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Children living with long-term conditions: a meta-aggregation of parental experiences of partnership nursing.

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Children living with long-term conditions illness: a meta-aggregation of parental experiences of partnership nursing.

Running title: Parent-nurse partnership in paediatric nursing

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Children living with long-term conditions: a meta-aggregation of parental experiences of partnership nursing.

Abstract:

Aim: To explore how parents of children with long-term conditions experience partnership in paediatric and neonatal nursing care, and to identify existing partnership barriers and facilitators.

Background: Parent-nurse partnership is fundamental to paediatric and neonatal nursing. Partnership is characterised by five attributes: parental participation, negotiation, mutual trust and respect, shared roles and decision making, and communication. Little is known about the parental experiences of partnership nursing specific to children living with a long-term condition.

Design: A qualitative meta-aggregation review following Joanna Briggs Institute meta-aggregation approach.

Methods: A comprehensive search was conducted in six electronic databases. Studies were assessed according to the inclusion and exclusion criteria. Qualitative findings with illustrative quotes from included studies were extracted and grouped into categories which informed the synthesised findings. This review has been reported according to the PRISMA guidelines.

Findings: A total of 4,404 studies were screened, 162 full-text studies were assessed against the inclusion and exclusion criteria, and a total of six studies were included. The meta-aggregation developed three overarching synthesised findings which were: a) empowering parents to become involved, b) effective communication to recognise mutual expertise, and c) collaborative nurse-family relationships.

Conclusion: Parents valued collaboration where both parents and nurses are recognised equally for their skills and expertise. A power struggle existed between parents and nurses when expertise was not recognised. Parents appreciated nurses who empowered them to develop new skills and knowledge in the care of their own child.

Relevance to clinical practice: Nurses need to recognise the skills and knowledge that parents have surrounding the care requirements of their own children. Collaboration and negotiation are key to successful partnership between nurses and parents. Nurses need to frequently reflect on how they are successfully partnering with both parents and children and ensure all parties in the nurse/parent/child triad feel supported and empowered.

Keywords: Partnership, parent-nurse relationship, paediatric nursing, nursing, neonatal nursing, meta-aggregation, family centred care.

Introduction

Children diagnosed with a long-term condition are now living longer with improved health outcomes and quality of life due to advancements in research, treatments and emergency technologies in health care (AIHW, 2020; Compas et al., 2012; Wijlaars et al., 2016). According to the Australian Institute of Health and Welfare (AIHW), a long-term condition is defined as a chronic illness, disease or condition that is expected to last more than six months in duration (AIHW, 2020).

Recent statistics from the Australian Bureau of Statistics show that 20.1% of children under the age of 14, have at least one long-term condition (Australian Bureau of Statistics, 2018). Worldwide, 13 – 27% of children are calculated to be living with long-term conditions, depending on the definition used to define a chronic or long-term condition (Wijlaars et al., 2016). These children often require nursing and medical care in their home environment, which is usually provided by families and parents (commonly termed as caregivers, guardians or primary carers) (Kelo et al., 2013; Kepreotes et al., 2010; Shields, 2011). United States of America population health needs identify 64% of parents with children living with a long-term condition care for their children independently (Lindley et al., 2016). Roughly a quarter (24%) of parents engaged in home care nursing providers and 12% used respite facilities independently (Lindley et al., 2016). Acute presentations for children with long-term conditions account between 15% - 35% of all paediatric admissions and 43 – 62% of all associated paediatric hospital costs in the Australia and the United States of America (Bell et al., 2020; Gold et al., 2016). Long-term conditions can be placed into two separate healthcare services, paediatrics and neonatal care. Conditions commonly managed at home include asthma, diabetes and epilepsy, whereas conditions requiring frequent hospitalisation include haematology/oncology conditions, cystic fibrosis and cardiovascular defects (AIHW, 2020). Paediatric nursing involves nursing care provided to infants, children and adolescents that are under the care of a paediatric service in acute and community care settings (Wilkins et al., 2014). Neonatal nursing is care provided to newborns and infants who remain under neonatal services until discharged or transferred to paediatric services (Meeks et al., 2013).

Given the expertise and knowledge that parents have about their own children, they frequently become experts in their own child’s care and provide important information to health care professionals (HCP) such as nurses, doctors and allied health (Balling & McCubbin, 2001; Fisher, 2001; Nightingale et al., 2014). Consistently, research findings show that parents who take an active role in management of their child’s care report reduced anxiety and stress, and improved health-related quality of life (Barnes et al., 2020; Hopwood et al., 2016; Swallow et al., 2008). However, confusion exists surrounding negotiation of roles in the care of child. Parents and nurses can have different beliefs in how involved each participant should be and nurses often assume parents will undertake a certain role without negotiating their decisions with parents (Stuart & Melling, 2014). When a child affected by a long-term condition is admitted to hospital, parents indirectly surrender their control of their child’s care to the treating clinical paediatric team (Balling & McCubbin, 2001; Nightingale et al., 2014). This transition of care and control requires a therapeutic relationship between parents and HCP so that parents develop a sense of trust and respect for the HCP (Balling & McCubbin, 2001; Kelo et al., 2013).

Family Centred Care (FCC) is one of the central theoretical models of paediatric and neonatal nursing (Arabiat et al., 2018). It recognises the importance of family in the care of a neonate, child or adolescent and is a commitment by HCP to involve the families in decision making and care of the child (Arabiat et al., 2018). In the last 10 years, there has been a shift by many health care settings to embrace a patient and family centred model of care (Institute for Patient and Family Centered Care, 2020; Lloyd et al., 2018; Longtin et al., 2010). Patient and Family Centred Care recognises that both the patient and family are central to the patients care, however they are unique entities, and both require communication and collaboration, in partnership with health care professionals (Institute for Patient and Family Centered Care, 2020). There have also been developments in other theories and models of care relevant to paediatric and neonatal nursing, such as Pragmatic Care (Randall, 2018) and Family Integrated Care (Banerjee et al., 2018). These alternate theories follow the same core principles as FCC and Patient and Family Centred Care to promote safe and quality nursing care and to develop a therapeutic relationship with parents and children (Banerjee et al., 2018; Randall, 2018). However, these alternate models of care are less focused on the unique triad relationship that exists in neonatal and paediatric nursing care, focusing more on individual relationships or nursing care goals. Triadic partnership in nursing occurs when both the child and the parent are considered equal partners with the nurse in the care provided, which is a theoretical underpinning of Patient and Family Centred Care (Institute for Patient and Family Centered Care, 2020).

Partnership is an important concept in paediatric and neonatal nursing where parents are the primary carers of their children (Bally et al., 2018). The term partnership nursing is used to define the integral relationship that exists between parents and nurses in the care of paediatrics. The concept of partnership is defined by five attributes which include: shared roles and decision making, parental participation, mutual trust and respect, communication and negotiation (Davis et al., 2007; Dennis et al., 2017; O'Connor et al., 2019). Effective partnership nursing allows the nurse and parent to collaborate together for the best interests of the child. This can also allow parents to feel empowered and involved in their child's care (Hill et al., 2018; Hopwood et al., 2016). Parents who do not have the confidence to start role negotiation (prehaps due to the belief that they lack the correct skills and knowledge) may perceive nurses as the gatekeepers to their individual level of involvement (Hill et al., 2018; Hopwood et al., 2016).

Research has identified challenges of partnership with parents and inconsistencies in the relationship between parents and nurses. Specifically, issues include a distinct lack of effective communication, negotiation of parental participation, shared roles and shared decision making (Corlett & Twycross, 2006; Uhl et al., 2013). Evidence shows the importance of developing a professional relationship between nurses and parents that is based upon mutual trust and respect. However, there can be an inert power struggle between nurses and parents (Aarthun & Akerjordet, 2014; Brødsgaard et al., 2019; Power & Franck, 2008). Parents have previously experienced a lack of empathy, collaboration and communication from nurses which negatively impacted their ability to participate in the care of their own children (Brødsgaard et al., 2019; Butler et al., 2014; Corlett & Twycross, 2006; Thompson et al., 2020).

A mixed methods study with nine parents in the United States of America (USA) participated in semi-structured interviews to describe their own experiences of partnership nursing (Uhl et al., 2013). One of the main issues that parents grappled with was a lack of consistency in how nurses partnered with parents. This study is viewed with caution due to the small sample size and low survey return rate of 10.2% (n=134 of 1320 surveys sent out) which limits the generalizability of the results (Uhl et al., 2013). Other single setting studies on partnership nursing with parents of children with long-term conditions found that parents expected to be treated as experts in the care of their own children (Baird et al., 2016; Giambra et al., 2014). Baird et al. (2016) explored partnership nursing with parents of children with long-term conditions in a single paediatric intensive care unit in the USA and found that parents reported inconsistencies in the continuity of care of their child which created issues of distrust, as some nurses provided greater insight into their child's medical diagnosis and care requirements compared to other nurses. Parents expressed that they wanted their own individual level of expertise and knowledge of caring for their child to be valued and appreciated by nurses (Baird et al., 2016). Their study was conducted in a single centre with a homogenous participant group which limited the transferability of the study findings.

Existing systematic reviews have concluded that nurses are often hesitant to involve parents due to clinical demands, fear of legal backlash, and have made uninformed assumptions of how involved parents should be without parent discussions (Power & Franck, 2008; Shields, 2011). A small integrative review of six studies found that parents of children with long-term conditions wanted to be treated as the experts in the care of their own children and they placed a high value on negotiation of roles and participation (Giambra et al., 2014). However, this review had a number of limitations which included: a) the studies included did not provide perspectives from both mothers and fathers, b) only parents of children who were healthcare technology dependent (such as oxygen or ventilators) were included, c) and is now clinically outdated by year of publication (Giambra et al., 2014). Corlett and Twycross (2006) conducted a literature review to identify barriers to parent-nurse partnership and found that parents wanted to be more involved in the care of their children when they were admitted to hospital settings but experienced a lack of negotiation with nursing staff limited how they could be involved in their child's care. The scope of their review was limited in advancing understanding of the experiences from the parents and family's perspective, because their review explored experiences of partnership from the nurses' perspective only (Corlett & Twycross, 2006). Given the prevalence of long-term conditions in children, coupled with high rates of hospitalisations, it is timely to understand the experiences of partnership nursing from the parents' perspectives to inform future directions for practice and research.

In summary, existing literature reviews (Aarthun & Akerjordet, 2014; Brødsgaard et al., 2019; Butler et al., 2014; Hill et al., 2018; Kepreotes et al., 2010; Power & Franck, 2008) which have been conducted to date are limited because they have not explored experiences of partnership nursing among parents of children living with long-term conditions or have combined HCP as one group in partnership and thus, provide little insight into the parental experiences of partnership nursing.

Aim

This timely review aims to synthesise evidence in relation to parental experiences of partnership nursing with children living with long-term conditions. A secondary aim is to identify what parents perceive as barriers and facilitators in developing partnerships with nurses in caring for their child.

