Journal of Pediatric Nursing 46 (2019) 18–25

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Parental Perspectives on Roles in End-of-Life Decision Making in the Pediatric Intensive Care Unit: An Integrative Review

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ARTICLE INFO

Article history:
Received 29 August 2018
Revised 14 February 2019
Accepted 19 February 2019

Keywords:
Role
Parent-child
Good parent
Pediatric intensive care unit
End of life
Decision making
Integrative review

ABSTRACT

Problem: Little is known about how parents perceive their role or the role of health care providers (HCPs) during end-of-life decision making (EOL DM) in the context of the pediatric intensive care unit (PICU).
Eligibility criteria: The authors searched CINAHL, PubMed, Ovid Medline, Web of Science, Social Science Database, PsycINFO, and Google scholar for English language studies performed in the United States related to parental perception of parental or HCP roles in EOL DM in the PICU since 2008.
Sample: Eleven studies of parents and health care providers (HCPs) of critically ill children in the PICU and/or receiving inpatient pediatric palliative care, and bereaved parents of PICU patients.
Results: Most parents reported belief that EOL DM is within the domain of parental role, a minority felt it was a physician's responsibility. Parental EOL DM is rooted more firmly in emotion and perception and a desire to be a 'good parent' to a child at EOL in the way they see fit than HCP recommendations or 'medical facts'. Parents need HCPs to treat them as allies, communicate well, and be trustworthy.
Conclusions: Role conflict may exist between parents and HCPs who are prioritizing different attributes of the parental role. The role of the nurse in support of parental role in the PICU is not well-elucidated in the extant literature.
Implications: Future research should focus on what parents need from HCPs, especially nurses, to support their parental role, and factors that facilitate the development of trust and good communication.

Background

The death of a child is a devastating event with long-lasting emotional and physical consequences for their parents (Behrman & Field, 2003; Hinds & Kelly, 2010; Shudy et al., 2006). These negative parental outcomes can include prolonged, unresolved grief, anxiety, depression, and- critically- a threat to one's parental identity (Doorenbos et al., 2012; Hinds, Schum, Baker, & Wolfe, 2005; Hinds et al., 2009; Hinds & Kelly, 2010). In the United States, children die most often in pediatric intensive care units (PICUs) (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013), where one way that parents attempt to fulfill their role is participation in end-of-life decision making (EOL DM) (Curtis, Foster, Mitchell, & Van, 2016; McGraw et al., 2012). For the purposes of this review, EOL DM pertains to critical treatment decisions, for example use or escalation of vasoactive medications, intubation, surgical interventions, dialysis, ECMO, or limitation of intervention (LOI) orders.

It is essential to understand the context in which EOL DM for children occurs. Yet studies of EOL DM for children do not tend to focus on the PICU population, where the nature and modes of death, events leading up to death, experience of parents, and developmental stages of children are different than those in the neonatal ICU, hematology/oncology wards, or at home with hospice (Burns, Sellers, Meyer, Lewis-Newby, & Truog, 2014; Fontana et al., 2013). Nor do studies sufficiently address the complex, integrated relationships between parents and health care professionals (HCPs) that may impact the decision-making process; the nurse-parent relationship is particularly missing from the existing literature. The context of the PICU, the roles parents and HCPs play, and the relationships between them all influence how decisions are made, by whom, and in what ways, and must be better understood.

The aim of this integrative review is to understand and summarize the literature regarding parents' preferences, experiences, and perceptions of parental and HCP roles in PICUs within the United States during EOL DM. It fills a critical gap in the literature by focusing both on parents' perspectives of their own role, as well as the roles of PICU HCPs who participate in EOL DM.

Methods

The search strategy for an integrative review of the literature was developed with the help of a senior medical research librarian. Using a combination of MeSH headings and keywords related to the parent's or HCP's role in EOL DM, CINAHL, PubMed, Ovid Medline, Web of Science, Social Science Database, PsycINFO, and the first 200 records of

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https://doi.org/10.1016/j.pedn.2019.02.029

Google Scholar were searched for peer-reviewed English language studies published in academic journals since 2008. A PRISMA flow diagram (Fig. 1) was used to track and guide the search which yielded an initial 2889 total results (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2009).

Because EOL DM is highly culturally influenced (Curtis et al., 2016; Devictor & Latour, 2011) studies performed outside of the US were excluded. Studies that focused only on NICUs, hospices, outpatient clinics, or acute care wards, non-PICU specific reviews, case studies, decision-making tools and testimonials, recommendations, and opinions were also excluded. There were ninety-nine abstracts left for review after duplicates were removed. Eighty-nine abstracts were rejected. One additional study was identified via hand-searching, yielding a total of eleven studies. The studies were evaluated using CASP critical appraisal checklists, a tool used to appraise study aims, methodology, design and implementation, data collection and analysis, possible ethical dilemmas, and potential contribution of findings to the literature (Critical Appraisal Skills Programme [CASP], 2018). Each article was repeatedly manually reviewed. The authors then extracted data by searching for patterns and themes regarding parental and HCP roles across the eleven articles.

Results

Of the eleven studies, three were mixed-methods (Hill et al., 2015; Michelson et al., 2009; October, Fisher, Feudtner, & Hinds, 2014), three were quantitative (Feudtner et al., 2010, 2015; Madrigal et al., 2012), and five were qualitative (Brooten et al., 2013; Carroll, Mollen, Aldridge, Hexem, & Feudtner, 2012; McGraw et al., 2012; Michelson, Patel, Haber-Barker, Emanuel, & Frader, 2013; Mooney-Doyle, dos Santos, Szylit, & Deatrick, 2017). Three were retrospective (Brooten et al., 2013; McGraw et al., 2012; Michelson et al., 2013). Four were components of a larger, prospective cohort study on parental decision making at a single institution (Carroll et al., 2012; Feudtner et al., 2010, 2015; Hill et al., 2015). Key themes that emerged include: 1) parents focus on fulfilling the role of a ‘good parent’ at the end of a child's life, defining characteristics of a ‘good parent’ similarly regardless of situation; 2) the majority of parents assume they should be responsible for EOL DM, although a minority regard that task as a physician's responsibility; 3) decision-making is highly personal, and more rooted in emotion and perception than in medical facts or physician recommendations; 4) parents need HCPs to be trustworthy, to communicate well, and to handle disagreements about decisions as allies rather than adversaries. Results of the review are summarized in Table 1.

