Nurse experiences of partnership nursing when caring for children with long-term conditions and their families: a qualitative systematic review.

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Nurse experiences of partnership nursing when caring for children with long-term conditions and their families: A qualitative systematic review

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Abstract

Aim: To explore the experiences of partnership nursing among nurses when caring for children and young people with long-term conditions, and their families.

Background: Partnership nursing is promoted as a positive model of care among paediatric nurses, where shared roles and decision-making, parental participation, mutual trust and respect, communication and negotiation are valued to create positive care experiences and enhance patient outcomes. Little is known about how nurses use partnership with both the patient and the parents in this triad to deliver partnership nursing.

Design: A qualitative systematic review followed Joanna Briggs Institute meta-aggregation approach and has been reported according to PRISMA guidelines.

Methods: A comprehensive systematic search was conducted in seven electronic databases. Studies were assessed according to a pre-determined inclusion criteria. Qualitative findings with illustrative participant quotes were extracted from included studies and grouped into categories to inform overall synthesised findings. Methodological quality assessment was conducted.

Findings: A total of 5837 publications were screened, and 41 qualitative studies were included. Three overarching synthesised findings were identified: (1) Using education to promote feelings of safety and support, (2) Partnering to develop a strong therapeutic relationship and (3) Optimising communication underpinned by shared decision-making principles to deliver individualised care.

Conclusion: Nurses demonstrated successful partnership in their practice, but focused on developing dyadic nurse–parent and dyadic nurse–child partnerships. Future practice development that creates a three-way triadic partnership may aid therapeutic relationships and shared decision-making.

> **Implications for clinical practice:** Clinicians can reflect on how dyadic partnerships (focusing on the child or the parent) may exclude opportunities for coherent care. Further exploration in practice, policy and research as to how nurses determine child competency and child and parent level of engagement in triadic partnership may improve the potential of meaningful shared decision-making.
>

1 | INTRODUCTION

Children with long-term conditions represent a total of 43% of all children (AIHW, 2022). More than 20% of children are diagnosed with two more than two long-term conditions (AIHW, 2022). Long-term conditions, such as cancer, asthma and diabetes, have been intrinsically linked to increased morbidity and mortality; as well as more frequent hospital admissions and adverse events (AIHW, 2022; Lambert & Keogh, 2015).

When caring for children and young people living with long-term conditions, paediatric nurses need to focus on developing effective partnerships with both their paediatric patient (referred to as 'children' throughout this paper, but include infants, children and young people) and their family members (parents, guardians or caregivers; Eull et al., 2023; Vaknin & Zisk-Rony, 2011). There is an important distinction in developing a partnership with parents, as parental involvement is necessary for all aspects of care, given the important relationship between parent/child and the legal requirements of parental consent for medical procedures and treatment (Library of Congress, 2015).

Partnership nursing is a term used to describe the unique relationship that is defined by five attributes: shared roles and decision-making, participation, mutual trust and respect, communication and negotiation (Barratt et al., 2021; Davis et al., 2007; Dennis et al., 2017; O'Connor et al., 2019). Generally, partnerships have been accepted as two dyads, the nurse–parent and the nurse–child; however, historic research showed the importance of stepping away from dyadic relationships to a triadic partnership between the child–parent–nurse (De Civita & Dobkin, 2004). Development of this suggested model of triadic rather than dyadic partnership as a specific phenomenon in paediatric nursing has not been well defined and has not advanced in clinical practice (Coyne, 2006; Smith et al., 2015). However, the development of triadic partnerships in paediatric nursing would neatly reflect the principles of multiple models of care over time, namely family centred care (FCC) and patient and family centred care (PFCC). Specifically, FCC was the main approach used in paediatric nursing following the implementation of the Convention on the Rights of the Child, which viewed the family as central to the care provided (Coyne et al., 2018). In the last 10 years, however, there has been a shift to PFCC, which acknowledges that the patient and

> **What does this paper contribute to the wider global clinical community?**
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> - Nurses demonstrate sufficient knowledge and understanding of dyadic collaborative partnerships with parents and children with long-term conditions.
> - Nurses require further knowledge, training and support when caring for complex long-term conditions in paediatric populations.
> - Nurses can prioritise the development of triadic partnerships and future research can work to clarify how to support nurses to achieve this.

family members are integrated members of the same family, but also unique individuals with unique care needs and requirements (Hanson et al., 2017; Institute for Patient and Family Centered Care, 2020). In contrast, triadic partnership is considered where the paediatric nurse aims to collaboratively provide tailored individualised care while maintaining legal and ethical standards in parallel with both the children and their families.

Previous research conducted among paediatric nurses lacks insight into how nurses provide triadic partnership with children living with long-term conditions and their families (Barratt et al., 2021, 2022; Dennis et al., 2017; Giambra et al., 2014). Research has explored partnership with children living with long-term conditions among healthcare professionals, but not explicitly within the paediatric nurse population (Kuhlthau et al., 2011). Research has also demonstrated that nurses lack awareness as to how to effectively engage with families in the care process and promote effective partnerships (Dennis et al., 2017). Power imbalances may also undermine successful partnerships in paediatric nursing because nurses control information and care boundaries, which may contribute to fear and frustration with a lack of control among parents, and children alike (Dennis et al., 2017).

Previous research has focused more on the dyadic nurse–parent and nurse–child relationships (Coyne et al., 2016; Peña & Rojas, 2014; Pritchard Kennedy, 2012), instead of seeing the partnership between the three parties. It is unknown if the complexities in the delivery of partnership in care change with each nurse,

healthcare setting and service, or the patient condition. Previous research into the views of parents and children with long-term conditions demonstrates a need for partnership within this subgroup of paediatric health care (Barratt et al., 2021, 2022). Both parents and children have reported a lack of power and control to develop the partnership, leaving a high level of decision-making, negotiation and communication initiation to nursing staff (Barratt et al., 2021, 2022).

Given the dearth of knowledge on triadic partnership nursing, it is important to critically synthesise all existing research that focuses on the key attributes of triadic partnership from the nurse's perspective given recent systematic reviews have considered perspectives from children (Barratt et al., 2021, 2022) and parent (Barratt et al., 2021, 2022). Understanding the nurse's experiences of developing and building partnerships with both parents and children with long-term conditions with help address practice gaps and informed future directions from research.

2 | AIM

This qualitative systematic review aims to critically synthesise all research on the experiences and perceptions of triadic partnership and its attributes from the perspective of paediatric nurses who care for children with long-term conditions and their families.

3 | METHODS

3.1 | Research design

A qualitative systematic review (Florczak, 2019; Tufanaru, 2016) was chosen to explore the experiences and perceptions of paediatric nurses who care for children with long-term conditions. Specifically, this review followed the Joanna Briggs Institute (JBI) approach (Aromataris & Munn, 2020) and the qualitative findings were pooled using a meta-aggregation method (Hannes & Lockwood, 2011). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist (PRISMA) was used, see Supplementary File 1 for the completed PRISMA checklist (Page et al., 2021). This review was registered with PROSPERO (CRD42021265652).

3.2 | Search strategy

An initial scoping review of the literature was completed, and key search terms were extrapolated which identified there were no previous systematic reviews conducted or were in progress. Following this process, the search strategy for electronic databases was developed in consultation with an expert academic research librarian and the primary author (MB). The Population, Intervention, Comparison and Outcomes (PICo) mnemonic was used along with extrapolated

key search terms to create the search architecture (Counsell, 1997). This review considered publications that explored nurses (P) and their experiences of caring for children with long-term conditions (I) when working in partnership with children and their families in the paediatric healthcare setting (Co).

The keywords used included:

(P) Nurs* And (pediatric or paediatric or neona*).

(I) Partnership* or "partnership nursing" or participation* or collaboration* or role* or negotiation* or "decision-making" or respect* or involvement* of trust* or communication* or shared roles or "partnership model" or "partnership in care" or "nursing partnership" or "shared decision-making" or "participation in care".

(Co) Children* or "young person" or "young people" or adolescent* or youth or child* or teen* or infant* or baby* or babies or parent* or mother* or father* or famil* or paediatric or pediatric or neonatal or neona*.

The search was conducted in multiple databases (CINAHL, MEDLINE, PUBMED, SCOPUS, WEB OF SCIENCE, PsychInfo and Google Scholar). Grey literature was searched via two databases (MeDNar and OpenMD.com). The reference lists of all included studies, as well as relevant systematic reviews, were manually searched for additional publications that were relevant to the search criteria. Database searching concluded in December 2022. An example of the search strategy is provided in Table S1.

In the context of this systematic review, a long-term condition was defined as any illness, disease or condition lasting more than 6 months (AIHW, 2018). Studies were included if they were published between 2010 and 2022 with the underpinning clinical rationale that there has been a shift in paediatric nursing to a 'Person and Family Centred Care' approach, which focuses on the need for triadic partnership between the nurse, parent and children (Lambert & Keogh, 2015) over the past 10 years. Other inclusion criteria included:

- English language, full-text peer-reviewed qualitative studies irrespective of design.
- Research that focused primarily on the experiences of nurses caring for children with long-term conditions and their families.
- Research that focused on the attributes aspects of triadic partnership nursing: shared roles and decision-making, parental participation, mutual trust and respect, communication and negotiation (Barratt et al., 2021; Davis et al., 2007; Dennis et al., 2017; O'Connor et al., 2019).
- Research based in all areas of paediatric/neonatal nursing including acute, subacute, palliative care, home and community-based nursing care.
- Primary qualitative studies published between January 2010 and December 2022. Mixed method studies with qualitative components were also considered, but only qualitative data were to be extracted.

Studies were excluded from the systematic review if they were not primary peer-reviewed qualitative studies, such as discussion papers, literature/systematic reviews and doctoral dissertations.

Mixed methods studies where no qualitative findings were clearly present to extract were also excluded. Studies were excluded if the focal topic of the study was the transition of a child from paediatric to adult health services or the patient population nursing staff provided care for did not include children with long-term conditions.

3.3 | Eligibility

All titles, abstracts and full-text studies were screened against the inclusion and exclusion. Any disagreements were resolved by discussion between the three authors. All eligible studies were exported into Covidence software to manage the entire screening process.

3.4 | Data extraction

Data extraction in the review included characteristics of each study (author, year, geographic location, study aim, sample size, gender of participant, mean age and years of work, ethnicity of participants, methodology, methods and data analysis technique). If a study did not present specific characteristic data, 'not stated' was written in the presentation of included study characteristics. Findings and illustrations were extracted from each study (Aromataris & Munn, 2020). Findings included direct metaphors and statements made by the authors in the presentation and narration of their own findings (Aromataris & Munn, 2020). Illustrations were direct participant quotes (Aromataris & Munn, 2020).

Throughout the data extraction, all appropriate findings relevant to the systematic reviews study aim were presented with relevant illustrations. Each finding was given a level of credibility as per JBI methodology (Aromataris & Munn, 2020) and was classified as unequivocal (findings that were supplemented with illustrations to demonstrate evidence beyond reasonable doubt), credible (findings that were supplemented with illustrations but could be challenged due to a lack of data) and unsupported (findings that were not supported with illustrative participant quotes).

As per JBI methodology, only unequivocal and credible research findings were included in the meta-aggregation (Aromataris & Munn, 2020). Any unsupported findings were excluded from the synthesis, on the basis that they would not provide critically appraised quality data in the synthesis (Aromataris & Munn, 2020).

3.5 | Quality assessment

All studies included in the systematic review were quality appraised using the JBI Critical Appraisal Tool for methodological quality (Aromataris & Munn, 2020). Each study was scored individually against the 10 questions in the JBI Critical Appraisal

Tool. Quality appraisal using the JBI Critical Appraisal tool was discussed by all three authors, and any disagreements were discussed. Given the variety of studies matching the inclusion criteria, no studies were excluded from the systematic review based upon methodological quality ratings, to describe the current state of evidence. As a systematic review of primarily qualitative studies, this review was deemed a Level 6 in the appraisal of the level of evidence (Ackley, 2008).

3.6 | Data synthesis

After each finding was given a level of credibility (unequivocal, credible and unsupported), the unequivocal and credible findings were given labels to be included in the data synthesis (e.g. Finding 1 was labelled F1). Unsupported findings were given a different label called US (e.g. The first unsupported finding was labelled US). An explicit interpretative process following JBI methodology for meta-aggregation and using thematic analysis was then followed (Tufanaru, 2016). Each of the unequivocal and credible findings was then synthesised into categories based on similar meanings and themes, using thematic analysis (Tufanaru, 2016). The categories with similar themes were then grouped together and developed into synthesised findings, using thematic analysis (Tufanaru, 2016). The process of data synthesis was completed by all reviewers and any disagreements regarding the synthesis were discussed until a consensus was reached.

4 | FINDINGS

A total of 9378 studies were identified through database searching, with an additional 45 studies imported into Covidence through checking of reference lists and previous systematic reviews. No studies were identified through grey literature websites. Of the 9423 studies, 3586 were removed as duplications and 5837 studies were screened. A total of 406 studies were reviewed in full-text (to be as inclusive and detailed as possible) and 365 studies were excluded with reasons, see Figure 1. A total of 41 published studies were included in the qualitative meta-aggregation synthesis.

4.1 | Characteristics of the studies

The characteristics of the included studies are presented in Table 1. The studies were conducted in a range of countries: United States of America (USA) ($n=9$), United Kingdom (UK) ($n=6$), Brazil ($n=4$), Sweden ($n=4$), Canada ($n=3$), Norway ($n=3$), Italy ($n=2$), Malaysia ($n=2$), Australia ($n=1$), Finland ($n=1$), Iran ($n=1$), Ireland ($n=1$), Portugal ($n=1$), Saudi Arabia ($n=1$), Spain ($n=1$) and The Netherlands ($n=1$). The paediatric clinical groups included: oncology
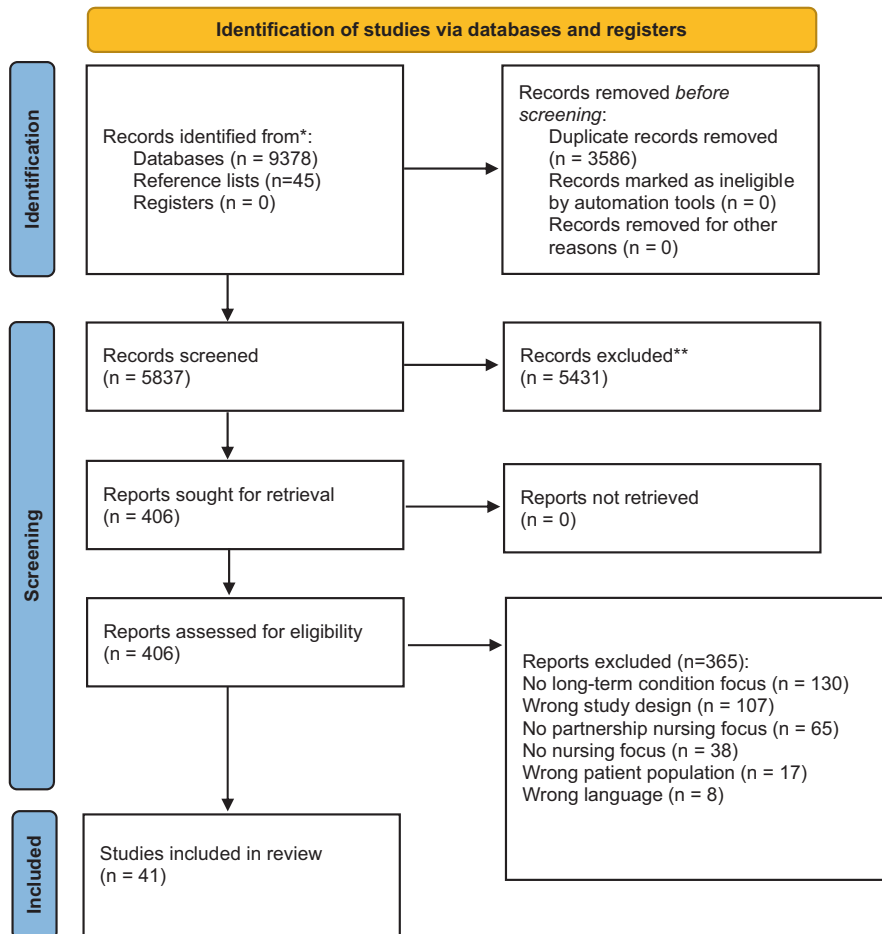
FIGURE 1 PRISMA diagram. *From*: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. [Colour figure can be viewed at wileyonlinelibrary.com]

($n=16$), areas with mixed long-term conditions ($n=9$), paediatric intensive care unit (PICU) ($n=3$), cardiology ($n=2$), mental health services ($n=2$), respiratory ($n=2$), emergency department ($n=1$), endocrinology ($n=1$), intellectual disability ($n=1$), palliative care ($n=1$), renal ($n=1$), rheumatology ($n=1$) and school nursing ($n=1$). Multiple methods were used in the data collection process across the 41 included studies, with the majority using interviews ($n=33$), as well as focus groups ($n=12$), observation ($n=5$) and written narrative ($n=3$). The results of the quality assessment of the included studies are presented in Table 2.

4.2 | Meta-synthesis of qualitative data

A total of 247 findings were extracted from the 41 included studies, with a total of 30 findings labelled as unsupported and removed from the meta-synthesis (see Table S2). The remaining 217 findings were synthesised into 52 categories based on similar themes and meanings, see Table 3. The 52 categories were then synthesised three synthesised findings, see Table 3. The three synthesised findings included (1) 'Using education to promote feelings of safety and support', (2) 'Partnering to develop a strong therapeutic relationship' and (3) 'Optimising communication underpinned by shared decision-making principles to deliver individualised care'.

4.3 | Synthesised finding one: Using education to promote feelings of safety and support

The first synthesised finding related to nurses' awareness of the importance of education for themselves, their patients and their families. There were 17 categories that contributed to the first synthesised finding, see Table 3.

Education, training and knowledge were consistently reported across multiple included studies. Nurses discussed their own deficits in knowledge and education when it came to the care of children with long-term conditions, and nursing staff articulated that they needed further training and education in a variety of the long-term conditions (Chong & Abdullah, 2017; Montgomery et al., 2017; Sørensen et al., 2022; Zaal-Schuller et al., 2018). Nursing staff felt that with further education and training, they would have more confidence in caring for children with long-term conditions and their families, to empower themselves with evidence-based knowledge, which in turn, would help to empower those they care for (Aein et al., 2011; Alahmad et al., 2020; Chong & Abdullah, 2017; Landon et al., 2019):

> I have never had any education in training sessions for [educating parents on] needle injections. I did not really know what kind of medicine it was; I could only give subcutaneous injections.
>
> (Sørensen et al., 2022, page 140)

TABLE 1 Characteristics of included studies.

Author/year/ country	Study aim	Participant data (only nurse data are provided)	Methods
Aein et al. (2011) Iran	To generate a theory of nurse–parent interaction process in the care of hospitalised children	N = 17 Mean age = 32 (range 24–50 years). Women = Not stated. Mean years of work = 5 (range 5 months—30 years). Ethnicity = Not stated	Methodology: Grounded theory. Method: Interviews and observation. Analysis: Not clearly stated.
Alahmad et al. (2020) Saudi Arabia	In-depth interviews with several nurses working in Saudi Arabia to explore their views on childhood cancer care and the ethical issues involved	N = 17 Mean age = Not stated Women = 82% (n = 14) Mean years of work = Not stated Ethnicity = 9 Saudi Arabian, 6 Filipino and 2 Other	Methodology: Not stated Method: Interviews Analysis: Not stated
Bagnasco et al. (2013) Italy	To investigate the healthcare professionals' perceptions of the autonomy of the dyad (parents and sons) in the management of a chronic disease (children with cystic fibrosis and neuromuscular disease)	N = 12 Mean age = Not stated (range 25–37 years) Women = 100% Mean years of work = Not stated (range 2–15 years) Ethnicity = Not stated	Methodology: Descriptive Method: Focus group and interviews Analysis: Thematic analysis
Baird et al. (2016) USA	To explore the delivery of continuity of nursing care in the PICU from the perspective of both parents and nurses	N = 12 Mean age = Not stated (range 20–>60 years) Women = 100% Mean years of work = Not stated (range <2 to >20 years) Ethnicity = 10 Caucasian, 1 Black and 1 More than one race	Methodology: Situational analysis Method: Observations and interviews Analysis: Constant comparative analysis
Bettle et al. (2018) Canada	To describe parent and paediatric oncology nurse perspectives on sources of pain that children with ALL experience and what parents do to relieve their child's pain	N = 8 Mean age = Not stated (range 23–55 years) Women = Not stated Mean years of work = 9.5 (range 1–18 years) Ethnicity = Not stated	Methodology: Positive appreciate inquiry Method: Interviews Analysis: Thematic analysis
Bruce and Sundin (2018) Sweden	To illuminate paediatric nurses' (PNs) perceptions of support for families with a child with a congenital heart defect	N = 8 Mean age = 51 (range 41–58 years) Women = 100% Mean years of work = 14 (range 1–31 years) Ethnicity = Not stated	Methodology: Qualitative content analysis Method: Interviews Analysis: Not clearly stated
Calza et al. (2016) Italy	To investigate paediatric nurses' perception of the factors that influence the process of care in foreign paediatric patients who have received stem cell transplantation (SCT) and their families	N = 27 Mean age = 35.6 (range 23–55 years) Women = 92% (n = 25) Mean years of work = 9.6 (range 6 months—25 years) Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Content analysis
Carter et al. (2012) Canada	To understand the experiences of RNs and ED-RNs caring for patients with ED and to explore the barriers and facilitators to integrating the ED-RN role to inform others who are implementing specialised nursing roles	N = 9 Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Descriptive Method: Focus groups and interviews Analysis: Thematic analysis
Chong and Abdullah (2017) Malaysia	To explore the experiences of community palliative care nurses providing home care for children with life-limiting illnesses	N = 16 Mean age = 29.5 (range 24–62 years) Women = 100% Mean years of work = 2.5 (range 1–18 years) Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Thematic analysis
Delaney and McIntosh (2021) USA	To gather information on how expert C/A advanced practice psychiatric nurses (APPNs) view their role and assess/treat children and adolescents with complex mental health issues	N = 15 Mean age = Not stated (range 35–74 years) Women = 80% (n = 12) Mean years of work = 22 (range 5–40 years) Ethnicity = 14 Caucasian, 1 African American	Methodology: Descriptive Method: Interviews Analysis: Thematic analysis
Denis-Larocque et al. (2017) Canada	To explore nurses' perceptions of caring for parents of children with medical complexity [CMC] in the paediatric intensive care unit [PICU]	N = 10 Mean age = Not stated (range 28–53 years) Women = 70% (n = 7) Mean years of work = Not stated (range 3–30 years) Ethnicity = Not stated	Methodology: Interpretive descriptive Method: Interviews Analysis: Inductive content analysis