Methods

Research design

A meta-aggregation systematic review (Florczak, 2019; Tufanaru, 2016) was chosen to explore the parental experiences of partnership and to elicit any potential barriers and facilitators to partnership nursing in clinical practice. Specifically, this meta-aggregation 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 (PRIMSA) was used see **Supplementary File 1** for completed checklist (Moher et al., 2009).

Search strategy

A preliminary search of CINAHL was completed to search and identify keywords in the search architecture. Keywords were identified from relevant article titles and abstracts. Following this, the search strategy was developed in consultation with an academic research librarian and the primary author (M.B). The PICo mnemonic was used to identify relevant articles and included studies. The review considered studies that included parents of children with long-term conditions (P) and their experiences of partnership nursing care (I), in both hospital and community/home based settings (Co).
The keywords used:
(P) Parent, mother, father, guardian, family, primary carer.
(I) Partnership, partnership nursing, participation, collaboration, negotiation, decision making, respect, involvement, trust, communication, shared roles.
(Co) Paediatric, pediatric, paediatric nursing, pediatric nursing, child, children, neonatal, neonate, infant.

The search was conducted in the following electronic databases (CINAHL, MEDLINE, PUBMED, SCOPUS, Web of Science and Google Scholar). Grey literature was searched (MedNar and OpenMD.com), and a review of reference lists of all included articles were manually searched for additional studies to increase the inclusiveness of the search. Similar article recommendations on specific databases and websites when accessing full text reviews were also searched (snowballing). Database searches were conducted in August 2020 and concluded in October 2020. The search architecture and examples of the search strategy in databases are detailed in **Table 1.** When searches revealed limited results based on search architecture, keywords related to long-term conditions were excluded to increase the number of studies to be reviewed, as detailed in **Table 1**.

Eligibility criteria and study selection

Studies were assessed against the following inclusion criteria:

- Qualitative studies that primarily focused on the experiences of parental partnership between parents and nurses.
- Studies that explored any of the five key attributes of partnership (shared roles and decision making, parental participation, mutual trust and respect, communication and negotiation) (Davis et al., 2007; Dennis et al., 2017; O'Connor et al., 2019) and/or explore the barriers and facilitators of partnership of nursing.
- Qualitative research in neonatal/paediatric settings, including acute care centres, palliative care and home/community-based services.
- Qualitative research that focused on long-term conditions, or specific long-term conditions (such as cancer, diabetes etc.) and specific wards where chronic or complex patients are more regularly admitted (such as children cancer wards, paediatric and neonatal intensive care units) in the context of experiences of partnership among families of children with long-term conditions.

Exclusion criterion included:

- Quantitative studies.
- Studies that explored partnership between parents and other HCP groups where the distinction between partnership with nurses was not identified.

Studies were included if they were published between 2010 and 2020 with the underpinning clinical rationale that partnership and partnering with patients and their families has become a central focus over this time (Frakking et al., 2020). Only qualitative studies that were published in English were included. Mixed method studies were assessed against the inclusion criteria and were considered if they presented relevant qualitative data. All studies were exported into Covidence software to manage the screening process.

The review process was led by the primary author (MB) who screened all titles and abstracts according to the inclusion and exclusion criteria. A proportion of the title and abstract screening (approximately ten percent of all studies) were assessed by secondary authors (KB, CP) to ensure continuity of applying the inclusion and exclusion criteria among the review team. Any disagreements were resolved by discussion. The full-text articles were assessed against the inclusion and exclusion criteria. Quality appraisals were completed by the primary author (MB) in close collaboration with the secondary authors (CP). Any concerns regarding inclusion of full text studies were discussed among all three reviewers.

Quality assessment

All included qualitative studies were critically appraised initially by the primary author (MB) for methodological quality using the JBI Critical Appraisal Tool (Aromataris & Munn, 2020). Each article was scored individually against the JBI Critical Appraisal Tool questions and any questions which could not be answered by a Yes/No answer were given an unsure mark by the primary author. Quality appraisal was discussed between all three authors (MB, KB, CP)and disagreements surrounding quality were resolved by discussion. Given the low number of included studies relevant to the study aim, all studies were included in the qualitative meta-aggregation, regardless of their quality score. This was to describe the current state of evidence available in the past 10 years. This review was deemed a Level 6 in the appraisal of level of evidence (Ackley, 2008).

Data extraction

Characteristics of each study were extracted and included: author, year, geographic location, phenomena of interest, study aim, study population, sample size, methodology, methods, duration, limitations, author notes and key findings relevant. 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).

During the data extraction, each finding was presented with relevant illustrations to ensure rich data collection. The findings were each given a level of credibility as per JBI methodology (Aromataris & Munn, 2020) and were 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).

Only unequivocal and credible research findings were included in the meta-aggregation in keeping with JBI methodology (Aromataris & Munn, 2020). As per JBI protocols for meta-aggregations of qualitative studies, unsupported findings were excluded from the synthesis (Aromataris & Munn, 2020).

Data Synthesis

Credible and unequivocal findings found in the data extraction were given labels (e.g., Finding 1 was label F1) and were synthesised into categories based on similar meanings and themes, using thematic analysis (Tufanaru, 2016). These categories with similar themes were then developed into synthesised findings (Tufanaru, 2016). The process of data synthesis was completed by all reviewers and any disagreements regarding the synthesis were discussed until consensus was reached. Findings linked to barriers and facilitators of partnership were identified separately and were used in the synthesis of categories into synthesised findings.

Findings

A total of 7503 studies were identified through database searching, with 90 additional records imported into Covidence through snowballing, reference checking of previous systematic reviews and grey literature websites. 4404 articles were title and abstract screened, with 162 articles full text articles reviewed. 156 articles were excluded, see **Figure 1** for rationale of exclusion. The PRISMA diagram and reasons for article exclusion are presented in **Figure 1**. A total of six studies were included in the qualitative meta-synthesis. The results of the quality assessment of the included studies are presented in **Table 3**. All the articles were included regardless of quality and provided rich detailed accounts of parental experiences of partnership nursing in children with long-term conditions.

Characteristics of the studies:

The characteristics of the studies included in the qualitative meta-aggregation are presented in **Table 2.** The studies were conducted in a range of countries: USA (n=2), Portugal (n=1), Canada (n=1), UK (n=1), and Ireland (n=1). Participants represented in these studies comprised of only mothers (n=2), both mothers and fathers (n=22) and nurses and parents (n=2). The long-term conditions among the children included mixed long-term conditions (n=2), intellectual disability (n=1), acute lymphoblastic leukaemia (n=1), asthma (n=1) and moderate to severe traumatic brain injury (n=1). Settings included acute care paediatric settings (n=3), oncology clinic (n=1), family home (n=1) and clinic and family home setting (n=1). Only two studies (Giambra et al., 2014; Roscigno, 2016) stated the culture background of the participants, both of which were biased in favour of Caucasian participants (82% and 93% respectively). Interviews were conducted in all studies, with one study comprised both observations and interviews.

The qualitative studies included in the meta-aggregation used a variety of different methodologies and frameworks. Thematic analysis and grounded theory were the most commonly described by the authors (Bettle et al., 2018; Callery & Milnes, 2012; Giambra et al., 2014).). However, there was a lack of description by some authors (Alves et al., 2017; Doody et al., 2018; Roscigno, 2016) regarding their methodology which calls into question the rigour of these studies. Grounded theory was clearly stated by one author (Giambra et al., 2014).

and this approach was justified by the lack of theories about partnership between nurses and parents of children with long-term conditions. The study by Giambra et al., (2014) focused specifically on the parent experiences of shared communication between parents and nurses rather than focusing on the concepts and processes of communication.

Meta-synthesis of qualitative data

A total of 80 findings were extracted from the six included studies (see **Supplementary Table 1**), with 12 findings classified as unsupported due to a lack of data surrounding the statements in the full text included papers. Three findings were classified as credible and the remaining 65 were classified as unequivocal. The 68 unequivocal and credible findings were then groups together based on similarity in themes and meaning were synthesised into categories. Nine findings were identified as facilitators to effective partnership and seven findings were identified as barriers to partnership. The remaining 52 findings were then synthesised into 24 categories, see **Table 4**. Some findings were synthesised into their own category due to their unique stance on the parental experiences of partnership.

Synthesised findings

The 24 synthesised categories were aggregated with facilitators and barriers to partnership to create three synthesised findings in this meta-aggregation, see **Table 5**. The three synthesised findings included: ‘empowering parents to become involved’, ‘effective communication to recognise mutual expertise’, and ‘collaborative nurse-family relationships’.

Synthesised finding: Empowering parents to become involved.

The first synthesised finding related to the parental education and training needs to enable parents to become more involved in their child’s care. There were seven categories which contributed to this synthesised finding see **Table 5**.

Parents believed that partnering with nurses enabled them to be more involved and they could actively participate in the care of their child, which in turn created a sense of empowerment (Alves et al., 2017). Parental empowerment increased decision making capabilities and confidence levels, specifically when it came to the negotiation of care and decision making (Alves et al., 2017; Bettle et al., 2018; Roscigno, 2016).). Parents reported improved quality of life, both for themselves and their children when they were actively and involved in their child’s care (Alves et al., 2017). When nurses did not facilitate effective participation with parents, parents felt disempowered and struggled with the lack of involvement in their child’s care which caused distress:

> *“You just sit and watch your child, and (normally) you do all you can to help them, but then when certain things like this happen, you can’t do anything to help them because either you don’t have the expertise, or you know, it requires something else. So, it was just, it was painful.” (Roscigno, 2016, page 13)*

Negotiation was only discussed by two authors briefly but the attribute was clearly valued by the parents in these studies (Alves et al., 2017; Giambra et al., 2014). Parents felt that without a formal negotiation process of care delivery between themselves and nurses, they would be unable to discuss how involved they wished to be in their own child’s care and identify what knowledge and skills they could provide (Giambra et al., 2014). A central focus of partnership with nurses was the requirement of individualised and tailored education, training and support that the nurses could, and should provide to parents (Bettle et al., 2018; Doody et al., 2018). Parents who wished to learn new skills surrounding their child's care requirements wanted to be given the opportunity to receive education from nursing staff, for example, medication administration and symptom assessment (Bettle et al., 2018; Callery & Milnes, 2012). By having an interactive teaching process, nurses were able to offer useful and individualised information surrounding a child's diagnosis and nursing care requirements, as well as the development of technical skills for parents which could be used in both a hospital and home environment:

> *"... They [the nurses] teach us as the book says ... it was fun to see the techniques of those people ... by doing new things ... we learned a lot (P6)." "They [nurse?] had knowledge ... they have the necessary knowledge ... they know the situations (P8)." "Each one [nurse?] has ... in the end it's all the same, but each one has its own ways of doing and we have been picking up a way from one part of another and we have made our method, right ... And we do it at home (P9)." (Alves et al. 2017, Page 5)*

The ability to offer individualised education and training that suited a family's home and lifestyle was recognised as a key element provided by nurses to enhance partnership (Bettle et al., 2018; Doody et al., 2018). Parents appreciated the education and knowledge exchange between themselves and nurses, and parents felt that this in turn increased their participation and empowerment (Alves et al., 2017). Parents recognised parental empowerment as an important process which was achieved by supportive parent education and the nurses accepting parental involvement and participation in a child's care (Alves et al., 2017; Roscigno, 2016).