Perspectives on parental role

The “good parent”

The concept of being a good parent to a child at the end of their life was an organizing theme of three studies (Feudtner et al., 2015; McGraw et al., 2012; October et al., 2014). Two of the studies specifically

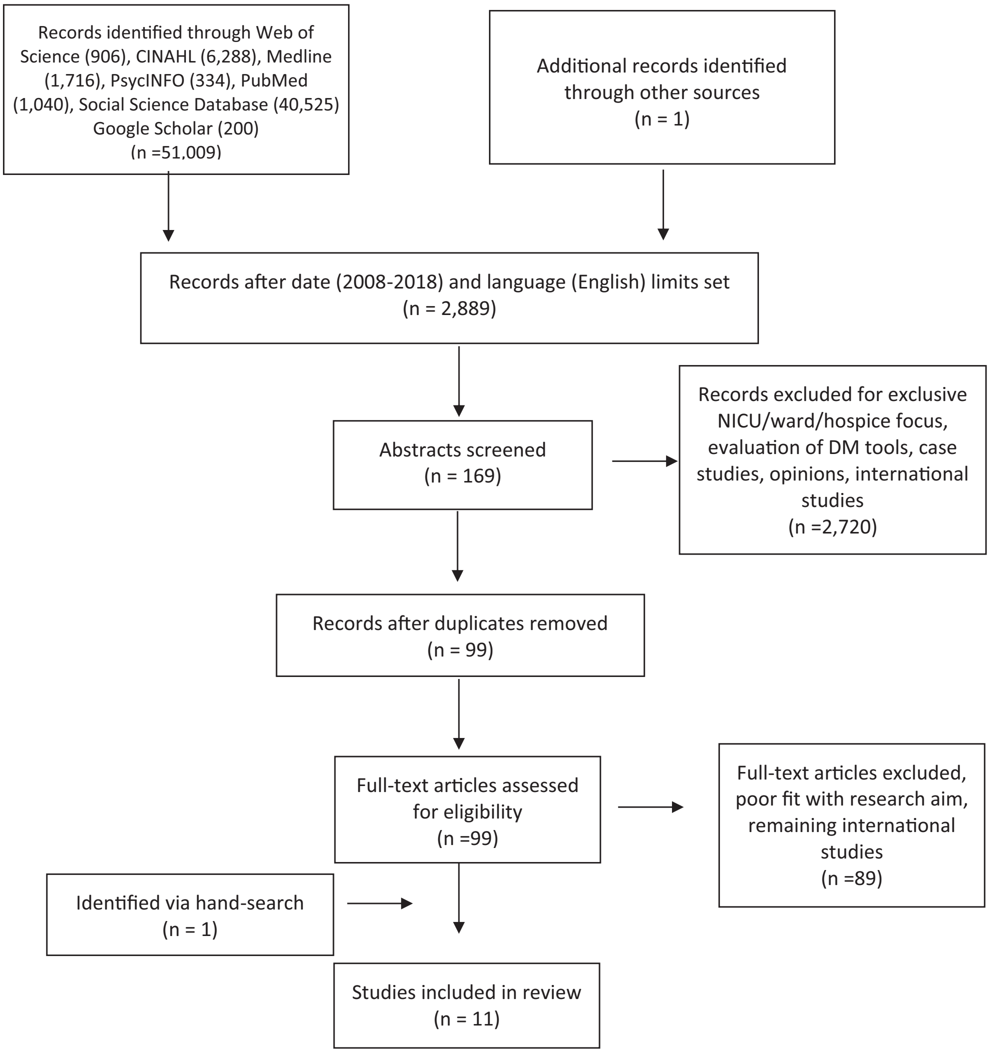

Fig. 1. PRISMA literature search flow diagram.

utilized a “Good Parent” discrete choice tool, developed from priorities described and defined by parents in a pediatric oncology setting (Hinds et al., 2009). The Good Parent Tool was used to ask parents to rank the characteristics and responsibilities that make a good parent from most to least important to them (Feudtner et al., 2015; October et al., 2014). These characteristics included: advocating for the child, prioritizing the child's needs, focusing on health and longevity, ensuring the child feels love, making informed decisions, maintaining legacies, and focusing on the spiritual well-being of the child. The third study found that participants described wanting to be the “best” parents they could by actively participating in decision making, creating as secure, private space amid the busy hospital environment, and providing love and comfort to the child (McGraw et al., 2012).

Authors of these studies report that parents identified or similarly ranked the same traits as integral to the identity of a ‘good parent’ regardless of the child's age or whether their child was at the end of life, was newly diagnosed, or had a long-term, chronic condition (Feudtner et al., 2015; McGraw et al., 2012; October et al., 2014). Notably, while not explicitly utilizing “good” or “best parent” terminology, authors of several other studies also describe that participants valued being in charge of decision making, focusing on what is best for the child, and expressing love and care for their child as being vitally important to them in their role of caring for seriously ill children, (Brooten et al., 2013; Carroll et al., 2012; Michelson et al., 2009; Mooney-Doyle et al., 2017).