(Continues)

TABLE 1 (Continued)

Author/year/country	Study aim	Participant data (only nurse data are provided)	Methods
Forsey et al. (2013) UK	To examine how doctors' and nurses' perspectives on the emotional care of parents might inform future training and policy in communication skills training	$N=12$ Mean age = Not stated Women = 92% ($n=13$) Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Constant comparative analysis
França et al. (2013) Brazil	To investigate and analyse communication in palliative care contexts from the perspective of nurses, based on humanistic nursing theory	$N=10$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Humanistic nursing theory and phenomenology Method: Interviews Analysis: Not clearly stated
Gårdling et al., 2015 Sweden	To explore radiotherapy nurses' perceptions of their experiences of caring for children undergoing radiotherapy treatment for cancer	$N=12$ Mean age = Not stated Women = 100% Mean years of work = 13 (range 1–28 years) Ethnicity = Not stated	Methodology: Phenomenographic Method: Interviews Analysis: Not clearly stated
Giambra et al. (2017) USA	To expand our understanding of the process of communication between parents of hospitalised technology dependent children and their nurses	$N=9$ Mean age = Not stated Women = Not stated Mean years of work = Not stated. (range 8 months–10 years) Ethnicity = 8 Caucasian, one African American	Methodology: Grounded theory Method: Interviews Analysis: Not clearly stated
Halpin (2018) UK	To explore the perspective of all the specialist nurses in community paediatric teams in one NHS trust on their role in preschool autism assessment	$N=6$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Critical reflective inquiry Method: Written narratives, discussion group and interviews Analysis: Not clearly stated
Hendricks-Ferguson et al. (2015) USA	To explore the palliative care and end of life communication perspectives of 14 novice paediatric oncology nurses	$N=14$ Mean age = 28 (range 25–31 years) Women = 100% Mean years of work = Not stated (all less than 1 year of work experience) Ethnicity = 100% Caucasian	Methodology: Phenomenology Method: Focus groups Analysis: Not clearly stated
Høiseth et al. (2014) Norway	To explore interactions between parents, nurses and young children during paediatric nebuliser treatment in terms of tact as a pedagogical concept	$N=5$ Mean age = Not stated Women = 80% ($n=4$) Mean years of work = Not stated range 2–32 years) Ethnicity = Not stated	Methodology: Pedagogical Method: Observations Analysis: Hermeneutic approach
Hopia and Heino-Tolonen (2019) Finland	To explore how nurses describe significant incidents when encountering families and family members during the child's hospitalisation in the paediatric oncology unit	$N=16$ Mean age = 39 (range 29–49) Women = 100% Mean years of work = 12 (range 6–22 years) Ethnicity = Not stated	Methodology: Phenomenology Method: Written data collection Analysis: Inductive content analysis
Jestico and Finlay (2017) UK	To explore the extent to which qualified nurses perceive that pre-registration nurse education prepares them to care for children with cancer; to consider the implications for children's nursing pre-registration curricula	$N=6$ Mean age = Not stated Women = Not stated Mean years of work = Not stated (range 2–27 years) Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Thematic analysis
Landon et al. (2019) USA	To describe the experiences of nurses who delivered the communication intervention in a behavioural oncology clinical trial for parents of adolescents and young adults (AYAs) with cancer	$N=12$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Interviews and written answers Analysis: Thematic analysis

TABLE 1 (Continued)

Author/year/country	Study aim	Participant data (only nurse data are provided)	Methods
Lee et al. (2019) Malaysia	To examine the role of children in communication and decisions regarding their nursing care in a paediatric oncology ward in Malaysia	$N = 19$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Focused ethnography Method: Observations and interviews Analysis: Not clearly stated
Mellor et al. (2015) UK	To examine the ethical issues that non-adherence in paediatric chronic renal failure generates using data gathered from nurses on a paediatric dialysis	$N = 11$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Conventional content analysis
Mendes (2013) UK	To elicit experienced nurses' descriptions of their practice and the interventions they used to carry out ideal home nursing care practice	$N = 7$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Descriptive design Method: Interviews Analysis: Content analysis
Mimmo et al. (2022) Australia	To understand what constitutes a good experience of care for inpatient CYP with intellectual disability as perceived by nursing staff	$N = 29$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Interpretative design Method: Focus Groups Analysis: Interpretative phenomenological analysis
Moen et al. (2014) Norway	To explore the public health nurses role in relation to families with ADHD	$N = 19$ Mean age = Not stated (range 27–62 years) Women = Not stated Mean years of work = Not stated (range 0–30 years) Ethnicity = Not stated	Methodology: Phenomenology Method: Group and induvial interviews Analysis: Not clearly stated
Montgomery et al., 2017 USA	To describe the commonalities of experienced nurses' perceptions of communicating during palliative care and end of life care and perceptions of barriers and facilitators to effective communication	$N = 27$ Mean age = 42 (range 27–54 years) Women = 100% Mean years of work = Not stated Ethnicity = 100% Caucasian	Methodology: Health as expanding consciousness Method: Interviews Analysis: Not clearly stated
Neal (2022) USA	To investigate experiences and knowledge development of paediatric nurses in inpatient settings caring for children with chronic, complex healthcare needs and their families	$N = 8$ Mean age = Not stated Women = 90% ($n = 7$) Mean years of work = Not stated Ethnicity = Seven Caucasian, one African American	Methodology: Empirical phenomenology Method: Focus groups and interviews Analysis: Not clearly stated
Neilson et al. (2013) UK	To explore influences on the experiences of paediatric nurses providing out of hours palliative care within the family home to children with cancer	$N = 12$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Social worlds theory Method: Interviews and focus groups Analysis: Grounded theory analysis
Newman et al. (2019) USA	To provide an exploration of paediatric oncology nurses' experiences with prognosis-related communication (PRC)	$N = 18$ Mean age = 37.4 (range 27–67 years) Women = 100% Mean years of work = 13.7 (range 0.5–44 years) Ethnicity = 100% Caucasian	Methodology: Mixed methods Method: Focus groups Analysis: Not clearly stated
Newman et al. (2020) USA	To report nurse descriptions of prognosis-related communication and they experience it within their daily practice	$N = 18$ Mean age = 37.4 (range 27–67 years) Women = 100% Mean years of work = 13.7 (range 0.5–44 years) Ethnicity = 100% Caucasian	Methodology: Mixed methods Method: Focus groups Analysis: Not clearly stated
Panicker (2013) Ireland	To explore nurse's perception of parent empowerment in chronic illness	$N = 14$ Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Focus groups Analysis: Thematic content analysis

TABLE 1 (Continued)

Author/year/ country	Study aim	Participant data (only nurse data are provided)	Methods
Pennafort et al. (2014) Brazil	To describe the perception of nurses regarding educational practices conducted with children with diabetes in a hospital unit	*N* = 6 Mean age = 25 (range not stated) Women = 100% Mean years of work = Not stated Ethnicity = Not stated	Methodology: Descriptive Method: Interviews Analysis: Content analysis
Reisinho et al. (2020) Portugal	To describe the nurse's role in the transition processes of adolescents with cystic fibrosis and their parents	*N* = 20 Mean age = Not stated (range 28–53 years) Women = Not stated Mean years of work = Not stated (range 5–27 years) Ethnicity = Not stated	Methodology: Exploratory and descriptive Method: Interviews Analysis: Categorical content analysis
Ringnér et al. (2013) Sweden	To describe discursively constructed interactions between parents and healthcare professionals (HCPs) in a paediatric oncology ward	*N* = 14 Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Observations and interviews Analysis: Not clearly stated
Rosselló et al. (2015) Spain	To identify the psych pedagogical training needs of the paediatric nurses in the largest public hospital of the Balearic Islands, Spain	*N* = 15 Mean age = Not stated Women = 80% (*n* = 12) Mean years of work = Not stated Ethnicity = Not stated	Methodology: Mixed methods Method: Interviews Analysis: Content analysis
Samuelson et al. (2015) Sweden	To investigate the experiences of Swedish community nurses in caring for sick children at home, as this is a growing population of patients in community care	*N* = 12 Mean age = 49 (range 30–66 years) Women = 100% (*n* =) Mean years of work = 17 (range 4–42 years) Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Content analysis
Silva et al. (2016) Brazil	To understand the nurse interactions in the nursing care management to hospitalised children with chronic conditions	*N* = 8 Mean age = Not stated Women = 87% (*n* = 7) Mean years of work = Not stated (range 4–32 years) Ethnicity = Not stated	Methodology: Grounded theory Method: Interviews Analysis: Comparative analysis
Sørensen et al., 2022 Norway	To explore nurses' perceptions of their educational role, pedagogical competence and practice in teaching children with rheumatic diseases and their parents to manage subcutaneous injections at home	*N* = 14 Mean age = 40.5 years Women = 100% Mean years of work = 9.5 years Ethnicity = 100% European	Methodology: Exploratory Method: Focus groups Analysis: Thematic analysis
Teixeira Fernandes Dos San et al. (2020) Brazil	To investigate nurses' experience in caring for children with cancer under palliative care	*N* = 12 Mean age = Not stated (range 25–65 years) Women = Not stated Mean years of work = Not stated (range 3–34 years) Ethnicity = Not stated	Methodology: Exploratory Method: Interviews Analysis: Categorical content analysis
Zaal-Schuller et al. (2018) The Netherlands	This study aims to answer three questions: (1) To what extent are nurses involved in discussions about end of life discussions with parents and physicians? (2) What do nurses add to these discussions? And (3) how do nurses evaluate their involvement?	*N* = 13 Mean age = Not stated Women = Not stated Mean years of work = Not stated Ethnicity = Not stated	Methodology: Not stated Method: Interviews Analysis: Not clearly stated

Being more informed and trained in long-term conditions allowed nurses to work more effectively with children and their families, as they could demonstrate their knowledge and skills, which would provide feelings of safety and support, especially to parents (Gårdling et al., 2015; Newman et al., 2019; Silva et al., 2016). The training that nurses received often came from more senior staff, in-services from their employers, or from the parents and the children they were caring for, who were seen as knowledgeable in their care requirements:

> What I know I've learned by myself because in college I had no such training. For me, the practice and my children [my patients] were what really taught me. (N5)
> (Rosselló et al., 2015, page 40)

TABLE 2 JB QARI quality table. [Colour table can be viewed at wileyonlinelibrary.com]

Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Aein et al. (2011)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Alahmad et al. (2020)	N	N	N	N	N	N	U	Y	Y	Y
Bagnasco et al., 2013	N	Y	Y	Y	Y	N	N	Y	N	Y
Baird et al. (2016)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Bettle et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bruce & Sundin, 2018	N	Y	Y	Y	Y	N	N	Y	Y	Y
Calza et al. (2016)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Carter et al. (2012)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Chong and Abdullah (2017)	N	Y	Y	U	U	N	N	Y	Y	Y
Delaney and McIntosh (2021)	N	Y	Y	U	U	N	N	Y	U	Y
Denis-Larocque et al. (2017)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Forsey et al. (2013)	N	N	N	N	N	N	N	Y	Y	Y
França et al. (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gårdling et al. (2015)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Giambra et al. (2017)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Halpin, 2018	Y	Y	Y	Y	Y	N	N	Y	N	Y
Hendricks-Ferguson et al. (2015)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Høiseth et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hopia & Heino-Tolonen, 2019	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Jestico & Finlay, 2017	N	Y	Y	Y	Y	N	N	Y	Y	Y
Landon et al. (2019)	N	N	N	N	N	N	N	Y	Y	Y
Lee et al. (2019)	Y	Y	Y	U	U	N	N	U	Y	Y
Mellor et al. (2015)	N	N	N	N	N	N	N	Y	Y	Y
Mendes, 2013	N	Y	Y	Y	Y	N	N	Y	Y	Y
Mimmo et al. (2022)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moen et al. (2014)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Montgomery et al. (2017)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Neal (2022)	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Neilson et al. (2013)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Newman et al. (2019)	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Newman et al. (2020)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Panicker, 2013	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Pennafort et al. (2014)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Reisinho et al. (2020)	N	N	N	N	N	N	N	Y	N	Y
Ringnér et al. (2013)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Rosselló et al. (2015)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Samuelson et al. (2015)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Silva et al. (2016)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Sørensen et al. (2022)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Teixeira Fernandes Dos San et al. (2020)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Zaal-Schuller et al. (2018)	N	N	N	N	N	N	N	Y	Y	Y
Yes	Y									
No	N									
Unclear	U									

Key Questions

1. Is there congruity between the stated philosophical perspective and the research methodology?

2. Is there congruity between the research methodology and the research question or objectives?

3. Is there congruity between the research methodology and the methods used to collect data?

4. Is there congruity between the research methodology and the representation and analysis of data?

5. Is there congruity between the research methodology and the interpretation of results?

6. Is there a statement locating the researcher culturally or theoretically?

7. Is the influence of the researcher on the research, and vice-versa, addressed?

8. Are participants, and their voices, adequately represented?

9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?

10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

TABLE 3 Synthesis of findings to categories to synthesised findings. [Colour table can be viewed at wileyonlinelibrary.com]

Findings	Categories	
F66, F67, F68	Negotiation of care with the parents is very important to ensure safe care is given	Using education to promote feelings of safety and support
F55, F182	Nurses empower parents by educating and coaching them when needed	
F116, F134	Nurses needed to be task driven and use active listening to support education and shared decision-making with parents	
F104, F125	Nurses felt it was difficult to set clear boundaries with children if they did not receive the support from parents	
F51, F79, F96, F111, F115, F152, F156, F201, F212, F216	Nurses need to offer emotional support to patients and their families	
F49, F81, F139, F174	Understanding what the child and parent needs are enhances safe patient care and the relationship between the nurse and family	
F31, F32	Nurses need to interact with both children and their families to promote feelings of safety	
F16, F24, F25, F187, F188, F190	Educating parents and children improves their autonomy and safety	
F28, F183, F193	Education is done in both written and verbal formats and is tailored to individual needs	
F3, F4, F39, F202	Nurses need further training and time to provide psychological support	
F45, F155, F210, F217	Nurses need further training and education in the variety of long-term conditions and procedures they come across	
F2, F11, F46, F114, F147, F179	Nurses caring for children with long-term conditions need to be well-trained, and this confidence often comes from experience	
F60, F61, F113	Both senior nurses and parents teach nurses about conditions and treatments that they are unfamiliar with	
F10, F161, F184, F185, F186, F195	Nurses have a responsibility to educate their patients and families	
F84, F102, F103, F209	Nurses need to care for children using age-appropriate play techniques to increase feelings of security	
F127, F128, F129	Nurses who needed to set clear boundaries with children surrounding their adherence felt that it strained the nurse–patient relationship	
F144, F145, F208	Working within a multidisciplinary team with teamwork allowed for smoother patient care and education	
F8, F9, F12, F54, F105, F109, F110	Parents who are agitated or anxious can have a detrimental affect on the child's care and how nurses partner with them	Partnering to develop a strong therapeutic relationship
F5, F53, F91, F97, F143	Nurses felt that parents have expertise in their own children and can care for their children more effectively than nurses can	
F1, F175	Nurses must also care for parents who have their own needs and expectations	
F29, F82, F94, F181, F196	Nurses felt that parents needed to have an active role in their child's care to empower them	
F6, F63, F87, F88, F92, F95, F154	Sharing and recognising mutual expertise with parents builds a trusting therapeutic relationship	
F112, F117	Nurses wished for more time to spend with parents to ensure their psychological and communication needs are met	
F70, F142, F164, F204, F205	Negotiation of roles and participation can only occur when there is a mutual trusting relationship between the nurse and parent	
F50, F58, F59, F62	Parents know their children best and nurses tap into this wealth of knowledge to care for their patients effectively	
F73, F74	Stressful and ethically complex situations challenge the nurse–parent relationship at times	
F64, F90	Nurses felt that all families have their own personalised preferences when it came to care and felt critiqued by parents	
F42, F56, F57, F71, F138, F166	It is important to develop a therapeutic relationship with the patient and family	
F35, F36, F160	Partnering with families of different cultural and language backgrounds to the nurse can be more difficult	

TABLE 3 (Continued)

Findings	Categories	
F43, F78, F140, F149 F191, F214	Rapport, trust and understanding are essential in developing therapeutic communication exchanges	
F20, F22, F108, F148, F203, F206	Continuity of care can make partnership easier to develop between nurses and families	
F21, F72, F80, F136, F137, F168, F169	Being emotionally attached to a family can blur professional boundaries and make complex situations more difficult	
F23, F126, F162, F176	Nurses are present and involved in all areas of care for children and their families	
F18, F33, F135, F141, F211	Nurses need to treat their patients as individual children, not patients, in order to gain mutual trust	
F47, F52, F151, F189	It is important to have a one-on-one individualised relationship with the child to cement a trusting therapeutic relationship	
F26, F27, F89, F145	Communication is a two-way exchange between parents and nurses to share mutual expertise	Optimising communication underpinned by shared decision-making principles to deliver individualised care
F34, F37, F75, F165	Miscommunication between nurses and parents can lead to distrust and adverse feelings	
F133, F163, F177	Nurses needed to be mindful of when to offer information in communication and when to let parents lead the discussion	
F7, F48, F124	Nurses are accountable for the child's care and parents need to respect this responsibility	
F40, F41, F86	Nurses can feel confused and agitated when there are differences between the standards of care and expectations of care delivered	
F65, F69, F130, F131, F132, F167	Nurses need to be flexible and respectful in the care they provide to suit a families individualised needs	
F158, F159, F180	Nurses advocate for both the child and family's best interests	
F83, F197	Both parents and children should be involved in the decision-making process	
F76, F77, F85, F98, F170, F199, F200, F213	Transparent and clear verbal and non-verbal communication with both parents and children is vital to safe patient care	
F30, F157	Nurses believe that giving patients and families feelings of hope is an important aspect of support	
F93, F99, F150, F194, F215	Nurses felt both like a gateway and advocate between parents and the rest of the multidisciplinary team	
F100, F101	Nurses struggled to bring up difficult conversations with families	
F118, F119, F120	Nurses recognised the need to involve the child in the shared decision-making process; however, this did not always happen	
F13, F14, F15, F19, F198	Children who understand their condition, treatment and procedures should be involved in the decision-making and consent process	
F17, F38, F121, F122, F123, F192	Older children have more say about their treatment and procedures, but nurses sometimes struggled with this concept	
F44, F106, F107, F153, F171, F172, F178	Communicating with the child can be difficult when parents wish to hide the truth of the child's condition from them	
F173, F207	Honest communication with children is vital to ensure the best possible care is provided	

Nurses also felt a responsibility to educate parents on their child's long-term condition, to ensure that high quality care continued to be delivered in the home to reduce risks or complications (Gårdling et al., 2015; Mimmo et al., 2022; Silva et al., 2016). When working with parents, an exchange of information was often provided, demonstrating that both nurses and parents had expert knowledge and could work together to provide high quality safe care (Bagnasco et al., 2013; Delaney & McIntosh, 2021; Denis-Larocque et al., 2017; Jestico & Finlay, 2017; Neal, 2022; Panicker, 2013; Pennafort et al., 2014; Reisinho et al., 2020):

> You grow as a professional the more you're exposed to families of children with chronic illnesses, because

they (the parents) may teach you strategies that work for the child that may be transposable to other children and other families.

> (Denis-Larocque et al., 2017, page 151)

Education delivered in workplace settings was valued because it enhanced safe care and facilitated nurses to ensure families felt supported. There was also a focus on ensuring children also received education (Bettle et al., 2018; Pennafort et al., 2014). Nurses recognised the importance of educating children so as they matured and developed, they would learn autonomy and decision-making skills about their condition:

> Every time we apply insulin, we provide full orienta-
> tion, we don't like to do it, we want the child to do it
> so that they can learn and be more autonomous. (I5)
>
> (Pennafort et al., 2014, page 134)

Educating children though was seen as a skill and a responsibility by nursing staff (Alahmad et al., 2020; Neal, 2022; Pennafort et al., 2014; Reisinho et al., 2020). When educating children, nurses needed to consider their age and level of maturity and use a variety of age-appropriate play skills and techniques. Often, nurses worked with parents to educate children, by creating a united front to ensure that the children were taught skills that the parents agreed to (Hopia & Heino-Tolonen, 2019; Mellor et al., 2015). However, many children felt unease and worried when they were admitted to a hospital, so emotional support was an important factor for nurses when educating children:

> … one thing that I've seen quite a few people do, for
> example, if you are doing a set of obs [vital signs]
> or something, you can do it on yourself before you
> are doing it to them, to try and show that it's not
> harmful.
>
> (Mimmo et al., 2022, page 2940)

4.4 | Synthesised finding two: Partnering to develop a strong therapeutic relationship

The second synthesised finding was related to nurses awareness of developing a strong therapeutic relationship between nurse, child and parent. There were 18 categories that contributed to the second synthesised finding, see Table 3.

