in relation to data collection methods

Study details	Participants	Methods	Findings	Comments
Source of funding QUT Vice Chancellor's Women in Research Grant, Queensland Nursing Council Novice Research Grant and the Centaur Memorial Fund Fellowship.				
Full citation Hexem, K. R., Mollen, C. J., Carroll, K., Lanctot, D. A., Feudtner, C., How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times, Journal of Palliative Medicine, 14, 39-44, 2011 **Ref Id** 357821 **Study type** Qualitative study (descriptive phenomenology: part of prospective	**Sample size** 73 parents - representing 50 families: consented to participate 61 parents - representing 41 families (children receiving paediatric palliative care): were interviewed (analysed) **Inclusion criteria** Parents whose children were not able to make medical decisions due to age or impaired cognitive capacity, Parents able to speak English **Exclusion criteria** Parents who were emotionally unstable Parents whose children had died, were discharged, or were too critically ill (as determined by the referring physician) **Characteristics** Children: n=41	**Details** SAMPLE SELECTION Not reported SETTING Participants in the study were parents of children who had enrolled in the Decision Making in Pediatric Palliative Care Study, a prospective cohort study conducted at the Children's Hospital of Philadelphia (CHOP) and funded by the National Institute of Nursing Research. DATA COLLECTION Semi-structured individual interviews (2 open-ended questions + unspecified number of follow-up questions) DATA ANALYSIS Thematic analysis according to the grounded theory:	**Themes/categories** **Attitude towards religion** <u>Having a formal religion, being positive about it</u> Some parents identified themselves as members of a particular religious faith, and described their affiliations very positively, ' *'We're Presbyterian and we have a church that we're very involved in, and that's been a wonderful support.''* (parent) <u>Spirituality or life philosophies but without formal religion</u> Other parents described themselves as not regular church attendees still often felt a connection to God or sense of spirituality: *"If I want to talk to God, I just will.''* (parent) *"I haven't been drifting toward any type of spirituality; I don't know what kind of spirituality it would be, but it would probably be my own.''* (parent) <u>Unwilling to discuss religion, spirituality, or life philosophies</u>	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sample selection clearly reported. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings	Comments
cohort study design) **Aims** To clarify and illustrate the role of religion, spirituality, or life philosophy (RSLP) in the lives of parents of children with life-threatening conditions. **Country/ies where the study was carried out** US **Study dates** 2010: publication accepting date not reported: data collection date **Source of funding** National Institute of Nursing Research (NR010026)	Age: 1 year or less = 10 (24.4%); 1–4 y = 13 (31.7%); 5–9 y = 10 (24.4%); 10–17 y = 7 (17.1%); 18–24 y = 1 (2.4%) Gender: Female = 21 (51.2%); Male = 20 (48.8%) Race: White = 27 (69%); African American = 8 (20.5%); Asian = 1 (2.6%); More than 1 = Race 3 (7.7%) • Parents: n = 64 Age: 21–34 years = 22 (35.5%); 35–38 years = 17 (27.4%); 39–66 years = 23 (37.1%); Type: Mom = 37 (57.8%); Dad = 24 (37.5%); Other = 3 (4.7%) Race: White = 47 (79.7%); African American = 7 (11.9%); Asian = 1 (1.7%); More than 1 Race = 4 (6.8%)	Interviews were selected in a randomized order, then sequentially read and coded individually by the study authors. Study authors met regularly to examine emerging themes Any discrepancies amongst coders were resolved through discussion that reached consensus.	While most parents reported some level of religious, spiritual, or other beliefs or observances, some answered the inquiry with a quick *''No,'' ''No, not really,'' or ''Umm, no''* **Common aphorisms** Overall outlook Parents offered statements pertaining to their overall outlook on the situation *''That's just life'' ''What's going to happen is going to happen''* While some phrases referenced the sacred *''It's in God's hands''* Goodness Parents frequently mentioned the quality of goodness. ''God is always good.'' ''I just believe in God and I try and find the good in things.'' Additionally, some parents described their children's presence in the world as a gift. ''Every day is a gift, because she was only given three days [to live]. So every other day with her is a gift.'' Human capacity Parents spoke about their sense of human capacity, or how a given parent expected to function in the situation. *''We're not given more than we can handle.'' ''One day at a time, one step at a time, one mile at a time.''* Everything happens for a reason A statement that parents used most often was that *''Everything happens for a reason.''* Parents seemed to identify their religion with that statement.	**Data analysis:** The analytical process was described in detail; researchers critically reviewed their own roles in the process but was unclear whether saturation in terms of analysis was achieved. **Findings/results:** Results were presented clearly. The researchers' potential influences in the analytical process were not clearly reviewed **Overall quality:** Moderate **Other information** None

Study details	Participants	Methods	Findings	Comments
			"I do believe in that higher faith, so I believe that there was a reason why [our child] was put here, given to us." Just because parents believed there were reasons, however, did not mean they always found those reasons easy to accept. *"I think there's a reason for everything. I'm not always happy about it."* **R&S aspects related to the child** <u>Child's value, dignifying child's existence</u> Many parents found their RSLP helpful in dignifying their child's existence and specialness. *"where [our child] fits in God's plan and why children like her may be born and, actually, their very special significance."* *"It would be wrong for me to just say that, well, her life isn't really important. You know, she is not as important as some of the other kids because she's disabled and she would be much happier in a different place. That's not true because, in my Bible, anyway, every person is important to God, equally important."* Other parents saw their children as having a role on earth to help bring people together spiritually. *"[Our child is] like Mother Teresa; she would walk into a room, and everybody would be around her, you know? And so I say that she's brought down here to bring all these people together and to show [them] something."* <u>Belief in afterlife</u> *Parents used many different words to describe life for their children after their*	

Study details	Participants	Methods	Findings	Comments
			deaths, including: "afterlife," "a life after this life," "golden gate," "a better place," "a happy place," and "heaven." Belief in an afterlife was "reassuring," providing "peace" and "acceptance," and helped parents to be "not afraid" of their children's deaths and "trust in God to take care of [our child]." "The peace is there, knowing that, in the end, ultimately, while we won't have immediate perfection, we'll have complete perfection in heaven." **Practices** Prayer Most parents reported prayer praying for their children, both alone and in prayer groups. One important aspect of prayer was that it could happen anywhere. *"The chapel is here, but I feel like you don't have to be in a chapel to pray." (parent)* Reading the bible Many parents also reported reading the Bible in response to stressful life events. *"All the trials they went through in life and how their faith in God brought them through – that helps me a lot." (parent)* **Perspectives** Medical circumstances Parents sometimes contrasted their RSLP beliefs with their beliefs in the medical profession. Sometimes a pastor was seen as being able to mediate between the parents and the doctors. *"[Our pastor] can understand a lot of the things that the doctors need him to process [for] us on our belief level." (parent)*	

Study details	Participants	Methods	Findings	Comments
			Help in decision making For some parents the decisions were less difficult when they felt as if they knew or accepted God's will: *"Knowing that there is a God, that gives me peace, and it helps me to deal with the difficult decisions." (parent).* Other parents sought the formal guidelines of their religion: *"I want to know what the church teaches on extraordinary measures as to ordinary measures, to give you comfort about DNRs and how far do we go, and just something to really be at peace about." (parent)* Locus of control, patience Parents talked about what aspects of their child's medical situations they could and could not control: *"wanting to plan things, to control things" with her religion's teachings, which she said helped give her patience and gave her the ability to "think things through." (parent)* **Positive outcomes** Support from the community Participating in a particular religious community resulted in parents receiving support from a large number of fellow congregants, the pastor, and God. This support ranged from phone calls, e-cards, and cooking meals to people praying for the child and family. *"People we don't even know [are] praying for this little guy."*	

Study details	Participants	Methods	Findings	Comments
			Parents benefited from prayer groups, and saw the church as providing *''a network''* and a source of *''unconditional support and love.''* Pastors were occasionally referred to as *''good friends.''* Parents also felt supported by God. *''Casting all your care to Him gives you the feeling that you're not alone.''* <u>Peace and comfort</u> Parents also reported that feelings of trust in God resulted in feelings of peace and comfort. *''It comforts us as parents spiritually to think that hopefully, when she passes, she'll have an opportunity [in Heaven] to do [normal] things and it's just a happy place.''* <u>Moral guidance</u> Some parents associated their religion with trying to be good. *''I am supposed to be taking care of my child, and therefore going home and being lazy . . . that would be wrong.''* Other parents found religion helpful in coping with their anger. One mother remarked on the need to keep her ''*Christian cool''* when communicating with a doctor, and another said, ''*Every time I'm mad or upset, I start writing to Him.''* **Difficulties** <u>Questioning</u> *Many parents reported questioning their faith, experiencing feelings of anger and blame toward God, and rejecting of specific religious beliefs and communities.*	

Study details	Participants	Methods	Findings	Comments
			"No matter what, it's hard. There is pain. You don't want to let go." *"I believe I will have a spiritual connection with my daughter when she passes, but just right now, I have a lot of questions that are unanswered, so I fluctuate back and forth."* Feeling anger and blame toward God Even while expressing anger at God, parents said that their anger was not incompatible with their faith. *"I do believe in God, but I'm kind of angry at him right now." '* *'I have the question in my mind, why, why us? What did we do wrong? What did she do wrong?"* Rejecting Some parents moved away from their faith as a result of a child being seriously ill. *"I used to be a lot more religious, and I've had a really hard time with it."* *"I'm not going to sit and pray and hope that [my child] gets better. We're going to bring her to the hospital."*	
Full citation Lundqvist, A., Nilstun, T., Dykes, A., Neonatal end-of-life care in Sweden: the views of Muslim women, Journal of Perinatal & Neonatal Nursing, 17, 77-87, 2003	**Sample size** 11 women **Inclusion criteria** Women who had migrated to Sweden at age 18 or older, currently living in Sweden, and who had at least 1 infant born in Sweden Women from each 5 countries: Iran, Iraq, Somali, and Turkey.	**Details** SAMPLE SELECTION SETTING Women had migrated to Sweden DATA COLLECTION A 42 open-ended interview manual was developed based on literature research and previous studies	**Themes/categories** **Care during the dying** Predetermined lifetime Some (Muslim) women hesitate to participate in discussion related withdrawal of treatment with their physicians. Some women were uncertain about it, and other found it incompatible with their religion: *"I believe in God, that it is God who has given me this ill baby and it is His will that I shall take care of the baby. God has given me the medicine too, but I will not take part in*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the