However, while the studies have identified ‘good parent’ attributes that are comparable across circumstances, they emphasized that parents actualize these characteristics differently and may do so based on personal experience, stage of clinical disease progression, or emotional state. Two studies found the most commonly held good parent attributes that parents endorsed included making sure the child feels loved, focusing on the child's health, and making informed medical decisions (Feudtner et al., 2015; October et al., 2014). Feudtner et al. (2015) found that those parents whose children had a newer diagnosis focused more on understanding their child's health, and rates of anxiety and depression were higher in those who focused on being informed advocates. McGraw et al. (2012) found that the way parents felt about their ability to be a good parent at end of life shaped their feelings about the child's death; those who believed they had been unable to enact their parental role as they felt they should experience lasting regrets.

Decision making

Responsibility for decisions

Six studies in this review suggest that parents expect to be responsible for final decision making regarding withdrawal or withholding of life-sustaining treatment, and that they viewed this is a vital component of their parental role (Carroll et al., 2012; Feudtner et al., 2015; Madrigal et al., 2012; McGraw et al., 2012; Michelson et al., 2009; Michelson et al., 2013). Carroll et al. (2012) and McGraw et al. (2012) point out that the role of decision maker may be a natural extension of parental self-perception as the expert on the child; as in, ‘I am the person who should make the decision because I am the person who knows my child best.’

Decision-making and emotion

In these studies, parental EOL DM was often rooted in emotion, personal experience, and observation of their child (Brooten et al., 2013; Carroll et al., 2012; Madrigal et al., 2012; McGraw et al., 2012; Michelson et al., 2009). There was a suggestion that the associations parents bring to decision making (including perception of suffering, past experience, faith background, and trust in the physician) were more important to parents than ‘medical facts’ when they were making end-of-life decisions (Madrigal et al., 2012; Michelson et al., 2009; Michelson et al., 2013). In five studies, the negative feelings that accompanied an awareness of their child's suffering and poor quality of life were the driving force behind parental participant's decisions to limit or to withdraw care (Carroll et al., 2012; Feudtner et al., 2010; Hill et al., 2015; Madrigal et al., 2012; Michelson et al., 2009).

Perspectives on health care professional role

Decision making

Notably, in the Madrigal et al. (2012) study a substantial minority (18.9%) of study participants preferred that physicians take responsibility for making the ultimate decision regarding withdrawing life-sustaining treatment. In their study of bereaved parents, Michelson et al. (2013) found that for some parents, after a period of time in the very regimented ICU where physicians orders controlled nearly all facets of parents' lives, “suddenly” being handed the most important decision of all was a startling, burdensome, and uncomfortable role-reversal, and participants continued to prefer the physician remain in the role of decision-maker.

Communication

Given the magnitude of the task of EOL DM and the emotionally charged climate in which it takes place, it is no surprise that six studies emphasized the importance of good communication between HCPs and parents (Carroll et al., 2012; Feudtner et al., 2010; Hill et al., 2015; Michelson et al., 2013; Mooney-Doyle et al., 2017; October et al., 2014). Three studies reported that parents found the use of medical jargon alienating and overwhelming and needed medical information repeated multiple times in plain language (Brooten et al., 2013; Carroll et al., 2012; McGraw et al., 2012). Brooten et al. (2013) reported that some parents did not have a good understanding of the expected disease progression or the likelihood of death, and pointed to poorly timed, abrasive, abrupt, or absent communication as the cause.

Trust

Michelson et al. (2013) reported that whether or not to trust their HCPs as an important non-medical decision parents face at the end of their child's life (Michelson et al., 2013). Factors contributing to parental trust of HCPs include observed problems such as medication errors (McGraw et al., 2012) and perceived lack of HCP experience (Brooten et al., 2013; Carroll et al., 2012). Two studies describe that trust was eroded by open conflict with or between HCPs about what is the best course of action (Brooten et al., 2013; Michelson et al., 2013). Michelson et al. (2009) convey that parents in their study were sometimes reticent to trust HCPs because they were cognizant that HCPs often make mistakes, have been wrong previously, or “are not God.”

Parent-provider disagreements

Brooten et al. (2013) pointed out that when parents were unwilling or unable to choose to limit interventions or withdraw care, they potentially knew that they were not fulfilling their parental role in the way HCPs would like them to do. While parents and HCPs can sometimes feel at odds with one another regarding decision-making at EOL, parents in the PICU may visualize the most important part of their parental role is to advocate for their child or ensure their longevity, to the dismay of PICU HCPs, who want parents to focus on protecting their child from perceived suffering (Feudtner et al., 2015; Hill et al., 2015). Mooney-Doyle et al. (2017) report that no matter which parental role function took on primacy for participants, disagreement with HCPs was painful and isolating, and parents preferred HCPs to “fight with me and not against me” for their children (p. 167).

Discussion

This review aimed to examine what is known about how parents define and experience roles in the PICU in the context of EOL DM. The studies presented here begin to outline how parents perceive the important components of parental role, including what a good parent is and what a good parent does. It is imperative to recognize that the studies show

Table 1
Studies included in review.