Within the included studies, there was a large focus on the relationship that nurses developed with parents. The parent–nurse relationship is unique in paediatric care as both nurses and parents are significant care providers to children in their care, and both had to work together to negotiate care, responsibilities and duties for the child (Aein et al., 2011; Delaney & McIntosh, 2021; Giambra et al., 2017; Halpin, 2018; Mimmo et al., 2022). Nurses identified the importance of them leading conversations given their legal and ethical duty of care to their patients, but also valued and recognised the expertise parents have for their own children (Aein et al., 2011; Denis-Larocque et al., 2017; Giambra et al., 2017; Halpin, 2018; Montgomery et al., 2017). Recognising mutual expertise between parents and nurses helped to build a trusting relationship and helped to empower parents to have an active role in their child's health care:

> They know what's best for their children, and it's not
> their first time at the rodeo … They know what the
> care is, what the treatment is, what to do to get the
> best outcomes for their kids.
>
> (Denis-Larocque et al., 2017, page 151)

However, the partnership between nurses and parents could be difficult to navigate in stressful or ethically complex situations, especially when parents were agitated or anxious about their child's long-term condition (Aein et al., 2011; Alahmad et al., 2020; Delaney & McIntosh, 2021; Denis-Larocque et al., 2017; Hopia & Heino-Tolonen, 2019). Parents had their own needs and expectations when it came to their child's care and nurses saw parents almost as an additional patient, who required their own strong relationship, care and support (Aein et al., 2011; Denis-Larocque et al., 2017; Giambra et al., 2017; Hopia & Heino-Tolonen, 2019; Newman et al., 2020).

Developing a strong, supportive partnership with all members of the family was imperative for nursing staff when caring for children who have long-term conditions:

> I think if you can build up a good relationship with the
> family that certainly anchors everything else in place.
>
> (Neilson et al., 2013 page 451)

Rapport, trust and understanding of the family dynamics and relationships were essential for nurses to develop strong therapeutic relationships (Chong & Abdullah, 2017; França et al., 2013; Mimmo et al., 2022; Reisinho et al., 2020; Teixeira Fernandes Dos San et al., 2020). Often, children with long-term conditions were under the care of paediatric nurses far longer than children with acute conditions, which helped to allow a strong relationship to develop, but it could also be a difficult path to navigate whether nurses became emotionally attached to the family:

> With our chronic kids, I always end up really close
> to the families, just maybe because they're here for
> so long and I always have them. I don't know if that's
> easier with your communication or it makes it more
> difficult because you get in a relationship with them
> and then you want to filter what you're saying be-
> cause you don't want to ruin the relationship. I feel
> like you get a friendship and that feels like, okay, now
> that we have this nice relationship, I don't want to say
> anything that's going to make you mad or hurt your
> feelings. I feel like it becomes more difficult that you
> would think. It's not easier. I think it's more difficult
> because you almost feel a connection and you don't
> want to hurt them because it hurts you. (Participant
> RN203)
>
> (Baird et al., 2016, Page 8).

Nurses often talked about the partnership they developed with parents or the family as a whole, but rarely talked about how they partnered with children and developed a nurse–child relationship. When nurses discussed the nurse–child relationship, there was a clear understanding that mutual trust was needed between the nurse and child and this could only occur when the nurse saw the child as an individual and a child, rather than as a patient (Bagnasco

et al., 2013; Bruce & Sundin, 2018; Mendes, 2013; Mimmo et al., 2022; Sørensen et al., 2022). Seeing the patient as a child was important to some nursing staff, as it changed the way they provided care:

> I don't see the abnormal. I see a beautiful child, and that's what I see and I play with and I work with.
>
> (Mendes, 2013, page 416)

Trust remained central in the nurse–child relationship, as well as, seeing the patient as an individual child, who had their own needs and wants outside the family dynamics or their parent's preferences:

> You have to communicate with him/her as if he/she wasn't ill, for example, you have to ask simple questions related to his/her hobbies, favourite movies/ books. This relationship based on mutual trust helps us to make fun of the disease.
>
> (Bagnasco et al., 2013, page 126)

4.5 | Synthesised finding three: Optimising communication underpinned by shared decision-making principles to deliver individualised care

The third synthesised finding was related to the value that nurses placed upon communication and how it influenced the partnership. There were 17 categories that contributed to the third synthesised finding, see Table 3.

Communication was seen as the most important attribute when developing a therapeutic partnership between nurses, children with long-term conditions and their families. Nurses felt that transparent, clear verbal and non-verbal communication was vital to deliver safe patient care (Denis-Larocque et al., 2017; França et al., 2013; Giambra et al., 2017; Halpin, 2018; Newman et al., 2019; Ringnér et al., 2013; Teixeira Fernandes Dos San et al., 2020).

Communication was seen by nurses as a way to share expertise and information between themselves and parents, as this allowed an increase in trust and rapport (Bettle et al., 2018; Giambra et al., 2017; Mimmo et al., 2022). However, nurses needed to be mindful of when to offer information and when to let parents lead the discussion (Mendes, 2013; Neal, 2022; Newman et al., 2020). Allowing parents to take charge increased parental empowerment and strengthened the parent–nurse relationship, however nurses were ultimately responsible for the child's care and parents sometimes forgot this, which affected the relationship:

> … I adjusted the serum to continue for six hours but mother increased the flow 2 or 3 times faster … The mother sees herself entitled to do this … I become very angry because I'm accountable … (Nurse 10).
>
> (Aein et al., 2011, page 848)

Communication was used by nurses to ensure a shared decision-making process occurred between themselves, parents and children; however, when the topic was sensitive or there was many different opinions, nurses struggled to communicate effectively for the best interests of the child (Gårdling et al., 2015; Hendricks-Ferguson et al., 2015; Ringnér et al., 2013). Nurses felt that children should also be involved in the shared decisions-making discussions and tried to advocate often for this to occur, but the child involvement in decision-making discussions did not always happen:

> … the family would not allow the young teenager to know her diagnosis or prognosis … knowing the patient did not realise her life was coming to an end very quickly was gut-wrenching. She was never allowed to voice anything related to the end of her own life. I hated that experience.
>
> (Newman et al., 2019, page 110)

Communication with children was also seen pivotal to ensure individualised care was delivered. Nurses felt that they needed to be honest in their communication with children, but parents often acted as gateways between themselves and children which affected how nurses could engage their patients in decision-making or consent processes (Chong & Abdullah, 2017; Hopia & Heino-Tolonen, 2019; Montgomery et al., 2017; Newman et al., 2019, 2020). In the care of older children, nurses also struggled with ensuring the child was more involved in their own health care, preparing them for transition into adult services, but recognised that children needed to be empowered and learn self-determination skills (Bagnasco et al., 2013; Carter et al., 2012; Mellor et al., 2015; Reisinho et al., 2020). Nurses recognised the value of older children being involved in their own care and having clear communication with their patients, but emotional situations were difficult to navigate:

> I sometimes feel adolescents, their emotion is a bit different from the younger child or adults. They … like … turn more to emotional, more anger. Sometimes they are more angry, how do we deal with that? … How do I communicate with them? (Nurse 9).
>
> (Chong & Abdullah, 2017, page 127).

> And (adolescent patient) asks just the right questions, dancing around the issue because her mom is always present … I can just read in her eyes, 'My mom isn't saying it and I'm not going to say it because mom's gonna cry.'
>
> (Montgomery et al., 2017, page E50).

5 | DISCUSSION

This qualitative systematic review aimed to synthesise the existing studies to understand how paediatric nurses' experienced triadic

partnership nursing and the attributes of partnership when caring for children with long-term conditions and their families. Three synthesised findings were aggregated and composed of a total of 52 categories.

The findings demonstrated that the attributes of triadic partnership (shared roles and decision-making, parental participation, mutual trust and respect, communication and negotiation) exist in the nursing care provided to children with long-term conditions and their families, but is not provided consistently to all families, or necessarily in a triadic nature. The development of relationships was often seen as dyadic in nature, with nurses focusing on developing a strong nurse–parent partnership and a nurse–child partnership, rather than a child–parent–nurse partnership. The lack of evidence or acknowledgement of a triadic child–parent–nurse partnership within the studies is cause for concern. Triadic models of care exist in other areas of health care (De Civita & Dobkin, 2004; Eull et al., 2023; Lenne et al., 2023; Williams et al., 2022). These models have a focus on building a partnership that uses shared decision-making as well as understanding the unique needs a child may have due to their age, maturity or level of competence. The use of dyadic nurse–parent and nurse–child partnerships rather than a child–parent–nurse partnership can cause friction within the therapeutic relationships, as parents and children struggle to voice their wishes and concerns in a shared, collaborative space (Barratt et al., 2021, 2022).

The reasoning behind nurses developing two dyadic partnerships rather than one singular triadic partnership may be due to age and maturity in children and the complexities of achieving this in practice. There was an absence of insight or explanation in relation to how nurses determine the level of competence a child has in terms of decision-making capabilities and involvement in their own health care (Alahmad et al., 2020; Gårdling et al., 2015). It is unclear in the synthesis how nurses decided on involving children in a more substantive partnership or the method of engagement nurses would use to bring children with long-term conditions into a triadic partnership. As children mature in age and experience, there is a generalised belief that they will wish to take more control over their own life and health care decisions, playing a more active role in the decision-making process (Ruhe et al., 2015; Vaknin & Zisk-Rony, 2011). How that actually occurs in practice on a day-to-day basis, and how organisational policies, cultures and legal frameworks underscore those practices are less well understood and warrant further research.

Another rationale for nurses developing two dyadic partnerships instead of a singular triadic partnership between themselves, children and parents may be due to nurses often needing to provide care and support to the parents, who could be seen as a secondary patient. Parents were often seen by nursing staff as overwhelmed, especially in the first few months of a new diagnosis and required their own emotional support, care and education (Rodgers et al., 2018). Nurses may struggle to navigate the need to provide care to parents as a secondary patient as well as seeing the parent as another form of carer or potential gatekeeper who has decision-making responsibilities and should be consulted

in all aspects of care (Lenne et al., 2023). Empowering parents to become successful carers of their children is a crucial responsibility of nursing staff, as high levels of empowerment were seen as confidence-boosting and promoted feelings of mutual trust and respect, consistent with previous research (Barratt et al., 2021; Brødsgaard et al., 2019). The review also highlighted opportunities for empowering parents to support their children in their own development of self-advocacy over time as children grow up with their long-term conditions.

In the meta-aggregation, nurses also described the frustration they felt when there was ineffective partnership, such as parents going against decisions made by the nursing staff to ensure safe care is delivered. There is a clear need for power and control, with nurses' rationale for this surrounding their need to be accountable and responsible for their patients and patient's welfare. This contradicts central goals in the current nursing model of Patient and Family Centred Care, where parents and children are recognised as experts in their own right, and given greater responsibility to become an active team member within the partnership (Institute for Patient and Family Centered Care, 2020; Mikkelsen & Frederiksen, 2011). Previous research has also demonstrated that both the parents and the nurse hold themselves responsible and accountable for the care of the child, which can cause friction between both parties, as well as confuse nurses who see parents as a potential secondary patient (Barratt et al., 2021; Harrison, 2010). If a nurse can recognise the importance of partnering with parents, it may improve parental feelings of empowerment and control, allowing the parents to develop a trusting relationship with nursing staff and feel comfortable in voicing their concerns (Barratt et al., 2021; Lim & Cho, 2022).

Creating a triadic partnerships between a nurse, parent and child with a long-term condition may promote more effective and safer care for the child and family. This is crucial as children with long-term conditions often face longer hospital admissions and have an increased morbidity and mortality (AIHW, 2022). Often, the level of child and parent involvement changes based on the nurse providing the care on that day, with the nurse utilising subjective data and information to determine how care will be provided and the roles each party will play (Barratt et al., 2021, 2022). Previous research has demonstrated that children benefit from having an active role in partnership with their parents and nursing staff (Barratt et al., 2022). Children who have a more active role in their own health care often find their own voice within the partnership as they have been taught the importance of shared decision-making and autonomy from a younger age, which can help empower their self-advocacy for a condition that they may have for their entire life (Barratt et al., 2022; Coyne et al., 2014). In this review, nurses often involved children with minor decisions, such as the time for a blood test or colour of dressings, leaving major decisions to be discussed exclusively between the nurse and parents, consistent with previous research (Coyne et al., 2014). The decision to include a child seems to be subjective and individualised to the nurses own beliefs and experiences (Coyne et al., 2014; Vaknin & Zisk-Rony, 2011). In a triadic partnership, the nurse may still use subjective data to establish

a child's level of maturity, competency and engagement, but must seek to recognise the value and expertise that both the child and parent have and consider this in the care they are delivering. Seminal research has demonstrated that a triadic partnership may reduce the risk of conflict between the child–parent–healthcare professional as children grow and demand more power and control over their health care, as they have been valued in the partnership and given more power and control as they matured, rather than feeling a need to fight for power and control (De Civita & Dobkin, 2004).

Previous research has also identified that healthcare professionals may relate differently to patients and families with different levels of health literacy and sociodemographic characteristics that are different to their own, and that these communication and relation barriers impact on effective ingredients of partnership (Brødsgaard et al., 2019; Johnston et al., 2015; Kwame & Petrucka, 2021; Salvador et al., 2020; Tallon et al., 2017). This review has shown the importance nurses place on skilful communication with both parents and children. Nurses who have excellent communication skills and are accomplished in developing a therapeutic relationship with the children and families may find it easier to negotiate a successful child–parent–nurse triadic partnership. However, communication within health care often focuses on information sharing rather than encouraging triadic collaboration (Smith et al., 2015).

5.1 | Implications for future research

This systematic review highlights the opportunities to develop an effective child–parent–nurse partnership. Triadic partnership nursing needs further research—into what triadic approaches are effective and how nurses navigate the different needs and timings of the child and the parent (while also navigating complex clinical environments with varying resources). Given the subjective nature of partnership and involvement in the partnership, further research needs to clearly bring new knowledge in relation to how nurses involve both parents and children with long-term conditions, and identification of the enablers and barriers to negotiating an effective triadic partnership where all three parties feel valued and heard. Future research also needs to clearly document how nurses and parents are determining the level of involvement a child has in their own health care based on their level of competence and capacity. While evidence shows that nurses are partnering with children and their parents, further clarity on what triadic partnership means in this subgroup and how to support nurses to achieve it is required.

5.2 | Implications for clinical practice

The development of a triadic partnership through recognition of the value of both parents and children with long-term conditions needs to be a priority for paediatric nursing staff. To promote effective partnership, nurses need to understand their strengths and limitations surrounding long-term conditions and seek further support and education on the variety of complex conditions and treatments they may be exposed to. Healthcare systems need to also work to support nurses in developing further skills and training on the value of partnership and ways to identify and support the parent and child's voice in order to promote empowerment and feelings of control. Partnership nursing is a skill that can be used by all nursing staff to develop a therapeutic working relationship with families of children with long-term conditions, but requires acknowledgement that all partnerships are different, based on family structure, health literacy and attitudes towards health care. Furthermore, policy needs to reflect the importance of the child's voice and clearly describe the value that children bring to their own health care.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Supplementary Tables

Supplementary table 1: Example of search architecture in database.

Database and date	Scopus 3/01/2023
Key search terms	Nurs* And (child* or pediatric or paediatric or neona*)
	Partnership* or "partnership nursing" or participation* or collaboration* or role* or negotiation* or "decision-making" or respect* or involvement* of trust* or communication* or shared roles or "partnership model" or "partnership in care" or "nursing partnership" or "shared decision-making" or "participation in care"
	Children* or adolescent* or youth or child* or teen* or infant* or baby* or babies or parent* or mother* or father* or famil* or paediatric or pediatric or neonatal or neona*
Parameters	Year (2010-2022), English language
Total search results	1468

Supplementary table 2: Extraction of verbatim findings and illustrations, credibility scores

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
Aein 2011	Parents need care themselves due to being there all days and nights that has made nurses having to face mother's needs and expectations, which puts them under extra pressure.	"... You in fact are working with two clients: the patient and his/her mother with her own needs and expectations … (Supervisor 1)" (Page 845)	X			F1
Aein 2011	Nurses require more time, and skills in working with children, which put them under extra pressure and make time management more demanding.	"Nursing procedures for children are more challenging. Paediatric nurses should be more skilful and patient … (Supervisor 3)" (Page 845)	X			F2
Aein 2011	A lack of interpersonal skill, could lead to nurses' incompetence in providing psychological support.	"... We did not receive training for how to communicate to patients ... I don't know how to support them psychologically. (Nurse 4)" (Page 847)	X			F3
Aein 2011	Shortages in human resources resulting in a lack of time have also led to the children being psychologically not prepared for the procedures by nurses.	"I don't really talk to the child. We do not have time... (Nurse 6)" (Page 847)		X		F4
Aein 2011	Nurses' attitude that children are more conveniently cared for by their mothers acts as a facilitating factor in delegating some aspects of care to parents.	"Children are more convenient being cared by their mother than a nurse. This is why we want mothers to do some nursing care. (Nurse 10)" (Page 847)	X			F5
Aein 2011	The degree to which nurses trusted mothers' ability to carry out specialized aspects of care depended upon nurses' experience.	"When the mother says, 'I have learned NG (Nasogastric) Tube feeding', some of junior nurses believed mother's claim, but I say 'I come and watch you do it'. (Nurse 3)" (Page 847)	X			F6
Aein 2011	In such cases, some mothers with frequent experience of hospitalizations undertake certain nursing tasks, without consultation with nurses because they think it is a simple task and does not need much expertise. It jeopardizes quality of care and because nurses would be accountable for the consequences of such actions, it leads to dispute between nurses and mothers.	"... I adjusted the serum to continue for six hours but mother increased the flow 2 or 3 times faster … The mother sees herself entitled to do this … I become very angry because I'm accountable … (Nurse 10)" (Page 848)	X			F7
Aein 2011	In cases where mothers were frequently interfering with the treatment plan and quarrelling with the nurses, more experienced nurses made effective use of the authority of the father or other influential members of the family to force the mother to observe the boundaries as the staff had intended.	"When I am not able to resolve the issue with the mother, I talk to the father or who in the family is she close to. It is very effective. (Nurse 10)" (Page 848)	X			F8
Aein 2011	Nurses did not allow mothers, whose presence caused increased anxiety in children and made them less cooperative or were interfering with the nurses' jobs, to be present. This was one way nurses controlled the parent–nurse boundary.	"...As a rule, no, they interfere, not only the mother is agitated but it has an effect on us too. We say if you want to act like this back off. (Nurse 3)" (Page 847)		X		F9
Aein 2011	Delegating aspects of care to mothers without negotiating with them caused their wishes not being taken on board. Some nurses reported that some mothers looked down upon nurses' duties. Consequently, they resisted fulfilling the tasks assigned to them or at time complained to the managers and therefore nurses called them 'uncooperative' parents.	"... A lot of parents view it in a negative light. Some are insulting … it is your duty'. (Nurse 8)" (Page 847)			X	US1

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
Alahmad et al., 2020	Patients with cancer are among the longest-term patients, and, along with their relatives, nurses are in the closest contact with them. A special relationship develops between the nurse and the child.	"I was so happy because I saw the fruit of my work." (Page 4)			X	US2
Alahmad et al., 2020	The role of the nurses extends beyond the care of patients, to help in educating patients and in medical research.	"As a nurse, I play the role of witness in collecting informed consent process." (Page 4) "All staff working in caring of patients with cancer should have a duty to educate patients on how to deal with their diseases." (Page 4)		X		F10
Alahmad et al., 2020	Nurses participating in our study agreed that a nurse should be patient, courteous, well informed, and well-trained in this field.	"Nurses who work with children of cancer should be nicer and should have training on how to deal gently with children and their families." (Page 4)		X		F11
Alahmad et al., 2020	The nurses interviewed in our study considered parental consent mandatory and necessary from the moment the child is admitted to the hospital, as well as during the course of diagnosis and treatment. This consent should easily understandable and contain all the required information for an informed decision.	"We need consent in each stage of treatments plan." (Page 4) "It is important to the family to know if the treatment is curative or palliative, because this may help them in preparing themselves." (Page 4)			X	US3
Alahmad et al., 2020	Nurses reported that parents' emotional and psychological states sometimes made it difficult to obtain consent from them.	"The main problem is that the parents are usually being emotional, under strong feelings and maybe not completely able to make proper decisions." (Page 4) "I do not think our practice in getting consent is adequate—we need to help them in taking decision. I always see it as shared decision and a shared responsibility between parents and healthcare providers." (Page 4)	X			F12
Alahmad et al., 2020	When it comes to child assent, nurses agreed that children with cancer are often weak and require care, so the child's own decisions cannot be relied upon.	"Children are not who take decisions," (Page 4) "From age of 12 years, we have to seek permission from child besides of parental consent." (Page 4)	X			F13
Alahmad et al., 2020	Another nurse expressed that the child's understanding of their illness, the procedure, and the treatment provided was more important than age.	"When the child can understand, he should be involved in consenting process." (Page 4)	X			F14
Alahmad et al., 2020	It was stressed that any information given should be provided in a simplified way, and—if possible—used as an opportunity to teach the child.	"The child can understand, and the nurse can educate him about his disease." (Page 4)		X		F15
Bagnasco et al., 2013	All nurses stated that they play a crucial role in helping parents and their children to increase the level autonomy and safety.	"Our job is to educate parents to help them increase both their self-esteem and their confidence in our competences and in nursing techniques." (Page 126)	X			F16
Bagnasco et al., 2013	All nurses are aware that adolescence is considered the most critical period of the individual's life, because it entails a series of changes that mark the transition to adulthood.	"In our practice, we meet adolescents who underestimate the disease, and refuse therapies." (Page 126)	X			F17
Bagnasco et al., 2013	All nurses reported that, at least in the hospital, they tend to give greater independence to boys, and reduce the role of the parents. Admission is the first step to win their trust.	"You have to communicate with him/her as if he/she wasn't ill, for example, you have to ask simple questions related to his/her hobbies, favourite movies / books. This relationship based on mutual trust helps us to make fun of the disease." (Page 126)	X			F18