Study details	Participants	Methods	Findings	Comments
Ref Id 359356 **Study type** Qualitative study (descriptive phenomenology) **Aims** To explore how immigrant Muslim women view current Swedish neonatal end-of-life care. **Country/ies where the study was carried out** Sweden **Study dates** Data collection: not reported 2003: Accepted for publication: **Source of funding** Council for Medical Care Research in Southern Sweden	Women who didn't have to have had experience with foetal impairment or neonatal death **Exclusion criteria** Not reported **Characteristics** Childbirth experience range: 1 to 9 children (median 3). Migration date to Sweden: between 1988 and 1997 Age range: 32 and 54 years (median 36 years) Other: Ten women were married and 1 was widowed. The mean length of residence in Sweden was 10 years.	The final questionnaire focused on care before birth, care directly after birth, care when the infant was dying and care after death All women were given the same questionnaire, that included hypothetical situations DATA ANALYSIS Content analysis: In stage 1 the transcripts were read through and analysed seeking general themes immersed in the data. In stage 2 the text was read again to freely generate and describe all aspects of the content. In stage 3, similar categories were collapsed into broader categories and worked through in producing a final list. To increase integrity of the data, a second person read 4 interviews, using this list, in order to corroborate the categories and reach consensus.	*any discussion" (W2)* *"No, I don't want to participate in a conversation about it [withdrawing], I think it is God who makes the decision, I am being very distressed, it is too difficult to talk about it" (W8)* **Care after death** Memories Some parents (Muslim women) said that mementoes were forbidden in their religion *"Photos is okay before the baby is death. When the baby is dead, no. I don't want it. Other mementos than pictures of the living baby is too hard to look at. We are not doing that. All that reminds us of the baby is given to someone else in order to forget" (W3)* *"Mementos do not support [me]. You will have the baby in your heart"* Special tradition Participants (Muslim women) know that their religion prescribes some ceremonies in the way the body should be wrapped and washed. *"It is the religion, it is a special person that has to wash the baby. It is not I. If it is a women, a woman does it. If it is a man, a man does it. But with my baby it doesn't matter, but the mother and the family don't have to do it. It's because of that they know the baby and it is too hard for them. Not the staff, it is a special washing" (W6)* Life after death Some parents are asked regarding the autopsy (cause of death not clear or need for further investigation), and many found this	respondents not clearly reported **Data collection:** Data collection process and discussion on whether saturation has been reached for any of the themes were not clearly reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information** Small sample size Includes Muslim women only Indirect population, as not all women had experienced foetal impairment or neonatal death

Study details	Participants	Methods	Findings	Comments
			frightening. They said a dead infant is still living in a sense, but in another shape, and an autopsy would impede this, and the death infant feels the pain. *“I was very astonished when I came here [to Sweden] and heard about this [autopsy]. We think that the day the person is dead, he is not living, but he’s still living [in a sense]. The dead person is crying and saying why shall I die” (W5)* *“It’s Allah who decides if a baby shall live. Allah does not mean that all babies shall go on with their life. He can stop it. I don’t want to know anything about genetics, a subsequent baby will come” (W6)* <u>Belief in the future</u> It is practice (in Sweden) to offer parents the possibility to see and be with the dead infant for some days after death, to help in dealing with grief. Most women (Muslim women) said they did not want to be with the infant after death. Also their religion prescribes that the decesased should be buried within 24 hours. *"I have heard a woman whose baby died and was buried the same day. Women don't use to be present at the burial, and the mother was not there. After two days the mother doubted that the baby really was dead. She was desperate and asked them to take the dead baby to her. After many discussions the baby was taken from the grave and the mother saw her baby. But, the mother had to suffer so much, they said that she did not trust in God and that she was not one of us" (W2)*	

Study details	Participants	Methods	Findings	Comments
			"When one is dead, one is dead. The mother will be vulnerable. I would indeed not like this [being with the baby after death]" (W5)	
Full citation Meyer, E. C., Ritholz, M. D., Burns, J. P., Truog, R. D., Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations, Pediatrics, 117, 649-57, 2006 **Ref Id** 334888 **Study type** Qualitative study (descriptive phenomenology) **Aims** To identify and describe the priorities and recommendations for end-of-life care and communication from the parents' perspective.	**Sample size** 96: eligible sample 56: analysed sample (parents) **Inclusion criteria** Parents whose children had died after the foregoing of life-sustaining treatment **Exclusion criteria** Not reported **Characteristics** Relationship to child: including 36 (64%) mothers and 20 (36%) fathers. Mean age = 42.3 years (±8.4) Marital status = 75% married. Religious identification 50% Catholic, 34% Protestant, 5 % Jewish, 2% Muslim, 9% indicated no religious affiliation	**Details** SAMPLE SELECTION Not reported SETTING The study was part of a larger 3-site study, including Children's Hospital Boston, Massachusetts General Hospital, and Tufts New England Hospital, which used retrospective parent self-report questionnaires to examine parental perspectives about end-of-life care. This study was carried out along with Robinson 2006 DATA COLLECTION Questionnaire with open-ended questions. The Parental Perspectives Questionnaire (4 open-ended questions) DATA ANALYSIS Content analysis: By marking and categorizing key words and phrases to identify topics and issues of relevance to the parents. Agreement about thematic content and labeling occurred when the primary	**Themes/categories** Parents found their faith to be important in: Make meaning of the situation Providing guidance Help in decission making Coping In particular, parents found comfort in the following: Praying Seeking councel from religious personnel Receiving social and emotional support from religious communities Parents who reported the faith to be important to them, emphasized its positive aspects. *"My faith and trust in God, who was in charge of Jessie. Knowing she would not suffer more when she went to be home to be with the Lord"* Other parents acknowledged their deep spiritual distress: *"Just when I needed my faith, I hated it, for deceiving both my child and myself!"*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process and discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out US **Study dates** Not reported: data collection 2005: accepted for publication **Source of funding** Nathan Cummings Foundation (New York, NY).		coders reached consensus through the process of rereading and discussion. Parental priorities were established if they appeared in ≥20% of the parental responses. Independent reading and coding of the parental responses by co-authors as validation.		the analytical process critically reviewed; **Overall quality:** Moderate **Other information** Same population as Robinson 2006, different themes reported Self-administered questionnaires Mixed religious backgrounds, although most of them were Catholic or Protestant
Full citation Robinson, M. R., Thiel, M. M., Backus, M. M., Meyer, E. C., Matters of spirituality at the end of life in the pediatric intensive care unit, Pediatrics, 118, e719-29, 2006 **Ref Id** 335030 **Study type** Qualitative study (descriptive phenomenology)	**Sample size** 56 parents whose children had died **Inclusion criteria** Parents whose children had died in the ICU after the foregoing of life-sustaining treatment **Exclusion criteria** Not reported **Characteristics** Relationship to child: including 36 (64%) mothers and 20 (36%) fathers. Mean age = 42.3 years (±8.4) Marital status = 75% married. Religious identification 50% Catholic,	**Details** SETTING The present study was part of a larger 3-site study that administered parent self-report questionnaires to examine parental perspectives of end-of-life care in the PICU, including Children's Hospital Boston, Massachusetts General Hospital, and Tufts New England Hospital. This study was carried out along with Meyer 2006 DATA COLLECTION Questionnaire with open-ended questions.	**Themes/categories** **Explicitly Spiritual/Religious Themes** Four themes emerged: Prayer Prayer was found to be a helpful coping strategy, and parents would advice other parents to pray: *“We. . .prayed a tremendous amount.”* *“Pray for strength.”* *“Be strong and pray.”* *“Pray and don’t be afraid to ask the staff questions.”* *“Pray!”* Faith Parents identified their faith in God as most helpful to them at the end of their child’s life and they would suggest it to other parents who were facing similar situations:	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process and discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings	Comments
Aims To identify the nature and the role of spirituality from the parents' perspective at the end of life in the PICU and to discern clinical implications. **Country/ies where the study was carried out** US **Study dates** Not reported: data collection 2005: accepted for publication **Source of funding** Nathan Cummings Foundation (New York, NY).	34% Protestant, 5 % Jewish, 2% Muslim, 9% indicated no religious affiliation	The Parental Perspectives Questionnaire (5 open-ended questions) DATA ANALYSIS Content analysis: By marking and categorizing key words and phrases to identify topics and issues of relevance to the parents. Agreement about thematic content and labelling occurred when the primary coders reached consensus through the process of rereading and discussion. Interrater agreement was acceptable at 83% between the primary coders and the secondary coder Independent reading and coding of the parental responses by co-authors as validation.	*"My faith and knowing that my child had the same faith."* *"My faith and trust in God who was in charge of Jessie. Knowing she would not suffer no more when she went home to be with the Lord."* *"The people God provided for us along the journey, friends, family, doctors, nurses, clergy."* *"Put your faith in God."* *"Trust in God."* However one mother found her faith not helpful: *"Just when I needed my faith, I hated it, for deceiving both my child and myself!"* Access to and Care From Clergy Parents identified the importance of ready access to both their own familiar community clergy person and the hospital chaplain: *"The services of my rabbi [were most helpful]."* *"Allowing our minister. . .to have access to us."* *". . .a discussion with our pastor confirming we had the scriptural authority to make these decisions [withdrawal of life-sustaining therapies] was very helpful."* One parent specifically noted the pivotal role of health care team members in identifying when spiritual care might be beneficial: *"The nurse was extremely helpful. . .making suggestions for a chaplain."* Belief in the Transcendent Quality of the Parent-Child Relationship That Endures Beyond Death	**Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Moderate **Other information** Same population as Meyer 2006, different themes reported Mixed religious backgrounds, although most of them were Catholic or Protestant