Authors/year Title/location	Purpose/aim	Sample	Intervention description	Research design	Key results	Limitations	Implications
Brooten, D., Youngblut, J.M., Seagrave, L., Caicedo, C., Hawthorne, D., Hidalgo, I., & Roche, R. (2013). Parent's perceptions of HCPs actions around child ICU death: What helped, what did not. South Florida	Describe parents' perspectives of helpful/unhelpful HCP actions surrounding EOL period	63 English and Spanish speaking bereaved parents of 47 patients. 44% fathers 73% non-white participants Convenience subgroup of larger study.	Semi-structured interviews, 7 months after death	"Qualitative methods" Part of retrospective longitudinal cohort mixed method study	What helped: Good communication, Providers 'did everything' Parental role preserved in care and DM What did not: Decisional conflict between parent/provider, Communication problems "Insensitive staff" ranked highest problem by gender, ethnicity, and unit	Pts only had to be in ICU for @ least 2 h to be included Mix NICU/PICU Unclear theoretical/methodological approach Use of term HCP makes distinguishing role-specific actions difficult	Changes in parental role are major stressor Observed child suffering increases parental anxiety and decreases ability to comprehend team communication Difference in problem ranking between mothers and fathers- need more fathers in studies Need to examine family relationships with nurses, including cultural influences
Carroll, K.W., Mollen, C.J., Aldridge, S., Hexem, K.R., & Feudtner, C. (2012). Influences on DM identified by parents of children receiving pediatric palliative care (PPC). CHOP	Characterize the DM process of parents of children receiving PPC	16 English speaking parents of ICU patients receiving PPC 44% fathers, 33% non-white participants Subset of Decision Making in Pediatric Palliative Care Study (DPPC)	Semi-structured interviews of parents in the midst of making decisions	Qualitative prospective cohort	DM takes place in broad personal, relational, emotional, and familial context DM is social/interactive process Parents struggle with defining what is good/best interest for child and family	Poorly defined methodology Already receiving PPC Mix NICU/PICU	Parental DM processes are grounded in relationships with others (staff, friends, family), emotions, perception of child QOL/suffering, self-perception of parental role, not just 'medical facts'. Parents need clear, honest, easy to understand, frequent, compassionate communication
Feudtner, C., Walter, J.K., Faerber, J.A., Hill, D.L., Carroll, K.W., Mollen, C.J., Miller, V.A., Morrison, W.E., Munson, D., Kang, T.I., & Hinds, P.S. (2015). Good-parent beliefs of parents of seriously ill children. CHOP	Assess/Rank the importance that parents place on various good-parent beliefs when making decisions about their child's care	200 English speaking parents of 158 critically ill children in ICU 30% fathers 81% white 98.5% insured 76.5% preexisting complex chronic condition Part of DPPC	+/− Affect Scale (PANAS) Dispositional Hope Scale, (DHS) Hospital Anxiety/Depression Scale (HADS) "Good Parent" discrete choice tool	Quantitative prospective cohort	Top attributes: making sure child feels love, focus on child's health, making informed decisions. Keeping realistic outlook ranked lowest. Fathers, Latinos, single parents, low SES, lower education level, newly diagnosed all focused most highly on "child's health" attribute. Highest anxiety/depression scores in advocacy/informed group	Already receiving PPC Mix NICU/PICU Mostly women, white, well-educated Majority complex chronic condition	Parents have cherished and varied beliefs about parental role and importance of duties to child. Best interest is personally defined and likely highly influenced by perception of role duties Need to examine long-term changes in parental GP beliefs Nurses can help parents be 'good parents' if they understand what aspect they are prioritizing
Feudtner, C., Carroll, K.W., Hexem, K.R., Silberman, J., Kang, T.I., & Kazak, A.E. (2010). Parental hopeful patterns of thinking, emotions, and PPC DM CHOP	Examine whether parental hope, perception of child's health, and positive/negative affect is associated with limitation of intervention (LOI) DM	43 English speaking parents of 33 children receiving PPC 21% fathers, 81% white Part of DPPC	Parental rating of child's health (current & retrospective) Assessment of LOI order status PANAS HADS	Quantitative prospective cohort	42.4% had LOI orders enacted w/in 6mo Negative affect scores higher in: parents of younger children ($p = 0.03$), children with no role in DM ($p = 0.01$), and parents with less higher education ($p = 0.01$). Higher baseline hope associated with subsequent LOI orders, but higher positive affect associated with lower rates LOI orders Perception of declining trajectory associated with increased LOI orders	Already receiving PPC Some missing data Mix ward/PICU/hospice Mostly white women	Parents capable of maintaining hope even while planning for an unwelcome outcome, and hope may even be protective in allowing parents to function.
Hill, D.L., Miller, V.A., Hexem, K.R., Carroll, K.W., Faerber, J.A., Kang, T., & Feudtner, C. (2015) Problems and hopes perceived by mothers, fathers, and physicians of	Describe and examine concordance of problems and hopes reported by mothers, fathers, MDs of children receiving PPC	71 parents & 43 MDs of 50 children receiving PPC 35% fathers 47% female physicians MDs 100%	Semi-structured interviews, self-report agreement re: problems and hopes on Likert scale, observed concordance of problem and hope domains	Mixed-method prospective cohort	Problem/Hope Domains from most to least common: Physical body, quality of life, medical knowledge, suffering, medical care, miracle or cure, length of life, meaning. Lower concordance between mothers and MDs and fathers and MDs than	Already receiving PPC Mix units/NICU/PICU Some patients died in course of study Nurses not included	Differences in hopes/problems may be r/t role differences- parents may see their role as being obligated to hope for miracle, while MDs may perceive duty to not endorse false hope. Need larger sample, longitudinal

(continued on next page)

Table 1 (*continued*)