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			UE	C	US	
Bagnasco et al., 2013	In very young children, the burden of the disease is mitigated by the reassuring presence of an adult.	"The children face the disease as their parents do." (Page 126)		X		F19
Baird et al., 2016	Support for continuity was not a dichotomous "yes or no" answer, but rather occurred along a continuum, with some nurses expressing more support for the concept than others. For example, several of the nurses identified the mutual benefits of continuity, citing the ease with which care can be provided when the nurse is familiar with a child and that child's routine.	"I think [continuity] makes a huge difference for the families and for the nurses, because especially with our really intricately detailed and fine-tuned care patients, you know how they prefer things and their family doesn't have to explain again, 'Actually, we really want the dressing this way' or, you know, those little things. So it just makes the day very natural and smooth. (Participant RN404)" Page 7)	X			F20
Baird et al., 2016	Another downside to continuity was the possibility of emotional entanglement: They worried that the relationship with the family could become "messy," that they would cross professional boundaries, or that they wouldn't be able to take a break from caring for the child and family when the need arose. One nurse indicated that continuity lists promoted the placement of nurses onto "pedestals," and she worried about "falling from the pedestal" and becoming a disappointment to the family.	"With our chronic kids, I always end up really close to the families, just maybe because they're here for so long and I always have them. I don't know if that's easier with your communication or it makes it more difficult because you get in a relationship with them and then you want to filter what you're saying because you don't want to ruin the relationship. I feel like you get a friendship and that feels like, okay, now that we have this nice relationship, I don't want to say anything that's going to make you mad or hurt your feelings. I feel like it becomes more difficult that you would think. It's not easier. I think it's more difficult because you almost feel a connection and you don't want to hurt them because it hurts you. (Participant RN203)" (Page 8)	X			F21
Bettle et al 2018	Similar to parents, nurses described the importance of building trusting relationships by providing the family with a consistent nurse contact/ family centred care to partner with as parents navigate the ALL (Acute Lymphoblastic Leukemia) pain experience.	"The nuts and bolts of it is a liaison … a consistent liaison for families between the healthcare team here, the home resources or home health care team, and the families. We're probably the most consistent go to person (Nurse 7, line 22-25)." (Page 49)		X		F22
Bettle et al 2018	Nurses established this partnership with parents at diagnosis and continued to support parents throughout treatment.	"… The family is directly involved right from the start. There is never a point where a family is not fully included in anything that we do with their child, whether it's procedural pain or if it is treatment related pain or diagnosis related pain. (Nurse 3, line 298-301)" (Page 49)	X			F23
Bettle et al 2018	Nurses described how parents were overwhelmed when their child was diagnosed and as a result they tailored parent education to help parents learn about medication side effects, prognosis, protocols.	"Sometimes our teaching is a bit trial and error because we don't know necessarily how the parents are going to learn information or retain information. So, I think we try to do as an effective job as we can, but sometimes what works for one family won't work for another family. (Nurse 2, line 557-560)." (Page 49)	X			F24
Bettle et al 2018	Nurses used repetition and ongoing reminders to ensure that parents have a good understanding for example.	"Once treatment has begun, we tell them a lot of the side effects of the drugs and we have to keep reinforcing things because it's new to them (Nurse 3, line 484-485)." (Page 49)	X			F25
Bettle et al 2018	Nurses engaged parents in a 2-way information exchange that drew from parent and nurse expertise.	"We sit down and we tell them what to look for . . . having the knowledge of what is indicating that their child is in pain because some kids can be in pain and they can still be playing away (Nurse 5, line 467-469)." (Page 49)	X			F26

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Bettle et al 2018	Nurses specifically relied on common behavioural signs of ALL pain and parents' expert knowledge of their child to assess pain.	"It's funny because I say like you know your child better than anybody else and that's kind of what you have to go by. Like you know when your child is not feeling well, it's very apparent to a mom or a dad if you spend enough time around child you know the second something is off. (Nurse 2, line 350-353)" (Page 49)	X			F27
Bettle et al 2018	Nurses described how they used both written and verbal teaching strategies to guide parents' medication administration then parents take this knowledge, and they tailor strategies to meet their child's needs.	"The medications we send them home on so they don't have to be here every time they need medication. So parents are responsible for that and responsible when they are at home for reading their child's pain. We kind of give them an arsenal of drugs and explain to them how they can use them and what timeframe and then we, after a while, sort of let the parents give them in a way that works best for their child. (Nurse 2, line 327-331)" (Page 50)	X			F28
Bettle et al 2018	Nurses discussed in detail parents' active role in managing procedure pain by applying a wide variety of distraction strategies. Over time and with experience, parents were able to develop and advocate for step-by-step procedural routines that work for their child.	"There is one girl that I can think of that used to like lose her mind over having her port accessed, hated it, had a couple of really bad experiences and really didn't like it. So what the mom ended up doing is we introduced the whole iPad concept and then the mom will snuggle up right behind her, not holding onto her anymore because she does so well. She holds the iPad and holds it right over her face so she can't see what is going on with the port. (Nurse 2, line 507-512)" (Page 50)		X		F29
Bruce & Sundin 2018	The PNs (Pediatric Nurses) also believe that families are supported when they are able to believe in the future and a feeling of hope and that it is important for the families to know whom they can turn to and to have a feeling that the PNs understand their child and their child's needs.	"You often say [to the parents] that most things will work out, but it's a really tough trip; it's really tough." (Page 955)		X		F30
Bruce & Sundin 2018	Parents who feel safe contribute to greater feelings of safety in the child. The PN needs to interact with both the child and the rest of the family and needs to be able to create opportunities for cooperation with the entire family.	"They might be hysterically scared parents, but I am supposed to be helping the child … I'm a support to the child, but it is the parents I talk to." (Page 956)		X		F31
Bruce & Sundin 2018	The PNs consider that families feel supported when the PN talks and listens to the child because this confirms to the families that the nurse cares.	"… Maybe just listen to them … and maybe they can talk to some of the physicians, but still know that I'm there. The fact that they know they can turn to me." (Page 956)		X		F32
Bruce & Sundin 2018	When the PNs felt they had given support to the child or the family, they felt positive about their work.	"They need different support depending on where they are …Some do not need that much at all; they come here and know what needs to be done." (Page 957)			X	US4
Bruce & Sundin 2018	The PNs consider that children with congenital heart defects) would like to be, and should be, allowed to be like everyone else. PNs should let the children be like other children as much as possible, but still be there and be supportive of them.	"We try to make them a safe adult, treat them like an adult, but we continue to have our safety net there for them, so if they fall, we'll catch them." (Page 958)		X		F33
Bruce & Sundin 2018	Even though the PNs try to meet the families at their knowledge level, it can be difficult if the PNs experience that families have their own routines and want to manage their life on their own terms. PNs in such	"No, I can't, I have not asked that … what kind of support families desires, I can only say what I think, but it is not the same thing … I don't know what they desire." (Page 958)			X	US5

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	situations often find it difficult to know what kinds of support the families, including siblings, want and need.					
Bruce & Sundin 2018	A lack of support might also be when the relationship between the nurse and the family is adversarial, when a deeper connection between them is missing, or when the nurse does not do something because of the assumption that someone else had already done it.	"I believe that as health care is now, I think that the families meet so many professionals, so when you as a nurse stand there yourself, you might think that this is not something that I will bring up because it will probably be one of my other co-workers who will do it." (Page 958)		X		F34
Calza et al., 2016	They also recognized that nurses can end up educating a non-Italian patient with a different cultural background at any time of the day and night.	''… We often have to call the interpreters during the night to relax the parent: they are alone, far from home and the child is in critical conditions. I would like to do much more than to just help to understand the language, but also understand why things are as they are.'' (Page 12)	X			F35
Calza et al., 2016	All respondents reported that the biggest and most difficult obstacle to overcome was ''language.'' The messages and notices that nurses conveyed to non-Italian patients and families were interpreted in a different way and ''with a different meaning'' compared to the Italian patients and families.	''Children often speak Italian better and before their parents.'' (Page 13) ''The use of the telephone translator is rare. It is very impersonal, cold. The child helps us, but surely it would be better to have a cultural mediator available in the unit. The telephone translator is used mainly at night in the case of an emergency.'' (Page 13)		X		F36
Calza et al., 2016	The majority of the nurses were extremely frustrated by having to face linguistic obstacles on a daily basis.	''Sometimes non-Italian speaking mothers say yes, but from their faces I can see that they are worried, because they actually have understood what I said, what to do, or what is happening! It is terrible! And this makes me feel sad and frustrated.'' (Page 13) ''It is always difficult to understand pain in children, especially in non-Italian children with a different cultural background, I do not know if the say that they are well because it is true or if they say so because they are afraid we administer drugs: I try to understand this from their nonverbal communication.'' (Page 13)	X			F37
Carter et al., 2012	Patients who refused or rejected care frustrated and discouraged nurses. The nurses understood that the behaviours were a symptom of the illness but found working with the patients difficult nonetheless.	"It's the manipulation. You think it's a personal attack against you and it's not; it's all part of their disease process." (Page 551)		X		F38
Carter et al., 2012	Many nurses did not have specific training to care for children and adolescents with ED and were not confident in their ability to provide the required emotional support. This raised concerns about the adequacy of nursing care for patients.	"If they get upset or they're crying, there's very little that the nurses can offer because we haven't been given a lot of the training in terms of how to counsel them." (Page 551)	X			F39
Carter et al., 2012	Nurses also described how their inability to provide the best care for patients left them feeling dissatisfied with the work they did. This nurse described how she felt after working with both ED patients and oncology patients.	"So at the end of the day you kind of feel like a lackluster nurse because you're not able to spend time with this patient who needs your care. And just as much as one of our cancer kids needs that chemo or blood transfusion, this child needs someone to speak to. So it was very frustrating." (Page 552)		X		F40
Carter et al., 2012	Inconsistent use of the guidelines, driven by a desire to personalize care, confused the nurses and made planning care for the patients difficult.	"They tried to standardize the plan of care, but then there's always an exception to the rules, and oftentimes, it's confusing." (Page 552)		X		F41

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			UE	C	US	
Carter et al., 2012	The ED-RNs (Registered Nurse) were most satisfied with the relationships with the patients and families.	"I like how we can form a relationship with them. It's not always right away or anything like that, but it's nice working through it with them, forming a bond with them and helping them bit by bit." (Page 554)		X		F42
Chong & Abdullah 2017	Rapport was deemed highly essential prior to any communication with children and it took more time to establish compared to adult patients. Conversations with adolescents were challenging, as their thought processes and actions seem less logical than adults and they were found to be more emotional. All nurses acknowledged their inadequate communication skills.	"The way they communicate is not like adults, (adults) can mention to us what is their problem, what is their difficulties … but not with children … I mean their level of understanding, it's not easy to explore from children … so (we) try other ways to speak to them … like art therapy. (Nurse 12)" (Page 127) "When you talk to children, you appear a bit like … 'gentler' … your tone become nice for children to hear. The words that you use are very simple, not too many and … sometimes we use what children like. For example, (if) they like cartoon so we talk about that more or (if) they like … drawing, we (draw) together … during the drawing they also talk, so we can listen and share … (Nurse 11)" (Page 127) "I sometimes feel adolescents, their emotion is a bit different from the younger child or adults. They … like … turn more to emotional, more anger. Sometimes they are more angry, how do we deal with that? … How do I communicate with them? (Nurse 9)" (Page 127) "I feel frustrated when they don't … they cannot think like what we think, as an adult. We think that this is good, but even though they suffer, they don't want to comply with the treatment regime … that make me feel very frustrated, sometimes feel like giving up. (Nurse 7)" (Page 127)	X			F43
Chong & Abdullah 2017	Establishing trust with parents required time; hence it was challenging for nurses to build rapport with parents when referrals are made only at the end of life and when they have had a long relationship with their primary team. Nurses encountered heightened emotions in parents of their patients, there was anxiety, regret, fear of loss, and anticipatory grief. Understanding what patients want may also be difficult when parents colluded and were not truthful to their child.	"It's like sometimes they ask you questions like how long my child will live … for adult patients we can give them the direct prognosis on how long, but sometimes with their parents, if you give them direct answers it will be a bit difficult for them. There is a way of communication with the parents. You can't talk to them really direct, you can't talk to them like you talking to other adult patients. Sometimes we need to spend more time with the parents because they are quite easily break down in front of us … (Nurse 3)" (Page 128) "I feel that parents are more emotional (when) caring for their child and sometimes when I reflect back … wonder if parents were making the right choice for the child … because they are too emotional, most of the time. (Nurse 2)" (Page 128)	X			F44
Chong & Abdullah 2017	Nurses had referrals for patients with both cancer and non-cancer. Some of the illnesses were unfamiliar to them and they felt challenged when parents wanted information about complications of the medical illness and prognosis. They found assessment of child's needs more difficult without use of verbal communication.	"… Because children disease are sometimes … 'funny', lots of names you never heard before. And … I … feel that the disease for children, (parents) want cure or something like can reverse. They) want that, (they) don't want to hear like nothing can be done. So that's why it's challenging, you really need to understand the disease … even some of medication, children and adult the dosage are not the same. Like for adults, when you already been	X			F45

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Author	Verbatim Findings	Verbatim Illustrations	Quality UE	C	US	Label

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		using the same dosage you will remember but children, you don't use and sometimes the weights are different … it's not easy, it's not easy. (Nurse 11)" (Page 128) "We are not really trained in paediatrics. So we are just learning just as we see cases, so I would think that if there is a specific training or some additional … specialization or some additional knowledge will be good … Just to help us to be able to identify what is going on. Because paediatrics is really a world on its own, it's very different from the adult world … (Nurse 17)" (Page 128) "So for me to advice the parents is like … ''hey, who are you to give the advice for the parents? You yourself don't have any children and you are not having their … parenting experience,'' sort of like that. (Nurse 2)" (Page 128)				
Chong & Abdullah 2017	Nurses felt the learning experience from each family enhanced their confidence and resilience. Following the death of their patients, some nurses were worried for the parents and knowing that they were coping was comforting.	"I feel this is something special … like I am a special person, like a angel that go in to the house to help them. When I'm on call, when I go and see a child … when I'm driving on the road … I will feel like … I'm quite … like special on the road. There are lots of cars even though very jam (traffic), but the other car is not going to see patient but I'm the one going to see the patient. So actually, I'm doing a quite meaningful job. When you enter the house, when you see the parents, they are very grateful, they say thank you that you are coming in to help … then you will feel that it's worth it. Even though you physically tired, but you worth it to help them. There is no regret to go in to help them because they appreciate us. (Nurse 9)" (Page 129) "Try not to think of … role of a mother because I'm a mother, try not to think of my children or anyone, family member, immediate family member … try to think of ''I'm a nurse'', focus, and I'm going to help the children and family, that's it. Don't let anything interfere during the conversation or during the visit. (Nurse 11)" (Page 129)		X		F46
Da Silva et al., 2016	In interaction of nursing professionals with the child hospitalized with a chronic condition, there are reports that express feelings of devotion and concern from the first to the second.	"We try to have a loving, caring relationship with the child. (E5)" (Page 559) "It is difficult, we create a great emotional bond, and then try to protect that. (E7)" (Page 559)		X		F47
Da Silva et al., 2016	Some nurses reported difficulties in interacting with the family in the management of nursing care.	"What I find more difficult is the relationship between companion and the professional ... because the companion is always intervening. (E1)" (Page 559)		X		F48
Da Silva et al., 2016	The management of nursing care begins on admission of the child with a chronic condition, and this is a moment of interaction that enables the identification of needs that will guide the planning of care.	"So the first thing I see when I know that a child with a chronic diagnosis will be admitted, I try to learn why the child is coming to the hospital ... I try to see what this child needs, if she needs oxygen, to be suctioned, if she has a tracheostomy, if she has gastrostomy. I try to see about everything a chronic patient can usually need within an institution, and then I prepare everything. (E6)" (Page 559)	X			F49

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Da Silva et al., 2016	Family members are also involved in implementing that activity. They contribute by providing important information for nurses, which are configured as subsidies for care management, and cooperate in performing some direct care for the child.	"I try to get into all the rooms, ask the mothers and companions how that child is today, if her condition is improving, I think this is important. (E2)" (Page 559)	X			F50
Da Silva et al., 2016	Nursing professionals expressed interest in offering comfort, care, emotional and spiritual support to promote the permanence of the family and minimize their suffering.	"With the companion, a caring relationship, helping in whatever is needed, giving them emotional support, sometimes spiritual, I try to be as close as possible to them. (E5)" (Page 560)		X		F51
Delaney & McIntosh 2020	Several mentioned that they laughed a lot with the teens they treated. They also believed youth connected with them. Articulating how this connection builds over the years was often difficult to explain.	"After a while you know that kids connect to you. But why- It is hard to explain. Maybe it is because I let them control the discussion a bit. I tell them, you do not have to say anything you do not feel comfortable talking about." (Page 44)	X			F52
Delaney & McIntosh 2020	One predominant theme revolved around the hopeful attitudes they held for families; an attitude which seemed core to their approach. The respondents told us repeatedly of the respect they have for families; their belief that often parents were doing the best they can.	"If I am not engaging and assisting the family in change along with the child, I feel that, um, I really don't have the impact I want to. So, I've always considered myself as-predominantly a family therapist." (Page 45) "I try really hard not to do anything that would make them think you're blaming them … and be as empathic as I possibly can." (Page 45)		X		F53
Delaney & McIntosh 2020	This idea of respecting the parents' efforts led to a second foundation of the partnership; understanding what the parent and family needed. In talking about their approach to treatment planning, participants established what parents expected from treatment and their priorities.	"You need to meet the family with what they need. And also, to create a ladder so they can see some level of hope." (Page 45)			X	US6
Delaney & McIntosh 2020	Trust also came into play when the APPNs (Advanced practice psychiatric nurse) broached difficult topics, such as how parents' behaviours could contribute to the child's anxiety or reenforce behaviours.	"Requires that level of getting into that space with families where they'll trust what you have to say." (Page 45) "My population tends to be very high emotional reactivity, which means they're screaming sometimes even in here… We are trying to have enough trust with these families to say, "Let's try this—let's-let's take a look at this." And if you don't have that level of trust, if they don't see you on their team, you can't say things that they'll respect. Like, hey, did you notice, like when your voice is higher, how he started getting more activated or he was reacting?" (Page 45)		X		F54
Delaney & McIntosh 2020	There was a strong sense of understanding, coaching, and empowering parents to do be able to deal with their child's often difficult behaviours. A vital component was helping parents with parenting, often seen as providing concrete support.	"I am here to see what they are dealing with and understand it and try and provide them with some skills. When they leave, I ask-did I do anything to help them address that issue." (Page 45)		X		F55
Delaney & McIntosh 2020	Knowledge, trust, and equal footing intertwined in how these APPNs approached families; demonstrating again that it was not so much what they did, as who they are.	"It's important that families feel supported and feel like I'm a part of their family or I'm on their team, which has also resulted in a high level of responsibility—like, I usually respond to my families within 12 to 24 hr. I mean, it's rare that I don't get back to somebody, and I feel that that level of, um—I don't know—responsiveness also helps kids get well or helps families to be able to keep moving forward with their treatment." (Page 45)		X		F56

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Delaney & McIntosh 2020	Some point in the interview, each participant discussed the relationships they formed with children and their families. They often depicted the relationship in terms of the everydayness of how they interacted with the child and their families.	"I'm trying to be more of a coach, a teacher, a model for them and what to do." (Page 45) "What's most effective when we're trying to help the child in the family environment is that the parents actually feel better, and then they feel more confident, and then they're able to do what we're asking to do with the child, which is, often, something that doesn't come naturally in their parenting." (Page 45)	X			F57
Denis-Larocque et al., 2017	Nurses acknowledged that parents of CMC (Chronic medical conditions) were experts in their caregiving role. In particular, they understood that parents' expertise was related to their previous experiences with the health care system, as well as caring for the child at home.	"They know what's best for their children, and it's not their first time at the rodeo. . . They know what the care is, what the treatment is, what to do to get the best outcomes for their kids." (Page 151)	X			F58
Denis-Larocque et al., 2017	More specifically, nurses emphasized that parents of CMC were aware of the intricacies of their child's care.	"They are there 24/7, they know their kids super well. . . The parents pick up on things before we do, (they) even make observations before I would have picked up [on them], so for sure they're experts." (Page 151)	X			F59
Denis-Larocque et al., 2017	Despite recognizing parents' expertise, many nurses explained that their education and experience in paediatric critical care did not adequately prepare them to interact with the population of CMC.	"We realize that we're, kind of, thrown to the wolves." (Page 151) "You're a new nurse (in the unit), you're not really sure (and so you ask yourself), 'Do you follow what you want to do? Do you follow what the parents want to do?'" (Page 151)			X	US7
Denis-Larocque et al., 2017	When asked how nurses learned to care for parents of CMC, participants mentioned getting advice from senior nurses and listening to nursing reports and nurses' past experiences. They also described learning from parents themselves.	"You grow as a professional the more you're exposed to families of children with chronic illnesses, because they (the parents) may teach you strategies that work for the child that may be transposable to other children and other families." (Page 151)		X		F60
Denis-Larocque et al., 2017	Nurses experienced a steep learning curve, as caring for these parents required them to adjust to a new caregiving role. Rather than teaching parents about the child's condition, nurses often became the learners, taking their cues from parents.	"Your nursing role will definitely be different fora complex patient. . . You get used to working with the families rather than teaching them." (Page 151)	X			F61
Denis-Larocque et al., 2017	Despite the difficult role change, many nurses realized the importance of relying on parents' expertise through experience.	"The parents. . . know their kids so well that you'll be able to interpret your information or your assessments using the knowledge that the parents have of their child." Page 152)	X			F62
Denis-Larocque et al., 2017	Nurses believed that recognizing parent proficiency and insight both empowered the parents and improved the care giving partnership.	"Recognizing their expertise, 'I think I would like you to show me how you do this and this, so that I do it the way you do it' … is usually empowering for the family." (Page 152) "I find that the parents are your best teammate … Learning to care for parents of CMC is learning how to work with them." (Page 152)	X			F63
Denis-Larocque et al., 2017	Most nurses recognized that parents of CMC had unique preferences regarding their degree of involvement in their child's care.	"Every family has their own thing that they absolutely want to be more involved with." (Page 152)		X		F64