Synthesised finding: Effective communication to recognise mutual expertise.

The second synthesised finding was related to effective communication between parents and nurses which recognised mutual expertise in the care provision of the child. There were seven categories which contributed to this synthesised finding, see **Table 5**.

Good communication was central in effective partnerships and enabled parents to advocate for their children with nursing staff (Giambra et al., 2014). It was important that nurses were able to communicate their own level of knowledge and expertise because if they did not convey this to parents, parents felt the need to be vocal in their child's advocacy:

> *"But, yeah there are times when I have felt like I really had to step in and say she's not the property of the hospital, she's my baby, you're not going to do this." (Giambra et al. 2014, Page 19)*

Parents noted that their ability to advocate for their child was dependent on their own experience and expertise, and those parents who had further education from nurses were able to advocate more effectively (Giambra et al., 2014**).** Parents felt a need to continue to advocate for their child until nursing staff were able to demonstrate their skills and knowledge (Giambra et al., 2014**).** Demonstration of skills and knowledge from both parents and nurses in the partnership, meant that mutual trust and respect flourished. Parents needed to have trust and respect for the nursing staff who were directly involved in the care delivery of their child's care. This in turn enabled parents to have a break and rest from the constant monitoring of their child because parents felt that their child was safe and trusted hands in the care of nurse (Giambra et al., 2014**).** The communication exchange between nurses and children was pivotal from the parental perspective because it facilitated the development of a trusting relationship and greater individualised exchanges of knowledge (Callery & Milnes, 2012). Parent understood that communication was essential to sharing knowledge and creating individualised care plans that was tailored for the family and nursing staff:

> *"I want communication to be more than just a … divulging information at me to a dialogue with me … I just expect you to respect me as a mom and to not just spit information at me but to incorporate me into the care or the communication about my son." (Giambra et al. 2014, Page 20)*

Parents also articulated that they needed nurses to be non-judgemental in their communication exchanges with them, and valued nurses who were caring and understood the family's situation (Doody et al., 2018). Positive working relationships flourished when nurses demonstrated respect towards the family and parents used the term 'alliance' to recognise the two-way information exchange needed to allow each party to demonstrate their knowledge and expertise (Doody et al., 2018; Giambra et al., 2014). Communication was a mechanism to learn about mutual expertise and nurses needed to acknowledge the parents existing knowledge and skills in the care of their child. Effective communication also helped to develop a trusting relationship develop between the nurse and the parent (Doody et al., 2018; Giambra et al., 2014).

Synthesised finding: Collaborative nurse-family relationships.

The third synthesised related to the therapeutic relationship between parents and nurses which facilitated optimal partnerships.

Parents articulated value in collaborative relationships between themselves and nurses, however they felt that it was not always on equal footing, where both parties had equal voices, shared decision making and some grappled with role negotiation (Bettle et al., 2018). Parents appreciated being given the decision regarding how involved they wanted nursing staff to be in the care of their child:

> *"They're (the nurses) just so good about that too, going down the list of what's needed and kind of confirming how much involvement we want them to have." (Giambra et al. 2014, Page 20)*

The therapeutic relationship was built on trust, with the nurse involved in the care of the child, but also in the care and wellbeing of the family (Bettle et al., 2018). Collaboration helped develop rapport between parents and nursing staff, with various nurses creating different levels of interpersonal relationships based on how nurses viewed collaborating with parents:

> *"They (nurses) would talk to me just like they would want me to talk to them. They would just look me in the eye and tell me, 'This is exactly what's going on' and, you know, 'We hope' and 'We just don't guarantee' and 'This is what we know', 'This is what we do,' 'This is what we're looking for.' 'Just you know, I've seen some people come in here a lot worse than this and be just fine later on.' 'There's never any reason to give up hope." (Roscigno, 2016, Page 10)*

Parents recognised the collaborative efforts of nurses who coordinated and communicated all decisions relating to the care of their child, whether it was direct care required or liaising with other HCP (Doody et al., 2018). Doody et al., (2018) aimed to describe parental experiences of partnership with children affected by intellectual disability and clinical nurse specialists (CNS). Parents described how CNSs continually advocated and supported the families, as well as knitted together the MDT which aimed to improve overall quality of life for their children and families:

> *"There's an ease for me knowing (named CNS) is there every day, and she has been with us all the time and any advice we want or need (named CNS) is there, she will link in and see how she can support you (Pauline)."*
> *(Doody et al, 2018, Page e83)*

Parents discussed how they recognised the importance of a therapeutic relationship that existed between themselves, their families, and nurses, with their child being the centre and focus of the partnership (Callery & Milnes, 2012). Parents felt it was critical that the relationship was positive, with clear goals and recognition of achievements (Doody et al., 2018). Without collaboration between parents and nurses, parents felt greater responsibility of their child's wellbeing and security when admitted to a health care facility (Giambra et al., 2014)**.** When collaboration between parents and nurses was evident, parental educational and the child's care requirements were met by nurses and parents, which then focussed on the normalisation of the child having a long-term condition which further strengthen autonomy (Doody et al., 2018). It was clear that parent's valued and appreciated the care provided to their families by nursing staff and recognised those that go above and beyond clinical requirements (Callery & Milnes, 2012). Like negotiation, parents saw collaboration as being nurse led, in which the nursing staff themselves dictated how and when parents were allowed to be involved in the care of their own children, as opposed to parents and nurses meeting as equal partners to collaborate together for the best interests of the child (Giambra et al., 2014; Roscigno, 2016).

Parents recognised that all nursing staff were different in how they approached nursing children with long-term conditions (Alves et al., 2017; Giambra et al., 2014).). However, a lack in consistency of how care was provided caused parents to feel distrust in their relationships with nurses, until such a time that nurses could prove their knowledge and expertise (Giambra et al., 2014; Roscigno, 2016). Parents saw partnership as a collaborative effort, where both parties brought their skills and knowledge to the relationship, and parents could be easily frustrated if their own knowledge and expertise were discounted by nurses (Giambra et al., 2014). Nurses who could demonstrate their own expertise as well as recognise the parents expertise were deemed as facilitators to partnership (Alves et al., 2017; Bettle et al., 2018). Parents needed the partnership to be flexible and tailored to the meet the needs of their family, however this was not easily accomplished when nurses were unwilling to collaborate or communicate ineffectively with parent (Callery & Milnes, 2012; Doody et al., 2018; Giambra et al., 2014). A poignant topic made by parents, was the need for nurses not to diminish their need for hope (Roscigno, 2016). Nurses who attempted to weaken a parents hopefulness for positive outcomes were seen as detrimental aspects to effective partnership, as parents felt that this hope drove their beliefs and positivity in light of bleak situations to optimise coping strategies (Roscigno, 2016).

Discussion

This meta-aggregation aimed to synthesis existing literature surrounding parental experiences of partnership nursing among children living with a long-term condition and what parents believed were the barriers and facilitators to effective partnership. Three synthesised findings were aggregated which composed of a total of 24 categories, as well as barriers and facilitators.

Supportive parent education described the parental need for tailored education, training and skills that recognised what an individual parent needed. Parents noted that many nurses create their own assumptions of what parents required, which did not reflect best practice (Giambra et al., 2014; Roscigno, 2016). Parents needed to be able to negotiate the education and skills training that they required from nurses when unsupervised by healthcare professionals in their home care environment (Uhl et al., 2013). Nurses who did not negotiate with parents about their needs were not fully informed about what skills and training parents already had or what was viewed by the parents as important aspects of their child's care requirements (Uhl et al., 2013).

Clinical nurse specialists (CNS) seemed to offer more individualised parent focused training and support compared to ward based nurses, which suggests that those nurses which were more embedded in a family took into account personal requirements and tailored training and skills plans of care (Alves et al., 2017; Doody et al., 2018). A CNS is an advanced practice nurse who provides expert knowledge and skills related to specific conditions or body systems and care coordination. These nurses have been found to alleviate parental fears and improve the trust in the parent-nurse relationship (Doody et al., 2018; Mohr & Coke, 2018). However, not all parents and childen will experience the CNS level of knowledge in their health care encounters, depending on service provision and access. Consequently mutual collaboration at all levels of nursing support, where sharing of knowledge builds parental trust.

The findings from this meta-aggregation recognised the need for collaboration between nurses and families of children with long-term conditions. Collaboration was often nurse led, with parents only being able to partner with nursing staff when nurses chose to do so. Collaboration is described as a approach where two parties are on equal footing and join together, recognising each other's strengths (Lai, 2011). It is seen as a partnership that has equality between all parties and has shared goals, interaction. and negotiation of roles between all parties involved in the collaboration (Lai, 2011). What has been described in the findings within this review is not true to the definition of collaboration. Nurses who decided to lead collaboration or parental involvement overlooked specific attributes of partnership which recognised parents as experts in the care of their own children. Parents reported that nurses are the gatekeepers to their level of involvement, instead of being recognised as an equal party that is a valuable source of information to the HCP (Brødsgaard et al., 2019; Nightingale et al., 2014). This review has identified that little is currently known about the process in the negotiation of care as central considerations to partnership. Negotiation of care should be a continuous process that ensures parents and nurses frequently discuss and share decisions regarding how a child should be cared for, and who is responsible for ensuring which aspects of care is delivered, and by whom (Sousa et al., 2013).

Previous studies have demonstrated a lack of negotiation within the parent-nurse relationship in practice, in particular with negotiation discussions not being planned or conducted in a consistent manner throughout a child's hospital admission (Corlett & Twycross, 2006; Sousa et al., 2013). Often, parents can feel uncomfortable when they are burdened with a high level of responsibility in a hospital setting and can find this difficult to discuss with nursing staff (Sousa et al., 2013). On the reverse side, elsewhere some parents have reported that they would have preferred to complete more nursing care tasks than they are given permission to do, in order to create a sense of control in a sometimes traumatic situations but felt uncertain at disrupting the routines set by nursing staff (Sousa et al., 2013).). This review has outlined a lack of research into how parents perceived negotiation in their partnership with nursing staff and suggests that these issues remain present in the healthcare system. Negotiation should be revisited frequently in the care of the child, however the findings presented in this review do not describe how often negotiation occurs. A lack of evidence exists into how negotiation of care occurs in different timepoints throughout the lifespan of the long-term condition, and further research is needed to specifically explore the dynamics and process of negotiation in clinical and home care settings.