Authors/year Title/location	Purpose/aim	Sample	Intervention description	Research design	Key results	Limitations	Implications
children receiving palliative care. CHOP		Non-Hispanic white Part of DPPC			between parents re: perceived problems Fathers more likely to report hope for miracles or longevity than mothers or MDs		design, examination of how age and diagnosis influence hopes/problems
Madrigal, V.N., Carroll, K.W., Hexem, K.R., Faerber, J.A., Morrison, W.E., & Feudtner, C. (2012). Parental DM preferences in the PICU. CHOP	Assess parental DM preferences in PICU and examine whether they vary with demographics, health care experience, condition, or parental affect	87 English speaking parents of 75 children in PICU >72 h 66.3%white 30.5% fathers 83.2% partnered	Pediatric risk of mortality III (PRISM III) Scores PANAS ADHS Self-report Likert scale “Parental Decision Preference” ranging from self, shared, MD	Quantitative prospective cohort	40% preferred shared DM, 41.1% mostly making decision on their own, 18.9% MD/mostly MD make decision. Chronic conditions not associated with preference for autonomous DM. Higher positive affect, more likely to prefer shared DM model. Negative affect not associated with any DM preferences.	Mostly white, middle class, English speaking, “No financial worries” (55%)	Relationship between affective state and DM preference needs further study Differences between: Moms & dads, influence of financial difficulties/SES, racial/ethnic/cultural differences, need longitudinal study. Need to investigate relationship between parents/MD and DM preference
McGraw, S.A., Truog, R.D., Solomon, M.Z., Cohen-Bearak, A., Sellers, D.E., & Meyer, E.C. (2012). “I was still able to be her mom”-parenting at the end of life in the PICU. 2 PICUs in NE US academic medical center children's hospitals.	Examine how parents of children dying in PICU understood their role	Purposive sample of 18 English speaking parents of children who died in PICU at least 6 months prior	Semi-structured telephone interviews about events within 72 h of child's death	Qualitative retrospective cohort	Parents emphasized importance of role maintenance and being “best parents”. Parents want central role in 3 domains: - Providing love, comfort, care - Creating security/privacy - Exercising responsibility for “what happens” DM View selves as literal and figurative protectors and advocates for children	Unclear methodological/theoretical underpinnings Mostly white middle-class women, English speaking, only 1 father Low response rate, majority had chronic conditions rather than acute or traumatic	Parents unable to feel they ‘did the best they could’ had long lasting regrets. Want to remain central to child's care. Practitioners need to communicate clearly about how parents specifically want to fulfill their role & show their love at EOL Parents need a ‘sacred space’ in the PICU that they control
Michelson et al. (2013). EOL Care decisions in PICU: Roles professionals play. 2 US tertiary care PICUs	Describe roles/responsibilities of PICU HCPs in EOL DM from point of view of parent and HCP	18 English speaking parents of children under 8 who died in PICU >6 months earlier 48 HCP who care for PICU patients 42% RNs	In depth interviews with parents Focus groups with HCPs	Qualitative Retrospective cohort	Decisions faced by family included medical and nonmedical decisions. Nonmedical includes accepting/trusting team, agreeing to involvement of hospice, involving other family members. Identified HCP roles: family supporter, parent advocate, information giver, general care coordinator, decision maker, EOL coordinator, point person. Point person is contact for family who fosters trust between family and team	Mostly White, English speaking Retrospective with varying bereavement periods Use of term HCP makes distinguishing role-specific actions difficult	1st framework describing HCP role from parent POV Important to study role shift/reversal at EOL DM (responsibility shift from HCP to parent) Need to study how roles of MDs/RNs interact with other parental influences (family, friends)
Michelson, K.N., Koogler, T., Sullivan, C., del Pilar Ortega, M. Hall, E., & Frader, J. (2009). Parental views on withdrawing life-sustaining therapies in critically ill children. 2 US academic tertiary care PICUs	Explore factors described by parents in the PICU as important in pediatric EOL DM	70 English or Spanish speaking parents with 1–7 day PICU stay 21% fathers 68% HS education or less 57% non-white participants Recruited only African American & Hispanic parents in last 6 months of study	Semi-structured interviews regarding hypothetical DM scenarios	Mixed methods prospective cohort	Factors ID'd as important influences on parental LOI decisions: Quality of life, suffering, ineffective treatment, faith, time, financial considerations, general rejection of withdrawal, mistrust of MD, reliance on intuition. 96% participants felt parents should make EOL decisions, but 50% of these parents felt physician should also participate	Hypothetical questions answered by parents whose children expected to live Attending pointed recruiters towards (or away from) certain families	Parents identify as responsible for EOL DM Perception of suffering important factor in DM, physician prognosis carries less weight, especially when parents do not have trusting relationship with HCP
Mooney-Doyle, K., Rodrigues dos Santos, M., Szylit, R., Deatrick, J.A. (2017). Parental expectations of	Describe parental expectations of and meaning ascribed to HCP support of parenting roles and goals during child's LTI	31 English-speaking parents of children not expected to recover from	Secondary analysis of semi-structured interviews	Qualitative descriptive. Theoretical underpinning: Family	Themes Help me survive this Let's fight together: please fight with me and not against me to care for my family	Secondary data analysis Not exclusively PICU Majority white, female participants Use of term HCP makes	Parents believe HCPs can help them fulfill parental role to ill child & healthy siblings Parents expect relationships with staff that are honest,

support from HCPs during pediatric life-threatening illness: A secondary, qualitative analysis. Mid-Atlantic children's hospital		life-threatening illness. 19% fathers 64.5% white		Adjustment and Adaptation Response Model	- Let me care for, protect, and communicate love to my child Guide me through the darkness, I am suffering - How should I manage this? - What is the right decision?	distinguishing role-specific actions difficult	communicative, and supportive/caring. They utilize these relationships to decrease isolation & support DM Parents are in distress when they feel HCPs do not care for them or their child
October, T.W., Fisher, K.R., Feudtner, C., & Hinds, P.S. (2014). The parent perspective: "Being a good parent" when making critical decisions in the PICU. Single urban tertiary medical center PICU	Identify factors important to parents of children in PICU making decisions Identify HCP actions that help parents fulfill their definition of the Good Parent	43 English speaking parents of 29 children 42% male 75% non-white 37% HS education or less or less	PRISM score & PICU length of stay Good Parent Ranking Tool, completed via interview completed within 24 h of family conference	Mixed method cross-sectional	No association between parental demographics or child's condition for any themes identified Most helpful HCP actions to support 'good parent' 1."Keep us informed" 2."be attentive" GP Theme Ranking: Understand/focus on child's health ranked 1st of 11 attributes Informed DM ranked 3rd Ensure child feels loved 4th "Keep realistic outlook" ranked last	-Enrollment limited to weekdays, dependent on attending approval Focus on complex, chronic illness Only some couples interviewed together Not at immediate EOL, not all decisions were EOL decisions Use of term HCP makes distinguishing role-specific actions difficult	Potential for the idea of the "good parent" to improve parent/HCP relationships, understanding, and DM process Parents embraced title of "good parent" because it accurately described role they were struggling to fulfill Parents ID same attributes of and desire to be a good parent regardless of personal background, disease characteristics

that parental perception of and attempts to actualize their role are not static. Parents ascribe the duties associated with parental role different levels of importance based on highly personal factors and the perceived needs of the child (Feudtner et al., 2015; McGraw et al., 2012; October et al., 2014). Additionally, they may focus on a particular task because they believe they are the best or only person for the job (Brooten et al., 2013; McGraw et al., 2012).