Study details	Participants	Methods	Findings	Comments
			Some parents offered heartfelt, emotionally charged advice to other parents, emphasizing the undeniable love and transcendent nature of the parent-child relationship that never dies but rather continues beyond death: *“Keep talking to your child—let your child know that you are OK. That it is OK for them to go on. I held my daughter and never stopped talking to her, reassuring her. It helped me to tell her that she would always be with me, so strong in my heart.”* *“To know that [you] will never forget your child.”* *“Just remember that they lived a good life and you did everything possible for your children and also believe they are in no pain anymore and that their [sic] up in heaven happy and always watching over you like you watched over them and never forget how special they were.”* **Implicitly Spiritual Themes** Wisdom borne of their experience Wisdom that parents shared with others included the following: *“Listen, learn, accept, and let time do its job.”* *“Prepare yourself in advance if, as was the case in our situation, you know someday it is going to happen. . . . Finally, don’t second guess the decision; think about it but to doubt yourself later on would eat you up.”* *“There will always be a void, but the pain eases.”* *“Don’t blame yourself for things that were clearly out of your control. Believe [you] were terrific parents.”*	

Study details	Participants	Methods	Findings	Comments
			“. . .[W]e must accept what will be. There is no answer to why this is happening. It is unfair and unjust and will never go away. We cannot change the situation no matter how hard we love or try.” <u>Guidance according to one’s own values and virtues</u> Several parents advised others to honor and be guided by their own values as a way to approach difficult end-of-life decision-making: *“Based on your own values and decisions, make the best choice you can.”* *“Do what you feel is emotionally right for you, your family, and your child.”* *“Know when to say enough is enough.”* *“Ask yourself, would I want my child to have a poor quality of life if he/she survives?”* Some parents emphasized the value of drawing on traditional spiritual virtues, such as hope, trust, and love, to survive emotionally and to discover meaning in the child’s death: *“Hope is essential, don’t give it up. Even now, I realize that was so important.”* *“Never give up hope.”* *“Trust that the best people are doing the best they possibly can for your child.”* *“Put your faith in God and your trust in the skilled doctors and nurses at the hospital who are caring for your child.”* *“There are only 3 things that are everlasting—faith, hope, and love. Love being the most important.”* *“Tell your child you love them, no matter what.”*	

Study details	Participants	Methods	Findings	Comments
			"I've learned a lot about the depth that some people are able to love or at least show love." *Finally, some parents refrained from offering specific advice to other parents, spiritual or otherwise, some noting that each person's situation was "too personal and subjective."*	
Full citation Talbot, K., Transcending a devastating loss: the life attitude of mothers who have experienced the death of their only child... co-published simultaneously in Bereavement: Client Adaptation and Hospice Services (ed: Donna Lind Infeld, and Nadine Reimer Penner), Hospice Journal, 11, 67-83, 1996 **Ref Id** 423989 **Study type** Mix-Methods research using both qualitative and quantitative data	**Sample size** 80 mothers: quantitative data 10 mothers: qualitative data **Inclusion criteria** Not reported: quantitative data Five with the highest and five with the lowest LABI (Life Attitude Profile-Revised) scores: qualitative data **Exclusion criteria** Not reported **Characteristics** Geographical location: 32 US states Race: white= 94% Education level: college graduates= 51% Marital status: married=66% Religious affiliation: mostly protestant •	**Details** SAMPLE SELECTION Not reported SETTING Not reported DATA COLLECTION Likert type Questionnaire (Life Attitude Profile-Revised): quantitative data Semi-structured interviews: qualitative data DATA ANALYSIS Not reported.	**Themes/categories** **Profile of perpetual bereveament** Some mothers showed ambivalent feelings about living, remaining angry at God and/ or their church and were unable to incorporate their child's death into a beneficial belief system: *"Don was my life. He's what I looked forward to in getting old and him getting married and having a life and making me grandmother and havin my house filled with little kids runnin around and there's nothin now – absolutely nothin – and it has – it's made me so angry and it made me so angry at God that this happened… Everything that I had, that I looked forward to in getting old was taken and it's like my mind just stops right there. I can't see any further than that. I can't imagine what else there would be. I want someone to tell me what I'm supposed to be doin" (Ellen)* **Profile of survival** Some mothers have learned from bereavement, and integrated this into a new identity: *"After Bobby's death I found compassion for other people that I did not know existed in my personality. I can walk in a room sometimes now and I can zero in on the person that's in*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported; no details given about data saturation **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process: no details

Study details	Participants	Methods	Findings	Comments
Aims To measure mothers' attitudes about life five or more years after the death of their only child **Country/ies where the study was carried out** US **Study dates** Not reported **Source of funding** Not reported			*the room that is hurting terribly for whatever reason. It's like a homing device. It has - Bobby's death has made me a much better person. It's made me aware that everyone out there in the entire world belongs to a family. And everybody loves; everybody grieves; everybody hurts; everybody has joy. It's another lesson that God is teaching me in this journey that I'm on to survive the death of my son" (Irene)*	given about analysis saturation **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Indirect population (73% of the deaths were accidental). Data analysis not stated Mostly protestants
Full citation Zelcer, S., Cataudella, D., Cairney, A. E., Bannister, S. L., Palliative care of children with brain tumors: a parental perspective, Archives of Pediatrics & Adolescent Medicine, 164, 225-30, 2010 **Ref Id** 335260	**Sample size** n=47 families were eligible n=41 families were eligible [after exclusions] n=17 families were analysed (25 parents of 17 deceased children) **Inclusion criteria** Parents of children who died of a brain tumor while under the care of the Children's Hospital, London Health Sciences Center, between January 1, 1996, and December 31, 2006. **Exclusion criteria**	**Details** SAMPLE SELECTION Not reported SETTING Parents of children who died of a brain tumor while under the care of the Children's Hospital, London Health Sciences Center, during a 10 years study period (1996 to 2006) DATA COLLECTION Focus group interviews semi-structured format n=3: 8 to 10 participants in each group interview	**Themes/categories** **Sources of spiritual support during the dying trajectory** Maintaining **hope** was a recurrent theme in all focus groups. Families described the need to hold tow beliefs: the realisms of the poor diagnosis, and the search for a miracle. *"You always have that hope that this is going to be the one that solves everything; you don't want to give that up" (FG2)* Parents described the **strength and the resilience** displayed by their (adolescent) child during the illness. They admired their child, as they did not feel they would have had the same fortitude. *"We were surrounded with love. He knew that; he was so good, he directed his own*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Small sample size, gathered from a single institution. The relationship between the researcher and the respondents not clearly reported

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study (descriptive phenomenology) **Aims** To explore the end-of-life experience of children with brain tumors and their families **Country/ies where the study was carried out** UK **Study dates** January 1996 - December 2006: data collection 2010: publication **Source of funding** This study was supported by a grant from the Pediatric Oncology Group of Ontario [*The sponsor did not have any role in the design or conduct of the study; in the collection, analysis, or interpretation of*	The death of a child within the past year [from the data collection period] Families identified by their primary oncologist as having the potential to experience significant psychological repercussions from participating **Characteristics** Parents n=25: sex: male n= 9 race: white n=25 Children n=17: sex: male n=12 age at the time of death(years): 1-5 n=3; 8-11 n=3; 12-19 n=11	DATA ANALYSIS Thematic analysis: 6-step process outlined by Braun and Clarke (1. familiarizing oneself with the data, 2.generating initial codes, 3. searching for themes, 4. reviewing themes, 5. defining and naming themes, and 6. producing the report) Data analysis was conducted by 2 members of the research team (S.Z. and D.C.). using NVIVO 7 software	*care and he directed us and he had a good quality of life." (FG2)*	**Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers critically reviewed their own roles in the process but was unclear whether saturation in terms of analysis was achieved. **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process were not clearly reviewed **Overall quality:** Moderate **Other information** The Authors were unable to establish contact with many eligible families.

Study details	Participants	Methods	Findings	Comments
the data; or in the manuscript preparation, revision, or approval]				
Full citation Foster, T. L., Gilmer, M. J., Davies, B., Barrera, M., Fairclough, D., Vannatta, K., Gerhardt, C. A., Bereaved parents' and siblings' reports of legacies created by children with cancer, Journal of Pediatric Oncology Nursing, 26, 369-76, 2009 **Ref Id** 441150 **Study type** Qualitative study (descriptive phenomenology) **Aims** To explore bereaved parent and sibling perspectives of how children living	**Sample size** N=99 people (40 families of children who died from cancer) 36 mothers 24 fathers 39 siblings **Inclusion criteria** Families who: had a bereaved sibling 8 to 17 years old were fluent in English, and Lived within 100 miles of the hospital. Adopted, half-siblings, who: lived in the home during the deceased child's treatment, or if the parent reported that the sibling had regular ongoing contact with the child who later died **Exclusion criteria** Missing data Did not attend an home visit **Characteristics** Mothers mean age = 40.50 years (SD = 7.35), race: 78% (n = 28) were Caucasian.	**Details** SAMPLE SELECTION This study was part of a larger ongoing longitudinal study of families after the death of a child from cancer. SETTING Three participating children's hospitals in the United States and Canada DATA COLLECTION Individual interviews including an open-ended question with each participating family member: Some parents/kids/teens have told us that their child/brother/sister did or said something before he/she died so that they would be remembered. Others haven't said much. What, if anything, did your child/brother/sister do or say so that he/she would be remembered? (Probe if needed: Did your child/brother/sister leave a special message or give you something special to keep?)	**Themes/categories** **Children doing and saying things to be remembered** Children did things to be remembered, such as making crafts for others, giving away belongings or gifts and writing letters to loved ones, *"She [20-year-old] gave me lots of stuff. She gave me like a bunch of old t-shirts because she loved t-shirts. Those are special*." (sibling) *"Mommy, you have to give it to them after I am gone. And they have to know that I wanted them to have this to remember me."* (bereaved mother of a 3-year old child) *"… All that I care for is that you remember me and don't forget me."* (bereaved sister of an 11-year old) **Children not saying or doing things to be remembered** Other participants reported that children did not intentionally do or say things to be remembered because of their illness, age, or unexpected death. *"We didn't know he [16-year-old] was going to pass away so quickly. When my mom was talking to him about making a will or whatever, he said he wasn't ready for that. And she felt we could, that he could wait a little bit longer cause they thought he was gonna pass away at the end of the summer,*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported and about the roles of the researchers **Data analysis:** Researchers did clearly review their own roles in the analytical process and saturation in terms of analysis was discussed achieved