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
Denis-Larocque et al., 2017	In acknowledging parents' preferences, nurses demonstrated flexibility and respect, two traits necessary when reconciling expectations. This could, however, create additional challenges.	"With chronic patients, some parents want to be really implicated … Meeting each other's expectations can be a little difficult." (Page 152)		X		F65
Denis-Larocque et al., 2017	According to nurses, reconciling expectations revolved around negotiating parental involvement in care. This negotiation process required, at times, having to "convince" parents about the way care needed to be provided. When parents' caretaking techniques were not efficient, or when patient safety became a concern, nurses high-lighted the importance of further discussion and renegotiation.	"If a family insists on suctioning and you don't think that they're doing it effectively, [then] let them suction, assess, and then after maybe you can say: 'I still hear a lot of secretions on auscultation, do you mind if I suction or do you mind if I call the RT to suction?'" (Page 152)		X		F66
Denis-Larocque et al., 2017	Situations in which nurses felt less inclined to negotiate occurred when the acuity of the child's condition escalated.	"When the child is in distress, we have a tendency to put the parent aside while we provide care to the child." (Page 152)	X			F67
Denis-Larocque et al., 2017	Nurses generally encouraged parents to participate in their child's care, which not only facilitated the nurse's job, but empowered the parents. In contrast, one participant explained that an overreliance on parents could become detrimental to their well-being.	"We're just there monitoring and doing the minimal … Maybe we're relying too much on them, and they feel they can never leave the (child's bedside)." (Page 152)	X			F68
Denis-Larocque et al., 2017	Nurses recognized that an open-minded attitude and flexibility in the child's caretaking routine allowed them to form partnerships based on mutual trust.	"Showing some openness or being flexible in terms of how you will run your shift with the child, (are) basic elements of building trust with the parents. You start developing a therapeutic relationship based on this trust." (Page 152) "When I go into the room, I immediately focus everything I've got on those parents. I call it 'bombarding' them with information. It's this bombardment of openness, kind of like a virtual hug, that I find important when working with parents." (Page 152)	X			F69
Denis-Larocque et al., 2017	Participants explained that the time spent caring for the child with medical complexity typically allowed nurses and parents to get to know each other well enough for trust to strengthen and flourish. Once a trusting relationship was established, nurses noted many benefits.	"When you start building trust, then you can care for them further by taking over some of the tasks when you see that they're tired and have other things to attend to … I think they leave much relieved, thinking: 'My child will be fine in this nurse's hands.'" (Page 152)	X			F70
Denis-Larocque et al., 2017	Nurses described their relationships with parents of CMC as fluid, changing over time and through the evolving nature of the child's condition. Relationships typically progressed from being strictly professional in early stages to containing more of a personal component.	"There's more of an intimacy that develops, because you get to know them over time. You know them more as individuals." (Page 153)		X		F71
Denis-Larocque et al., 2017	This shift in the nature of the relationship challenged the nurse-parent partnership, while at other times strengthening it. This was particularly apparent during changes in the acuity of the child's condition, when the emotionally-charged nature of the situation was more poignant to nurses due to their close relationship with the parents.	"When you are emotionally attached to the family, it is much more difficult, especially when the situation is critical … The emotions become impossible to cope with, which can unfortunately affect the relationship with the parents." (Page 153)	X			F72

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Denis-Larocque et al., 2017	Challenges to the nurse-parent partnership often resulted from ethically-complex situations, especially with regards to end-of-life discussions.	"(When we know) that patients have life threatening non-curative diseases, and the parents probably know but haven't fully accepted it, then that's when I feel like I'm walking on eggshells … It becomes a difficult situation." (Page 153)		X		F73
Denis-Larocque et al., 2017	Nurses noted that these tensions often led to deterioration in relationships with parents, to the point of losing an already established partnership at a time "when the parents need us the most."	"The only thing she (the child) seems to feel is pain … from my perspective, there's no joy for that child, and yet the family wants us to continue (treating). That's when I struggle." (Page 153)		X		F74
Denis-Larocque et al., 2017	To preserve the nurse-parent partnership, nurses stated that communication held a central role in promoting trust, as did self-reflection.	"It's very easy to reflect on your own practice: 'Did I do anything that would (cause this situation)?' If I did something, I apologize, we talk it through and frequently it's just a question of perspective." (Page 153)	X			F75
Denis-Larocque et al., 2017	Nurses emphasized the importance of transparent communication in maintaining the nurse-parent partnership.	"I find just sitting and listening to them … and being honest and open is helpful because sometimes, most times, it's that we want the same thing, but are just coming at it from two different ways." (Page 153)	X			F76
França et al., 2013	The interviewees refer to the importance of human relationships, showing that both verbal and non-verbal communication established with the child experiencing the process of terminal illness, is considered to be the basis of a good interpersonal relationship, intended to enable being-better.	"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 (N1)." (Page 783) "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 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 (E2)." (Page 783) "If the child is conscious, I say: be calm, everything will be OK, try to relax, breath normally, stay quiet, try to sleep … So the communication act has to be directed to all the senses" (E3)." (Page 783) "When you have a child who is in the terminal phase and you give your support through communication … you reassure the child … It's gratifying; it's necessary correct communication, whether it is verbal or non-verbal communication. So, you leave with peace of mind, that you did your job well; and you're not scared of whatever comes to you, in the face of things that you do (E5)." (Page 783)	X			F77
França et al., 2013	Communication is a process of involvement that is established, 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.	"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 (E6)." (Page 784) "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 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. (E7)." (Page 784) "Verbal and nonverbal communication is very important because, in the face of a terminal patient, you cannot, visually show what you're feeling, because he knows … We cannot ever go there showing suffering in our eyes. No matter what her condition, sometimes, is pre-coma … she doesn't talk, but sees and listens (E8)." (Page 784)	X			F78

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Forsey et al., 2013	Nurses emphasised how their role entailed responsibility for providing emotional care for parents and described how they talked to parents about whatever they needed, which included overt emotional discussion.	"They can phone you up, have a chat and you maybe make them feel better (E.N1)." (Page 263)			X	US8
Forsey et al., 2013	Nurses therefore wanted to care for families emotionally and to develop close relationships with them, and they thought that this was an essential part of their role. They spoke of how they developed intimate knowledge of families and felt this helped them to meet parents' needs.	"You know what mum likes, you know what [child] likes, you know how she has her medicines, you can tell if there's something not quite right (D.N2)." (Page 263) "And it's not all medically things you're talking about. But sometimes that (emotional talk) is what that family need. (E.N1)" (Page 264)	X			F79
Forsey et al., 2013	Therefore, in providing emotional support, nurses described having to learn and maintain professional boundaries, adding that these could be hard to control or were a source of worry, and nurses described feeling overwhelmed by some families who were highly emotionally dependent.	"You've got to try and help them through it, and because you're helping them through it that then gets you deeper into that relationship … It can be quite difficult when you want to … but then you feel yourself being drawn in. (C.N5)." (Page 264) "Some people … end up falling into the trap … of wanting to be everything and anything to families and um it's just not achievable … and becomes very manageable and you end up being exhausted … both physically and mentally. (B.N3)." (Page 264)		X		F80
Gardling et al., 2015	The results showed that the RTNs (Radiotherapy nurse) strived to offer holistic care, which they described as covering various elements. They considered it important to take responsibility regarding the care they provided for child and family (parents and siblings), as well as for the technical aspects of the procedure, but they also indicated that holistic care requires taking responsibility for the development of their profession.	"(You need) to be well prepared, more prepared than you are with adults. And you are more accurate…Then it's not just the child but the parents as well. You want everything to be in place. (11)" (Page 662)		X		F81
Gardling et al., 2015	In providing holistic care, another responsibility was caring for the parents. The RTNs believed that the parents needed to be involved in their child's treatment because when parents knew what was going to happen, they were less anxious and so was their child. Parents were seen as resources because they knew their child best and could offer valuable support.	"Much time is devoted to create a relationship with the parents. So that parents feel secure in that I will take care of their child. I think that's really important. So that they can feel calm and secure … It is important to try to build up their confidence so that they can rest in that moment. (7)" (Page 662)	X			F82
Gardling et al., 2015	The child's and the parents' participation in decisions regarding the care emerged as an important concern for the RTNs, and during care, the focus needed to be on child's and parents' wishes and emotional well-being.	"One must try to capture the child's interest so that they do not feel afraid of me or find it unpleasant to come. … try to be partly on their level, speak so that they can understand what it is about. The parents are involved, and I communicate with them so that they feel secure. If the parents feel a sense of security so does the child. (10)" (Page 663)	X			F83
Gardling et al., 2015	The RTNs reported that in order to know how to care for the children, the RTNs needed to show an interest in each child, listening so as to understand him or her.	"I once had a girl who screamed every time. Initially, I loosened the mask a bit, but she continued to scream. When I told her, 'Now I will put the mask on again so we can treat you,' she replied, 'Yes.' And so I did and she screamed …She received a long treatment, and she was always happy when she came to us. Afterwards, I talked to her about her screaming: I asked her if			X	US9

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		it helped, and she said yes. 'Were you angry at me when I put the mask on?' I said. 'Angry? No!' (9)" (Page 663)				
Gardling et al., 2015	The RTNs expressed the desire that all children felt secure, regardless of whether they were awake or under deep sedation or anaesthesia. This feeling of security could be created by the RTNs own efforts to individualise care and to cultivate a relationship with the child by talking about hobbies or favourite music, for instance.	"I tend to explain things why we do this and why we do that. I think this is really important because it eliminates much concern. Some are receptive to it, and others are not. One must also feel and listen. And if you do that, they become more secure in a completely different way. (9)" (Page 663)		X		F84
Giambra et al., 2017	It was apparent from the nurses' narratives that they share the parents' desires for their children to receive the safest and best care possible.	I think it's imperative that the staff communicate with the families to give them the safest care that we can." (Page 33)		X		F85
Giambra et al., 2017	Occasionally, policy driven care was in conflict with the home routine for the child. This created tension between the nurse and parent. The nurses wanted to include the parents and follow the home routine but felt obligated to follow hospital policy	"… Usually as long as it's done in a safe manner I'm all about if that's how they want it done I'll do it their way… as long as it's safe for the child of course." (Page 33)		X		F86
Giambra et al., 2017	All three felt comfortable admitting their lack of knowledge with parents and actively engaged other medical professionals when they had questions. This statement may reflect the influence of nursing experience on nurse communication with parents.	"I guess I don't communicate a lot with them if they already know what's going on," (Page 33)			X	US10
Giambra et al., 2017	Many of the nurses gave examples of how they established their expertise with the parents. Some discussed building a relationship while others stated they worked specifically to gain the parent's trust	"But if I break that trust and I don't do what I told them I was going to do then it doesn't work. It just causes friction." (Page 33)		X		F87
Giambra et al., 2017	Most of the nurses interviewed spoke very highly of the expertise of the parents of technology dependent children. The nurses who perceived themselves as expert in the care of these children expressed more frequently they believed the parents had expertise than nurses who did not perceive themselves as expert. The more experienced nurses spoke of using the parent's expertise to further their own understanding or help others.	"They (parents) also help us (nurses) to learn as well…. They give us pointers on how to teach the parents (of other technology dependent children) for their home, their transition to home, so we learn from each other." (Page 33)		X		F88
Giambra et al., 2017	For the nurses, asking questions was integral to learning optimal care for the child and understanding parent expectations. Nurses stated they asked parents questions about the child's medications, home routines, what is normal for the child and how they want care done.	"I learned a long time ago, you need to ask the parents. So what brings you back? What's going on? Tell me what's going on, and they will." (Page 33)	X			F89
Giambra et al., 2017	Some of the nurses that expressed less confidence in their own expertise were less likely to ask for or trust the parent's input. Unlike the parents, the nurses expected questions.	"And if we do anything different they (parents) usually ask why, so you have to know why you are doing something." (Page 33)		X		F90
Giambra et al., 2017	One nurse related her experience with a child whose parents insisted something was wrong despite all tests being negative. The child was discharged. A day or so later, the child was readmitted and the cause of the problem the parents were concerned about was identified.	"I just think that you need to listen to them (parents). Even if it's the craziest idea that you've ever heard, you need to listen and know that they know their child." (Page 33)		X		F91

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			UE	C	US	
Giambra et al., 2017	In addition to discussing how they learn from parental explanations, the nurses identified how they explain things to these expert parents. Many said they used evidence or explained the rationale for a particular treatment or care process to help parents understand why it was being initiated or changed.	"When we have some new information to offer up, we'll kind of refer back to the way they have done it and we'll either say this is an evidence – best practice or it has come from the doctor's suggestion." (Page 33)	X			F92
Giambra et al., 2017	Unlike the parents, the nurses spoke of calling on the doctors or advanced practice nurses to help explain changes in the child's care. The nurses also used this hierarchy when advocating for the child or parent's wishes.	"I'm usually, not taking the parent's side, but these experienced parents, that I'm really having to advocate for them, because they can't go up and knock on the doctor's door, that's my role." (Page 33)		X		F93
Giambra et al., 2017	According to the nurses, the category of verifying the care for the child was divided into two distinct sub-categories. The first was verifying the child's home routine, including the medications and feedings. The second was verifying that the parent understood the care required for the child and could carry it out.	"… observing is a big thing. Because you could say you are going to do something and you can agree, but I think if you say you're going to do something it has to be observed." (Page 33)			X	US11
Giambra et al., 2017	Negotiating roles is just one aspect of the communication process leading to mutual understanding of the child's plan of care.	"I'm bringing this up is because this is what we've been taught for using this piece of technology but I respect what you have been doing in the past, not that it's wrong". (Page 33)			X	US12
Giambra et al., 2017	The nurses interviewed had multiple ways of explaining the achievement of mutual understanding of the child's plan of care. All the nurses tried to include the parents in creating or defining the plan. Nearly all the nurses stated they knew they were on the same page when both they and the parents were comfortable with the plan.	"It's really hearing the parents say that they're comfortable… and able to stand up, and when they are talking to the doctors, having that conversation, having that interaction between them, knowing that the communication is all the same." (Page 34)	X			F94
Halpin 2018	Nurses as 'knowledge brokers'. Although they acknowledge that parents know their children best, participants believe they have specific information and practical expertise around autism which they have a moral and professional duty to share with parents.	"My intention is to pass on the skills, and to help them have the sort of life they want. (N4, dis, 6, 22)" (Page 321)		X		F95
Halpin 2018	Nursing is key. These nurses describe their profession as 'key' in that nurses have a unique role in the child health team, which involves working with families in a way that positively influences parents' experiences of assessment and diagnosis.	"You pick up whatever the need is and you work with it… it's impossible to look at that family and say, 'You've only been referred for this problem.' (Gp dis, 18, 20)" (Page 321)			X	US13
Halpin 2018	They consider nursing to incorporate a broad range of knowledge and skills, including those learned from other disciplines, and they deliver them within a unique relationship of care.	"I think it's the combination of the assessment skills and the underlying family support. (Gp dis, 6, 17)" (Page 321)			X	US14
Halpin 2018	The nurse-patient relationship as core to nursing. All but one participant felt their 'patient' to be the whole family, rather than just the child. Once the relationship was established, they felt an ongoing personal moral responsibility to families that remained after discharge from the service.	"If that person phoned in 2 years' time and asked to speak to me, I would deal with that. (Gp dis, 7, 13)" (Page 321)			X	US15
Halpin 2018	Empathy for parents, who are perceived to be under stress. This is felt to be a particular nursing value.	"I just feel the nurse is there to support and carry it, until they have enough support to cope with it. (N2, dis, 2, 16)" (Page 321)		X		F96

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Halpin 2018	Respect for parents' views. This includes an intention to listen to parents and address their concerns, rather than prioritising the assessment agenda.	"Whatever your objectives might be for that visit, what the family's objectives are … are paramount. (Gp dis, 19, 2)" (Page 321)	X			F97
Halpin 2018	There is tension between this espoused value and the nurses' action in practice of attempting to influence parents to align their view of the child with the professional view.	"I think that not to do so is an act of omission in the same way that you wouldn't not give them a drug. (Gp dis, 8, 15)" (Page 322)			X	US16
Halpin 2018	Honesty. This value informs the nurses as they share information with parents about the assessment process and the diagnosis, and also informs their perceived role as interpreter, teacher and guide.	"It's in the NMC (Nursing and Midwifery Council, 2008) guidance. Not to do it in a blunt way, or to do it in a certain time frame, it's to do it in the best way for that family, but it has to be done. (Gp dis, 9, 6)" (Page 322)		X		F98
Halpin 2018	Advocacy for parents' views. The nurses feel that as a result of the relationship they build up with parents during assessment, they are the professional best able to be the voice of the voiceless and also to empower parents to speak up for themselves.	"in a meeting, she might not say anything or might not put things very well… and I might say, 'We have discussed this, and (N) did say.' (N4, dis, 3, 19)" (Page 321)		X		F99
Hendricks-Ferguson et al., 2015	The nurse participants' struggles occurred about if, when, and how to communicate for a variety of reasons.	"Do you let them approach you or do you bring things up? You can just tell they're struggling sometimes. I don't know how to approach the situation." (Page 246)	X			F100
Hendricks-Ferguson et al., 2015	The nurse participants expressed feelings of sadness when a child had prolonged, repeated struggles with side-effects of oncology treatments that required hospitalisations for PC (Palliative care)/EOL (End of life) care. This translated into profound regret about the child's repeated and long-term struggles and the emotional toll this had on the child's parents.	"It's hard to know when to say something and when not to say something. That's what I find trouble with, and he was really, really sick and was here pretty much the whole time. I went down with the family when they talked about taking him off the respirator, and that was hard, too." (page 246)		X		F101
Hendricks-Ferguson et al., 2015	The nurse participants described a lack of knowledge about factors related to a child's death process. Specifically, they reported having (a) high uncertainty about physical signs indicating that death was near, (b) low confidence in caring for a dying child, and (c) feelings of inadequacy about post-death care.	"The nurse was actually in the room when the doctors were in there, and some of the team units from PICU were there to transfer him to PICU and intubate him. And, she [nurse] said, 'Wait; let's take a deep breath. Mom and dad, is this, what you really want to do?' If she wouldn't have been in the room, I'm sure that he would have been transferred and intubated." (Page 247)			X	US17
Hoiseth et al., 2014	Social rituals mean here a set of actions that appear to bring humour and enjoyment into the treatment. Two kinds of rituals have been observed, namely play and celebration. Smiles and laughter in the caregiver–child interactions have been related to moments of light heartedness.	"In Evelyn's case, humor and enjoyment were expressed through play. Before the actual treatment started, Nurse Eric showed improvisational tact by using the mask, which was shaped as a duck, as a reference. This duck shaped mask was the only sample present at the ward. Together, nurse and child engaged in transforming the mask into a duck: Eric holds up the mask that is shaped as a duck and asks: "Shall we say hello to the duck?" Evelyn looks at the duck. "What does the duck say?" Eric asks. Evelyn smiles without saying anything. "Quack, quack, quack, quack," says Eric. "Does it say that? Wonder if it says that?" he continues to ask. "Quack," says Evelyn and smiles to Eric. "Yes," says Eric.		X		F102

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
		Evelyn points to the duck. "Yes, does it say quack, quack, quack?" he asks. "Yes," Evelyn replies. "Maybe you want to hold it yourself?" Eric asks. "Quack, quack," says Evelyn, while she watches Eric, who prepares the medication. (V3)" (Page 1628)				
Hoiseth et al., 2014	Adults' sensitivity toward children's experiences and ability to improvise can help to establish caregiver–child interactions that are characterised by humour and enjoyment.	"In the case of Harry, the importance of social rituals was emphasised when he himself took the initiative to celebrate. Nurse Cornelia used certain expressions such as "Hurrah for Harry" and "How big is Harry today?" when she sought contact with Harry before the actual treatment was initiated. At the time, Harry did not directly respond to this. However, halfway through the treatment Harry wanted to celebrate his efforts: After a while Harry turns his head and lifts his arms. He starts to clap and looks at Cornelia. "Yes," Cornelia says with a loud, singing voice while she removes the mask from his face and claps along. Cornelia and the parents cheer and laugh; so do I [observer]. "Hurrah for Harry," says Cornelia. Harry turns to the film again. "Yes, we need a hurrah for Harry," says Cornelia while she puts the mask back onto Harry's face. Harry does not pay any attention to the mask; he is focusing on the film. (V6)" (Page 1628)		X		F103
Hopia & Heino-Tolonen 2019	The respondents feel that it is difficult to become involved in the child's inappropriate behaviour without support from the parents. The child might express uninhibited behaviour and bite, kick or hit a nurse. In such cases, parents lack the capability to control their child's behaviour.	"Sometimes it feels like being a nurse is also like being an educator of the parents. (T7)" (Page e30) "I remember the feeling of irritation I had when the parent began to play along according to the child's rules. The child started making rules on how to act in the situation and the parent allowed this instead of setting limits for the child. Such situations where a child begins to boss their parents around and attempts to give orders to the nurse are not uncommon. As a nurse, I never give in to the child's demands, especially not if they are related to procedures that simply must be performed. (T9)" (Page e30)		X		F104
Hopia & Heino-Tolonen 2019	According to the respondents, some parents do not understand how important it is that the child is sufficiently co-operative during the treatment period. Respondents describe that, in spite of several counselling meetings, some parents never understand that the timely administration of medication or measuring the child's body temperature or blood pressure are essential parts of the child's treatment.	"It seems that more and more parents do not know how to be a parent. In my work, I meet an increasing number of parents who do not set clear limits for their children. (T7)" (Page e30)			X	US18
Hopia & Heino-Tolonen 2019	Some parents are fully focused on the treatment of the child and reviewing available treatment alternatives. In such cases, parents are unable to pay attention to or support the child's normal growth and development during the treatment.	"The parents are easily preoccupied by matters related to the treatment and distracted from the fact that the child's healthy functions require development and practice. One child was able to practice their motor skills only by playing with a nurse on the floor. (T12)" (Page e31)		X		F105

