Supplementary Table 2: Papers meeting inclusion criteria but not included in the synthesis

Author Year	Country	Setting	Child characteristics: Condition	Child characteristics: Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
Armentrout 2009[1]	United States	Hospital Home	All neonatal	Range: 2 days-2 mths	15 Parents - 11 Mothers - 4 Fathers	Grounded theory	To explore with parents how life support decisions were made for their infants, the roles they had in the decision-making process and how the decisions and subsequent death of their infants influence their everyday lives	Low	2
Armentrout 2007[2]	United States	Hospital Home	All neonatal	Range: 2 days-2 mths	15 Parents - 11 Mothers - 4 Fathers	Grounded theory	To addresses parents' perspectives about the life support decisions they made, their infant's death, and the nature and meaning of their everyday lives after the infant's death.	Med	2
Beecham 2017[3]	United Kingdom	Palliative care team	Mix of LLC conditions	Range: 0-17 yrs	21 Parents - 15 Mothers - 5 Fathers - 1 Stepmother	Grounded theory	To explore parents' experience in the UK of ACP discussions for children for whom cure is not likely.	High	1
Bogetz 2020[4]	United States	Children's hospital	All complex chronic conditions	Mean: 11.1 yrs Range: 1.9-2.03 yrs	110 Parents -83 Mothers - 19 Fathers	Prospective cross-sectional study	To elucidate supportive clinical care strategies identified by bereaved parents of children with complex chronic conditions.	Med	2
Bogetz 2021[5]	United States	Children's hospital	All complex chronic conditions	Mean: 11.1 yrs Range: 1.9-2.0 yrs	110 Parents - 83 Mothers - 19 Fathers	Prospective cross-sectional study	To elucidate supportive clinical care strategies identified by bereaved parents of children with complex chronic conditions.	Med	2
Branchett 2012[6]	United Kingdom	Not reported	All neonatal	Not reported	57 Parents - 54 Mothers - 3 Fathers	Inductive study	To determine what parents had experienced relating to neonatal palliative and end of life care and determine how this knowledge could be used to improve experiences for families in future.	Low	2

			Child characteristics						
Author Year	**Country**	**Setting**	**Condition**	**Age**	**Parent participants**	**Study design**	**Aim**	**Summary methodological assessment**	**Combined data richness /relevance score**
Brenner 2016[7]	Ireland	Hospice at home	Not reported	Not reported	7 Parents	Qualitative evaluation methodology	To understand the experiences of families receiving a nurse led pilot hospice at home programme and the experiences of healthcare professionals delivering and engaging with the programme	High	1
Brinchmann 2002[8]	Norway	Neonatal Units	All pre-term	Gestational age 24-40 wks	35 Parents - 19 Mothers - 16 Fathers	Descriptive study	To generate knowledge about parents' participation in life-and-death decisions concerning very premature and/or critically ill infants who are in hospital neonatal units	High	3
Brosig 2007[9]	United States	PICU NICU	all infants - mixed conditions	Mean: 62.9 days Range: 1-280 days	29 Parents -18 Mothers -11 Fathers	Explorative study	To identify factors important to parents in their infant's end-of-life care.	Med	2
Brouwer 2020[10]	Netherlands	Hospital	Mixed life threatening conditions	Range: 1-12 yrs	64 Parents - 42 Mothers	Qualitative study	To identify barriers, as perceived by parents, to good care for children with life-threatening conditions.	Med	2
Butler 2018 c[11]	Australia	PICU	Mixed conditions	Range: <1 yr->13 yrs	26 Parents - 18 Mothers - 8 Fathers	Constructivist grounded theory	To explore bereaved parents' interactions with healthcare providers when a child dies in a paediatric intensive care unit.	High	2
Butler 2019[12]	Australia	PICU	Mixed conditions	Range: <1 yr->13 yrs	26 Parents - 18 Mothers - 8 Fathers	Constructivist grounded theory	To describe bereaved parent recommendations for improvement in end-of-life care and bereavement follow-up when a child dies in intensive care	Low	1
Bužgová 2015[13]	Czech Republic	Home Hospital	Mixed life-limiting or life-threatening conditions - 2 cancer	1 mth-16 yrs	6 Parents	Qualitative study	To identify and describe the problems and experiences of family members caring for children with life-threatening or life-limiting diseases from diagnosis to the eventual death of the child	Med	1