Study details	Participants	Methods	Findings	Comments
with cancer created legacies **Country/ies where the study was carried out** US and Canada **Study dates** Publication date: 2009 Data collection: not reported **Source of funding** This research was supported by a grant from the National Institutes of Health (R01 CA98217)	Fathers mean age = 43.88 years of age (SD = 7.75) race= 83% (n = 20) were Caucasian Siblings mean age =12.28 years of age (SD = 2.64) Gender= female (64%, n = 25), Race: Caucasian (72%, n = 28), Deceased children mean age = 12 years of age (SD = 5.27) at the time of death	Data were collected approximately 10.68 months (SD = 3.48) after the child's death DATA ANALYSIS Content analysis: Three researchers reviewed the suggested coding scheme and extracted quotes and regularly discussed the rationale for emerging categories They examined all data based on the final coding scheme and typed findings in narrative form, presenting each major category and exemplary quotes from participants. Member checking with 6 families occurred 12 months after the initial visit.	*but it ended up he sort of ended up passing away in the middle of the summer. And so because it's so abrupt, he never actually told anybody, you know, about this and I want you to think of me when you look at this and that kind of stuff."* (sibling) Other family members said that their child with cancer did not need to do or say anything to be remembered. *"I think she [14-year-old] was well aware of how deeply loved she was. So she didn't need to leave anything behind."* (father) *"I asked her [17-year-old] actually if there was anything that she wanted me to relay to anybody, and she said, 'nope' cause everybody knew it from her that she loved them … She never wanted to be famous or anything, but she wanted to be remembered."* (mother) **Deceased children's belief about afterlife** A large number of participants recounted deceased children's beliefs about an afterlife. Many talked about children believing they would go to Heaven or be with Jesus after they died: *"Nine days before she died, she told me that she was going to go be with Jesus soon … 'God's put peace in my heart'*." (mother) "*She [3-year-old] told me not to worry about it that she was going to make it all right with her friend. She went to Care-a-Lot Heaven. And knew she was going and told me that I would be there to meet her at the spot when it was my time to go. So she knew she was going. And I'll never forget that. Being able to know that she would not forget me. Because*	**Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process were not critically reviewed **Overall quality:** Moderate **Other information** Only study that includes siblings

Study details	Participants	Methods	Findings	Comments
			she would be waiting for me at the spot. Knowing that, I knew she was going to be fine." (mother) Other parents found comfort in remembering children saying they were going to Heaven: "*He [16-year-old] said, 'I'm gonna go now, okay … I'm gonna go to Heaven.' … he said he was gonna be okay*." (Father) Whereas some parents recalled their child's belief about Heaven or Jesus: *"I knew that she was really gone. She gave me a very big smile, so I know that wherever she is, she is okay and she was telling me that "Mom, its okay." That's why I'm not worried. I know she's okay and I know she wanted to be okay with whatever or however." (mother)* *"If I don't come home, don't feel sorry for me, be envious of me."* (mother) **Effects on children with cancer and their family members:** <u>Inspiration for children with cancer</u> Their [bereaved parents] personal experience of living with cancer inspired the children to affect the lives of others: "*really made a strong impact on a lot of people, because of his strong faith and trust in God to be in control and do what He knows is best for everybody*." (mother) "*I've never seen anyone that had an effect on so many people so young without any effort … I mean … she said in her letter … she said,"… I'd like to be well but I am not. And if my sickness in any way causes someone to come to Lord, to get close to Lord, then it's worth it all …"* (father)	

Study details	Participants	Methods	Findings	Comments
			Cancer also inspired children to prepare themselves for death mostly through confiding their wishes to loved ones: “*Mom, I want you to buy this for me,” you know, her [deceased child], me, and (other friends) all their friends, “because they’re wings, it’s like angel wings for a Christmas present for them so we can all be angels*.” (mother) “*She was only 2 [years old], but she and my wife had these necklaces … Right before she went into surgery—(Deceased child)’s [necklace] said “Faith” and (wife)’s [necklace] said “Strength.” And (deceased child) made them change … she [deceased child] wanted to trade*.” (father) <u>Inspiration for bereaved families</u> References to God were evident in many messages about how to live life: “*His statement was God … He [ill child] said, ‘Jesus died on the cross for our sins, and I thank God for that.’ … So that will always be a mark*.” (father) One mom carried on her son’s legacy. She said her 16-year-old ill son always had a special message: “*His legacy he left was, ‘Do you know God?’ He did this to everybody that he ever met … He would get the conversation around to God*.” (mother) At the end of her interview, the mom was asked by the interviewer if there was anything else she would like to share. She asked, *“Do you know God?*”	

Study details	Participants	Methods	Findings	Comments
Full citation Meert, K. L., Thurston, C. S., Briller, S. H., The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study, Pediatric Critical Care Medicine, 6, 420-7, 2005 **Ref Id** 441154 **Study type** Qualitative study (prospective) **Aims** To gain a deeper understanding of parents' spiritual needs at the time of their children's death in the pediatric intensive care unit (PICU) and during bereavement.	**Sample size** 33 parents interviewed (Parents of children died during the study period) **Inclusion criteria** Parents and/or legal guardians of children who died in the PICU of the Children's Hospital of Michigan during the study period (1999-2000) **Exclusion criteria** Not reported. **Characteristics** Carers Type of carers (n=): 20 mothers, 12 fathers, 1 grandmother with legal guardianship; Race(n=): 18 white 15 black Religious affiliation: Protestant 21 Catholic 7, Jewish for 2, unreported 3. Deceased children Gender: 15 (58%) boys 11 (42%) girls median age at time of death was 4.5 yrs (3 days to 24 yrs)	**Setting** US **Data collection** Semi-structured, in-depth interviews were conducted in a conference room at the hospital were conducted jointly by 2 authors lasted 1-2 hours each **Data analysis** Thematic analysis: 2 investigators who conducted the interviews analyzed the transcripts and a third investigator, a medical anthropologist, provided guidance for the qualitative data analysis. The thematic analyses were then compared to find overlap and consensus regarding the phenomenon represented and the label applied. The two investigators repeated the process of independently A research assistant independently coded the transcripts using the coding dictionary to further validate the coding. Any	**Themes/categories** **Connection with the child** Parents described the need to maintain a relationship with the child through presence, words, symbols: *"You know, nobody don't want to leave their child in ICU by themselves and not know what's going on. As long as your child is there, you gonna want to be close to your child where you can go back and forth. Cause my child never go through nothing without me being there." (Mother)* *"I don't know if this is spiritual or not, um, after she passed away one thing that helped us to say our good-byes was that we were able to hold her, you know, to hold her as long as we wanted to. We were able to rock her in our arms and feel her little body. We knew she was gone but just to have that closeness with her one more time." (Mother)* Parents could maintain a connection with their child after death through thoughts, memories, images or memorials: *"They wouldn't let us take anything. I wanted her gown because it was the last thing she wore. I wanted the sheet from the bed, I wanted her bracelet from the hospital. They said they couldn't give us anything."* (Mother) *"The chaplain took pictures of her and cut a lock of her hair and gave it to me. It was supportive, you know, she really cared."* (Mother) *"so one of my needs that was met spiritually was coming back to the hospital to the memorial that they offer. That meant so*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Sampling strategy described. The relationship between the researcher and the respondents was reported **Data collection:** Data collection process and discussion on whether saturation has been reached for any of the themes were both clearly reported **Data analysis:** The analytical process was described in detail; researchers did critically review their own roles in the process and saturation in terms of analysis was achieved **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed;

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out US **Study dates** 1999-2000: data collection **Source of funding** Children's Research Center of Michigan, Detroit, MI.	Diagnoses included: congenital heart disease in eight (31%), trauma in five (19%), malignancy in three (12%), respiratory failure in two (8%), other iil other illnesses in eight (31%) Cause of death: Eighteen children (69%) died as a result of a chronic illness eight (31%) died as a result of an acute illness or injury diagnosed within 48 hrs of death	discrepancies in coding were resolved by consensus.	*much to me, this is where I left him"* (bereaved mother) **Prayer, ritual, sacred text** Parents described that some activities helped them to strengthen one's bond with transcendent reality and one's faith tradition: *"I just prayed that God would have mercy and let her live. And I prayed that God would help me through it." (Father)* Parents often felt the need for others including family, friends, and staff to pray on their behalf; for some parents, such community prayer provided a tremendous sense of spiritual suppor: *"I felt the whole world was praying for H___. Everybody knew her in some way, shape or form, either from her bone marrow drive, the TV, the hospital. So I felt we had big support spiritually."* Some parents expressed the need for prayer by hospital chaplains or other clergy. *"Like the chaplains, I needed somebody to come in here and pray with me."* (Parent) *"Somebody walks in and says 'Do you want to say a prayer?' It's not like I didn't want to pray for E___, it's just, I really was praying on my own. I just didn't want that."* (Mother) *"If someone's gonna come in and say a prayer, I would just have liked it to be somebody of my religious persuasion. They had the wrong kind of collar walk in our room."* (Father) *"I think it's nice that there's a chapel available. I used it basically just as a place that was quiet."* (Father)	**Overall quality:** Moderate **Other information** Indirect population, data was not reported separately, 69% of children died as a result of a chronic condition and 31% of children died as a result of an acute illness or injury