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Hopia & Heino-Tolonen 2019	When a decision about providing a child or young person with palliative care is made, parents might forbid telling the child about their imminent death. Some parents forbid telling their child that they will not recover.	"The disease has continued to spread and we should now talk about arranging suitable conditions and treatment for the rest of the child's life. The problem is that the parents forbid telling their child about the circumstances. (T4)" (Page e31)		X		F106
Hopia & Heino-Tolonen 2019	Nurses respect and observe the parents' decision to not tell the child about their actual condition. However, because of such a decision, respondents say that they are constantly on guard about the topics and manner of discussions held with the parents and the sick child.	"There are parents who will not tell the truth even when their child asks directly if they are going to die. (T15)" (Page e31)			X	US19
Hopia & Heino-Tolonen 2019	There are discussions with the parents about why the child would benefit from being made aware of the real circumstances and how this can make communication between the family members easier. Respondents wonder why parents will not let their children know the truth and who they think they are protecting by hiding these facts.	"The matter has been discussed numerous times with the parents, but they are not willing to change their view. On the other hand, the staff cannot overrule the parents' decision. Sometimes, we just have to accept this fact even if we do not think that it is for the best of the child. (T4)" 9Page e31)		X		F107
Hopia & Heino-Tolonen 2019	Their work is arranged so that a single nurse does not treat a specific child for several successive shifts. In addition, the child may have several personal nurses or the child can be treated only by experienced nurses. However, this has proven to be difficult in the respondents' opinion. If a child is treated by several nurses, no one gets to know the family or their habits sufficiently well.	"None of the nurses got close enough with the parent to find out what caused their distrust towards nurses. (T3)" (Page e31)		X		F108
Hopia & Heino-Tolonen 2019	Nurses can also easily become nervous about the treatment of the child and the time spent with the parents in the room is kept at a minimum. The possibility of threatening situations is taxing to nurses.	"One situation was difficult as I was not familiar with the parent's behaviour and predicting their reactions was challenging. I saw myself considering very carefully what to say to the parent and how to word it. (T10)" (Page e32)		X		F109
Hopia & Heino-Tolonen 2019	The parent's behaviour can change radically in different stages of the child's sickness. Once the child's active treatment has been stopped and the palliative care initiated, there is a phase where some parents can express sudden and unforeseen changes in their behaviour. For example, a parent can stop communicating about the child's condition and treatment with nurses and keep to themselves while the nurses treat the child.	"When the family was told that there was no cure for their child's disease, their reaction to the stressful news was very powerful. The formerly open, friendly and really talkative parent became silent and sometimes even expressed somewhat inappropriate behaviour towards the nurses. (T15)" (Page e32)		X		F110
Hopia & Heino-Tolonen 2019	The respondents reflect on whether they have been able to provide the parents with sufficient support in situations where they have been preoccupied with treating and monitoring the child.	"The parent of the child required the support of a more experienced nurse. I was able to concentrate only on the treatment of the child. (T11)" (Page e32)		X		F111
Hopia & Heino- Tolonen	The respondents also feel that they have not been able to provide parents with the support, care and time they feel the parents require because of too busy work shifts.	"A child who was administered palliative care had their parents present and we had agreed that they could spend time with each other, and I would check up on them every once in a while. However, despite my promise, I did not		X		F112

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
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Tolonen 2019		have the time to visit them even once during the night on my own initiative. (T6)" (Page e32)				
Jestico & Finlay 2017	The expertise of families reinforced to participants that they were far from being experts themselves and Bulley (2000) notes that this disparity in knowledge can lead to nurses feeling intimidated by parents.	"(It) was always drummed in to you… the parent knows the child better. (Sarah)" (Page 65) "It is a bit scary…They are experts…and they do know more than us. (Ruth)" (Page 65)	X			F113
Jestico & Finlay 2017	Feelings of anxiety amongst newly qualified nurses are not conducive to this model but as participants gained more experience, they became more accepting of the parents' expertise.	"As I got more experienced, I was more confident to say that I didn't necessarily know. (Ellie)" (Page 65)			X	US20
Landon et al.,2019	NIs also described an increased appreciation of families' issues and concerns, realizing there is much more going on in the family than just the ill AYA (adolescent and young adults).	"I have a better understanding of just how many stressors families [are] already dealing with, and how cancer isn't the only thing in their lives. They were already really busy and then this [cancer] happened. They have a lot of things to juggle, and so do we, but taking the time to stop and listen and build that trust… is so important to both them and special to us…it forges a bond." (Page 5) "It [being an NI] made me take a step back and look at what the parent is going through… family members are at the hospital for long periods of time, dealing with high stress circumstances. There is no break for them." (Page 5)	X			F114
Landon et al.,2019	NIs also gained increased understanding that not everyone copes well.	"If a family lacks coping skills, it is likely the reason for their behaviour – it's not necessarily a reaction to what the providers are doing and saying." (Page 5)		X		F115
Landon et al.,2019	As listening skills increased, so did NIs' insight into families' daily lives. This included a better understanding of parents' stressors, in addition to the stressors of having an AYA with cancer.	"You have a greater appreciation for all these families struggle with, day in and day out." (Page 6)			X	US21
Landon et al.,2019	NIs also noted they were more likely to be proactively engaged with families on their units outside of the study.	"Being a NI has made me more in tune with the needs of the parents I care for in my 'regular' job too. I am much more likely to offer my full attention to families when I encounter them now because I realize how important it is to listen to what they are going through and help them deal with all the aspects of their situation, not just their child's medical care." (Page 6)			X	US22
Landon et al.,2019	Reflecting on the knowledge and skills learned and being used, NIs noted that [nurses] are very task oriented. NIs gained an appreciation of the need for these kinds of interactions with families.	"I need to spend more time just listening … not just about the tasks I need to complete for our shift, but really being a person that can just listen … as RNs we are very task driven and … [we need to] take that extra time to offer and hear what other concerns they [parents] may have." (Page 6)	X			F116
Landon et al.,2019	NIs highly valued the opportunity to take time to be truly present and listen well to their patients and their families. Reflecting on the value of the experience, they used words such as "luxury", "privileged", and "precious" to describe their time with the study parents.	"[It is] honouring that [the parent] was able to share emotions with a 'complete stranger'." (Page 7) "I literally never get uninterrupted time with parents." (Page 7) "Unfortunately, because of the work flow at the clinic it is not always possible to have this kind of interaction." (Page 7)		X		F117

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Lee et al., 2019	The above scenario serves to illustrate that the nurse, Alma relayed the information to Jenny instead of Alexis. Although Alexis appeared to be conscious and alert, behaviour associated with receptivity to information, he was not addressed directly by Alma; rather the nurse and his parent conversed about him in his presence. Alexis was visible within the communication process, but the nurse and his parent were essentially ignoring him. He sat mutely in the background within the communication process.	"Alexis, 11 years, diagnosed with chronic lymphoblastic leukaemia, was admitted for chemotherapy. He was under the care of Alma (the nurse). At his unit, Alexis is sitting on the bed watching TV. Alma (the nurse) comes in and informs his parent, Jenny, that they must transfer to a single room because Alexis is suspected of having an eye infection. Alexis appears distracted by the conversation between Alma and his parent. He stops watching TV and turns to Alma but does not say any words. He seems interested and continues listening to the conversation. Jenny asked, ''How long do we have to be in that room?'' Alma answered, ''Until the blood culture result is normal, then you will be transferred back to the shared room.'' Jenny smiles and says, ''Hopefully not long, I don't like the room because it feels isolated, no friends to chat with.'' Without a verbal response, Alexis continues observing the conversation between his parent and Alma. Neither Alma nor Jenny involved Alexis in the discussion." (Page 717)	X			F118
Lee et al., 2019	The role of the child as active participant conceptualizes the situation where the children were most visible within the communication and decisions process. In this situation, children were able to voice out their wishes in the communication process. Ann (the nurse) was directly communicating with Alexis by informing him of what was going to be happen to him. However, it appeared that this was largely focused on the nurse's accomplishment of her routine tasks, and not specifically tailored to Alexis's agenda. When the nurse attempted to communicate with Alexis, the parent interposed not only to answer for him, but also to voice her own preferences to have the procedure after her son had eaten his breakfast. Alexis appeared to have opportunity to express his preferences to have the pain medication immediately.	"Alexis, 11 years, has a severe mouth ulcer and experiences severe pain. Ann, the nurse in-charge of him, comes in to his unit to commence an IV Morphine infusion for him. Ann told Alexis that she is going to start the medication to ease the pain. However, Jenny (the mother) told the nurse to give the medication after her child takes his breakfast. Alexis appeared in pain and informed the nurse to give the medication straightaway, with the hope that he can eat peacefully after the medication is infused. Jenny, without any objection, just smiles and looks at her son. Ann, without delaying starts the infusion as requested by Alexis." (Page 717)	X			F119
Lee et al., 2019	The opportunity being offered by the adults (parents and nurses) to children, would allow children to be active participant and able to make their own decisions according to their needs. In this scenario, it can be seen that whenever the opportunities were given to the children, they would take the opportunity. Initially, Bella is explaining about the reinsertion of the tube to Albert and his mother.	"Albert, 8-year-old boy is under the care of Bella (the nurse). Albert is on nasogastric tube (a narrow bore tube passed into the stomach via the nose) because he refuses oral medicine. In this case, the tube is mainly for the purpose of giving oral medication. He is scheduled for the change of RT (replacement tube). During the removal of the tube, Albert appears calm, he follows Bella's instruction to breath in and out, and he does not struggle or cry. The tube was successfully removed without difficulty. When Bella prepares to reinsert the new tube, Albert starts to cry, and he refuses the reinsertion. He pushes Bella's hand away. Bella, with a firm voice, says: ''If you are willing to take your medication orally, I will not insert the new tube.'' Albert continues crying. Bella repeatedly tells Albert that the RT will not be inserted if he is willing to take his medication by mouth. A bit later, suddenly Albert in a crying tone says: ''I will take the medication by mouth.'' Albert promises to take the medication by mouth. Finally, Bella	X			F120

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		decides not to reinsert the tube and gives Albert time to take his medication. Before leaving, Bella reminds Albert that she will come back to check if he has taken his medication." (Page 717)				
Mellor et al., 2013	Participants struggled with the issue of how to balance the responsibilities of the minor, parent and HCP (Healthcare professional), especially with their sense that responsibilities passed between parties. They thought that minors need to learn to take some responsibility in order to prepare them for adulthood.	"... you've got to try and give them some control but ... it's very difficult especially in that age group like adolescents." (Page 153)	X			F121
Mellor et al., 2013	It is important to achieve a balance between over- burdening and overprotection when transferring responsibility for decision-making to the minor as s/he matures.	"... some parents ... they give too much responsibility so it's ... balancing what suits each person, the mother and the child." (Page 153)	X			F122
Mellor et al., 2013	Participants thought adherence in younger minors was more successfully achieved because the parents have more control over their behaviour, whereas adolescents generally spend more time away from their parents' direct sphere of influence.	"… some parents find it easier when the children are small because you are more directive. (N8)" (Page 153)	X			F123
Mellor et al., 2013	Paediatric nurses share the care of patients with parents. Some participants thought that the boundary between professional and parental responsibilities is clear.	"… parents' responsibility is [for] the things that go on at home and the nurses' responsibility is [for] things that go on here." (Page 153)		X		F124
Mellor et al., 2013	Others thought they adopted some parenting roles in relation to minors, suggesting that the division was actually less clear-cut.	"... your own parental instinct kicks in a little bit ... it is all part of your parental side that's taking over from your nursing side." (Page 153)			X	US23
Mellor et al., 2013	Participants reported reacting negatively to non-adherence, describing their frustration with parents and minors, reflecting the difficulties of working on the dialysis unit.	"... it was just so frustrating that some [parents] just go from one extreme to the other ... do you understand, or do you not care? They're just so blasé about it do you not realise we're changing the meds for a reason, we're giving this fluid restriction for a reason, we're telling you all this keep them clean keep them dry for a reason. (N3)" (Page 153) "...they've [the minors] had all the input you can offer but yet they still decide to cheat so it's really . . . frustrating. (N9)" (Page 153)		X		F125
Mellor et al., 2013	A variety of responses to non-adherence were reported but participants referred to being guided by a central principle of acting in the minor's best interest.	"... at the end of the day our most important objective is doing the very best for their child. (N6)" (Page 153) '... bringing them back [to hospital] is in their best interests but they don't actually learn from that because they know if they come in heavy and finish heavy, you'll just bring them back the next day. (N7)" (Page 153)		X		F126
Mellor et al., 2013	Concentrating on the minor's best interest can put a strain on the relationship between the nurse and minor because it requires the nurse to enforce behaviour that the minor finds unpleasant and undesirable.	"... it can sometimes put pressure on but ... if you try and work with the child and the family you can ... alleviate ... you can explain again why the importance of compliance ... is in their best interests. (N9)" (Page 153) "... praise can be easy to do in a child you know on a younger child you can do star charts that excites them. (N1)" (Page 153)	X			F127

Author	Verbatim Findings	Verbatim Illustrations	UE	C	US	Label
		"... we've had a few occasions when we've had a child refuse to go on the machine… so we have to start using play tactics with them. (N11)" (Page 153)				F128
Mellor et al., 2013	Two participants discussed how physical restraint was some- times used to facilitate treatment when a minor resisted.	"... the ultimate (is) the child who refuses treatment outright ... with a younger child ... below 10, we have sort of held them ... with an older child ... we wouldn't . . . restrain a child of over . . . 12. (N10)" (Page 153) "... we don't like to restrain right but when you're dealing with a [central venous catheter] it's very crucial that the child has to be kept still. (N11)" (Page 153)	X			F128
Mellor et al., 2013	Hospitalisation, as a means of ensuring a controlled environment in which adherence could be imposed, was also reported as a response to non-adherence, though hospitalisation, or the threat of it, only works as a means of altering behaviour if the minor prefers to be at home.	"... he knows if needs be we'll admit him but a lot of the children are very familiar with us and quite like being here so they don't see that as a punishment. (N7)" (Page 154)		X		F129
Mendes 2013	The participants also described their sensitivity to the families' loss of privacy and the steps they took to respect and preserve family privacy. This involved being there to care for the child without being intrusive with the rest of the family.	"Sometimes it would be nice to make myself invisible." (Page 415)			X	US24
Mendes 2013	In addition to respecting the families' home and privacy, participants described the importance of respect for parents' decisions regarding the care of their child. This included caring for the child the way the parents wanted, even if the nurse might ordinarily carry out interventions in a different way.	"There are a lot of ways to hold the broom and it will still sweep," (Page 415) Another emphasized that it "won't change the course of history" to do things in a way that followed the parents' wishes." (Page 415)	X			F130
Mendes 2013	The primary reason for respecting parent wishes was to acknowledge parents' control of their home and their child's care.	"The respect that you owe the parents and their home is huge, and when it comes down to a decision that has to be made, I [leave] that decision to the parents ... that gives the parents the control that they need because you're in their home and their child's sick and they need to have some control." (Page 415)	X			F131
Mendes 2013	Another participant summarized the importance of respect.	"You respect privacy, decisions, lifestyle, respect all of the various rights, and in return the family and the patient **will respect** you." (Page 415)	X			F132
Mendes 2013	Participants' descriptions of communication focused not on what they communicated about but on how they communicated. They described their way of telling parents something without telling them directly.	"Diplomacy goes a long way." (Page 415)			X	US25
Mendes 2013	They also described keeping their thoughts or opinions to themselves to allow the child's parents to make a decision based on their own needs and desires, unbiased by the opinions of the nurse.	"Everybody has their own opinions, their own ideas, but you need to know when to voice them is when you're asked your opinions. If you're not asked, then don't volunteer it." (Page 416)	X			F133
Mendes 2013	Listening to parents as they expressed their concerns was described as important to teaching parents and as a way of assisting them in decision	As one participant described, being "humble." Another described this humble listening, saying that, "We're not there to shine, to show that we're better		X		F134

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	making without telling them what to do. This type of listening involved not just hearing what the parents said.	than them. ... Not to bring them down ... building them up, making them feel confident." (Page 416)				
Mendes 2013	Participants described the importance of caring not just for the child, but for the parents, siblings, and the family as a whole.	"They described caring for children "as if they were mine." (Page 416)			X	US26
Mendes 2013	Caring for a child also involved respecting the child and getting to know the child as a person, not just as a patient. This kind of caring included the ability to read the child's signals, to know when the child was unhappy or uncomfortable, not feeling well or in pain.	"I don't see the abnormal. I see a beautiful child, and that's what I see and I play with and I work with." (Page 416)		X		F135
Mendes 2013	All of the participants valued maintaining professional boundaries as part of ideal home nursing care and all were aware of the problems caused by crossing these boundaries.	"I'm friendly ... but I try to keep a little bit of distance, just so you don't get that total friend ... I try to keep that separation." (Page 416)		X		F136
Mendes 2013	Although their definitions of professional boundaries varied, the participants described the importance of maintaining a balance between closeness or caring and keeping a professional separation, and they noted that once the line is crossed, it is difficult to go back to a balance.	"... I think that can suffer because you get relaxed and comfortable and the home part overtakes the nursing part, and I think you need to find a little balance between the home and the nursing, and I think that when you can find that balance you can maintain that professionalism, that inspires confidence in the families." (Page 416)		X		F137
Mimmo et al 2022	Form connections through play: In all the focus groups the participants agreed that using rapport to build familiarity with a CYP with intellectual disability helped the child feel safe and comfortable in hospital. The groups identified the importance for nurses to use play and rapport to form connections with CYP where they had had some distressing experiences.	"… we had one patient who was extremely difficult with a medical prognosis as well as an intellectual disability, and this child was needing a lot of extra care, … It was really lovely to be able to see him and us interact when things were going good for him. … when we were having great days, it was nice to be able to interact with him." (Page 2938) "They would be singing songs, and we'd put videos on that he would enjoy, … Listening to him laughing … I remember the first time I ever heard him laughing, and it was just such a joy to be able to hear him laugh … It was a really sweet thing." (Page 2938) "Use your interpersonal skills and rapport building, … make the young person feel comfortable and feel relaxed … can really make a big difference in their comfort levels and hospital experience." (Page 2938)	X			F138
Mimmo et al 2022	Prepare and adapt before admission: The nurses agreed that knowing a CYP had intellectual disability, especially before arriving on the ward, allowed them to prepare and adapt their care delivery to suit the CYP's needs. The nurses described ways in which they used knowledge of a CYP with intellectual disability to facilitate care planning, arrange for specialized equipment, and make adaptions to the ward environment to optimize safety and quality.	" … for patients that are coming in for a booked admission … [clinical nurse specialists] will have communicated with them … they'll get a bit of a history on the child … they'll find out about the intellectual disability … if they then do need to be in a quieter room or, […] if they are an absconding risk .. do we need to put things in place to make this a safer environment for them." (Page 2939) "… a lot of our kids, they'll have introduction booklet that the parents prepared for …. as an overview of what they like or what they do not like and what to look out for." (Page 2939)	X			F139

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
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Mimmo et al 2022	Know what the child needs and find ways to communicate: The nurses identified that not being able to get to know a child because there was no carer was problematic, particularly if a child was in discomfort, and the nurses sought other ways to find out about the child. The nurses also recognised the importance of knowing the needs of a CYP with intellectual disability to optimize their care, in particular their method of communication, and used various strategies to capture key pieces of information from parents/carers.	"One thing I found a little distressing … where they come in and there's no support person, there's no carer, and they are very disabled physically, … and you do not know how to make them comfortable and no one's there to tell you how." (Page 2939) "I think it is really important to actually spend time having a chat with the parents and potentially the child about how they best communicate." (Page 2939)		X		F140
Mimmo et al 2022	Preserving dignity, using empathy and compassion: Across the focus groups getting to know the CYP with intellectual disability recognized their innate humanity. They felt it was important to treat a CYP with intellectual disability as a human being; preserving dignity and advocating for the child, particularly when managing pain and end of life, and using empathy and compassion.	"… talking to the patients whether or not they can talk back to me … treating them as though they can listen so talk to them … just say, hi, … treat them with dignity." (Page 2939) "Sometimes with our palliative kids, we'll get really creative and we'll put fairy lights in their room, or we'll paint their nails." (Page 2939)		X		F141
Mimmo et al 2022	Delivering family centred care: Nurses described negotiations with parents to come to mutual agreement on the care needs of their child as part of their family and child centric approaches while others espouse that the prevailing practice in the unit was the family centric model.	"It [family centred care] is incorporating the family in decision-making and getting to know the parents and/or the carers and the child and the particular triggers and the things that they are afraid of, for instance. Or the things that they really enjoy doing." (Page 2939) "… each child with an intellectual disability is going to have communication challenges unique to them … their families are going to be the best way to know whether they are in pain, they are upset, if they are happy, whatever's going on." (Page 2939)		X		F142
Mimmo et al 2022	Helps to have a carer at the bedside: For some nurses having a parent or carer at the bedside to 'help us look after them' was how they practiced family centred care, and seen as a marker for ensuring a good experience for a child with intellectual disability. The parent/carer was available to tell them what their child needed and so they could help attend to the child's daily care needs. For some nurses not having a parent or carer at the bedside was considered 'bad' as it 'ruins everything'; others recognized their role in supporting parents, as there may be additional or conflicting responsibilities for parents to manage on top of their hospitalized child.	" I think it's bad [when a child with intellectual disability does not have a carer with them] because we often aren't really familiar with the child. We also cannot provide them that one on one care that they really need, because we do not have the staffing for that. … these kids are super complex … we usually practise like what—family- centred care here, we cannot do that with a child, because it's just them … hard for them, and that's hard for us." (Page 2939)	X			F143
Mimmo et al 2022	Negotiating time and role conflicts for nurses with meeting needs of CYP with needs of organization: Descriptions of role conflict arose when nurses described trying to negotiate a child's care needs against the needs and capabilities of the hospital/organization. Senior nurses described how, as they gained experience, they would use their clinical judgement to negotiate and prioritize the care needs of a CYP with intellectual disability against their	"… there's a lot of disruption to their routine which for a lot of kids is really upsetting … often makes them worse or triggers more seizures … it's quite distressing for a lot of patients and carers." (Page 2939) "… it's my job … if a parent or carer is not there, spending that individualized time with that child … nurses now, you are a lot more time poor, so you do not necessarily have that time to allocate, to sit down and go,		X		F144