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
Cacciatore 2019[14]	United States	Not reported	Mixed conditions - mostly cancer	4 mths-22 yrs	17 Parents - 13 mother - 4 Fathers	Qualitative descriptive methodology	To qualitatively evaluate parents' perceptions of their experiences with HCPs before and after the death of their child in a variety of settings and geographic locations	Med	2
Caeymaex 2011[15]	France	NICU	Mixed conditions - 71% preterm	Mean gestational age 31.2 weeks	164 Parents - 103 Mothers - 61 Fathers	Retrospective longitudinal design	To explore parents' experience of the EOL DMP for their child in the NICU.	Med	3
Coats 2016[16]	United States	Pediatric BMT unit	All cancer all received a bone marrow transplant	Range: 2-8 yrs	7 Parents - 5 Mothers 2 Fathers	Grounded theory	To describe parents' experiences and their perspectives of transitions that occurred along the trajectory of their child's illness	High	2
Collins 2016[17]	Australia	Paediatric hospice	Mixed conditions all life limited conditions	median 10 yrs Range: 3mths-17 yrs	14 Parents - 12 Mothers - 2 Fathers	Cross-sectional, prospective, qualitative study	To provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with a life-limiting condition in Australia	High	1
Contro 2002[18]	United States	Children's hospital	Mixed conditions	Range: 0-18	61 Parents -40 Mothers (incl 2 foster and 1 step) - 21 Fathers	Mixed methods	To obtain personal accounts of families' experiences to learn ways in to improve care for pediatric patients and their families	Med	2
Contro 2004[19]	United States	Children's hospital	Mixed conditions	Range: 0-18	61 Parents -40 Mothers (incl 2 foster and 1 step) - 21 Fathers	Mixed methods	To examine patient care from hospital staff and family perspectives	Med	1
Cortezzo 2015[20]	United States	NICU	All neonatal	Range: 1->14 days	7 Parents - 6 Mothers - 1 Father	Exploratory cross-sectional study	To determine the perceptions of end-of-life care practices and experience with infants who have died in the NICU among neonatologists, advanced	Med	1

Author Year	Country	Setting	Child characteristics Condition	 Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
							practitioners, nurses, and parents, and also to determine perceived areas for improvement and the perceived value of a palliative care team.		
Davies 2004[21]	United States	Home-based hospice care	Mixed conditions	Range: 3mths-14 yrs	8 Fathers	Grounded theory	To enhance understanding of fathers' experiences with a child who is seriously ill and dies.	High	2
Davies 2010[22]	United States	Hospital	Mixed conditions	Mean: 4.45 yrs Range: 1 day-20 yrs	36 Parents -25 Mothers - 11 Fathers	Grounded theory	To learn about experiences of Mexican American and Chinese American families who require pediatric palliative care	Med	2
Davies 2013[23]	United States	Mixed	Mixed conditions	Range: 0-21 yrs	60 Fathers - 55 Fathers - 3 Step-Fathers - 2 Other	Grounded theory	To improve end-of-life care for children and their families by exploring the fathers' experiences	High	2
Einaudi 2010[24]	France	Perinatal unit	Mixed conditions - all perinatal	Range: birth-3 mths	12 Parents - 10 Mothers - 2 Fathers	Qualitative descriptive study	To understand the parental response to perinatal death by describing the experiences of the families involved	Low	1
Flavelle 2011[25]	Canada	Home Hospital	Osteosarcoma	15 yrs	n/a	Phenomenology case study	To provide a unified description of an adolescent's experience of living with and dying of cancer	High	3
Fortney 2020[26]	United States	NICU	Mixed conditions	Mean: 40.9 days	46 Parents - 30 Mothers - 16 Fathers	Exploratory study	To examine bereaved parents' perceptions of infant suffering in the NICU	High	2
Gaab 2013[27]	New Zealand	PPC service	Mixed conditions	Range: 3-18 yrs	19 Parents - 12 Mothers - 5 Fathers	Not reported	To describe the experiences of a sample of primary caregivers who have children in palliative care.	Med	1