Study details	Participants	Methods	Findings	Comments
			Connection with others Some parents saw their relationships with others as a source of spiritual support. These included spouses, parents and other family members, friends, neighbors, coworkers, clergy, health professionals, and parents of other PICU patients: *"And if somebody's there by theyself, please try to get somebody there to be with them. I think that's more important than anything cause nobody should have to go through that alone." parent "I used to surf (the Internet) and I'd meet people on line, talk to parents who have children with the same problem and who lost their kids and stuff. Cause talking to someone with the same problems, whose child died with the same hypoplastic left heart as mine, exchanging stories and stuff was good. That helped a lot. It was encouragement." (Mother)* *"Their prayers, their hugs, just being there, just knowing they cared. I remember when S___ was 12 and he had open heart surgery. He was in the sixth grade and the outpouring of cards and letters and pictures and it just meant so much to us. I think that's what always helped me was to know that people cared and that they would be there to help."* (Mother) **Bereavement support** Parents needed their suffering and grief, to be acknowledged. They would like to receive bereavement support but also general guidance: *"Who would ever think that we would have a child who would die. I mean, maybe we*	

Study details	Participants	Methods	Findings	Comments
			would have to make arrangements for our parents one day, but you'd never think your child. And especially, we've never had any of that experience, to have to deal with death and that type of thing." (Mother) *"Somebody should have come in and said, 'We're going to do this and then this is going to happen. She'll let out a last gasp, and you'll hear her breath and know that she will not be in pain, or she will be, or she cannot feel this, or she will.' So, like I said, number one would be, I wish somebody would have been there to walk us through it, what death is all about."* (Father) *"And we did call and wanted to talk to the doctor, just to ask them a few questions. And so later they called and right away, they accommodated us. They made time to meet us and Dr.___ talked to us. I would recommend that as time goes by and it's right for people, to be offered, to come in and just vent their feelings." (Parent)* *"And I feel there should be a support system that follows up. We had friends and we had family but we had no professional access and that is what we would have liked to have gotten through the hospital"* (Parent) **Meaning and purpose** For parents, meaning and purpose was understood as the reason for one's being and the ways in which one's being contributes to the greater body of human good: *"To the day I die, I will find some meaning in what happened to my daughter, whatever it takes. I refuse to believe that she lived on this earth for 14 months and had no impact*	

Study details	Participants	Methods	Findings	Comments
			on anybody or anything. I am not going to allow that to happen." (Father) *"He was put here for a reason, and them 9 years, he had a good life. He brought a lot of joy in people's lives. He knew people in the church and he knew people in the streets. I've seen him melt hearts of people that were ice cold. Maybe that's why he was put here, you know."* (Parent) Although some parents felt that they had lost the meaning to their own life: *"And at the funeral, when I closed the casket, part of me went in that casket."* (Parent) *"She's just like the center focal point of our marriage and our lives now. You know, without her, I just don't know if I could do it."* (Mother) **Anger and blame** Many parents felt the need to attribute the child's death to a specific person, place, circumstance, or God: *"I'm always gonna believe there's something else I could've done, something else maybe his mom could've done." (Father)* *"At that time all kinda things went through my mind. From physical violence to just picking up something and throwing it. I wanted someone to feel as I felt right then. It wasn't pretty what I felt, you understand. It was like all the frustration through the years just gang up. I wanted to strike out at somebody."* (Father) "But, as far as I'm concerned, God did the worst thing possible He could have done to me and my wife. I mean, take the only thing	

Study details	Participants	Methods	Findings	Comments
			in the world that meant anything to us.” (Father)	
Full citation Reder, E. A., Serwint, J. R., Until the last breath: exploring the concept of hope for parents and health care professionals during a child's serious illness, Archives of Pediatrics & Adolescent Medicine, 163, 653-7, 2009 **Ref Id** 357929 **Study type** Qualitative study (descriptive phenomenology) **Aims** To investigate the concept of hope for families and paediatric health care professionals during a child's serious illness.	**Sample size** N = 39: Bereaved parents =12 paediatricians= 10 paediatric residents =8 and nurses =9 **Inclusion criteria** Not reported **Exclusion criteria** Not reported **Characteristics** Of the 12 parents, 9 mothers and 3 fathers participated and their children's age at time of death ranged from 2 months to 21 years. Attending physicians (5 female, 5 male) included representatives from paediatric intensive care (n = 4), general paediatrics (n = 2), and oncology, haematology, neonatal intensive care, and paediatric emergency medicine (n = 1 from each). Paediatric residents (7 female, 1 male) included 2 postgraduate year 1, 3 postgraduate year 2, and 3 postgraduate year 3 residents. Nurses (8 female, 1 male) were from paediatric oncology (n =	**Details** SAMPLE SELECTION Not reported SETTING This study was held at the Johns Hopkins Children's Center in Baltimore, Maryland, from September 2005 through June 2006. DATA COLLECTION Focus group interviews (N=8: 2 for each participant group) The duration of the focus groups ranged from 60 to 90 minutes Sessions were audiotaped, and transcriptions were performed DATA ANALYSIS Qualitative analysis of audio-taped sessions: Themes were identified in response to the questions. Any discrepancies were resolved by consensus	**Themes/categories** **Elements of hope related to spirituality** *"For me, I believe that you have to have some type of spirituality first to get through any situation in life, but as far as being hopeful, it's like, okay, this is bad, but we want to be able to make a good day, just life each day"* (parent) *"I accept hope as acceptance that no matter what happens, it's going to be okay and this kind of spells out everything" (parent)* *"I think hope from a family standpoint is driven by love that we can't even conceptualize personally in that situation as health care providers. I think it's the love for that child that drives that hope. I think that's maybe an element of the parent-child bond"* (nurse)	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** The relationship between the researcher and the respondents was not reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported and about the roles of the researchers **Data analysis:** Researchers did clearly review their own roles in the analytical process and saturation in terms of analysis was not discussed **Findings/results:** Results were presented clearly. The

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out US **Study dates** 2005-2006 **Source of funding** Children's Miracle Network at Johns Hopkins Children's Center.	5), neonatal intensive care (n = 3), and paediatric intensive care (n = 1).			researchers' roles and potential influences in the analytical process were not critically reviewed **Overall quality:** Low **Other information** Methods of sampling selection and data analysis not clearly reported
Full citation Ebmeier, C., Lough, M. A., Huth, M. M., Autio, L., Hospitalized school-age children express ideas, feelings, and behaviors toward God, Journal of Pediatric Nursing, 6, 337-49, 1991 **Ref Id** 441632 **Study type** Qualitative study (Grounded theory approach) **Aims**	**Sample size** N=28 children **Inclusion criteria** Hospitalization for an acute illness or exacerbation of chronic condition from which children were expected to recover permission from the parent parent verification that children had an idea of God and were in the appropriate grade in school **Exclusion criteria** Not reported **Characteristics** gender: 28 boys, 10 girls age range: 8-10 years religion: Catholic = 17	**Details** SAMPLE SELECTION Not reported. See inclusion criteria. SETTING The study was conducted in a large hospital on a paediatric unit in the US. DATA COLLECTION Storytelling of children through 4 pictures (pics designed by the investigators based on their experience and a literature review). This four pictures were showed during the interview by the investigators to each child. The pictures guided the interview (of the investigator) / storytelling (of the interviewed child)	**Themes/categories** **Attributes assigned to God** The attributes assigned to God were, as a whole, positive. God was seen as **helper-protector, comforter, counsellor and judge**. God would help the child feel better, go home, or *"get through this"*. "*Oh, thank you, you know what, nurse, I think God helped me get through this. I think if God was never here – I don't think I could – I think I'd cry and scream and stuff".* *"God's powerful"* (9 year-old child) God was also seen as **reassuring** the child, and this was reflected in sayings like this: "You'll be fine"; *"You're going to be all right"; "nothing's gonna happen to you"* God either told the child not to be afraid, gave the child a reason for the procedure, or reassure the child it would not hurt: "*God's saying it won't hurt. It'll just feel like a little pinch. Don't worry, don't worry, the shot won't hurt".*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Unclear sampling strategy used. The relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; unclear discussion on whether saturation has been reached for any of the themes reported

Study details	Participants	Methods	Findings	Comments
To contribute to nursing's understanding of children's relationship with god during an illness experience **Country/ies where the study was carried out** US **Study dates** Not reported **Source of funding** Marquette University Religious Commitment Funds and Sigma Theta Tau, Delta Grammar Chapter	other Christian denominations = 11 medical condition: 12 children were admitted with medical diagnosis (chronic condition) 9 children were hospitalised for surgery, 7 children were hospitalised due to accident-related problems	DATA ANALYSIS Thematic analysis based on the grounded theory principles using a "team approach".	God's **love and concern** was also raised by the children: *"He loves him, so he'll make the shot not hurt so bad"* *"He cares for him. He loves him and he's taking good care of him"* **Prayer** Formal prayer *"He/ she would say a prayer".* *"God could you please make me feel better"* *"Please help me not to be afraid"* *"Thank you God, for helping me get well"* *"He's praying to God that, well, I hope it does not hurt and I hope I get out pretty soon".* Informal prayer They also referred to children praying informally or just talking to God: *"Please help me"* *"Make me better"* *"Please help me get through without getting hurt"* *"Why do I have to go through it, I don't understand"*	**Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process, no details given about analysis saturation **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Small sample size Indirect study population, as < 50% were hospitalized due to a chronic condition
Full citation Jones, B. L., Companionship, control, and compassion: a social work perspective on the needs of children with cancer and their families at the end of life, Journal	**Sample size** 131 social workers **Inclusion criteria** Members of APOSW – Association Of Paediatric Oncology Social Workers (self-selected sample). **Exclusion criteria** Not reported	**Details** SAMPLE SELECTION Not reported SETTING This study was focused on the perceptions of members of APOWS. The association membership was used because it represented the population of interest in	**Themes/categories** **Symptom management** *"I think families and children need pain management that is physical, mental and spiritual"* **Rituals** *"[Families need] spiritual support and involvement in planning rituals around death"*	**Limitations** **Aim(s):** Aim of the study clearly reported, research method was appropriate for answering the research question **Sample selection:** Convenience sampling strategy used. The