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	clinical responsibilities. All nurses viewed the time constraints on their practice and hospital routines as contributors to poor care quality experiences for CYP with intellectual disability, and identified how this may also worsen a child's medical condition and cause unnecessary stress.	let us draw a picture about how you are feeling, or let us draw a picture about how you best communicate." (Page 2939)				
Mimmo et al 2022	Through effective communication: Nurses readily identified that effective communication with parents and carers was critical for optimizing care quality and safety during the admission and for a good care experience. Parents and carers were sought out by the nurses both for guidance on and learning about the care needs of a CYP with intellectual disability. If a parent or carer was not available at the bedside the nurses looked for other means such as communication folders or bedside communication boards to learn about the needs of the CYP. In particular, learning how the CYP with intellectual disability communicated was a key facet for ensuring good experiences of care.	"We sort of get guided by [a parent], so they have input as well, as how to talk to the child." (Page 2940) "… that goes back to having a chat with the parents as well, we are going to do this procedure, how do you feel your child will be best prepared? Having a good conversation and explaining the procedure, … what's going to work best for that child." (Page 2940)		X		F145
Mimmo et al 2022	Good communication and discharge planning have positive flow on effects: Through the focus group discussions communication across the multidisciplinary team was identified as an important channel for shared learning. This was evident in discussions on how colleagues in other teams or disciplines shared their knowledge of a CYP with intellectual disability with ward staff in planning for and realizing a successful admission. In the same vein, poor communication between teams despite extensive planning can have negative flow on effects, especially with regard to discharge planning.	"If there is good communication from the beginning, … the admission, you know how the kids are handed over to where they are going, a good communication." "… discharge planning for these kids, we know for maybe a week, or maybe not a week, but three or four days if they are going home, and we organize transport … plan everything for going home, … then we have got all these obstacles which delays, then, the discharge." (Page 2940)		X		F146
Mimmo et al 2022	Learning from each other, sharing with new staff: The nurses valued learning from each other and sharing knowledge learnt from the parent or their child with other colleagues, not just other nurses. Some identified that shared learning gave opportunity to act as advocates for their patients, or to support new staff, such as new graduate nurses and new doctors, who may be unfamiliar with the specific needs of the CYP with intellectual disability.	"… come out to the desk and be like lads, I've tried everything and the idea of getting a blood pressure cuff on or temps or whatever and then getting meds in. Then somebody will be like put it in a grape, he'll be like cool." (Page 2940) "… one thing that I've seen quite a few people do, for example, if you are doing a set of obs or something, you can do it on yourself before you are doing it to them, to try and show that it's not harmful." (Page 2940)	X			F147
Mimmo et al 2022	Continuity of care: Nurses recognized the importance of building relationships with the CYP with intellectual disability, not just their parent, through the use of rapport. Sometimes the relationship development was opportunistic, but it was important to use the trust for continuity of care, to maintain and sustain the relationship if it works for the CYP with intellectual disability	"Today I had one of my patients, he'd been in bed all morning, … one of the other nurses walked in, and his whole demeanour changed … he was so happy. He smiled and he was delightful, and he made some jokes." (Page 2942) "… it's just finding the appropriate—the most appropriate person to interact with the children or with the parent … going with the person that they get	X			F148

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			UE	C	US	
	and their parent/carer. Often colleagues observed this and made note of the bond particular staff members have, identifying that these relationships were markers of good care experiences for CYP with intellectual disability.	along well with so that we can build a rapport with the individual ourselves … then we are not reliant on the other people on after-hours or weekends." (Page 2942)				
Mimmo et al 2022	Using empathy builds trust and parent feels safe to leave bedside: Being empathic to build parental trust in the nursing staff was also seen as central to ensuring a good experience for the CYP with intellectual disability and their parent. Having a parent feel safe to leave their child's bedside overnight to get some rest was perceived by the nurses as an indicator of parental trust in nursing staff, and that they were doing a good job.	"… when their kids are here quite regularly, … they trust us … there will be parents who say he's in bed, asleep tonight. Like I know you'll ring me if there's any problems. I'll see you in the morning. Like that's nice to know that they will kind of relax a little bit and take the time to themselves." (Page 2942) "… if I put myself into those parents' shoes, or that patient's shoes, to me, that's an expectation. I would expect it's part of your role to have that conversation with the mum and provide that care, not just go in and not acknowledge the child." (Page 2942)	X			F149
Mimmo et al 2022	Working as a team to ensure good experiences of hospital care: One group shared a story about a long term patient who the whole team get to know, and how as a team rallied together to give this child a good experience, to feel comfortable and safe. The team recognized that although the admission had been difficult, it was important that the child had a good experience of care.	"… we had a patient who was here for a long time, … everyone had such a good relationship with him … It's not above and beyond, but it's more than what you would usually do. We would always come in and say hello, and give him a lot of attention, and he really thrived off that … You could see his eyes light up, … those kind of little acts made a big difference for him." (Page 2942) "… that little bit of extra effort to engage him with just some positive, fun, playful sort of banter, it was yeah, a positive experience for him, even though it was a very difficult, long admission." (Page 2942)		X		F150
Moen et al., 2014	The conversations with the child are described as focusing on how well he/she is managing and how the public health nurse (PHN) can best help the child to cope with daily life and strengthen his/her resources	"They have been given the diagnosis, and I don't have much to do with that side of matter. But I do think that I can offer support with the issues they encounter on a daily basis." (Page 517)		X		F151
Moen et al., 2014	To have a family-focused approach is a conception describing that some PHNs are offering support and supervision to the entire family in order to retain an overall perspective, while others are more concerned about the parents.	"I think there's a lot of basic nursing involved in viewing the family as a whole. It's not just seeing one person but seeing the whole … You don't get anywhere if you work on only one matter in a large family." (Page 518)	X			F152
Moen et al., 2014	To be an active partner is a conception describing the PHNs choice to include themselves as a collaborating partner. Some expect others to follow up on the child and the family, inviting the PHN to take part when necessary, while others describe a more active role.	"I feel that the challenge is to ensure that the family is given help long enough. Change takes time regardless. Often, someone spends a lot of time with the family, then it's gradually reduced and then they're left sitting there and it all disappears if here's nobody to keep hold of things. It all just fades away, and then the public health centre is often the only thing left." (Page 519)			X	US27
Montgomery et al., 2017	Participants across sites reflected on experiences in which parents' readiness was restricted by their desire to limit direct conversations with their child about EOL as an act of paternal protection. Parents protecting children from the truth related to their EOL trajectory resulted in a range	''I think that has always been a little difficult when parents don't want to tell their children, but you know, that child knows what is going on. I have just found that this is how people cope I and I just need to support them in the only way they know how to do it.'' (Page E50)	X			F153

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
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	of feelings for nurses, including acceptance, understanding, and frustration. In contrast, nurses also experienced children protecting parents, describing how adolescents and young adults did not want to share their understanding of the dying trajectory to prevent their parents from having an emotional response.	''And (adolescent patient) asks just the right questions, dancing around the issue because her mom is always present … I can just read in her eyes, 'My mom isn't saying it and I'm not going to say it because mom's gonna cry.''' (Page E50) ''You can't predict when they're going to be ready for that conversation. It just sort of happens. I mean, opportunity knocks.'' (Page E50) ''(Young patient) talked about how she wouldn't have any more pain she was not looking forward to death, but she saw the positives of her death … she was a very insightful little girl'' (Page E50)				
Montgomery et al., 2017	''Opportunity knocks'' reflected a prime communication opportunity that nurses seized when parents unexpectedly approached them with questions initiating EOL discussions. In addition to readiness, these experienced nurses reflected on the importance of communicating support to parents who were seeking validation of their actions and to children and parents who are vacillating in their acceptance of EOL.	''I see parents … they just want … that it's okay what they have been doing and it's okay to let go.'' (Page E50) ''That parent saying (they needed to do everything for their child) … it helped me to not be uncomfortable with that family, with how hard they were pushing … this family has to live on past the child's death with all the decisions made. Whatever decisions they make, it's okay.'' (Page E50)	X			F154
Montgomery et al., 2017	Nurses described the limited number of opportunities to care for children at EOL in the hospital setting, resulting in challenges to obtain competency. However, when nurses were able to gain experience engaging in PC/EOL discussions, they described an increase in overall comfort.	''We don't really talk (EOL with families). We don't really have the resources for it.'' (Page 51) ''It's out of my control; this disease has decided to take this turn. Now what's my job?'' ''It is frustrating to me that you have these patients, and they are very obviously dying, but nobody knows how long it is going to take somebody to die … and parents want to know when it's going to (happen).'' (Page 51)		X		F155
Montgomery et al., 2017	Nurses collectively described how their actions fostered physical and emotional connectedness near death. Specifically, nurses shared intimate moments in which they could sense death was near and coached parents and family members to physically hold their child during the last moments of life.	''I said, 'Do [the parents of the child] want to hold him?' The look on (the mother's) face was like, 'yeah,' and I said, 'Let's get her in bed.' I helped her get in bed with him and put her arms around him … I went to walk away and mom grabbed my hand and did not let me go … we held him and he died within minutes of her getting in bed with him.'' (Page 51) ''(The child's) his mother asked if I would tell him it was okay to die. That was probably the hardest thing I have had to do as a nurse. I gave (the child) permission that his Mom said it was okay and that she would be okay and his brother would be okay.'' (Page 51) ''(Child's mother) had said before she left, 'I know that he is gone but there is a part of me that just needs to know that (the nurses) will be with them. You won't leave him alone until the very last minute.' I had a hard time when they came and took him down the hall it was like I can't let him go because I am supposed to stay. I am supposed to continue to take care of him, and it is hard to just let them walk down the hall with the body.'' (Page 51)	X			F156
Montgomery et al., 2017	This theme included an important and sometimes overlooked aspect of communication: balancing messages of hope and realism. Nurses specifically described communicating with children and families about	''There is a difference between allowing people to maintain their hope and then giving them false information.'' (Page 51)		X		F157

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	hope, paying close attention to the balance and fear of providing false hope in the face of a known EOL trajectory.	''There's always that hope question, that's always the hardest thing. The definition of hope always changes. I remember 1 mom said, 'I still have hope,' and I said, 'I have hope, too.''' (Page 51)				
Montgomery et al., 2017	Experienced nurses believed that it was their responsibility to be an advocate for the child and family during PC/EOL. Focus group data represent nurses' actions that went above and beyond to fulfill the preferences of a child and their family members during the period of PC/EOL.	''(The patient) had started pain meds and (the nurse) said (to the parents), 'I just want you guys to know, I don't know how much longer he'll get to talk to you, so whatever you need to say or do, do it tonight. Every day before you go to bed, realize that this could be the last day you talk to him.' I think [the parents] were appreciative of knowing.'' (Page 52) ''My responsibility if there is something to say or to prepare the family that this is going to happen.'' (Page 52)	X			F158
Montgomery et al., 2017	Nurses anticipated the need to provide sufficient time for parents to pause and process provided information during a chaotic time point when a child's condition was viewed as unstable. In one particular situation, the nurse's commitment to advocate and have a conversation during a brief and critical period in the patient's trajectory allowed the parents to speak up and state their wish to not have their child transferred to the intensive care unit.	''I think we did that and did a good job with it, so it kind of makes a difference I think if you know it's coming, if you can plan for it.'' (Page 52) ''I said to the mother, 'You know, they have a different approach in intensive care than we have here. Their approach is about maintaining his airway and they will do things that we wouldn't do there. Are you prepared to have them intubate and then perhaps have to make that decision to take him off the ventilator?' I was by (the patient's) bedside, but I was looking at them. All of a sudden (the) dad said, 'Stop.' They were huddled together in a big hug and Dad said, 'Stop, stop. We are not going to do any more.''' (Page 52)		X		F159
Montgomery et al., 2017	Nurses also described balancing the spiritual needs with the child's needs while also being respectful of parents' spiritual convictions.	''It's like convincing (the parents) that you're not giving up hope on your Higher Power to help you … that it's all right to give pain medicine, but to make them feel that they weren't denouncing their religion or their faith by doing these things to make their child comfortable.'' (Page 52)		X		F160
Neal 2022	Katie saw the role of the nurse as learning about the child's previous experiences with asthma and building the caregiver's knowledge about managing their child's illness. This included preparing the child and family to identify triggers for asthma, learning ways to manage life with the diagnosis, understanding how things like allergies can be managed, and managing the impacts of asthma on daily life	"I'm not sure Mom is going to stand up for herself when she asks questions of the hospital team, and eventually of the primary care physician. Did they address her concerns and answer her questions? Did they really hear her? Can she fill these prescriptions? Does she speak English? How old is the child and how much care will mom be providing? That could impact the child's outcome, so I work with her to help her realize that her concerns are important." (Page 108)		X		F161
Neal 2022	Dan considered aspects in managing the hospital versus home care of children with sickle cell disease. He stated that children grow, and he, as a nurse, can anticipate change, while families become frustrated by the challenges of change. He believed that he could anticipate, for instance, that a one-year-old child with port access is likely to try to play with, pull on, and possibly dislodge the port. This is a pattern of practice that advocates anticipatory guidance.	"Sometimes families become frustrated with typical behaviors of children. Especially a first-time parent. The job of a one-year-old is to explore. No one-year-old understands that dislodging that port could be a really big problem. I try to listen to the family, help them adjust care, and focus them on the great, normal things that their child is doing. Those are causes for celebration, and sometimes we just use normal adaptations to help adjust to extraordinary issues." (Page 108)	X			F162

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Neal 2022	Tawny recalled that, as a young nurse, she learned from experienced nurses that "good instincts" were important in working with children and families. With each child and family, she learned that listening well, being sincere and honest, staying present in the moment, and connecting patients and families with the resources that could help them the most helped her to learn. Tawny relayed her experience with a family who found it difficult to make a decision about having a feeding tube surgically placed for their child	"The parents felt as though it was a defeat; the child would never recover. I was present with the parents on several occasions, allowing them to express their concerns. They gradually began to present the pros and cons of their decision and realized that there were additional challenges that could be resolved with the tube, like safer medication administration. The child had the surgery, and things actually were better for everyone. They came to their own conclusion. They just needed someone to listen to them work through the process." (page 109)	X			F163
Neal 2022	Tawny stated that when she enters each room, she "suspends judgment and just looks, listens, and watches," in order to think about the patient and any family members in the room. She lets them tell her what sort of day this is going to be.	"Each day can be different, based on all sort of things. How did they sleep? Is the child in pain? Is the family dealing with other things? They tell me how to proceed and I follow their lead. Then, we negotiate, if needed. I have found this works better than marching in and getting started." (Page 110)		X		F164
Neal 2022	Dan discussed aspects of caring for a child that have been modified and how he considers discussions with patients when things change for them.	"Care that frequently took hours in the past, now can be done in less than an hour. This transforms the process for families, and sometimes they are either amazed or distrustful. I have to work hard and plan how best to communicate changes as a really good, hopeful thing for their child. It can be touchy, and I really reflect on the message." (Page 111)		X		F165
Neilson et al., 2013	The social world of each child and family is unique. Developing a good relationship with the family from the outset was seen as essential in order to fully identify and meet their needs.	"I think if you can build up a good relationship with the family that certainly anchors everything else in place. (Case 11 CCN)" (Page 451)		X		F166
Neilson et al., 2013	There was a fine balance between the nurses' wanting to undertake their perceived role and their meeting the needs of the family.	"… very clearly at the beginning that they didn't want phone calls … they wanted to manage it all the way through … It's very hard as a nurse you want to get hands on and do but they didn't want that … It's trying to get that balance. Is it feeling uncomfortable for us? As long as it's right for the family then actually that's the main issue. (Case 4 CCN 2)" (Page 451)	X			F167
Neilson et al., 2013	The emotive nature of palliative care often results in close working relationships being developed between the nurses and family members, with the risk of a blurring of boundaries.	"… mum at the end she said I don't see you as nurses I see you as friends coming in the door … She said something like you know I'm more closer to you as my own family … (Case 3 CCN 2)" (Page 452) "It was like going out to some friend's house, we like the same sort of things, going to someone's house for you know 18 months to 2 years you get to know them really well don't you? You can't keep it totally professional all the time. You blur the boundaries. (Case 3 CCN 5)" (Page 452)		X		F168
Neilson et al., 2013	Recognition of the potential difficulties in balancing and establishing close working relationships with the child and family whilst maintaining a professional boundary was found.	"We're a service, we're not friends to a family, we're a service. (Case 4 CCN 1)" (Page 452)		X		F169
Newman et al., 2019	Nurses valued honest, realistic disclosure of prognostic information, and believed that the provision of such information to parents and patients was beneficial in a number of different ways. They believed that adequate prognostication allowed parents to communicate more freely	"Much better to provide therapeutic and relationship based care if every team member, including patient and family, are on the same page and have open dialogues." (Page 109)		X		F170

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	with their children and their children's medical teams about prognosis. This open communication facilitated decision making and care planning.					
Newman et al., 2019	Nurses reported experiencing considerable distress when they were instructed to not provide patients and/or parents with accurate diagnostic or prognostic details, or when caring for children whose parents were unaccepting of a poor prognosis. Nurses bore witness to suffering as they observed patients receive, what they perceived to be, futile care.	"The child was literally melting before our eyes, but we kept on doing procedures and giving medications … we should have stopped interventions and let the child leave this world peacefully. Instead it was medical and a code was called on a patient that was essentially already gone." (Page 110)		X		F171
Newman et al., 2019	Nurses described when parents would request that nurses not share the news of recurrence or even a diagnosis with patients. Nurses also reported that some parents would ask that staff not use the word "cancer" in front of their children. This along with limitations on disease related discussions forced the nurses into compromising positions where they had to lie to children, who asked them direct questions.	"… the family would not allow the young teenager to know her diagnosis or prognosis … knowing the patient did not realize her life was coming to an end very quickly was gut-wrenching. She was never allowed to voice anything related to the end of her own life. I hated that experience." (Page 110) "He wanted to know if his cancer was back and the nurses had to lie to him because this was his mother's wish." (Page 110)	X			F172
Newman et al., 2019	Nurses listed a number of positive aspects of communication surrounding prognosis. The approach including the focus of the message as well as tone was acknowledged as essential.	"… allowing the family to come to terms with the child's death." (Page 110) "The patient, her family and the physician team all did a great job of asking her what she wanted the remainder of her life to look and feel like. They were honest with her prognosis and explained what next steps could look and feel like as her disease progressed. Did she want to be in the hospital? At home? At a Hospice house?" (Page 110)		X		F173
Newman et al., 2020	The close relationships paediatric oncology nurses have with patients and families enable them to provide emotional encouragement and hope.	"I think it's more—we need to know what the prognosis is, and then, I, myself, think that it's more being support for the family … be that person to support them through it, answer their questions, be someone to lean on." (Page 316) "… I think just trying to be there if they want to talk—and showing them that even if a number is bad doesn't necessarily mean that (there is no hope)—there's still hope." (Page 316)	X			F174
Newman et al., 2020	Nurses commented on family members' expectations about what they, as nurses, know about patients' statuses and their plans of care.	"… families … expect us to, as nurses who take care of them a lot, to know everything that's been going on behind the scenes like scan results …" (Page 316)		X		F175
Newman et al., 2020	However, nurses in this study articulated how challenging this was if they were not included in conversations. One nurse shared strategies she used to make sure that she was present when important conversations were undertaken.	"I always try to be in the room when any doctor is in the room, I try to be in the room, so I know everything that was said by every person." (Page 316) "… I'm like, pretty curious and nosy and I like to know an answer when I'm asked a question from a family." (Page 316)		X		F176
Newman et al., 2020	In identifying their role as informants, nurses described responding to parental questions regarding prognosis, often clarifying or providing additional insight into information provided by physicians.	"… a lot is said in these conversations with them (physicians), and we're just that extra person to kind of reinforce what was said, and just help answer any other questions that they [patients and families] might have …" (Page 316)	X			F177
Newman et al., 2020	Nurses in this study detailed how they advocated for their patients and parents in the process of prognosis related communication (PRC). One	"Your kid does need to know, but we're going to help you with that process." (Page 316)		X		F178

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	nurse practitioner shared a situation in which the parents did not want to tell the child about his cancer diagnosis. She acknowledged that the parents knew their child best, and that she would work with them to talk to their son. Yet she relayed the importance of honesty.					
Newman et al., 2020	In this study, nurses indicated that they received little training in PRC. They shared their opinions that becoming competent in PRC cannot be facilitated by reading the literature or course participation. They believed that experience is required to feel more comfortable knowing how to respond to patients' and parents' questions and to not provide false hope.	"… you can teach some stuff about palliative care and end of- life through a book … but I still think a lot comes from experience. And the only way you'll get more comfortable with it is to sit in those discussions and be part of those discussions." (Page 316)	X			F179
Newman et al., 2020	Nurses described how experience can also build capacity to be a more effective advocate.	"… as you get more experience and you've seen more things, you have more experience to back up what your—if you're going to question—or even go to see if you can … go above—because that kid is what is important, not if you look stupid to a doctor or whatever." (Page 316)	X			F180
Newman et al., 2020	Nurses indicated that they wanted more clarity around whether to provide patients and parents with concrete information, for example, specific prognostic estimates, and whether their role is to provide patients and families with that type of information.	"I think it's hard . . . even as an experienced nurse." (Page 317)			X	US28
Panicker 2013	Most participants voiced that encouraging parents and supporting them to master their child's care will empower them. The presence of a supporting professional or the feeling that you are there to support is empowering to the parents. Several of the participants commented that parents' readiness to accept the care of their child is a key component leading to empowerment.	"Assessing a child and knowing what ever medication is going to sort the minor illness is something you do as part of parenting on everyday basis. But you are asking them to take on much bigger role and much bigger responsibilities here. So that is why you have to get in time and allow them to get information before you ask them to do this added responsibility, get their confidence especially." (Page 214)	X			F181
Panicker 2013	Most of the participants commented that empowerment helps parents to gain mastery over their child's care and provide a perceived control over the care. Education and training on the child's care will help the parents to develop the confidence in carrying out the care. Moreover this information and confidence will help parents to make informed decisions about the child's care. Thus, they can live their life with an improved sense of control.	"I think from the empowerment point, suppose the longer, the older the child gets, the parents lives longer with this condition, they have control over everything at home." (Page 214)		X		F182
Pennafort et al 2014	This category emphasized the role of nurses in health education from the moment the child is admitted to the paediatrics unit. It also indicated the need for an interdisciplinary team in order to provide comprehensive care to the hospitalized child with diabetes.	"The child arrives at the ward and we try to find out if he or she has already received orientation, because most of them first discover they are diabetic when they are admitted. Providing them with orientation from the beginning will help the patient further on to have control, to be educated and disciplined. We try to find out if they have already received orientation, for there is a ward in the outpatient clinic that deals solely with health education for diabetic children. (I2)" (Page 132)		X		F183
Pennafort et al 2014	The nurses also touched on the importance of providing orientation on how to control the disease. They emphasized that although there was a	"I think that the role of nurses, besides providing care in unit sectors, is essential for educating not only the child, but also their relatives, showing the	X			F184