			Child characteristics						
Author Year	**Country**	**Setting**	**Condition**	**Age**	**Parent participants**	**Study design**	**Aim**	**Summary methodological assessment**	**Combined data richness /relevance score**
Gilmer 2013[28]	United States	Hospital	Mixed conditions	Range: 0-14 yrs	15 Parents - 14 Mothers - 1 father	Not recorded	To describe parental satisfaction of their children's care at EOL and to identify parental needs for the development and provision of pediatric palliative care services	Med	1
Goldstein 2013[29]	United States	Not recorded	Mixed conditions	Range: 1 mth-11 yrs	16 families	Qualitative study	To explore current involvement of PCPs when their patients face the end of life and bereaved parents' attitudes toward it.	High	2
Gurková 2015[30]	Slovakia	Hospital Home	Cancer	Range: 8-20yrs	5 Parents - 4 Mothers - 1 father	Qualitative study	To illuminate and analyse experience of parents with failed treatment and the death of their child suffering from cancer	High	1
Hellmann 2013[31]	Canada	NICU	Neonates - Withdrawn artificial nutrition and hydration	Gestational age: median 40 wks Range: 31-42 wks	10 Parents	Mixed methods	To review the experience of the practice of withdrawal of artificial nutrition and hydration (WANH) and to describe parental perspectives on the process.	Med	1
Higgs 2016[32]	Australia	Not recorded	Spinal muscular atrophy (SMA) type 1	Range: <3 mths-12 mths	13 Parents - 7 Mothers - 6 Fathers	Qualitative study	To examine parents' perspectives of having a child with SMA type 1, from diagnosis to bereavement,	High	2
Johnston 2020[33]	United States	Home Hospital	Cancer	Mean: 9.8 yrs	28 Parents - 18 Mothers - 10 Fathers	Not reported	To describe bereaved parents' perspectives of high-quality EOL care in pediatric oncology	High	2
Jordan 2015[34]	United Kingdom	Hospital hospice Home	Mixed conditions	yange < 1 yr-18 yrs	25 Parents - 16 Mothers - 9 Fathers	Interpretive qualitative approach	To explore the experiences of parents caring for children with both malignant and non-malignant conditions throughout the entire trajectory of their child's illness and subsequent death.	High	2

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
Kars 2011[35]	Netherlands	Home	Cancer	Range 6 mths-16 yrs	42 Parents - 22 Mothers - 20 Fathers	Interpretative qualitative study	To elucidate parents' experiences when caring at home for their child with incurable cancer and to show how parents give meaning to their experiences throughout the end-of-life (EOL) phase	High	2
Kenney 2021[36]	International	Not recorded	Cancer	Mean: 12.42 yrs Range: 2-25 yrs	-127 Parents -98 Mothers -29 Fathers	Qualitative approach	To examine family communication and preferred forms of support among bereaved caregivers of children with cancer.	High	2
Lundqvist 2002[37]	Sweden	Hospital	Infants	Mean 5.6 days Range: 15 mins-2 weeks	16 Parents - 16 Mothers	Not reported	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	High	3
McHaffie 2001[38]	United Kingdom	NICU	Mixed conditions	Range: 0-9 mths	108 Parents	Not reported	To explore parents' perceptions of treatment withdrawal and the dying process	Med	2
Meert 2008[39]	United States	PICU	Mixed conditions	Median 1.6 yrs	56 Parents - 39 Mothers (incl. 2 legal guardian) - 17 Fathers	Qualitative interview study	To describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the pediatric intensive care unit (PICU)	Med	2
Meert 2008[40]	United States	PICU	Mixed conditions	Median: 4.5 yrs	33 Parents - 21 Mothers (Incl legal guardian) - 12 Fathers	Descriptive qualitative study	To explore parents' environmental needs during their child's hospitalization and death in the PICU.	High	2
Mekelenkamp 2020[41]	Netherlands	Hospital	All had undergone n pediatric hematopoietic	Range: <12->16 yrs	14 Parents - 7 Mothers - 7 Fathers	Qualitative descriptive study	To gain insight in parental experiences in EOL decision-making in allogeneic pediatric HSCT.	High	2