Study details	Participants	Methods	Findings	Comments
of Palliative Medicine, 9, 774-88, 2006 **Ref Id** 353605 **Study type** Mix-methods study using both quantitative and qualitative methods **Aims** To explore the social work perception of the psychosocial needs of dying children and adolescents and their families with the goal of developing a best practice model of care. **Country/ies where the study was carried out** US **Study dates** Not reported **Source of funding** Not reported	**Characteristics** Education level: 92% master's or high degree Gender: 91% women Practice setting: 80% in hospital	investigating the role of paediatric social workers' role in end-of- life DATA COLLECTION Questionnaire with open-ended questions. DATA ANALYSIS Template analysis (a kind of thematic analysis)		relationship between the researcher and the respondents not clearly reported **Data collection:** Data collection process clearly reported; no discussion on whether saturation has been reached for any of the themes reported **Data analysis:** The analytical process was described in detail; researchers did not critically review their own roles in the process, no details given about analysis saturation **Findings/results:** Results were presented clearly. The researchers' roles and potential influences in the analytical process critically reviewed; **Overall quality:** Low **Other information** Self-selecting sample Most of the participants were female

Study details	Participants	Methods	Findings	Comments

G.13 Review question: Pain management

What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of pain in infants, children and young people with a life-limiting condition?

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Anghelescu, D. L., Burgoyne, L. L., Oakes, L. L., Wallace, D. A., The safety of patient-controlled analgesia by proxy in pediatric oncology patients, Anesthesia and Analgesia, 101, 1623-1627, 2005 **Ref Id** 405148	**Sample size** • N=1,011 participants • 4,972 24-h periods ○ PCA by proxy: n=576 24-h periods ○ Standard PCA: n=4,396 24-h periods **Characteristics** • Age: up to 20 years • Condition: patients with cancer, including solid tumour,	**Interventions** • Standard PCA • PCA by proxy.The study did not describe the identity of the proxy (parent or nurse). <u>Other treatment details:</u> • PCA was administered using a CADD-Prizm® Infusion pump. • The opioids used included: morphine, fentanyl and hydromorphone	**Details** SAMPLE SELECTION Data obtained between February 1999 and December 2003 DATA COLLECTION Medical records and nursing records were used, including the specific PCA record sheet. A pain clinical nurse specialist analyse the records for indications or respiratory or neurological changes. • Respiratory change was limited to recorded decreased respiratory rate or pulse oximetry values. The significance of this change was assessed by the clinical judgement of the caregiver. The use of	**Results** Results are presented PCA by proxy vs Standard PCA: **Pain** Not reported **Control of other distressing symptoms** Not reported **ICYP levels of distress** Not reported **Family / carers levels of distress** Not reported **ICYP quality of life** Not reported **Family/ carers quality of life** Not reported **Adverse events**	**Limitations** **Appendix D. NICE checklist Cohort studies** <u>A. Selection bias</u> (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS <u>B. Performance bias</u> (systematic differences between groups in the care provided, apart from the intervention under investigation)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Country/ies where the study was carried out USA **Study type** Obervational, before-after implementation study **Aim of the study** To evaluate the safety of proxy-controlled analgesia at a paediatric cancer centre. **Study dates** February 1999 to December 2003 **Source of funding** Partly supported by the American	brain tumour and leukaemia **Inclusion criteria** Every patient who had received PCA in the previous 24-h was identified from the pharmacy records **Exclusion criteria** Not reported		Naloxene was also recorded. - Neurological change included any record of confusion, difficulty in arousing the patient, personality change, hallucinations or seizures DATA ANALYSIS Not reported	- Neurological complications: 0.34% (n=2) vs 0.75% (n=33) - Respiratory complications: 0.34% (n=2) vs 0.59% (n=26) - Naloxene administration: 0.17% (n=1) vs 0.05% (n=2) - Total of 24-h periods affected by complications: 0.87% (n=5) vs 1.48% (n=65) **Proportion of children taken home/ re-admission to hospital/ admission to hospice** Not reported	B1. The comparison groups received the same care apart from the intervention(s) studied: unknown B2. Participants receiving care were kept 'blind' to treatment allocation: no B3. Individuals administering care were kept 'blind' to treatment allocation: no Level of risk: HIGH RISK OF BIAS C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? unclear C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? unclear C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): NA Level of risk: UNCLEAR D. Detection bias (bias in how outcomes are ascertained, diagnosed or verified)

Study details	**Participants**	**Interventions**	**Methods**	**Outcomes and Results**	**Comments**
Lebanese Syrian Associated Charities					D1. The study had an appropriate length of follow-up:yes D2. The study used a precise definition of outcome: no D3. A valid and reliable method was used to determine the outcome: no (non-validated scales) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: HIGH RISK OF BIAS **Other information** • Indirect population (the population includes up to 20 year olds)
Full citation Hunt, A., Goldman, A., Devine, T., Phillips, M., Transdermal fentanyl for pain relief in a paediatric palliative care population, Palliative Medicine,	**Sample size** • N=41 children • n=26 completed the 15-day treatment phase, reasons for withdrawal: ○ 7 children died due to disease progression	**Interventions** • Intervention: Transdermal Fentanyl, 15-day phase • Comparison: Morphine Other treatment details: All participants had access to immediate-	**Details** SAMPLE SELECTION All patients aged 2 to 18 years who required opioid treatment for pain associated with a LLC and who were receiving oral morphine at least 30 mg/day for ≥ 48h. were offered to participate. DATA COLLECTION • Where possible, children completed assessments. Alternatively parents/	**Results** Results are presented before and after the intervention with Fentanyl was started: **Pain** 61% vs 72% **Control of other distressing symptoms** • Sleeping well: 71% vs 67% **ICYP levels of distress**	**Limitations** **Appendix D. NICE checklist Cohort studies** A. Selection bias (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
15, 405-412, 2001 **Ref Id** 405235 **Country/ies where the study was carried out** UK **Study type** Observational, before-after implementation study **Aim of the study** To examine the efficacy and safety of transdermal Fentanyl in children who were previously receiving oral morphine. **Study dates**	○ 8 were withdrawn due to inadequate response (n=5); change to parenteral opioids (n=1); adverse events (n=2) **Characteristics** • Median dose of oral morphine at entrance: 60 mg (range: 0 to 520) • Reasons for transfer to transdermal Fentanyl included: difficulty with or reluctance in swallowing oral medication and occurrence of unacceptable morphine side-effects	release oral morphine for breakthrough pain	carers made the assessments • Diaries included: use of rescue medication, bowel function and pain severity • Assessments were made when patches were changed, every 3 days, and included: pain control, sleep quality, convenience of the patch for both parents and children • Pain was assessed using the Face Affect scale, twice daily and before-1h. after rescue medication • Child's level of activity was reported every 3 days by parents using the Play Performance Scale • Global assessment of the treatment: made on day 15 (or on withdrawal of the study)	Not reported **Family / carer levels of distress** Not reported **ICYP QoL** Convenient for the child: 55% vs 89% Able to follow usual activities: 46% vs 52% **Parents/ carers QoL** Convenient for the parent: 58% vs 92% **Adverse events (due to medication and not the condition)** • Drowsy: 59% vs 48% • Constipation: 64% vs 52% • Dry mouth: 59% vs 32% • Nausea & vomiting: 77% vs 45% • Itchy skin: 55% vs 27% • Central nervous system symptoms possibly or definitely due to Fentanyl: n=13 (32%)	is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS B. Performance bias (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: unknown (it's likely that patients are receiving other treatments, other than opioids, for the management of their condition) B2. Participants receiving care were kept 'blind' to treatment allocation: no B3. Individuals administering care were kept 'blind' to treatment allocation: no Level of risk: HIGH RISK OF BIAS C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? unclear C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? unclear

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Feb 1996 to August 1998 **Source of funding** The study was supported by Jannssen-Cilag Ltd.	○ n=34 patch size 25 µg/h; n=5 at 50 µg/h; n=1 at 75 µg/h; n=1 at 150 µg/h • Age: median 10.5 years (range: 2.6 to 18.8) • Gender (M/F): 30/ 11 • Diagnosis: ○ haematologic al malignancy: n=4 ○ brain tumour: n=5 ○ other solid tumour: n=27 ○ neuro-muscular disease: n=5 **Inclusion criteria**		by parents and investigators, including pain control, side-effects, convenience, satisfaction of the treatment • Primary outcome measure: patients' or parents' satisfaction with the treatment made of the treatment made on day 15 (or on withdrawal of the study) • Treatment satisfaction was assessed using a 4-point verbal rating scale • Safety evaluations: ○ The occurrence of adverse events was noted during the study ○ Patient's heart and respiratory rate were recorded every 3 days	○ agitation n=5 ○ convulsions n=3 ○ hallucinations n=3 ○ paranoia n=2 ○ depression n=2 ○ insomnia n=2 ○ vivid dreams n=1 ○ dyskinesia n=1 ○ aggressive reaction n=1 ○ anxiety n=1 • Serious adverse events: death: none **Proportion of children taken home/ re-admission to hospital/ admission to hospice** • None	C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): NA Level of risk: UNCLEAR <u>D. Detection bias</u> (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up:yes D2. The study used a precise definition of outcome: no D3. A valid and reliable method was used to determine the outcome: no (non-validated scales) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: HIGH RISK OF BIAS **Other information** • Assessment of efficacy is a composite outcome, that includes pain • Potential conflict of interest