Parental empowerment of paediatric patients has been previously described in the literature as a method where parents are guided to develop the skills of care to better support their children, through the provision of resources, tools and training (Panicker, 2013; Segers et al., 2019). It is a process that occurs throughout the development of a therapeutic relationship between parents and nurses where the empowering, and the empowered, work together to set and achieve goals needed to provide the best possible outcomes for children (Panicker, 2013). It is also described as a goal, with parents who attained empowerment in a health care system were able to clearly articulate their need for negotiation, collaboration and made appropriate health care decisions to improve the quality of life for their child and their family (Cameron, 2018). Empowerment is not a method which occurs naturally or without assistance (Cameron, 2018). Nurses are responsible for working with parents to created levels of empowerment, particularly for those affected by long-term conditions because parents are likely to undertake a large amount of medical and nursing tasks when in the community setting (Cameron, 2018). Disempowerment remains an issue in today's healthcare system, where parents are forced into predetermined roles by nursing staff, instead of being considered a member of a collaborative team (Cameron, 2018). Parents may continue to feel disempowered by nursing staff because of a lack of mobilisation of effective partnership attributes as outlined in this review. Parents of children with a long-term condition can face a multitude of burdens placed upon them by a healthcare system which encourages care in the home environment rather than a hospital (Segers et al., 2019). When a child is admitted to the hospital for treatment or respite the parent surrender that tight control of their child's care and are subsequently only involved with the permission by nursing staff which can automatically create feelings of disempowerment (Corlett & Twycross, 2006). Regardless of the severity of a child's long-term condition, parents have assumed control of the management of their child's condition in the home and therefore, should not automatically relinquish that right at the doors of a healthcare setting. This review shows that education and training does occur between the parent and nurse, but it does not give substantial evidence in how or where this currently occurs. A dearth of evidence exists into the parental perspectives of training aids (such as posters or handouts) help to aid parental literacy in managing health negotiation.

Communication was the main research focus in two of the included studies (Callery & Milnes, 2012; Giambra et al., 2014). Parents felt that effective communication was essential to the partnership between themselves and nurses. This was consistent with previous research which has shown parents developed more trusting relationships with nurses when they felt that nurses listened to them and a facilitated a two-way mutual exchange of knowledge (Coyne & Cowley, 2007; Davis et al., 2007). In this review, parents discussed various levels of frustration they felt when their expertise was discounted, or communication was dismissed by nursing staff. This finding has been reported elsewhere, in that parents have struggled to communicate their need for control over their child's care with feelings of being overlooked, dismissed and placed into a role that they did not wish to have (Segers et al., 2019). A parent of a child with a long-term condition who does not require a large amount of home based nursing needs (such as a child with asthma who takes their medication regularly) may not have a large amount of nursing knowledge and may find it difficult to express their expertise to nursing staff (Callery & Milnes, 2012). In contrast, a child with a severe disability may have parents who understand all aspects of their child's care because they are their full-time caregiver and consequently, these parents will need different levels of nursing knowledge and communication. Communication is expected by parents to be individualised (Alves et al., 2017; Giambra et al., 2014). Nurses need to be able to demonstrate knowledge of a child's unique long-term condition and offer communication that is individualised to both the parents and the child (Uhl et al., 2013).

There was a lack of studies that explore partnership and families of children with long-term conditions in the neonatal settings and further research in this area would provide valuable insights into parent experiences. Previous literature that has explored parent-nurse partnership in neonatal settings suggested that negotiation and collaboration are recognised as important attributes of partnership nursing by parents (Brødsgaard et al., 2019). However, parents have expressed a power struggle can exists between themselves and nurses which can disempower new parents who require extra support in their grief and trauma (Brødsgaard et al., 2019). Parents of newborn children who have been diagnosed antenatally or early on in their life with a long-term condition must learn early on in their new child's life, skills and knowledge required to care for a child that may have more complex needs. Without research exploring how these parents' partner early on with nursing staff, little is known about how this partnership develops and what early steps could be taken to ensure parents feel empowered in the care of their child.

The six studies included in the meta-aggregation underscores that this is an emerging evidence base. A lack of evidence exists into how partnership occurs in practice and at what time points this partnership occurs or is re-established. The findings in this review show that parental needs are considered by nursing staff, but not how nursing staff partners with both parents and children when both parties have different views of partnership and participation. A grounded theory approach may be the most appropriate for further research into parental experiences as the approach is the most effective qualitative method for determining what has previously occurred and can help provide rich descriptions of the parental experiences of partnership. This would be beneficial, specifically in Australia, where no research into the parent-nurse partnership of children with long-term conditions currently exists.

Strengths and limitations

This study followed the guidelines set out by the Joanna Briggs Institute for meta-aggregation methodology. This review only included qualitative studies published in English, and other partnership research in other international countries and cultures might have been overlooked. Studies were excluded if they explored experiences of partnership among all HCP because all of these articles did not define which HCP were included. The findings of this review are confined to the evidence presented in the included studies. Namely, the differences in experiences of partnership in mothers, fathers, single parents, or parents who co-parent have not been addressed in the research conducted to date. Furthermore, there was a lack of divergence in the types of long-term conditions and a lack of multicultural participants in the included studies. Due to the small number of included studies, our findings may not accurately present the parental experiences of partnership in all health care settings but has taken stock of the evidence evidence-base to inform future directions for research.

Conclusion

Parents need to be recognised by nursing staff for their level of expertise and knowledge surrounding their own child's long-term condition and care requirements. A lack of research into parental experiences of partnership in both paediatric and neonatal settings can make it difficult to ascertain how parents truly experience partnership nursing across a variety of health care settings and divisions of medical groups. Clinical nurse specialists are recognised for their collaborative efforts towards parent-nurse partnerships, but general paediatric and neonatal nurses may lack the skills needed for effective partnership and collaboration to occur with parents who have children with long-term conditions. Parents have routinely recognised the triad relationship that exists between themselves, nurses, and their children, who often speak on behalf of their child in healthcare, which calls into question how the voice of the child is included in the triad relationship.

What does this paper contribute to the wider global clinical community?

Nursing staff need to recognise the importance of negotiation and collaboration in partnership arrangements with parents of children with long-term conditions through effective communication that recognises the mutual expertise of both parents and nurses, building collaborative nurse-family relationships that focuses on the needs of the family and child and where the nurse can empower the parents to become as involved in their own child's care suited to their preferences.

Author contributions

Study design: MB, CP, KB
Data collection and analysis: MB, CP, KB
Manuscript preparation: MB, CP, KB

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Table 1: Example of search strategy

Database: CINAHL 22/08/2020			
Search #	Concept	Key Terms	Total number of results
	Parents	parent OR parents OR parental OR mother OR father OR guardian OR “primary carer” OR famil*	
	Partnership	Partnership* OR “partnership nursing” OR participation* OR collaboration* OR negotiation* OR “decision making” OR respect OR involvement OR trust* OR communication OR “shared roles”	
	Chronic illness	“Chronic illness” or “long-term illness” or “complex*” or disease* or “multiple comorbidities”	
	MeSH Headings – Nursing Areas	(MH "Pediatric Nursing+") OR (MH "Pediatric Critical Care Nursing+") OR (MH "Pediatric Nurse Practitioners+") OR (MH "Neonatal Nursing+") OR (MH "Neonatal Intensive Care Nursing") OR (MH "Neonatal Nurse Practitioners")	
		#1 and #2 and #3 and #4 with limiters English and time frame 2010-2020	98
		#1 and #2 and #4 with limiters English and time frame	689
MEDLINE 22/8/2020			
Search #	Concept	Key Terms	Total number of results
	Parents	parent OR parents OR parental OR mother OR father OR guardian OR “primary carer” OR famil*	
	Partnership	Partnership* OR “partnership nursing” OR participation* OR collaboration* OR negotiation* OR “decision making” OR respect OR involvement OR trust* OR communication OR “shared roles”	
	Chronic illness	“Chronic illness” or “long-term illness” or “complex*” or disease* or “multiple comorbidities”	
	MeSH Headings – Nursing Areas	(MH “Pediatric Nursing+”) OR (MH “Nurses, Pediatric+”) OR (MH “Pediatric Nurse Practitioners”) OR (MH “Neonatal Nursing”) OR (MH “Nurses, Neonatal”)	
		#1 and #2 and #3 and #4 with limiters English and time frame 2010-2020	38
		#1 and #2 and #4 with limiters English and time frame 2010-2020	234

Table 2: Characteristics of included studies

Authors / Year	Title	Country	Aim / Research question (If stated)	Phenomena of interest	Setting	Methodology
Alves et al. 2017	The parental care partnership in the view of parents of children with special health needs.	Portugal	Aim: To understand how care partnership was experienced by parents of children with special healthcare needs (SHN).	Parents of children with SHN, which is defined as chronic physical, developmental, behavioural, or emotional disorders.	Paediatric hospital.	Qualitative, descriptive, exploratory
Bettle et al. 2018	Supporting parents' pain care involvement with their children with acute lymphoblastic leukemia: A qualitative interpretive description.	Canada	Aim: To describe parent and paediatric oncology nurse perspectives on sources of pain that children with acute lymphoblastic leukemia (ALL) experience and what parents do to relieve their child's pain. A second purpose was to identify key structures and processes that facilitate parents' ability to be involved and optimally manage the pain.	Parents of children with ALL who present to an oncology clinic.	Paediatric oncology clinic.	Positive appreciative inquiry and interpretive descriptive
Callery and Milnes 2912	Communication between nurses, children and their parents in asthma review consultations.	United Kingdom	Aim: To examine communication between nurses, children and parents in asthma review consultations.	Parents of children with asthma.	Clinics and home settings.	Observation of communication
Doody, Slevin and Taggart 2018	Families' perceptions of the contribution of intellectual disability clinical nurse specialists in Ireland.	Ireland	Aim: To explore families' perceptions of the contribution of clinical nurse specialists (CNS) in intellectual disability (ID) nursing in Ireland, through gaining insight, giving recognition and acknowledgment to the personal experiences of families and exploring a holistic view of CNS contribution.	Parents of children with ID who use a CNS service.	Family homes.	Exploratory qualitative approach
Giambra et al. 2014	The theory of shared communication: How parents of technology-dependent children communicate with nurses in the inpatient unit.	United States of America	Aim: To determine the process of parent–nurse communication from the perspective of the parents of health care technology intervention-dependent children who have been hospitalised.	Parents of children who are health care technology dependent and who have had a recent inpatient ward admission.	Paediatric hospital	Grounded theory methodology
Roscigno 2016	Parent perceptions of how nurse encounters can provide caring support for the family in early acute care following traumatic brain injury.	United States of America	No aim stated Research Questions: 1. What are the parents trying to tell us explicitly and implicitly about how they wish to be considered and treated in early acute care following children's moderate and severe traumatic brain injury (TBI)? 2. How do parents perceive caring from the nurses they encountered in early acute care? 3. Do parents' narratives confirm Swanson's theory as currently described by the five caring processes or do parents' narratives expand what should be considered regarding the caring processes in this context and with this group of parents?	Parents of children who had suffered a moderate to severe TBI.	14 different acute care hospitals across the USA	Descriptive phenomenology