Role conflict between HCPs and parents who prioritize making sure “everything” is done may be a source of contention. Both providers and parents have the ‘best interest’ of the child at heart; the issue is that ‘best interest’ is often personally defined and informed by the role of the individual (Kars, Grypdonck, de Bock, & van Delden, 2015). For HCPs, the conception of the best interest may mean prioritizing limitation of intervention (LOI) orders as a means to decrease suffering, while for parents it may translate to ‘leaving no stone unturned’ in pursuit of the child's longevity. Parents who ‘resist’ LOI orders may be trying both to give their child a chance and to find a way to “live with” their decision (Bluebond-Langner, Hargrave, Henderson, & Langner, 2017). A parent in the Michelson et al. (2013) study put it this way: “I still think I removed that breathing tube. The doctor might have removed it, but I did. Physically, the doctor, but emotionally, I did, and it hurts” (p. e40).

This review shows that good, thoughtful communication is important to parents, who want to know what to expect and what is expected of them in the unfamiliar environment of the PICU. Communication that is untimely, incomplete, abrasive, judgmental, one-way, or otherwise tone-deaf is upsetting and harmful to parents. Parents often wish to communicate their expertise in their child to the team; HCPs can look for clues about what is important to parents by creating time to observe, to listen, and to validate parental feelings and experiences. For example, studies have shown that continuity of nursing care leads to parental feelings of relief and trust (Baird, Rehm, Hinds, Baggott, & Davies, 2016; Butler, Hall, & Copnell, 2018); if nurses are aware that a parent prioritizes advocacy in their parental role, they can work to ensure continuity of care in an effort to reduce the anxiety that the responsibility of constant vigilance provokes.

In an examination of parental understanding and perception of roles in the PICU, it is important to consider the term “health care professional”, utilized here by the studies that did not focus specifically on physicians. The studies which utilized the HCP term either did not specify which roles were encapsulated by the term, or the majority of participants were typically providers and not bedside nurses. Nurses and doctors have different duties, hierarchical power placements, and relationships with family that a catch-all term such as HCP does not take into consideration (Butler et al., 2018; McGibbon, Peter, & Gallop, 2010). The specific role of the nurse is under-represented and under-examined in the studies reviewed here. Nurses are in sustained closer physical proximity to patients and their families and spend more time with them on a day-to-day basis than any other member of the team (McGibbon et al., 2010; Michelson et al., 2011). This unique position is ideal for the formation of close relationships with parents (Watson & October, 2016), and in fact, some studies show that parents rank nurses higher as sources of support and understanding during EOL DM than friends, extended family, spiritual directors, or instinct (Falkenburg, Tibboel, Ganzevoort, Gischler, & van Dijk, 2018; Madrigal et al., 2016). Several of the studies in this review confirm this, as parents pointed to their relationship with specific nurses as instrumental to their coping (Brooten et al., 2013; McGraw et al., 2012; Michelson et al., 2013). The quality of nursing care, or lack thereof, is remembered by bereaved parents long after the death of their child (Falkenburg et al., 2018; McGraw et al., 2012).

Despite this, none of the studies specifically investigated parental understanding of the role of the nurse or their interactions with nurses during decision making. Therefore, while previous studies show that the nurse role is important to parental support during EOL DM, the details of how this occurs are unclear. For example, in studies about family conferences (FCs), the method by which PICU teams most frequently address treatment decisions, nurses are either not discussed by authors at all (Smith et al., 2018), or it is noted that nurse attendance is not necessary for the conference to occur (Michelson et al., 2011; Watson & October, 2016). And although some participants and authors noted that after decision-making conferences, nurses and parents would spend a long time in continued private conversation in the room, the content, tenor, and purpose of these conversations is not known and has not been studied from either the nurse or the parent perspective (Michelson et al., 2011; Watson & October, 2016).

The lack of specific nurse representation in studies about EOL DM is problematic and troubling. For example, a simple database search for “physician role decision making PICU” returned 16,500 results, while the search “nurse role decision making PICU” returned only six records. The interpersonal work of nurses as they interact with parents in the crucial period of EOL DM may well be vital to the functioning of parents making decisions in the PICU. Yet the lack of visibility of nurses in existing literature suggests that perhaps nurses contributions in this arena are undervalued (McGibbon et al., 2010). Attention must be paid to the role of nurses in order to understand how they can best support parents in their vital quest to fulfill their parental role during EOL DM.

Limitations

Limitations of included studies

Three studies were retrospective in nature, and the time from bereavement to the study varied (Brooten et al., 2013; McGraw et al., 2012; Michelson et al., 2013). It is unknown whether the insights parents shared about end-of-life decision making in the PICU would be the same if they were gleaned while the child was hospitalized or what differing bereavement intervals mean for comparison of perspectives. Four studies were part of a single larger long-term study and pulled from a pool of parents whose children were already receiving palliative care and therefore may not accurately represent all parents (Brooten et al., 2013; Carroll et al., 2012; Feudtner et al., 2010; Feudtner et al., 2015). The Michelson et al. (2009) study asked parents of children in the PICU who were not facing LOI decisions their views on withdrawal of support rather than interviewing those currently facing those decisions. Although these were parents of critically ill children, it is conceivable that even in PICU parents hypothetical decision making is not comparable to actually being confronted with the task. Strikingly, the majority of the studies included in this review were conducted with almost all white and English-speaking participants. They were also predominantly women, with studies typically including only a small number of fathers.