Study details	**Participants**	**Interventions**	**Methods**	**Outcomes and Results**	**Comments**
	• Age: 2 to 18 years • Need for opioid treatment for pain due to cancer or other life-threatening conditions • Children receiving at least 30 mg/day for 48 h. • Children including regardless they had entered the terminal phase **Exclusion criteria** Not reported		○ Skin covered by the patch was checked at each patch change for signs of erythema, oedema, itching or papules/ pustpules (recorded as abstent, mild, moderate or severe) DATA ANALYSIS Not reported		
Full citation Ruggiero, A., Barone, G., Liotti, L., Chiaretti, A., Lazzareschi, I., Riccardi, R., Safety	**Sample size** N=18 **Characteristics** • Children	**Interventions** • Intervention: PCA pump (PCA VYGON freedom 5) programmed to deliver a booster dose of Fentanyl when required.	**Details** SAMPLE SELECTION Not reported DATA COLLECTION • Pain intensity was assessed using the Affective Facial Scale (AFS) and the Visual	**Results** Results are presented before and after the intervention (PPCH) was implemented: **Pain** <u>time A (before) vs time B (4h intervals)</u>	**Limitations** **Appendix D. NICE checklist Cohort studies** <u>A. Selection bias</u> (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is

Study details	**Participants**	**Interventions**	**Methods**	**Outcomes and Results**	**Comments**
and efficacy of fentanyl administered by patient controlled analgesia in children with cancer pain, Supportive Care in Cancer, 15, 569-73, 2007 **Ref Id** 356831 **Country/ies where the study was carried out** Italy **Study type** Prospective observational study, before-after **Aim of the study** To evaluate the efficacy and safety of Fentanyl delivered by patient-controlled analgesia (PCA) in	• Age: 6 to 15 years (median 10 years) • Gender (M/F): 11/ 7 • Moderate to severe cancer pain • Treated with opioids (parecetamol and NSAIDS failed) • All patients had a central or peripheral IV catheter • Children were neither physically nor neurologically impaired • Condition: ○ 10 children with primary bone tumour	Fentanyl was delivered IV for at least 48 h. • Comparison: oral morphine	Analogue Scale (VAS) depending on the patient's age and general clinical conditions. • PCA monitoring consisted of assessing pain intensity and vital parameters. • Data was collected before (time A) and during treatment (time B) at 4-h intervals for a total of 48h (time C) • At the end of the treatment, authors measured adherence and treatment efficacy using a questionnaire administered by a doctor DATA ANALYSIS Statistical significance was assessed using a paired t-test for paired data, assuming a normal distribution	• AFS score: 6.5±0.8 vs 4.3±0.5; p<0.001 • VAS score: 68.5±0.2 vs 39.8±5.6; p<0.001 <u>time B (4h intervals) vs time C (48h)</u> • AFS score: 4.31 vs 4.18; p=0.60 • VAS score: 39.8 vs 40; p=0.98 <u>time A (before) vs time C (48h)</u> • AFS score: 6.5 vs 4.18; p<0.01 • VAS score: 68.5 vs 40; p<0.01 **ICYP levels of distress** Not reported **Family / carers levels of distress** Not reported **ICYP quality of life** Not reported **Family/ carers quality of life**	not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS <u>B. Performance bias</u> (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: unknown B2. Participants receiving care were kept 'blind' to treatment allocation: no B3. Individuals administering care were kept 'blind' to treatment allocation: no Level of risk: HIGH RISK OF BIAS <u>C. Attrition bias</u> (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? 0 C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
children older than 6 with cancer pain. **Study dates** October 2002 to April 2004 **Source of funding** Not reported	○ 3 children with metastatic disease ○ 3 children with medulloblastomas ○ 1 children with metastatic Wilm´s tumour ○ 1 children with metastatic neuroblastoma **Inclusion criteria** Not reported **Exclusion criteria** Not reported			Not reported **Control of other distressing symptoms** Not reported **Adverse events** • 39% (n=7) of children reported adverse events ○ itchiness: 17% (n=3) ○ vomiting: 11% (n=2) ○ rashes: 11% (n=2) ○ constipation: none ○ major adverse events (such as apnea or bradicardia): none **Proportion of children taken home/ re-admission to hospital/ admission to hospice** Not reported	between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? 0 C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: LOW RISK OF BIAS D. Detection bias (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: unclear (most likely no, as the patients are followed for only 48h.) D2. The study used a precise definition of outcome: yes D3. A valid and reliable method was used to determine the outcome: yes (validated scales for pain) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: UNCLEAR **Other information** • Before-after study • Small population • Children with pain due to cancer only

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Schiessl, C., Gravou, C., Zernikow, B., Sittl, R., Griessinger, N., Use of patient-controlled analgesia for pain control in dying children, Supportive Care in Cancer, 16, 531-6, 2008 **Ref Id** 356839 **Country/ies where the study was carried out** Germany **Study type** Retrospective observational study, before-after	**Sample size** N=8 **Characteristics** • Age: 8.5 (3 to 17) • Gender (M/F): 5/ 3 • Diagnosis ○ Leukaemia: 37.5% (n=3) ○ Brain tumour: 37.5% (n=3) ○ Solid tumour: 25% (n=2) **Inclusion criteria** Children who were treated with IV PCA (Graseby® 3300, Smiths medical) in the last 7 days of their life. **Exclusion criteria** Not reported	**Interventions** IV PCA with a strong opioid. Morphine was the most used opioid, except in those cases where the child had a history of side effects, The IV opioid equivalent was calculated using standard conversion tables. Depending on the child's age, the boluses were activated by the child, the parents or the nurses. Median duration of treatment: 9 days (range: 1 to 50)	**Details** SAMPLE SELECTION Retrospective chart review of the medical chart of all children with cancer who died between January 1998 and January 2005 DATA COLLECTION • The information was obtained from each pump's bolus-event recorder. • Pain data was obtained from chart reviews. • Pain was assessed with a numerical scale (0 to 10 rating scale) by the child, the parents or the professionals. DATA ANALYSIS • Comparisons between analgesic doses and pain ratings were analysed using Wilcoxon test. • SPSS 11.5	**Results** Results are presented before and after the PCA intervention was introduced. **Pain** • 24h. before starting PCA (median, range): 3.7 (0 to 6) • range median after starting PCA: 0 to 3, p-value: ns **Control of other distressing symptoms** Not reported **ICYP levels of distress** Not reported **Family / carers levels of distress** Not reported **ICYP quality of life** Not reported **Family/ carers quality of life** Not reported **Adverse events**	**Limitations** **Appendix D. NICE checklist Cohort studies** <u>A. Selection bias</u> (systematic differences between the comparison groups) A1. The method of allocation to treatment groups was unrelated to potential confounding factors (that is, the reason for participant allocation to treatment groups is not expected to affect the outcome(s) under study): NA A2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders: NA A3. The groups were comparable at baseline, including all major confounding and prognostic factors: Not reported, but it is expected for patients to deteriorate with time Level of risk: HIGH RISK OF BIAS <u>B. Performance bias</u> (systematic differences between groups in the care provided, apart from the intervention under investigation) B1. The comparison groups received the same care apart from the intervention(s) studied: unknown B2. Participants receiving care were kept 'blind' to treatment allocation: no B3. Individuals administering care were kept 'blind' to treatment allocation: no Level of risk: HIGH RISK OF BIAS

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
implementation study **Aim of the study** To evaluate the use of PCA for paediatric cancer patients receiving terminal care. **Study dates** January 1998 to January 2005 **Source of funding** Not reported				Not reported **Proportion of children taken home/ re-admission to hospital/ admission to hospice** Not reported	C. Attrition bias (systematic differences between the comparison groups with respect to loss of participants) C1. All groups were followed up for an equal length of time (or analysis was adjusted to allow for differences in length of follow-up): NA C2a. How many participants did not complete treatment in each group? 0 C2b. The groups were comparable for treatment completion (that is, there were no important or systematic differences between groups in terms of those who did not complete treatment): NA C3a. For how many participants in each group were no outcome data available? 0 C3b. The groups were comparable with respect to the availability of outcome data (that is, there were no important or systematic differences between groups in terms of those for whom outcome data were not available): yes Level of risk: LOW RISK OF BIAS D. Detection bias (bias in how outcomes are ascertained, diagnosed or verified) D1. The study had an appropriate length of follow-up: unclear D2. The study used a precise definition of outcome: yes D3. A valid and reliable method was used to determine the outcome: no (non-validated scale for pain) D4. Investigators were kept 'blind' to participants' exposure to the intervention: no

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					D5. Investigators were kept 'blind' to other important confounding and prognostic factors: no Level of bias: HIGH RISK OF BIAS **Other information** • Small sample size • Before-after design

G.14 Review question: Agitation management

Not applicable to this review

G.15 Review question: Respiratory distress management

Not applicable to this review

G.16 Review question: Seizure management

Not applicable to this review

G.17 Review question: Managing hydration

Not applicable to this review

G.18 Review question: Managing Nutrition

Not applicable to this review

G.19 Review question: Recognising that a child or young person is likely to die within hours or days

What signs and symptoms, individually or in combination help to recognise that infants, children or young people are likely to be in their last days of life and which of them are considered most informative by healthcare professionals?