Table 2: Characteristics of included studies (Continued)				
Authors / Year	**Methods**	**Culture**	**Participants**	**Demographic data**
Alves et al. 2017	Unstructured interviews, from December 2013 to February 2014. All interviews were recorded and then transcribed, verbatim is not stated. Initial question: "I would like you to tell me stories that mention experiences in which you have had the opportunity to work together with nurses to provide care for your child along the way you have experienced."	None stated	10 parents of children with SHN	Child ages not stated. Child conditions included 50% (n=5) chronic renal failure, 10% (n=1) Hirschsprung disease, 10 % (n=1) cerebral palsy, 20% (n=2) short bowel syndrome and 10% (n=1) neuromuscular disease. 100% (n=10) mothers. Age range of mothers was between 20 -49 years old. Education ranges from basic to tertiary education. All mothers stated as being married. No other clinical or demographic data was reported.
Bettle et al. 2018	Narrative one-on-one interviews with principal investigator. Field notes were collected. Transcription of data not stated. Parent and nurse perspectives were separated before data analysis. Themes discussed in interviews included: pain sources of ALL, parent pain management strategies and key structures to support parents' optimal pain care involvement.	None stated	10 parents and 8 nurses	Child ages ranged from 1 to 8 years (mean = 5.4 years). 100% (n=10) biological parents and included 80% (n=8) biological mothers and 20% (n=2) biological fathers. Parent age between 31-41 (no other age data reported). Parents education level was 30% (n=3) completed high school, 50% (n=5) college diploma and 20% (n=2) completed university. Parental yearly income and marital status not stated. 8 nurse participants included age range 23 to 55 years old, 50% (n=4) family care coordinators and 50% (n=4) clinical care providers.
Callery and Milnes 2912	Observation and semi-structured interviews. Nurses were provided with digital recorders and asked to record consultations with consenting parents and children. Open-ended interviews based on a topic guide which explored: living and managing asthma, children's involvement in care, communication between children, families and health care professionals. All interviews were recorded and then transcribed, verbatim is not stated.	None stated	18 parents and 6 nurses	Child ages ranged from 7 to 12 years old. 6 nurses with specialities including asthma nurse specialists, specialist health visitors, children community nurses and practice nurses. No other clinical or demographic data was reported.
Doody, Slevin and Taggart 2018	Semi-structured interviews with a mean duration of 38 to 65 minutes. Field notes were collected. All interviews were recorded and then transcribed, verbatim is not stated. The themes discussed in the interviews (no questions have been stated) was personal caring, supporting, liaison, education and knowledge, and empowering.	None stated	10 parents	Child ages ranged from 4 to 19 years old. No other clinical or demographic data reported.
Giambra et al. 2014	Semi-structured interviews that were either face to face or via telephone – with a mean duration of 20 -50 minutes. All interviews were recorded and then transcribed, verbatim is not stated. Field notes were collected. Demographics data was collected, and the researcher asked parents to describe their story of their child, followed by a variety of questions regarding communicating with nurses. Parents received $25 gift card for completing the interview.	18% (n=2) African American, 82% (n=9) Caucasian	10 parents and 1 grandmother	Child ages ranged from 4 to 15 years old. 100% (n=11) female participants included 82% (n=9) biological mother, 9% (n=1) biological grandmother and 9% (n=1) adopted mother. Parents age was 27% (n=3) were 31-40 years old, 36% (n=4) were 41-50 years old, 18% (n=2) were 51-60 years old and 18% (n=2) did not respond. Parents education level was listed as 18% (n=2) general education development certificate, 27% (n=3) minor college/technical school, 27% (n=3) college graduate, 9% (n=1) post college graduate and 18% (n=2) did not respond. Child technology needs included 72% (n=8) feeding tube, 36% (n=4) tracheotomy, 9% (n=1) ventilator and 18% (n=2) insulin pump. Parental yearly income, marital status and hospital length of stay not stated.
Roscigno 2016	First interview was conducted in person between 4 and 36 months post a TBI. Second interviews were conducted by phone 12-15 months following first interview. Field notes were collected. Semi structured interviews lasting at least 90 mins each. All interviews were recorded and then transcribed, verbatim is not stated. In the second interviews, parents were asked to comment on the investigator's summary of all parents' experiences and appraisals, including parents' discussions of caring behaviours in early acute care.	93% (n=27) Caucasian. No other race or culture identified by author.	29 parents from 25 families	Child ages ranged from 12 to 20 years of age at study enrolment, but all injuries and first hospital admissions occurred prior to child's 18th birthday. 100% (n=29) biological parents included 65.5% (n=19) biological mothers, 7% (n=2) biological fathers and 27.5% (n=4) biological parent couples. Parent age and education level not stated. Yearly incomes reported as <$20,000 (n=3), $20,000 to <$60,000 (n=9), $60,000 to <$100,000 (n=9) and >$100,000 (n=4). Marital status reported as Single (n=8) and married (n=17). Median acute care hospital: Admission length was 31 days (Range= 3 to 110 days).

Table 2: Characteristics of included studies (Continued)

Authors / Year	**Inclusion criteria**	**Exclusion criteria**	**Ethics approval**	**Informed consent**	**Sampling technique**	**Data analysis**	**Summary of study**	**Limitations**
Alves et al. 2017	Parents of children who have been diagnosed with a SHN condition more than one year ago and have had a previous hospital admission and contact with nursing staff.	Parents of children who were newly diagnosed, or in transient health system.	Yes	Yes	Purposeful sampling.	Categorical analysis.	Parents valued empowerment and decision making that partnership nursing brings. Parents want to be more involved in decision making of their child's care.	Authors note: A lack of variety in chronic health conditions among the participants.
Bettle et al. 2018	English speaking parents and legal guardians of children aged 1 to 8 years either on active treatment or up to 12 months post completion of ALL therapy. Registered nurses working a minimum of one year in a paediatric oncology setting.	None stated	Yes	None stated	Purposeful sampling.	Thematic analysis.	Both parents and nurses' value the therapeutic relationship that exists between them. Parents have a strong desire to participate in child's care and value empowerment.	Authors note: Primary investigator works at the oncology clinic and may have increased the risk of social desirability bias, due to their personal knowledge of the participants. Small recruitment sample which limits transferability of the findings.
Callery and Milnes 2912	None Stated	None stated	Yes	Yes	Not clearly reported.	Conversation and thematic analysis.	Importance of equal voices between nurse, parent and child in asthma management discussions.	Authors note: Clinic nurses were responsible for gaining consent and recording interviews and because these nurses were interested in communication issues already, they may have introduced bias.
Doody, Slevin and Taggart 2018	Families of a child with ID using a CNS service.	None stated	Yes	Yes	Purposeful sampling.	Thematic analysis.	Families value the caring, support, education and empowerment given to them by CNSs. CNSs offer parents empowerment in the managing the care of their own child.	Authors note: Study has a small sample size and that the families recruited may have preconceived bias for home-based care performed by CNSs.
Giambra et al. 2014	English speaking parents over the age of 18, with health care technology dependent children between the ages of 4-15 years old who had been hospitalised in the last year.	None stated	None stated	Yes	Purposeful and snowballing sampling.	Constant comparative analysis.	Parents require effective and individualised communication from nurses that promotes trust and respect as well as recognition of their own expertise.	Authors note: Limitations of the study include a 100% female population of participants, small sample size and sampling performed at only one hospital setting.
Roscigno 2016	Parents of children who were between the ages of 6-18 years old at time of TBI, with moderate to severe TBI, who were still dependent on parents post injury. Parents needed to speak English and be able to consent to participation.	Parents of children with a prior spinal cord injury or significant developmental impairment.	Yes	Yes	Not stated	Direct content analysis.	Parents saw the nurses as gatekeepers to their level of involvement. They saw nurses as the forefront of all communication between themselves and other HCP.	Author notes: A small sample size that was homogenous in ethnicity.

(Labels: SHN= Special healthcare needs, ALL= Acute lymphoblastic leukemia, CNS= Clinical nurse specialist, ID= Intellectual disability, TBI= Traumatic Brain Injury, HCP= Healthcare professionals)

Table 3: Quality assessment of included studies

Quality – JB QARI	Alves et al. 2017	Bettle et al. 2018	Callery and Milnes 2012	Doody, Slevin and Taggart 2018	Giambra et al. 2014	Roscigno 2014
1. Is there congruity between the stated philosophical perspective and the research methodology?	Y	Y	N	N	Y	U
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	N	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	N	Y	Y	Y
4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	N	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	Y	Y	N	N	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	N	Y	N	N	N	N
7. Is the influence of the researcher on the research, and vice-versa, addressed?	N	Y	N	Y	N	Y
8. Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	U	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y

Y	Yes
N	No
U	Unclear

Table 4: Synthesis of findings into categories.

Label	Findings that have unequivocal and credible evidence	Synthesised category
F4	When mothers felt empowered to take care of the child, they became involved, assuming full care.	Participation led to parental empowerment.
F68	The nurses gave anticipatory guidance to the parents to prepare them in how to get involved in the care of the child. By preparing parents ahead of time, the parents could be empowered to be able to get their information needs met and to become involved in the decision-making process for their child as they wished.	
F2	The mothers work together with the nurses to obtain gains in well-being, quality of life and integral development of the children.	Participation improved family quality of life.
F12	With reflective experience and guidance from their nurses, parents gained confidence and were able to interpret their child's specific pain cues.	
F61	Parents noticed and appreciated the way some nurses actively listened to the parents regarding who their daughter was as a person. Nurses also listened to parents need to be involved in her daughter's care, so nurses found a way to bridge the two needs.	
F67	The need for nurses to allow parents to get involved in the care of the child.	
F8	As mothers felt empowered, they wanted to make the most decisions independently and/or in collaboration with the nurses, leading the decisions that involved managing the care for their children.	Shared decision-making led to parental empowerment.
F7	The mothers valued the shared care negotiation as part of the work in partnership with nurses.	Parents valued negotiation in partnership.
F45	Parents who were less sure of their own expertise and valued the nurses' expertise tested their knowledge against that of the nurses. An information exchange of this sort could also lead to role negotiation.	
F3	Participants wished to have the opportunity to learn how to deal with the complexity of children's health/illness situation.	Parents valued education and training from nurses.
F11	Several parents worked with their nurses to better recognize their child's pain.	
F15	Detailed advice and monitoring of how parents were looking after their children could also be valued.	
F6	Partnership is about interactive help and teaching process.	Partnership was an interaction teaching process.
F10	Parents said nurses provided them with information by taking steps to tailor their education and ensure parents understood their teaching.	Education and training needed to be individualised.
F27	A key element of providing information and demonstration was the manner in which the CNS provides this support and been cognisant of the overall work of the family and the necessity to create normality within the family.	
F30	Support was always client focused and tailored to their specific needs, and where these plans required specific interventions, the CNS was on hand to support, demonstrate and provide training where necessary	
F49	Communication was enhanced when nurses listened to parents.	
F52	When advocating for their child, the parent communicated with the nurse to ensure their child received safe, correct, and appropriate care. The parents described continuing to advocate for their child until they were confident that they and the nurse both had the same understanding of what the child needed and how best to provide that care.	Parents advocated for their children.
F53	Parents also noted that advocacy increased with their perception of their own expertise. Advocacy is entwined with asking questions and listening as well as explaining.	