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
			stem cell transplantation (HSCT)						
Meyer 2006[42]	United States	PICU	Mixed conditions	Range: 0-18 yrs	56 Parents - 36 Mothers - 2- Fathers	Qualitative study	To identify parents’ priorities and recommendations for improving the quality of end-of-life care and communication in the PICU.	Med	3
Mitchell 2020[43]	United Kingdom	Mixed	Mixed conditions	Median 9 yrs Range 5-18 yrs	19 Parents - 13 Mothers - 6 Fathers	Longitudinal qualitative study	To understand the experiences and perceptions of healthcare services of children with life-limiting and life-threatening conditions and their family members, including palliative care.	High	2
Monterosso 2007[44]	Australia	Palliative care service	Mixed conditions	Age at diagnosis Cancer Mean: 6 yrs Non-cancer Mean: 1.8 yrs	Phase 1 Quant: 129 Parents - 103 Mothers Phase 2 Qual: 38 Parents	Mixed methods.	To obtain feedback from families of children receiving palliative and supportive care about their care needs in hospital and in community settings.	Low	1
Moro 2011[45]	United States	Neonatal	Extremely premature	Range: 7 mths-12 years	5 Parents - 5 Mothers	Case study approach	To examine parent, nurse and physician perspectives regarding how parents make life support decisions for extremely premature infants from the prenatal through end-of-life period are presented	low	1
Neilson 2015[46]	United Kingdom	Role of GPs	Cancer	Range: 6-16 yrs	12 Parents - 10 Mothers - 2 Fathers	Qualitative study	To examine the role of the general practitioner (GP) in children's oncology palliative care from the perspective of GPs who had cared for a child with	High	1

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
							cancer receiving palliative care at home and bereaved parents.		
Pector 2004[47]	United States	Perinatal NICU	Multiple gestations (except 1) Mixed conditions	Not reported	71 Parents - 67 Mothers - 4 Fathers	Grounded theory	To assess the experiences of bereaved parents of multiples with resuscitation and life-support discussions, the death process, and conversations with health-care professionals about death.	Med	2
PintoTaylor 2020[48]	United States	Not recorded	LLCs	Median: 2 yrs	9 caregivers	Grounded theory	To explore the decision-making factors for caregivers of children with life-limiting illness through the use of qualitative interviews and thematic analysis.	High	2
Popejoy 2015[49]	United Kingdom	Not recorded	LLC or LTCs	Range: 3-15 yrs	Phase 1 Quant: 129 Parents - 103 Mothers Phase 2 Qual: 38 Parents	Exploratory study	To understand the 'lived experience' of parents throughout the process of making and revising end of life care decisions for their child.	High	2
Price 2011[50]	United Kingdom	Not recorded	Mixed conditions	Range: 2 mths-20 yrs	25 Parents - 16 Mothers - 9 Fathers	Qualitative study	To explore 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	High	2
Price 2012[51]	United Kingdom	Not recorded	Mixed conditions	Range: 2 mths-20 yrs	25 Parents - 16 Mothers - 9 Fathers	Qualitative study	To examine the experiences of bereaved parents concerning the care provided to children who died from cancer compared to those who died from a non-malignant condition	High	2
Pritchard 2009[52]	United States	Hospital	Cancer	Range: 2 mths-19.6 yrs	42 Parents - 39 Mothers - 3 Fathers	Descriptive exploratory study	To identify how these parents perceived when their child's death would occur	Med	2

			Child characteristics						
Author Year	**Country**	**Setting**	**Condition**	**Age**	**Parent participants**	**Study design**	**Aim**	**Summary methodological assessment**	**Combined data richness /relevance score**
Reilly 2010[53]	United Kingdom	Home Hospice Hospital	Intellectual disability Miixed conditions	Range: 23 mths-18 yrs	9 Parents - 9 Mothers	Interpretative phenomenological analysis	To focus on the experiences of mothers who lose a child with an intellectual disability in the UK, to provide a rich description of their bereavement experiences, and offer an interpretation of these experiences in terms of issues relevant to service providers, researchers and medical professionals	High	2
Rini 2007[54]	United States	Hospital	Mixed conditions	Range: 10 days-20 yrs	11 Parents - 9 Mothers - 2 Fathers	Descriptive design	To describe the presence (or the absence) and the role of anticipatory mourning in parents who recently experienced the death of a hospitalized child and to determine if there were consistent factors that they described as helpful or detrimental to them during this process	Med	2
Robert 2012[55]	United States	Hospital	Cancer	Mean: 15 yrs	14 Parents - 7 Mothers - 7 Fathers	Focus group methodology	To understand the needs and experiences of bereaved parents whose child had received care at one National Cancer Institute-designated comprehensive cancer center	High	3
Schutze 2021[56]	Germany	Specialised palliative care team	Life limiting conditions	Range: 4 mths-17 yrs	13 Parents - 9 Mothers - 4 Fathers	Not reported	To explore parents' experiences and their demands of collaboration with SOPPC (specialised outpatient pediatric palliative care) team	High	1
Shelkowitz 2015[57]	United States	Hospital	Neonatal	Gestational age Mean: 28.6 wks	28 Parents -27 Mothers - 1 joint response	Cross-sectional survey study	To explore the personal care options offered to parents as well as parental perceptions of the counseling they received regarding these options at their infants' end of life	Med	1