Limitations of this review

The review was limited by including only English-language studies with participants from the United States and a limited gray literature search. Additionally, despite the fact that the context of the PICU is very different than other units, it was difficult to find studies focused solely on the parenting experience of EOL DM in the PICU.

Research implications

Future research should focus on how parents view and understand the role of the nurse, especially as it relates to support of the parental role in end-of-life decision making. Given the proximate and intimate relationship nurses have with families and the effect nursing care can have on parents even after the death of their child, the interplay between the roles of nurse and parent in the PICU needs much more visibility and study. The factors that allow families to build trusting relationships with those caring for their child also deserve more attention. Finally, purposeful inclusion of underrepresented populations, such as people of color, fathers, non-English speakers, ‘non-traditional’ families, and parents with varying degrees of socio-economic stability is of vital importance in order to enhance understanding of the experiences of all families.

Conclusion

Parents who feel unable to fulfill their parental role as they see fit at the time of the child's death may be at increased risk for prolonged grief, anxiety, depression, post-traumatic stress symptoms, and permanently damaged parental self-concept. EOL DM is one of the final tasks parents perform, and they try to make decisions for their children in a manner consistent with what they believe to be their child's greatest needs and their own parental responsibilities. Knowing how they perceive their role, the roles of those around them, and what they need from those caring for their child may be a pathway towards understanding how to help them cope with the heavy burden of EOL DM. Future research should focus on clarifying the role of the nurse and on development of trust between families and PICU staff, particularly with underrepresented groups and “non-traditional” families.

CRediT authorship contribution statement

Rachel A. Bennett: Conceptualization, Formal analysis, Investigation, Writing - original draft. **Virginia T. LeBaron:** Writing - review & editing, Supervision.

Acknowledgements

Thank you to Dan Wilson, University of Virginia Claude Moore Health Sciences Library medical librarian and School of Nursing Library Liason for his invaluable assistance assuring the completeness of the literature search. Thank you also to Kathryn Laughon, PhD, RN, FAAN and Elizabeth Epstein, PhD, RN, FAAN for their guidance and support.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declarations of interest

None.

References

Baird, J., Rehm, R. S., Hinds, P. S., Baggott, C., & Davies, B. (2016). Do you know my child? Continuity of nursing care in the pediatric intensive care unit. *Nursing Research*, *65*(2), 142–150. https://doi.org/10.1097/NNR.0000000000000135.

Behrman, R. E., & Field, M. J. (2003). *When children die: Improving palliative and end-of-life care for children and their families.* Washington, DC: National Academies Press.

Bluebond-Langner, M., Hargrave, D., Henderson, E. M., & Langner, R. (2017). “I have to live with the decisions I make”: Laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses. *Archives of Disease in Childhood*, *102*(5), 468–471. https://doi.org/10.1136/archdischild-2015-310345.

Brooten, D., Youngblut, J. A. M., Seagrave, L., Caicedo, C., Hawthorne, D., Hidalgo, I., & Roche, R. (2013). Parent's perceptions of health care providers actions around child ICU death: What helped, what did not. *American Journal of Hospice & Palliative Medicine*, *30*(1), 40–49. https://doi.org/10.1177/1049909112444301.

Burns, J. P., Sellers, D. E., Meyer, E. C., Lewis-Newby, M., & Truog, R. D. (2014). Epidemiology of death in the PICU at five U.S. teaching hospitals. *Critical Care Medicine*, *42*(9), 2101–2108. https://doi.org/10.1097/CCM.0000000000000498.

Butler, A. E., Hall, H., & Copnell, B. (2018). Becoming a team: The nature of the parent-healthcare provider relationship when a child is dying in the pediatric intensive care unit. *Journal of Pediatric Nursing*, *40*, e26–e32. https://doi.org/10.1016/j.pedn.2018.02.002.

Carroll, K. W., Mollen, C. J., Aldridge, S., Hexem, K. R., & Feudtner, C. (2012). Influences on decision making identified by parents of children receiving pediatric palliative care. *AJOB Primary Research*, *3*(1), 1–7. https://doi.org/10.1080/21507716.2011.638019.

Critical Appraisal Skills Programme (2018). CASP [online] Retrieved from http://www.casp-uk.net. Accessed: June 2018.

Curtis, K., Foster, K., Mitchell, R., & Van, C. (2016). Models of care delivery for families of critically ill children: An integrative review of international literature. *Journal of Pediatric Nursing*, *31*(3), 330–341. https://doi.org/10.1016/j.pedn.2015.11.009.

Devictor, D. J., & Latour, J. M. (2011). Forgoing life support: How the decision is made in European pediatric intensive care units. *Intensive Care Medicine*, *37*(11), 1881–1887. https://doi.org/10.1007/s00134-011-2357-3.

Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J. R., & Hays, R. (2012). Palliative care in the pediatric ICU: Challenges and opportunities for family-centered practice. *Journal of Social Work in End-of-Life & Palliative Care*, *8*(4), 297–315. https://doi.org/10.1080/15524256.2012.732461.

Falkenburg, J. L., Tibboel, D., Ganzevoort, R. R., Gischler, S. J., & van Dijk, M. (2018). The importance of parental connectedness and relationships with healthcare professionals in end-of-life care in the PICU. *Pediatric Critical Care Medicine*, *19*(3), E157–E163. https://doi.org/10.1097/PCC.0000000000001440.