Study details	Participants	Methods	Themes/ categories	Comments
Full citation Shaw, K. L., Brook, L., Cuddeford, L., Fitzmaurice, N., Thomas, C., Thompson, A., Wallis, M., Prognostic indicators for children and young people at the end of life: A Delphi study, Palliative Medicine, 28, 501-512, 2014 **Ref Id** 362763 **Country/ies where the study was carried out**	**Sample size** • N=55 completed questionnaire 1 • N=49 completed questionnaire 2 (89% response rate) **Characteristics** • Specialty ○ Round 1: nurses 32.7%; specialist paediatricians 29.1%; community paediatricians 21.8%; consultants in paediatric care 10.9%; GPs 5.5% ○ Round 2: nurses 30.6%; specialist paediatricians 26.5%; community	**Details** SAMPLE SELECTION • The sampling strategy aimed at key palliative care environment and geographic diversity. • The panel included HCP from different target groups to cover different expert views. • The aim was to recruit 50 expert panel members. The intention was to recruit approximately 12 individuals per group, although a lower representation of some groups was expected given the	**Results** Scores are round 2 medians (mean absolute deviation from the median) Key to ratings: 1=always; 2=very often; 3=often; 4=sometimes; 6=rarely; 7=never; 8=no opinion *item modified in response to comments • Breathing and circulation ○ Breathing that is laboured/ irregular (where breathing was previously unaffected)*: 3 (0.41) ○ Breathing that is noisy/ bubbly (where breathing was previously unaffected)*: 3 (0.35) ○ Abnormal breathing patterns (e.g. apnoeas, Cheyne Stokes): 2 (0.33) ○ Previously beneficial oxygen in no longer effective: 4 (0.73) ○ Severe chest infection: 4 (2.29)	**Limitations** The quality assessment for this study was done using the proposed quality criteria for Delphi studies developed by Diamond et al. (2014) • Were criteria for participants reproducible? (yes, no) - YES. Recruitment was supported by key organizations in paediatric palliative care, who invited eligible individuals on their membership lists • Was the number of rounds to be performed stated? (yes, no) - YES. The authors performed 2 rounds. They used a modified approach method to ensure the items reflected the best available evidence, while

Study details	Participants	Methods	Themes/ categories	Comments
UK **Study type** Qualitative study (Delphi study) **Aim of the study** To identify signs and symptoms that indicate that a child with a life-shortening condition is moving into an end of life phase. **Study dates** Not reported **Source of funding** The work was funded by the Higher Education Council for Education.	paediatricians 24.5%; consultants in paediatric care 12.2%; GPs 6.1% • Number of years in specialty ○ Round 2 - median (range): 13 (3 to 31) • Number of CYP with LLC who seen in average month are likely to be in the last year of life - median (range): 30 (4 to 70) • Number of CYP with LLC seen in average month are likely to be in the last weeks/ days of life - median (range): 30 (4 to 70) • 85.7% involved in academic and service improvement activities **Inclusion criteria** • Individuals that were providing end of life care for children with LLC and had expertise • Sufficient length of service in this field • Frequent involvement with paediatric end of life care	limited numbers nationally. • Recruitment was supported by the Association of Paediatric Medicine, Together for Short Lives, Royal College of Nursing Paediatric Palliative Care Forum). SETTING Hospital, hospice and community service DATA COLLECTION A modified Delphi method (literature review and focus group) was used to ensure that the items reflected the best available evidence, while also reducing the number of itinerations for panel members. The aim was to generate a list of full consideration of relevant issues that are possible to define and collect. • Round 1. The panel was asked to independently rate each item and suggest	○ Objective methods showing a decline: 6 (1.12) ○ Persistent increased suction requirements: 4 (0.45) ○ Grey skin pallor: 3 (0.57) ○ Oedematous skin: 4 (0.69) ○ Oedema of extremities: 4 (0.60) ○ Instability of vital signs (temp, BP, RR, HR): 3 (0.64) ○ Peripheral shutdown (increased capillary refill time): 2 (0.39) ○ Pressure areas fail to heal despite optimal management: 4 (0.40) • Feeding ○ Not tolerating feeds/ less well absorbed: 3 (0.47) ○ Reduced urine output: 3 (0.49) ○ Anorexia (if orally feed): 3 (0.63) ○ Not wanting to drink (as opposed to eat) - if orally fed: 3 (0.38) ○ Cachexia: 4 (0.74) ○ Increasing feeding difficulties: 3 (0.61) • Neurological ○ Reduced level of consciousness (reduced GCS): 2 (0.20) ○ Intractable seizures despite optimal management: 3 (0.57) ○ New loss ability to feed self: 4 (0.65) ○ New loss of mobility: 4 (0.67) ○ New loss of continence: 4 (0.65) ○ New of accelerating muscle spasms: 4 (0.60)	also reducing the number of itinerations. • Were criteria for dropping items clear? (yes or not applicable, no) - NOT APPLICABLE. The authors did not set a specific threshold given that the criteria • Stopping criteria other than rounds specified? (yes, no) - NO • Total score: 2 **Other information** (-) Regarding sample selection, it is not clear if the participants that were eligible are representative of the population. It's likely that those who are members of one of the organizations have specific interest in the topic. •

Study details	Participants	Methods	Themes/ categories	Comments
	• Involvement in relevant service development activities **Exclusion criteria** • Not reported	other prognostic indicators. Baseline data was also collected to verify the panel's "expert status" (such as length of service in their specialty). They were also asked about the composition of their caseload, using definitions published by Together for Short Lives. • Round 2. The responses were collated and returned with a graphical indication of the panel's median scores and interquartile ranges. This second questionnaire also included the panel's clarification comments and additional suggested items. Participants were asked to re-score all items in light of the group's ratings and comments and they were given and opportunity to provide further clarification. • In both rounds participants were given 21 days to	○ New profound weakness: 3 (0.73) ○ Too weak to swallow tablets or medicines: 3 (0.69) ○ Less alert: 3 (0.35) ○ Unnatural tiredness: 3 (0.69) ○ No longer relating/ less responsive: 2 (0.33) ○ Asleep more often than awake: 2 (0.24) ○ Increased analgesia requirement/ increased pain: 3 (0.59) ○ New onset loss of distinction between day and night: 4 (0.79) ○ New or accelerating cognitive impairment: 4 (0.50) ○ Increased agitation: 4 (0.88) ○ Increased confusion: 3 (0.55) ○ Delirium: 4 (0.63) ○ Increased calmness/ severity: 4 (0.33) • Disease trajectory ○ Onset of significant new symptoms: 4 (0.48) ○ Increased appropriate hospital admissions despite community team care availability (2 annually): 4 (0.83) ○ Increased appropriate hospital admissions despite community team care availability (6 annually): 4 (0.54) ○ Increased appropriate hospital admissions despite community team care availability (>10 annually): 4 (0.71) ○ Increased frequency of chest infections: 3 (0.49) ○ Increased frequency of intercurrent illness: 4 (0.37)	

Study details	Participants	Methods	Themes/ categories	Comments
		complete the questionnaire with up to three email/ phone reminders where aproppiate. DATA ANALYSIS • Statistical analysis were done using SPSS 17.0. This determined whether the sample constituted one homogenous panel or several sub-panels. • Group differences were analysed using Kruskall-Wallis and Mann-Whitney tests. • The level of support for each item was indicated by the median and the level of consensus by the mean absolute deviation from the median. • The impact of the Delphi technique on final agreement and consensus was examined by assessing change between two rounds using Wilcoxon's signed rank test.	○ Persistent increase in care needs both day and night: 3 (0.37) ○ Takes longer to recover to usual level of health: 3 (0.40) ○ Does not return to previous level of health: 2 (0.29) ○ Increased medication needs: 3 90.53) ○ Increasingly sleepless nights: 4 (0.53) ○ Increasing contact with out of hours services: 3 (0.59) ○ Infections not responding to treatment: 3 (0.43) ○ Not responding to treatment/ intractable symptoms: 3 (0.31) ○ Increasing debility in response to lesser illness: 3 (0.25) ○ Episode of critical care: 3 (0.50) ○ Untreatable oncology/ hamatology condition: 4 (0.84) ○ Inoperable heart defect with persistent hypoxia bellow 70% or intractable congestive cardiac failure: 4 (0.90) ○ Intractable liver failure with encephalopathy: 4 (1.07) • Psychological ○ Attitude change in carer (more hopeless, more fear, more angry, more accepting, planning ahead for death): 3 (0.42) ○ Attitude change in CYP (more hopeless, more fear, more angry, more accepting, planning ahead for death): 4 (0.54) ○ Agreement that the CYP is not for ITU/ emergency care; has a DNAR: 3 (0.65)	

Study details	Participants	Methods	Themes/ categories	Comments
		• Given the variability of standards used to determine when consensus has been achieved, a specific threshold was not set. Instead it was hoped that the provision of comprehensive information about the perceived importance of items, degree of convergence and stability between rounds would allow transferability of the data to be judged.	○ Decreased participation in valued activities: 3 (0.65) ○ Difficulties talking about feelings with parents/ significant others: 4 (0.43) ○ Change in appearance (i.e. looks more unwell)*: 3 (0.46) ○ Reduced efforts to present self to usual standard (where CYP has some independence in self-care)*: 3 (0.59) ○ Referral to hospice: 4 (0.75) ○ Increase in family stress levels/ decrease in coping abilities: 4 (0.75) ○ Gut feeling/ intuition of health professional: 2 (0.33) ○ Gut feeling/ intuition of carers: 3 (0.58) ○ Gut feeling/ intuition of CYP where their cognitive function allows assessment: 4 (0.65) • New items suggested by the panel ○ Increasing irreversible loss of function of a major organ (e.g. lungs): 3 (0.79) ○ Repeated need for PICU (whether given or not): 3 (0.79) ○ Haemoptysis/ haemotemesis: 4 (1.00) ○ Severe/ persistent secondary pulmonary hypertension: 4 (1.44) ○ Increased frequency of blood stained or coffee ground aspirates from gastrostomy or nasogastric tube: 4 (0.83) ○ Bleeding with or without platelet support: 4 (0.90)	

(a) <Insert Note here>