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
Snaman 2016[58]	United States	Hospital	Cancer	Not reported	11 Parents - 9 Mothers - 2 Fathers	Not reported	To further characterize the grief journey of parents whose child died from cancer in order to better identify parents who can benefit from additional bereavement support and design strategies to improve bereavement services for these parents	Med	2
Steele 2005[59]	United States	Hospice	Mixed conditions	Not reported	Interviews: 36 Parents Survey: 105 Parents EoL Qs: 39 Parents - 24 Mothers -15 Fathers	Programme evaluation	To evaluate the Canuck Place children's hospice program. This article reports only on the end-of-life care component.	Med	1
Sullivan 2014[60]	Australia	Not reported	Mixed conditions	Range: 3 mths-10.5 years Mean: 3.5 yrs	25 Parents - 19 Mothers - 5 father	Exploratory descriptive study	To examine parents’ views and experiences of end-of-life decision-making	High	2
Sullivan 2020[61]	Australia	Not reported	Mixed conditions	Range: 3 mths-12 yrs	25 Parents - 19 Mothers - 5 Fathers	Exploratory descriptive study	To examine parents’ views and experiences of ELDM for their child	High	1
Tan 2012[62]	United States	Hospital	Mixed conditions - extreme prematurity - congenital heart diseases - genetic disorders	Range: 23-108 wks	14 Parents - 7 Mothers - 7 Fathers	Longitudinal prospective design	To prospectively describe the bereavement experience of parents whose infants die in acute care settings with a complex chronic condition	Med	2

			Child characteristics						
Author Year	Country	Setting	Condition	Age	Parent participants	Study design	Aim	Summary methodological assessment	Combined data richness /relevance score
Thienprayoon 2016[63]	United States	Hospice care	Cancer	Range: <2-18 yrs	31 Parents - 18 Mothers - 13 Fathers	Qualitative pilot	To explore parental perspectives of the hospice experience in children with cancer, and to explore how race ethnicity impacts this experience	High	2
Tutelman 2021[64]	United States	Home based palliative care	Mixed conditions	Mean: 10.5 yrs Range: 4-18 yrs	34 Parents - 24 Mothers - 10 Fathers	Qualitative descriptive design	To explore the concerns of parents who have a child in home-based PPC.	High	1
Verberne 2019[65]	Netherlands	Pediatric Palliative Care	Mixed conditions	Range: 0-18 yrs	32 Parents - 24 Mothers - 18 Fathers	Interpretative qualitative study	To examine experiences and coping strategies from the perspective of parents caring for a child receiving PPC	High	2
Weidner 2011[66]	United States	Hospital Home	Mixed conditions	Not reported	29 Parents - 20 Mothers -9 Fathers	Qualitative study	To identify and define the dimensions of pediatric end-of-life (EOL) care that are important to parents.	High	3
Wiener 2020[67]	United States	Mixed	Cancer	Mean: 12 yrs	127 Parents - 98 Mothers	Retrospective Survey	Aimed to assess the degree to which parents felt prepared to address their child’s medical problems and emotional needs at the EoL, as well as the implications from lack of preparation	Low	1
Yorke 2011[68]	United States	PICU	Mixed conditions	Range: 0-20 yrs	23 Parents (or Grandparents)	Mixed methods	To explore parents’ memories of having a child die in the PICU.	Med	2
Zaal-Schuller 2016[69]	Netherlands	Not reported	Severely disabled	Range: 0-19 yrs	17 Parents - 14 Mothers - 3 Fathers	Qualitative, retrospective study	To investigate the experiences of the parents and the involved physician during the end-of-life decision-making (EoLDM) process for children with PIMD	High	2
Zelcer 2010[70]	United Kingdom	Hospital	Brain Tumors	Range: 1-19 yrs	25 Parents - 16 Mothers - 9 Fathers	Qualitative thematic analysis	To explore the end-of-life experience of children with brain tumors and their families.	High	2

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