F54	Every parent interviewed described how they verified the nurses' understanding of their child's care. The parents' vigilance is evident in their descriptions of how they know if the nurse understood what they told them.	Nurses needed to demonstrate their knowledge and expertise.
F55	One mother related that she did not even go to the cafeteria if she did not feel confident in the nurse's expertise with her child. Parents felt very responsible for making sure the care their child received was optimal.	
F18	Parents valued nurses’ communication with their children.	Parents valued communication between themselves, child, and nurse.
F19	As well as putting their children at ease, parents saw that communication between nurses and children could reveal information that would not otherwise have been available.	
F58	Shared communication apparently results in a high degree of mutual understanding of the child's plan of care from the parent's perspective. When shared communication is not achieved, parents believe they have a different understanding of the plan of care than do the nurses. One parent felt that true shared communication amounted to cohesiveness between the parent and the nurse. Another described shared communication as working hand-in hand with the nurse.	
F20	Nurses listening in a non-judgemental manner was a key attribute to the formation of a caring relationship.	Nurses needed to be non-judgemental and listen to parents.
F21	This non-judgemental attitude created a sense that the CNS (clinical nurse specialist) understood the families’ situation and circumstances.	
F49	Communication was enhanced when nurses listened to parents.	
F26	CNSs were willing to demonstrate and seek feedback from the family and be open to questions which assisted or guided the family in the care process.	Nurses needed to seek feedback from parents.
F44	Some parents described asking questions in order to learn more about the care of their children. This was uncomfortable for some, but they felt it necessary. For other parents it was also a way to verify that the nurses understood what they had communicated about the child's care.	Communication led to education and training.
F46	Other parents insisted on having the nurse ask questions of the parent about the child's care. This not only allowed the parent to communicate their expertise to the nurse, but it also allowed the parent to determine the expertise of the nurse.	Communication demonstrated expertise of both nurse and parent.
F50	Explaining was used by these parents to impart their knowledge about their child's care and to verify the nurses' understanding of that knowledge.	
F51	Explaining is tied to asking questions and listening as these two communication acts are necessary for parents to not only explain their child's care but to ensure the nurse understands the care and incorporates it as part of the child's plan of care.	
F41	Intertwined within the CNS approach of working with the child and family was not only the acknowledgement of an individualised plan of care but also the acceptance of the role of the family in the decision-making process.	Parents played an important role in the decision-making process.
F57	The parents expressed appreciation for being asked to be involved in the care of their child.	
F64	Parents felt that caring nurses recognized parents’ competence and empathized how the early acute care system of care inherently disadvantaged the family, so those nurses did whatever they had to in order to mitigate those factors, which decreased the family’s workload and stress in being informed and involved in the child’s care and decisions. Creating a non-judgmental and accepting environment helped the family to heal from the emotional trauma they were initially exposed to, so that they could build up their resiliency for future roles and responsibilities. This nurse involved the family because she valued that it was the parents’ right to participate in their child’s care, but she also gave this parent permission to be in control of aspects of the child’s care, which decreased the mother’s stress and concerns for her own parenting behaviours.	

F9	Key attributes of a therapeutic relationship included establishing trust and how they developed a high level of trust with their nurses to the point that they considered the nurses a part of their “family.”	Parents needed to trust and respect nurses.
F62	Parents described their observations of how various nurses took on differing levels of interpersonal relationships with the parents in order to build a rapport with the family.	Partnership between nurses and parents created rapport.
F65	Collaboration created a trusting rapport between the nurse and the family.	
F29	The CNS was their first point of contact and someone they called upon regularly not only regarding CNS care and service, but the overall care and support required by the family as the CNS will actively engage with the other members of the team and come back to the family.	Nurses liaised with other HCP on behalf of family.
F32	The CNS worked in a manner to ensure the family was referred to the appropriate services and was open to the family seeking the CNS to refer them if they so wish.	
F34	This coordination and collaboration work of the CNS created as sense that the CNS functioned effectively as part of the team but more importantly the CNS was seen as part of the family team as well as working within the health profession team.	
F35	The CNS communicates their decisions to all concerned and ensures that all are aware in order to support effective collaborative working and where necessary was autonomous in decision-making.	
F33	CNSs support and coordinate appointments for the family and assist them in gaining the appropriate services and effectively planning ahead so all are prepared for upcoming events.	Nurses assisted the family in future care planning.
F1	The child was in the central position of the partnership.	The child was central to the parent-nurse partnership.
F13	The mother presented herself as an observer of a dyadic relationship between nurse and children, that was built on trust with the nurse’s level of expertise.	
F22	These feelings of the caring provided were greatly supported by the CNS presence throughout the care process and the sense of togetherness this created.	Nurses provided caring support to all family members.
F23	Participants emphasised that the CNS way of working created a true sense of togetherness in the caring process and supporting the family.	
F59	Parents’ stories highlighted the importance of creating and implementing a system of caring (coordinated, respectful, inclusive, individualized, and compassionate services for the families), not only individual caring interactions between each nurse and the family.	
F25	Participants also saw the CNS as having a more direct role in care and all care provision.	Nurses had a direct care role.
F56	The parents felt ultimately responsible for their child's care however, they recognized that the nurse also had a role to play in that care.	
F38	Inbuilt within information provision was also the creation of realistic expectations and planning ahead for all possibilities and that while the information was based on evidence, it was tailor made to the individual and family.	Nurses assisted the family in care planning.
F40	Participants clearly identified the CNS as both client/person and family-centred and that this team approach to care was created by the CNS acceptance of the families own expertise, individuality, and choices.	Nurses practiced child and family centred care.

(Label coding note: F1 = Finding 1 of data extraction, CNS= Clinical nurse specialist. All findings have a quality score of credible or unequivocal)

Table 5: Data synthesis of categories into synthesised findings

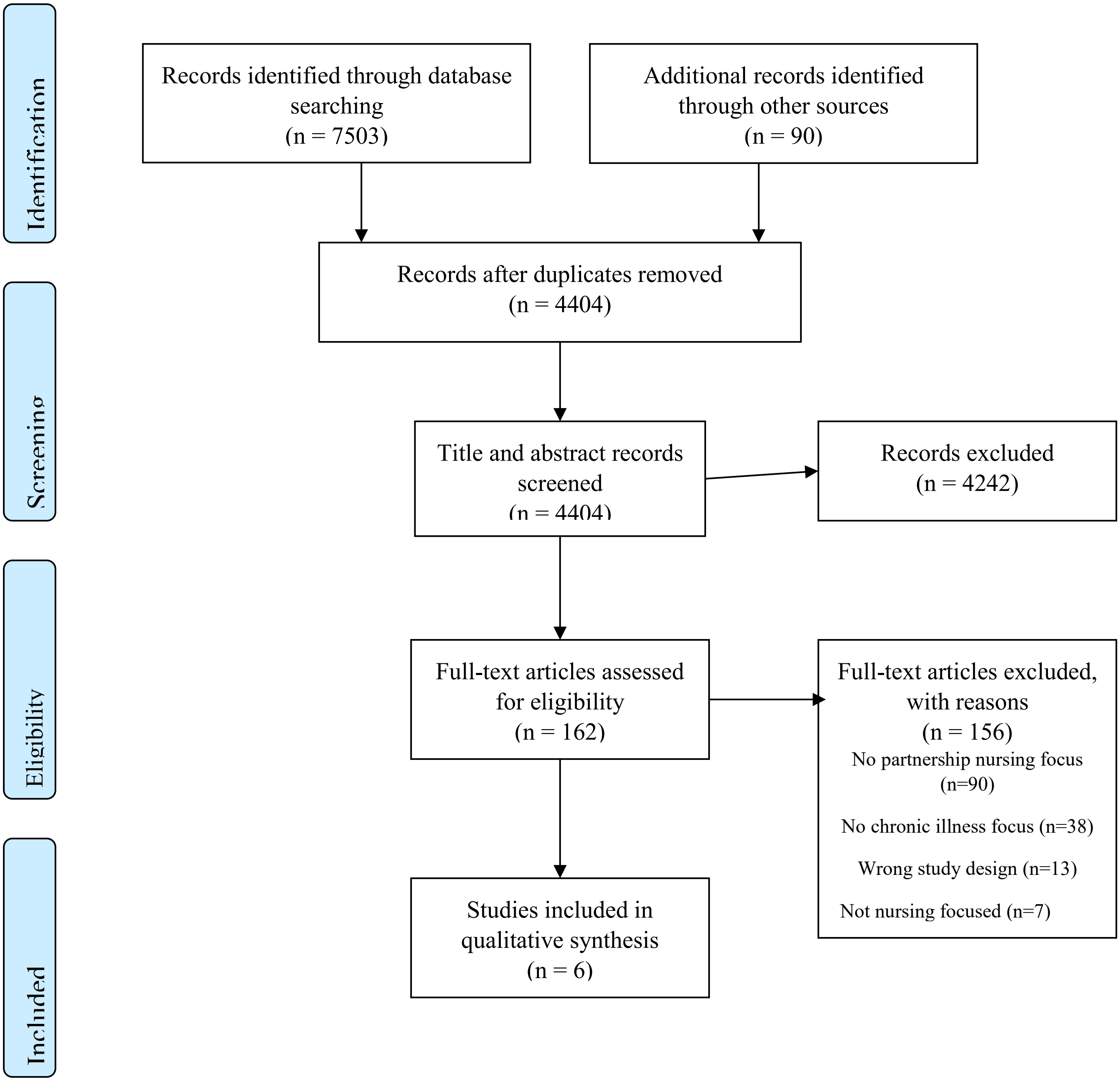
Findings	Synthesised category (built from table 4)	Synthesised finding
F4, F68	Participation led to parental empowerment.	**Empowering parents to become involved** Parents recognise the skills and knowledge that nursing staff have and wanted to be educated and trained by nurses to improve the care they provided to their children. When parents partner with nurses to be involved in the care of their own children, they felt empowered to make decisions, take charge of their child's healthcare needs, and this improved the quality of life, for both the parents, child and family.
F2, F12, F61, F67	Participation improved family quality of life.	
F8	Shared decision-making led to parental empowerment.	
F7, F45	Parents valued negotiation in partnership.	
F3, F11, F15	Parents valued education and training from nurses.	
F6	Partnership was an interaction teaching process.	
F10, F27, F30, F39	Education and training needed to be individualised.	
Findings	Facilitators to partnership:	
F53	Parents who have increased expertise feel that they advocate better for their child.	
Findings	Barriers to partnership:	
F31	Parents feel a lack of future preparation.	
Findings	Synthesised category (built from table 4)	Synthesised finding
F52, F53	Parents advocated for their children.	**Effective communication to recognise mutual expertise** Parents value the importance of communication between themselves and nursing staff. Parents regarded effective communication as a fundamental underpinning of partnership that enabled the development of mutual trust and respect between
F54, F55	Nurses needed to demonstrate their knowledge and expertise.	
F18. F19. F58	Parents valued communication between themselves, child, and nurse.	
F20, F21, F49	Nurses needed to be non-judgemental and listen to parents.	
F26	Nurses needed to seek feedback from parents.	
F44	Communication led to education and training.	
F46, F50, F51	Communication demonstrated expertise of both nurse and parent.	
Findings	Facilitators to partnership:	