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	nurse responsible for health education in the outpatient clinic, other nurses who work alongside children and their families in the ward also carry out educational actions.	complete importance of the insulin and diet in the child's life cycle. It is an important exchange, it makes our lives as nurses richer, makes us grow as professionals, as well as personally, due to the worth given to their health (the children's); nursing is really about the art of caring. (I3)" (Page 133) "All nurses here have the knowledge, but not everyone has the availability to talk and explain, not only because of how hurried the shifts are, but also because that's not the nurse's profile, most nurses here sit down with the mothers ... explain the disease, how to care for it, encourage the mother and the child to learn how to perform blood glucose self-tests, but since our shifts are so busy, it's hard, the time we have with them is short and we cannot dedicate ourselves only to them, for there are all the others as well. (I1)" (Page 133)				
Pennafort et al 2014	In this category, participants reported educational practices that effectively took place, which consisted main mainly of orientation. Some made reference to the objective: to facilitate the understanding and learning of children and family members regarding insulin therapy, diet, hygiene, physical activity and accident prevention.	"Educational practice has focused primarily on diet, the correct use of insulin, handling the equipment, the glucose test strip ... teaching the chaperone so that they can do it properly at home. It is important for the child to have a healthy diet in order to have better glucose control ... the correct way to wash hands. (I3)" (Page 133) "It is a matter of providing orientation on personal hygiene, preventing accidents, preventing cuts ... application site, hygiene; we always instruct them to wash their hands before capillary blood glucose, so that their little fingers are clean, because it is an entryway for infection, and we also provide orientation regarding their diet. (I1)" (Page 133)		X		F185
Pennafort et al 2014	Thus, nurses emphasized the relevance of educational practices in the hospital setting, considering it a strategy for the care of the child. They highlighted the fundamental importance of educating family members so that they can aid the child in carrying out their treatment, and thus avoid hospitalization and maintain a healthy lifestyle.	'This (educational practice) is important so that the child is not hospitalized again, so that they know that when diabetes is treated properly, with the due precautions, the child can lead a normal life like any other child. (I3)" (Page 134)	X			F186
Pennafort et al 2014	Encouraging the child's autonomy for applying insulin was also mentioned as an important tool that fosters responsibility for treatment and health improvement. This is especially applicable when the family is not involved in the treatment.	"We want the child to leave here well and continue to be well in his/her every day life, we want them to be able to go to school well, and if they need insulin injections, that they take their equipment with them or apply the injection before going to school. It's common to see mothers who do not take an interest in their child's disease, so they leave all the responsibility up to child and just don't care. (I3)" (Page 134) "Every time we apply insulin, we provide full orientation, we don't like to do it, we want the child to do it so that they can learn and be more autonomous. (I5)" (Page 134)	X			F187
Pennafort et al 2014	The nurses pointed out that the mother's level of education can influence the child's care.	"... it is noticeable when a mother has more education and it is easier for her to understand the explanations given by the nurses regarding her child's care, and this leads to better treatment adherence. (I4)" (Page 134)	X			F188

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Reisinho et al., 2020	The multiplicity of nurses' statements revealed that the identification of needs was considered fundamental for effective therapeutic nursing interventions. Also, the psychological support was mentioned by nurses as of major importance when adolescents are referred for lung transplantation, when hospitalised and when at home or school.	"… well, they're grown-ups, they're aware of the severity of the situation …" (N1) (Page 2) "… we're almost like a psychologist, we talk to them, support them …" (N6) (Page 2) "… they need a lot of psychological support, at home and specially at school, I have to be careful with that …" (N3) (Page 2)		X		F189
Reisinho et al., 2020	During hospitalization or even during a consultation, the participants identified skills and needs related to the surveillance and administration of inhalation therapy and to teaching strategies on the use of inhalation devices.	"…we're able to find out if they can, meaning if they are able to do this at home …" (N5) (Page 3) "…they and their parents need teaching on inhalation therapy, specially antibiotics …" (N7) (Page 3)		X		F190
Reisinho et al., 2020	Understanding adolescents and their parents' statements is crucial to nurses. Also, other statements were identified stressing the need to optimize the information provided and the importance of extending it to parents or significant others.	"… the way to communicate with adolescents and their family members, either parents, grandparents, caregivers …" (N2) (Page 4) "… it's mainly about . . . talking and listening . . . the helping relationship we're able to provide …" (N4) (Page 4) "… we enter their world, their language …" (N2) (Page 4) "… parents need a lot of support because this disease carries a lot of anxiety … they need someone to listen to them and accompany them …" (N11) (Page 4)		X		F191
Reisinho et al., 2020	Nurses also used distraction and positive arguments to encourage adolescents to choose lifestyles better adapted to their clinical condition.	"…a technique I use to encourage them to take their medication is to entertain them with something, that is, with what I know they like most …" (N2) (Page 4) "… there's no use in asking them to do something without encouraging them, we have to choose the words and activities they like …" (N4) (Page 4)		X		F192
Reisinho et al., 2020	The ability to communicative is strengthened with persuasive interaction.	"… it's important that we understand and explain to adolescents that we're there to help them and that they're growing and feel somewhat different, and that we need to understand each other …" (N16) (Page 4)			X	US29
Reisinho et al., 2020	From the transcribed interviews it was possible to observe that nurses' teachings were oriented to the adolescents' physical, psychological and social components.	"… the nurse must have the ability to teach … we have many teachings on how to use nebulizers, on respiratory care … the way they should interact with friends …" (N3) (Page 4)		X		F193
Reisinho et al., 2020	Nurses also emphasized the need to establish closer relationships and highlighted the fact that, as professionals, they should help bridge the gap between these adolescents and their teachers at school.	"… I think we must establish a connection between the adolescents and their parents because they need each other to function …" (Page 5)		X		F194
Reisinho et al., 2020	Parents are part of the complex network of care that nurses provide to the population under study, and some statements have emerged stressing the need for targeted training concerning nebulizer equipment, breathing exercises, oral therapy and food.	"… we're aware of how they handle the equipment because we need to train them carefully …" (N6) (Page 6) "… support parents and children in the supervision of the breathing exercises …" (N5) (Page 6)		X		F195

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		"… we have to give as much time as necessary for parents to learn the importance of administering the medication on time, namely the enzymes …" (N16) (Page 6) "… parents are very concerned about their children's feeding habits, so we teach them more pleasant ways to present the food …" (N7) (Page 6)				
Reisinho et al., 2020	To achieve a more effective partnership, nurses involve parents in supporting their children, encourage the less attentive, in becoming better caregivers and in helping them interact with other parents who succeeded in this task.	"… the more knowledgeable parents are the more involved they get …" (N3) (Page 6) "… sometimes parents don't get involved, or listen to our suggestions, … we really need to motivate them …" (N5) (Page 6) "… make the most of their potential and teach them the best we can …" (N15) (Page 6) "… I think it's very important that parents interact with other parents who have succeeded because they're a good example to help overcome these things …" (N16) (Page 6)	X			F196
Reisinho et al., 2020	Nurses saw themselves as promoters of behavioural changes, aiming at a change in lifestyles that contribute to the re-adaptation to new situations.	"…my biggest concern is that parents and children feel good in their everyday lives …" (N20)			X	US30
Ringnér et al., 2013	The different interpretative repertoires used by the HCPs are grounded in the focus of the HCP's attention: the child, the parent, or the whole family. Many of the interactions occurred in passing, typically during procedures such as changing the intravenous infusion set or giving the child oral medication. In most of the observed situations, the HCP used a child-oriented repertoire with parents of both younger children and teenagers. This repertoire is characterized by the HCP facing and talking directly to the child using age-appropriate language, as with this 7-year-old boy suffering from severe nausea.	"(The nurse sits on a chair next to the boy's bed, the nursing assistant stands at the foot of the bed, and the mother is in the parent's bed next to the boy. The nurse is about to give the boy an anti-emetic in his gastric feeding tube to relieve his nausea.) Nurse (addressing the boy): Do you want to choose which one of us will give you the medicine? Nurse assistant (also to the boy): Should mummy, daddy, or (the nurse) inject it? The boy: I feel really sick. Mother: But if you need to throw up, you just have to. Nurse (to the boy): It's tough, but you will feel better afterwards. Mother: And if you throw up the tube, we will just put it back. Nurse (to the boy): Does it happen often? (The boy nods.) Mother: It has happened both here and at the hospital in (their town). Nurse (to the boy): What tricks do you use? What is the best way of doing this?" (Page 38)	X			F197
Ringnér et al., 2013	The healthcare professionals (HCPs) also emphasized the rule of keeping the children in focus even if it is not always possible to speak directly to them.	"Nurse: You always try to turn to the child, but still, sometimes you end up talking over the child's head. It just happens sometime." (Page 39)	X			F198
Ringnér et al., 2013	HCPs can switch swiftly between using a child-oriented and parent oriented interpretative repertoire. They may for example start by	"(The mother starts talking about vaccinations. The ill girl wonders why she has not had her influenza shot. The nurse explains to the girl the principles for vaccinations in a simple manner and tells her why she	X			F199

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
	explaining something to the child, then turn to the parent to provide a more in-depth explanation.	did not get the shot.) The nurse (looks at the mother): We use to take a blood sample called viral serology to see how many antibodies you have. And then you should have above a certain number to be regarded as immune. I have to check her chart. But in general, you should be in the community, in school, and on public buses if you have the strength." (Page 40)				
Ringnér et al., 2013	Using a family-oriented interpretative repertoire, the HCPs constructed themselves as people who interact with the whole family as a unit; they talked to and about all family members present, even in matters that were clearly about the ill child. This repertoire was used somewhat more often when interacting with parents of teenagers, as illustrated in this excerpt of a situation in which the nurse handles the intravenous drip of a girl aged 15, while talking about what was said at the medical rounds.	"Nurse: I brought you a new infusion bag because this one will soon run out. I was going to ask you, what did [the physician] tell you when he visited? The girl: Well, it's starting tonight and going on for five nights and days. Father: And then there are drops in the eyes three times a day? Nurse: Indeed, eye drops, and you will also take cortisone tablets for five days. The same ones you had before in a lower dose. Father: So more tablets but not more often? Nurse: No, not more often but more tablets. Father (to his daughter): And then you are going to be a bit speedy? Nurse: Yes, you might be like that, and then you will be hungry too, but you might already have noticed that? The girl: Well, yes I have (everyone laughs)." (Page 41)	X			F200
Rosello et al., 2015	In general, the participants believe that families bear a psycho-emotional, physical and financial burden due to the impact of the children with chronic diseases on their families. It is common that families seek the collaboration of nurses to cope with the many duties required by the sick child, sometimes in ways the nurses consider apart from the professional tasks in their field of work.	"It is important to have family support. We have children whose parents do not comprehend them ... and neither does the rest of the family. And they provide less support. I think the cultural level also matters. With new technologies, the parents try to monitor everything and be up to date in every way to help their children through the internet and the associations. But many times they delegate to the nurses and want us to take the initiative of certain things… (N6)." (Page 40)	X			F201
Rosello et al., 2015	With regard to training, in general, the group of respondents felt they have gaps in terms of psychology training. From their perspective, this knowledge is important for the development of their professional practice. However, it is perceived as more relevant in primary health care than in specialized care due to the role of continuity of care for families throughout the life cycle in the primary level.	"I don't think I have much knowledge about the psychological development of children. I had some notion of psychology, but very superficial (N1)." (Page 40) "What I know I've learned by myself because in college I had no such training. For me, the practice and my children were what really taught me (N5)." (Page 40) "I think they need this knowledge in primary health care more than we do. They are the first to notice if they have language disorders or other alterations. I believe that this training should be mandatory for primary health care, because they are the first screening. For us I don't see it as mandatory, but as basic training (N3)." (Page 40)		X		F202

Author	Verbatim Findings	Verbatim Illustrations	Quality UE	C	US	Label
Rosello et al., 2015	In connection with the above, the participants agree that the support for families is favored when there is a significant level of trust and continuity of care. Thus, they consider that nursing professionals are located in a privileged position to provide psychological and emotional support.	"We're the ones who stay 24 hours with the children and their families. The amount of confidence that they have in us, they won't have in the doctor. We get to know them more, both the family as the children, we're the ones 24 hours there (N3)." (Page 40)		X		F203
Samuelson et al., 2015	Most of the nurses perceived their main task to be to carry out a healthcare initiative, according to their remit, and saw themselves as the extended arm of the hospital. At the same time, they emphasised the necessity of building a confident and trusting relationship with the parents to fulfil their task, and this was many times considered the most important aspect for them.	"… that they have trust in me … I think this is really important … it's the most important thing, that that side of things works because if it doesn't, you can't take responsibility for the child. (11)" (Page 2543)	X			F204
Samuelson et al., 2015	In the nurses' experience, the parents were initially controlling and needed to keep checking that their children were receiving the right care. The nurses felt like they were being watched and monitored by the parents, but as time went on and the parents understood that the nurses were competent, they relaxed and the need for control decreased.	"… they (the parents) just stare at your hands … what you're doing and what you're busy with. And once you've done that a few times, they know that you can manage, then you see … then they go and do other things. (5)" (Page 2543)		X		F205
Samuelson et al., 2015	As far as possible, the nurses tried to create continuity in their care contact with the family. When care interventions were spread across the course of a whole day, changes to the schedule could be made to minimise the number of nurses involved. Having two nurses share responsibility for a patient created continuity, which gave confidence to both the family of the sick child and the nurses themselves.	"… therefore … the continuity ... that we are a few nurses who go there, it provides security for the child and for the family … 8)" (Page 2543)		X		F206
Samuelson et al., 2015	The nurses found communicating with children to be a novel experience, describing them as very forthright and open to expressing what they felt in a completely different way to adults. Sometimes, the children would amaze the nurses with their direct communication and honest questions, and it could be a challenge to maintain composure and not buckle in an emotionally difficult situation.	"She can be very straight to the point and ask … 'D'you think I'm going to die?' And then like, being a mother … I'm completely horrified. And then you have to try to be professional and have the courage to stay. (1)" (Page 2544)	X			F207
Sørensen et al., 2022	Nurses also described that expectations of accommodating children's emotional expressions were a bit overwhelming. Even the most experienced nurses discussed the challenges of performing patient education alone. They often wished they could work in a team of two nurses.	"You are expected to find the most suitable distraction method for the child and, at the same time, perform a demanding technical injection, comfort anxious parents, and preferably sing along." (Page 139)		X		F208
Sørensen et al., 2022	The nurses were all aware that children's experience of their first needle procedure would shape later experiences and that physically restraining a child has the potential to worsen the fear of needles.	"Children who have experienced being held down during blood sampling will later on be terrified of everything. When two adults have to hold the child down…. After such a procedure, they don't even dare to measure their saturation or anything else." (Page 139)		X		F209

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
Sørensen et al., 2022	A few observations of patient education by an expert were seen as insufficient preparation to be responsible for the training sessions.	"I have never had any education in training sessions for needle injections. I did not really know what kind of medicine it was; I could only give subcutaneous injections." (Page 140)			X	F210
Sørensen et al., 2022	Several nurses agreed on the importance of creating good memories, encouraging the child to think of what they achieved, instead of reminding them of the times a procedure did not succeed. Some experienced nurses described how they sometimes had to provide a break during the procedure.	"If the child has rejected for an hour, we will not succeed in persuading the child. By taking a break, the child often regains some control so that we can complete the procedure." (Page 140)		X		F211
Teixeira et al 2020.	The participants mentioned aspects experienced during the assistance to children with cancer in Palliative Care, highlighting humanized assistance, comfort, listening, well-being, extended to family members.	"... I use my eyes and touch, and I am always willing to give the best care, humanized, guaranteeing the child's comfort and well-being, demonstrating security, and informing that they will always be around. (NUR.2)" (Page 691) "... It is important to offer support to the patient and their family, to accompany the grief of family members to comfort the loss. (NUR.3)" (Page 691) "I work with great love and do everything to promote the safety and well-being of the child/family ... it is necessary to listen and fulfill the needs of the child and their family, let them vent and question. (NUR.5)" (Page 691) "During the nursing visit, I hear the child a lot, complaints, compliments and requests. I watch when she does not want to talk and try to relieve suffering and prevent complications. (NUR.7)" (Page 691) "... To humanize care. Care must be integrated, giving full support to the patient. (NUR.9)" (Page 691)		X		F212
Teixeira et al 2020.	In this category, the process of communicating bad news between professionals and family members stands out, in addition to the presence of spirituality in the context of terminality.	"Approach clearly and objectively, obeying ethics in communication, respecting the emotional and expectations created by family members with skill and honesty, trying to reduce distress, depending on the child's condition. (NUR.1)" (Page 692) "Make good communication, not only verbally, but also with touch ... (NUR.2)" (Page 692) "… Involve the family in decision-making, using clear and simple language ... (NUR.3)" (Page 692) "... Leave the patient close, talk a lot with the patient and listen to them, trying to clarify their questions ... (NUR.4)" (Page 692) "Simple communication, patience, care, and being a Christian make me understand and put myself in the position of the other, helping in my way to meet the needs of the other. (NUR.6)" (Page 692)	X			F213
Teixeira et al 2020.	The nurses interviewed also highlighted difficulties when faced with the need to communicate bad news.	"This part of the bad news communication strategy is not very easy. The mother beside the child at all times is very difficult. I feel powerless to communicate the real fact. I prioritize the doctor to make this communication, I think they must provide this news. And then I do the welcoming, giving all possible assistance ... (NUR.8)" (Page 692)		X		F214

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
Zaal-Schuller et al., 2018	Most of the nurses indicated that they took the initiative to talk about observed decline in the physical condition of the child with parents before the actual discussion about EoLD (End of life decisions) with the physician occurred, for example, when parents visited the child in the group home. The nurses indicated that the parents particularly talked with them when they felt their child was suffering from unexplained physical problems, such as discomfort, and that they discussed the burden it put on their child's quality of life.	"Nurse 6: Her parents want me to join these discussions because their daughter is living here for 24 hours a day, so I take care of her much more than her parents do, although her parents visit her regularly. So, her parents really appreciate my presence, in fact they don't want me to miss any of these conversations. But that cannot always be done in practice." (Page 333) "Nurse 11: I was involved in the whole trajectory when she got the diagnosis. I can remember that when her condition deteriorated, she sometimes just stopped breathing and then she turned blue, that is a symptom of this syndrome. It was for this mother very hard to see that happen while knowing that she couldn't do anything to help her daughter. Especially because when that happened, she already had restrictions in her treatment. Her mother had doubts about these restrictions, and she discussed these doubts with me. I always assured her that she made the right decisions. It was the reality; it was the reality that she would die. I have had many of these conversations with the mother, about her daughter, about her condition, how to handle that and the best thing to do for her." (Page 333)	X			F215
Zaal-Schuller et al., 2018	Providing emotional support was the most commonly reported activity conducted to assist parents in these conversations. Several nurses explained that they provided emotional support by doing practical things, such as providing a glass of water or a handkerchief, and by carefully listening to what parents had to say. Some of the nurses mentioned that they also assisted parents by asking the physician to further explain the child's situation, or to clarify medical jargon, if they noticed that the parents were confused.	"Nurse 4: I want to make parents feel that I'm there to support them, and to make them feel that they'll make a good decision, whatever it may be. To make them feel that they don't have to be embarrassed about a decision they make. To make them feel: you are doing well, it doesn't matter what you'll decide, you'll make a good decision. Just being supportive towards them." (Page 334) "Nurse 5: 'During the conversations I'm the one who should deliver information which makes that parents and the physician make the right decision." (Page 334) "Nurse 11: It happens very often that, due to all the intense emotions, parents do not hear or understand everything said during these conversations. That makes it necessary to repeat things. To discuss things afterwards and to make it practical. Some things are very complicated and during the conversations sometimes parents don't dare to tell the physician that they don't understand." (Page 334)	X			F216
Zaal-Schuller et al., 2018	Some nurses had never been trained in discussions about EoLDs and how to have them, so they did not know what to say during these conversations. Other nurses thought that parents would not appreciate their presence. Some of these nurses suggested that their presence only added value when the parents were not sufficiently empowered, for example, when they were not well educated, or when they had language difficulties. Nurses who attended meetings with parents and physicians regarded their presence, in general, as valuable.	"Nurse 10: 'Her parents are very well able to do these conversations by themselves. Although information from us can be helpful. I wonder if they feel the need that any from us is present. Her parents find it hard to talk openly about this matter, so maybe they would really appreciate our presence. Also, because I don't know whether these parents feel supported by the physician during these conversations." (Page 335) "Nurse 13: I'm disappointed that we were not more involved in the decision not to resuscitate him. I really feel the need to discuss this with his mother and some colleagues of mine. I really want to know why she decided this, and	X			F217

Author	Verbatim Findings	Verbatim Illustrations	Quality			Label
			UE	C	US	
		I want to explain to her how I feel about it. Because, I think that if it's not going well with him, I will find it very difficult not to call the emergency number and not to give him first aid. But if you ask me: when will I say to his mother: "sorry, but I can't do this."? I don't know, I really don't know. What I know is that, although I feel really bad for her, but what about me? I'm the one who has to live with that decision the rest of my life. I have to come to terms with what I decide to do on that moment." (Page 335)				

Key: ALL= Acute Lymphoblastic Leukemia, APPNS= Advanced Practice Psychiatric Nurses, AYA= Adolescent and Young Adults, CMC= Chronic Medical Conditions, EOL= End of Life, EoLD= End of Life Decisions, HCP= Health Care Professional, NG= Nasogastric, NI= Nurse Interventionist, NMC= Nursing and Midwifery Council, PC= Palliative Care, PHN= Public Health Nurse, PICU= Paediatric Intensive Care Unit, PN= Paediatric Nurse, PRC=Prognosis Related Communication, RTN= Radiotherapy Nurse, TV= Television.

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 3 -4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 5
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 6 -7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 6 -7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 6 -7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6 -7
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 7
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	NA
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	NA
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Page 22-26
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	NA
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 29-30
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 14-15
	23b	Discuss any limitations of the evidence included in the review.	Page 14-16
	23c	Discuss any limitations of the review processes used.	Page 16
	23d	Discuss implications of the results for practice, policy, and future research.	Page 16
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	NA
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary Tables