Feudtner, C., Carroll, K. W., Hexem, K. R., Silberman, J., Kang, T. I., & Kazak, A. E. (2010). Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making. *Archives of Pediatrics & Adolescent Medicine*, *164*(9), 831–839. https://doi.org/10.1001/archpediatrics.2010.146.

Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., ... Hinds, P. S. (2015). Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, *169*(1), 39–47. https://doi.org/10.1001/jamapediatrics.2014.2341.

Fontana, M. S., Farrell, C., Gauvin, F., Lacroix, J., & Janvier, A. (2013). Modes of death in pediatrics: Differences in the ethical approach in neonatal and pediatric patients. *The Journal of Pediatrics*, *162*(6), 1107–1111. https://doi.org/10.1016/j.jpeds.2012.12.008.

Hill, D. L., Miller, V. A., Hexem, K. R., Carroll, K. W., Faerber, J. A., Kang, T., & Feudtner, C. (2015). Problems and hopes perceived by mothers, fathers and physicians of children receiving palliative care. *Health Expectations*, *18*(5), 1052–1065. https://doi.org/10.1111/hex.12078.

Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., ... Furman, W. L. (2009). “Trying to be a good parent” as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, *27*(35), 5979–5985. https://doi.org/10.1200/JCO.2008.20.0204.

Hinds, P. S., & Kelly, K. P. (2010). Helping parents make and survive end of life decisions for their seriously ill child. *The Nursing Clinics of North America*, *45*(3), 465–474. https://doi.org/10.1016/j.cnur.2010.03.006.

Hinds, P. S., Schum, L., Baker, J. N., & Wolfe, J. (2005). Key factors affecting dying children and their families. *Journal of Palliative Medicine*, *8*(Supplement 1), s70–s78. https://doi.org/10.1089/jpm.2005.8.s-70.

Kars, M. C., Grypdonck, M. H. F., de Bock, L. C., & van Delden, J. J. M. (2015). The parents' ability to attend to the “voice of their child” with incurable cancer during the palliative phase. *Health Psychology*, *34*(4), 446–452. https://doi.org/10.1037/hea0000166.

Madrigal, V. N., Carroll, K. W., Faerber, J. A., Walter, J. K., Morrison, W. E., & Feudtner, C. (2016). Parental sources of support and guidance when making difficult decisions in the pediatric intensive care unit. *The Journal of Pediatrics*, *169*, 221–226. https://doi.org/10.1016/j.jpeds.2015.10.061.

Madrigal, V. N., Carroll, K. W., Hexem, K. R., Faerber, J. A., Morrison, W. E., & Feudtner, C. (2012). Parental decision-making preferences in the pediatric intensive care unit. *Critical Care Medicine*, *40*(10), 2876–2882. https://doi.org/10.1097/CCM.0b013e31825b9151.

McGibbon, E., Peter, E., & Gallop, R. (2010). An institutional ethnography of nurses' stress. *Qualitative Health Research*, *20*(10), 1353–1378. https://doi.org/10.1177/1049732310375435.

McGraw, S. A., Truog, R. D., Solomon, M. Z., Cohen-Bearak, A., Sellers, D. E., & Meyer, E. C. (2012). “I was able to still be her mom”—Parenting at end of life in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, *13*(6), e350–e356. https://doi.org/10.1097/PCC.0b013e31825b5607.

Michelson, K. N., Emanuel, L., Carter, A., Brinkman, P., Clayman, M. L., & Frader, J. (2011). Pediatric intensive care unit family conferences: One mode of communication for discussing end-of-life care decisions. *Pediatric Critical Care Medicine*, *12*(6), e336–e343. https://doi.org/10.1097/PCC.0b013e3182192a98.

Michelson, K. N., Koogler, T., Sullivan, C., Ortega, M. d. P., Hall, E., & Frader, J. (2009). Parental views on withdrawing life-sustaining therapies in critically ill children. *Archives of Pediatrics & Adolescent Medicine*, *163*(11), 986–992. https://doi.org/10.1001/archpediatrics.2009.180.

Michelson, K. N., Patel, R., Haber-Barker, N., Emanuel, L., & Frader, J. (2013). End-of-life care decisions in the PICU: Roles professionals play. *Pediatric Critical Care Medicine*, *14*(1), e34–e44. https://doi.org/10.1097/PCC.0b013e31826e7408.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & the PRISMA group (2009). *Academia and Clinic Annals of Internal Medicine Preferred Reporting Items for Systematic Reviews and Meta-analyses, 151*(4), 264–269.

Mooney-Doyle, K., dos Santos, M. R., Szylit, R., & Deatrick, J. A. (2017). Parental expectations of support from healthcare providers during pediatric life-threatening illness: A secondary, qualitative analysis. *Journal of Pediatric Nursing*, *36*, 163–172. https://doi.org/10.1016/j.pedn.2017.05.008.

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: “being a good parent” when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, *15*(4), 291–298. https://doi.org/10.1097/PCC.0000000000000076.

Shudy, M., de Almeida, M. L., Ly, S., Landon, C., Groft, S., Jenkins, T. L., & Nicholson, C. E. (2006). Impact of pediatric critical illness and injury on families: A systematic literature review. *Pediatrics*, *118*(Supplement 3), S203–S218. https://doi.org/10.1542/peds.2006-0951B.

Smith, M. A., Clayman, M. L., Frader, J., Arenson, M., Haber-Barker, N., Ryan, C., ... Michelson, K. (2018). A descriptive study of decision-making conversations during pediatric intensive care unit family conferences. *Journal of Palliative Medicine, online ahead of print.*. https://doi.org/10.1089/jpm.2017.0528.

Watson, A. C., & October, T. W. (2016). Clinical nurse participation at family conferences in the pediatric intensive care unit. *American Journal of Critical Care*, *25*(6), 489–497. https://doi.org/10.4037/ajcc2016817.