F5	Having a reference nurse with extensive experience of the child gives parents piece of mind.	themselves and nurses. Communication demonstrates skills and expertise of both parents and nurses.
F47	Parents feel appreciated when they are listened to because they want their expertise heard.	
Findings	Barriers to partnership:	
F42	Communication which is not individualised or appropriate.	
F43	Parents feel frustrated when their expertise is discounted by nurses.	
F48	Parents feel frustrated and felt the care provided to be less than optimal when nurses did not listen to them.	
F66	Parents feel a need to protect their child when they do not perceive nurses to be knowledgeable.	
Findings	Synthesised category (built from table 4)	Synthesised finding
F41, F57, F64	Parents played an important role in the decision-making process.	**Collaborative nurse-family relationships.** Parents perceived partnership as a collaborative effort between themselves and nurses to deliver the most effective and safe care to their children. When the partnership focused on the needs of the child and family, parents trusted the nurses to advocate for their children.
F9	Parents needed to trust and respect nurses.	
F62, F65	Partnership between nurses and parents created rapport.	
F29, F32, F34, F35	Nurses liaised with other HCP on behalf of family.	
F33	Nurses assisted the family in future care planning.	
F1. F13	The child was central to the parent-nurse partnership.	
F22, F23, F59	Nurses provided caring support to all family members.	
F25, F56	Nurses had a direct care role.	
F38	Nurses assisted the family in care planning.	
F40	Nurses practiced child and family centred care.	
Findings	Facilitators to partnership:	
F14	Parents value nurse's expertise, availability, and responsiveness.	

F24	The key to caring is when the nurse knows the child and family and the child and family know the nurse.	
F28	Nurses who are flexible in the care they offer.	
F36	Nurses bring plans together that would otherwise be fragmented, disjointed and open to failure.	
F37	Nurses who use their knowledge and expertise to support the family in an appropriate manner.	
F60	Nurses who do not minimise a parent’s need for hope.	
F63	Nurses who go beyond medical needs in the care of children.	
Findings	Barriers to partnership:	
F16	Some parents choose to limit their contact with nurses.	
F17	Conflict occurs when there is limited collaboration.	

(Label coding note: F1 = Finding 1 of data extraction. All findings have a quality score of credible or unequivocal)

Figure 1: PRISMA diagram



Supplementary Table 1: Findings, illustrations and evidence

Author	Findings	Illustrations (Page number)	Evidence			Label
			Unequivocal	Credible	Unsupported	
Alves et al. 2017	The child was in the central position of the partnership care.	*"It was good … to have learned … for the child (P3)". (Page4)* *"And then … there was a nice little room for the boys to play, … it was the nurses who put the boys on the floor for them to play … they … must be healthy (P6)." (Page 4)* *"I saw that everything she had done … was just for his good (P7)." (Page 4)*		X		F1
Alves et al. 2017	The work in partnership was developed and the time it was spent were understood as resources for the mothers, who work together with the nurses to obtain gains in well-being, quality of life and integral development of the children.	*"Since birth, she has lived the first 10 months inside the hospital and … the constancy was daily … to perform with the nurses, from knowing how to handle a baby with the wires attached to it, from the feeding (P6)." (Page 4)* *"This partnership I established with them was, it was very good (P8)." (Page 4)*	X			F2
Alves et al. 2017	Most participants wished to have the opportunity to learn how to deal with the complexity of children's health/illness situation.	*" I had to do ... as if I were the nurse (P1)." (Page 5)* *"When we were doing the parenteral nutrition … we first had to see how they did it once or twice and then we started doing it and it went well (P9)." (Page 5)*	X			F3
Alves et al. 2017	The term parental involvement covers the caregiving and the decision making. In this perspective, the mothers felt totally involved in the care they gave their children. When they felt empowered to take care of the child, they became involved, assuming full care.	*"I became the nurse of A ... 24 hours, the father was the nurse's assistant (P6)." (Page 5)* *"... Since I was there, it was me who cared for the child from beginning to end ... they gave me this opportunity by being present (P8)." (Page 5)*	X			F4
Alves et al. 2017	Having a reference nurse meant being able to enjoy the care of a person with extensive experience, which gave them peace of mind.	*"The first time I did it alone at home was on the phone with the ... support nurse, to see if everything was fine and she said it was. I think it is important that we have someone to communicate with. It was a great opportunity and a great support that we had (P2)." (Page 5)* *"They are there ... to inform us. They do not leave us worried, therefore, there is always, there is communication, in every sense, there is communication, they communicate and they listen to us ... anything that happens at home, the first person I talk to ... is always a nurse (P5)." (Page 5)*	X			F5
Alves et al. 2017	They said that learning how to take care of the child was critical to their empowerment.				X	US1

Author	Findings	Illustrations (Page number)	Evidence			Label
			Unequivocal	Credible	Unsupported	
Alves et al. 2017	Nurses' ways of action emerge with emphasis on the nature of the partnership based on interactive help processes, making the relationship real and useful for both parents and the child.	*"…Had two nurses X and Y teaching me (P2)." (Page 5)* *"... I did an apprenticeship with each nurse ... those details, those doubts that arise in the situation, that we do not know what to do with and ask the nurse X and she says: Look, this way is better ... the ways in which each one works are different ... to put together what each one knows ... helped me ... it is all positive experiences (P5)." (Page 5)* *"... They teach us as the book says ... it was fun to see the techniques of those people ... by doing new things ... we learned a lot (P6)." (Page 5) "They had knowledge ... they have the necessary knowledge ... they know the situations (P8)." (Page 5).* *"Each one has ... in the end it's all the same, but each one has its own ways of doing and we have been picking up a way from one part of another and we have made our method, right … And we do it at home (P9)." (Page 5)*	X			F6
Alves et al. 2017	Parents value the nurse's sensitivity and attention to working the real and potential life circumstances of the child and his/her family, both at the most superficial and concrete level of clinical aspects, and in meeting specific emotional needs.				X	US2
Alves et al. 2017	The mothers valued the shared care negotiation as part of the work in partnership with nurses.	*"… They also hear us, they also hear us. For example, wearing a nightdress and telling them no, it is easier to take them by the arm, they listen to us, they obey our opinion (P5)." (Page 6)* *"... They were always open ... if there was anything that would be harmful to him ... they said ... and we understood ... they gave us various alternatives to everything (P9)." (Page 6)*	X			F7
Alves et al. 2017	As mothers felt empowered, they wanted to make the most decisions independently and/or in collaboration with the nurses, leading the decisions that involved managing the care for their children.	*"The first time I popped the bags I pierced a bag and filled the bed with liquid ... it was time to care for my daughter, but then I had another bag to warm ... and do it only half an hour later … I then phoned the nurse X who is the reference nurse and she said it made no difference and that I could do it half an hour later. I think that … it is a great opportunity and a great support that we have (P2)." (Page 6)* *"A decision I made, in which ... I was supported by my nurse (P5)." (Page 6)*	X			F8
Bettle et al. 2018	Every interviewed parent identified the process of developing meaningful relationships with their nurses. Key attributes of a therapeutic relationship included establishing trust and how they developed a high level of trust with their nurses to the point that they considered the nurses a part of their "family".	*"We're seeing them more, so they become more of a … kind of like your hospital family. So you get to trust them more. And then they just get to learn your patterns and the way you are and how you react to his pain (P8)." (Page 46)*	X			F9
Bettle et al. 2018	Parents were excited and they did not hesitate when they described the support that they received from their nurses.				X	US3

Author	Findings	Illustrations (Page number)	Evidence			Label
			Unequivocal	Credible	Unsupported	
Bettle et al. 2018	With their nurse's assistance, parents transitioned from being overwhelmed with having a child with a cancer diagnosis to having the knowledge necessary to care for their child and their child's pain care needs.				X	US4
Bettle et al. 2018	Parents said nurses provided them with information by taking steps to tailor their education and ensure parents understood their teaching.	*"Even though everyone was giving us a lot of information, just the time to digest. And they would keep reminding us of things and you know, just … not quizzing me but asking me if I understood and making sure it was all clear, I guess. Which was excellent because your life is turned upside down (P7)." (Page 47)*	X			F10
Bettle et al. 2018	Despite experiencing challenges with identifying pain, several parents worked with their nurses to better recognize their child's pain.	*"I would talk to them (nurses) and they would help me kind of talk to her. Because like I said, when you're 2 or you're dealing with a 2-year-old, you know, it's kind of hard. So sometimes they would ask her some questions … once they gave me like kind of those questions that I could ask, like where does it hurt, does it hurt a lot, does it hurt a little (P2)." (Page 48)*	X			F11
Bettle et al. 2018	With reflective experience and guidance from their nurses, parents gained confidence and were able to interpret their child's specific pain cues.	*"And then once we got to know, you know, exactly … actually just watching her body language just told us a lot because we'd just watch what she was doing and then we'd know, oh, that's … she's in pain now (P7)." (Page 48)*		X		F12
Callery and Milnes 2012	The importance of personal relations between her children with asthma and the nurse as well as the trust engendered as a result of her perception that the nurse had used her expertise to achieve control of asthma. The mother presented herself as an observer of a dyadic relationship between nurse and children.	*"And they've got that relationship with her and I wouldn't go anywhere else with them and it's trust as well because … I know that she's done so much work for them and their asthma like I said was so out of control when we went to see her she's actually worked with them and she has been with them right the way through and it's settled down now and it's all through … because of hard work she's done with them (C0361)." (Page 1643)*	X			F13
Callery and Milnes 2012	Relationships between nurses and parents were key to the successful development of alliances. Parents valued the expertise of nurses, their availability and responsiveness.	*"I could go and ask anything I wanted because they specialised in that … not have to make an appointment …and they're dead nice and they understand your situation and you can ask any silly question you want. (PC018)." (Page 1643)*	X			F14
Callery and Milnes 2012	Detailed advice and monitoring of how parents were looking after their children could also be valued.	*"She showed me how to use the inhalers properly, the spacer and then the blow one … you're not over or under medicating because you go there and you write it down on your chart and you show it, because you have a diary and stuff like that, then you show it to her and she goes 'Yes, that is great' (PC048)." (Page 1643)*	X			F15
Callery and Milnes 2012	Some parents preferred to limit their contact with professionals.	*"I don't think I would like too many people…like somebody come round and say 'You've got to do this and do that and do that' I would just rather be told once and that's it. (PC002)" (Page 1643)*	X			F16
Callery and Milnes 2012	Interactions between parents and nurses took place in the context of their respective motivations, expectations and health beliefs.				X	US5

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			Unequivocal	Credible	Unsupported	
Callery and Milnes 2012	Conflicts could result if health professionals were not involved in these informal experiments.	*"I got told off like for taking him off it and then I put him back on the Seretide twice a day and he said 'If you feel that he doesn't (need) it after like six weeks then take him off it six weeks before he was likely to go back, and then we'll see how he is when he goes to clinic' so that's what we've done (PC002)." (Page 1644)*	X			F17
Callery and Milnes 2012	Parents valued nurses' communication with their children. The personal element of therapeutic alliance was important because parents wanted their children to have friendly interactions with nurses.	*"I only moved to Doctor X because of the nurse … they have such a good relationship with Alice I'm not going to move them … it's that personal one-to-one contact that the child has with the asthma nurse and the child (PC036)." (Page 1646)*	X			F18
Callery and Milnes 2012	As well as putting their children at ease, parents saw that communication between nurses and children could reveal information that would not otherwise have been available.	*"They talk so freely with Alice she's so good with them as well… She can pick up things that maybe I can't pick up…maybe I can't understand or relate to…she does all that so it's for her and the child knows that they've got that extra contact (PC036)." (Page 1646)*	X			F19
Doody, Slevin and Taggart 2018	The personal caring aspect of CNS (clinical nurse specialist) work was expressed by all participants, and this was indicative of the relationship that existed which formed a positive working relationship between CNS and the family. Within this relationship, listening in a non-judgemental manner was a key attribute to the formation of a caring relationship.	*"It's the non-judgmental way she deals with us that is key … the CNS listens in a non-judgmental way and gives us relevant information and works with us. (Mary)." (Page e82)*	X			F20
Doody, Slevin and Taggart 2018	This non-judgemental attitude created a sense that the CNS understood the families' situation and circumstances.	*"The CNS treats us as individuals in the sense that we feel, this is new and we are going through it, I know it's not new to the CNS but she takes it as new for us and she will wait, she doesn't jump in with the answer or information, she will allow us to express it, discuss it, identify what we want, focus us on (name), her needs and wants or wishes (Paul)." (Page e83)*	X			F21
Doody, Slevin and Taggart 2018	These feelings of the caring provided were greatly supported by the CNS presence throughout the care process and the sense of togetherness this created.	*"There's an ease for me knowing (named CNS) is there every day, and she has been with us all the time and any advice we want or need (named CNS) is there, she will link in and see how she can support you (Pauline)." (Page e83)*	X			F22
Doody, Slevin and Taggart 2018	Participants emphasised that the CNS way of working created a true sense of togetherness in the caring process and supporting the family.	*"They're (CNSs) always with us if we need them it's not just a periodic visit. They support us, in times of stress, working directly with (named child) and us, show us what to do and is the only one who seems to be there directly for (named child) and us (Joe)." (Page e83)*	X			F23
Doody, Slevin and Taggart 2018	Key to caring was the aspect of knowing the person, and this was not just from the point of view of the CNS knowing the client it also included the CNS knowing the family and this was reciprocal as it also involved the family and client knowing the CNS.	*"I like the fact that I have people that know the child and the family and it's not like when you go into a service, the CNS knows the family and how we work and we know them and about their family and this is important so everything can come together and we can work well together (Marie)." (Page e83)*	X			F24

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			Unequivocal	Credible	Unsupported	
Doody, Slevin and Taggart 2018	Participants also saw the CNS as having a more direct role in care and all care provision.	*"With the others (MDT) you don't get to know them you might have one appointment in six months so you don't open up and say much to them, but you have built up a rapport with the CNS and anyway they just see a problem or solution and put in on paper (MDT), but it's us and the CNS that have to do it so you don't get to or really need to get to know them (MDT) (Tom)." (Page e83)*	X			F25
Doody, Slevin and Taggart 2018	The support aspect of the CNS work was described by participants as a valuable and important component and one that assisted them in maintaining family life and bringing the family together.				X	US6
Doody, Slevin and Taggart 2018	In addition to providing information, the actual understanding and putting that information into practice was supported by CNSs in their willingness to demonstrate and seek feedback from the family and be open to questions which assisted or guided the family in the care process.	*"She (CNS) is able to give the right information and the right amount but most of all she makes it relevant and she will check back with us in case we have any questions and ask us about what we have read, but more importantly she will give a hand when needed and show us or demonstrate how to do something and it's a very practical approach, then I can see how she did that and how I could do it and this reinforces the information she has given (Claire)." (Page e83)*	X			F26
Doody, Slevin and Taggart 2018	A key element of providing information and demonstration was the manner in which the CNS provides this support and been cognisant of the overall work of the family and the necessity to create normality within the family.	*"The information and demonstration is great and guided us as a family but it is also delivered in a manner that is considerate of the overall family function in the sense that I don't need to stand on foot while she talks me through it, I can do the normal family activities be it cooking or whatever and she will come into the kitchen and do it there as it's hard to get it all done (Jill)." (Page e83)*	X			F27
Doody, Slevin and Taggart 2018	Fundamental to supporting the family is the flexibility of the CNS and their willingness to conduct home visits. This was reported by participants as assisting them in maintaining a family/life balance and allowing the child to perform in their natural environment.	*"The home visit is so important and helps so much and they (CNSs) will even make it evening time if we were working or morning if I had a late start, it's here they get to know the child and the family and see what will work for them and us and what's in the home environment that can be used and it's great as she (child) will cooperate here as she knows everything and is comfortable, whereas we all get stressed in the clinics with the MDT as I want her to perform and she must feel the spotlight as she tends do little or nothing and they must think she has so little capabilities (Rose)." (Page e84)*	X			F28
Doody, Slevin and Taggart 2018	Support and home visits were further reinforced not only by the CNS flexibility but also by their accessibility as all families identified the CNS as their first point of contact and someone they called upon regularly not only regarding CNS care and service, but the overall care and support required by the family as the CNS will actively engage with the other members of the team and come back to the family.	*"Often I would text or email her (CNS) to say this is not working and she would come back to me or call out, she's our first point of contact and the one service we will always contact if there is an issue even if it's not their area we can discuss it and get their advice and they (CNSs) will advise us and follow up with the others (MDT) if they need to and come back to us (Frank)." (Page e84)*	X			F29

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			Unequivocal	Credible	Unsupported	
Doody, Slevin and Taggart 2018	Support was always client focused and tailored to their specific needs, and where these plans required specific interventions, the CNS was on hand to support, demonstrate and provide training where necessary	*"No matter what, there will be a plan and I did think what do we need it for at the start but I can see why now we all can see it and its clear how to do something or deal with something, when there're direct interventions she (CNS) will support us in supporting (child) be it with speech, movement, behaviour or whatever and she will always assist and give advice and new things to try and if we need it she will show us again and again (Paul)." (Page e84)*	X			F30
Doody, Slevin and Taggart 2018	Families did report a shortfall in the preparation for the future and or transition planning such as moving from preschool to primary school or between services such as child to adolescent.	*"They need to let the CNS into the school and the CNS needs to be talking to the special needs officers, teachers and special needs assistants, now they would have done it but it is an extra not a given, they work on a time period for example 0–4 and then they move to the next service but there is a lot going on and there needs to be a crossover between the services by the CNS for a period of time to assist and support this process as they know the child so well, when you move you have to start the process all over again and the new person is losing out on all the knowledge and information the CNS has about the child and it's not the same if it's down on paper (Tom)." (Page e84)*	X			F31
Doody, Slevin and Taggart 2018	The CNS worked in a manner to ensure the family was referred to the appropriate services and was open to the family seeking the CNS to refer them if they so wish.	*"She (CNS) will always ensure we are linked in with the other services we need by referring us but it's not just the ones she feels we need as if we come to her looking to be referred somewhere she will do that for us as well (Mary)." (Page e84)*	X			F32
Doody, Slevin and Taggart 2018	CNSs support and coordinate appointments for the family and assist them in gaining the appropriate services and effectively planning ahead so all are prepared for upcoming events.	*"They (CNSs) will link with the others so that I won't have to be coming in twice and make it as convenient as possible, or if the CNS felt a review was needed they would link in with the other specialists and get that done at the one visit, if I said I needed something she would come back to me and have coordinated it all, and she did the grant application and allowance application with us (Marie)." (Page e84)*	X			F33
Doody, Slevin and Taggart 2018	This coordination and collaboration work of the CNS created as sense that the CNS functioned effectively as part of the team but more importantly the CNS was seen as part of the family team as well as working within the health profession team.	*"The CNS is the link in the system that everything revolves around, without them the whole team would fall down as they are the ones that do the work and support us (Claire)." (Page e85)*	X			F34
Doody, Slevin and Taggart 2018	The CNS communicates their decisions to all concerned and ensures that all are aware in order to support effective collaborative working and where necessary was autonomous in decision-making.	*"It's difficult for the CNS as they are trying to keep everyone involved and informed, it's the CNS who ties everyone together and decide what will work and try things out, this is done while she presents us with all the options and assists us to make a decision, but the decision is a collaborative effort between the CNS and us as a family and we trust her at times when an immediate decision has to be made (Joe)." (Page e85)*	X			F35
Doody, Slevin and Taggart 2018	Throughout the interviews, participants discussed and identified the CNS as bringing the plans together and that without their involvement things would be fragmented, disjointed and open to failure.	*"The CNS will help us with (named child), she will carry out the steps or plans that others have given, along with whatever she is doing with us or wants to do with us, she's always aware of what's going on and how it is going to ensure everything is working and alright (Jill)." (Page e85)*	X			F36

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			Unequivocal	Credible	Unsupported	
Doody, Slevin and Taggart 2018	Throughout the interviews, the participants continually acknowledged the skill, knowledge and expertise of the CNS and that the CNS was able to use these attributes in an effective manner in order to support the family in an appropriate manner.	*"She (CNS) has years of experience and excellent knowledge and can share that with us, and to me this is what's effective for us (Frank)." (Page e85)*	X			F37
Doody, Slevin and Taggart 2018	Inbuilt within information provision was also the creation of realistic expectations and planning ahead for all possibilities and that while the information was based on evidence, it was tailor made to the individual and family.	*"She (CNS) always gives you the information that is useful at that time and share her experience, but it's the little things that make it, she will have the information in a pack with our and (child) names on it, starting with the date of the diagnosis and an explanation of what that means from (child) perspective, how it is affecting him and how he sees the word, how he communicates, how he may feel and his frustrations (Pauline)." (Page e85)*	X			F38
Doody, Slevin and Taggart 2018	Identified and discussed across all interviews was the educative role of the CNS as she not only delivered the information to each family, she also built on that information by providing courses/training for the parents and extended family.	*"She will educate others with or for us as well such as our family and it was great as the family are more understanding of (child) and our needs and have often popped in and given us a break now as a result (Claire)." (Page e85)*	X			F39
Doody, Slevin and Taggart 2018	Participants clearly identified the CNS as both client/person and family-centred and that this team approach to care was created by the CNS acceptance of the families own expertise, individuality and choices.	*"When we met the CNS she was able to sit there and talk to us from the child's perspective and reassure us that a lot of the issues we were having were not about (child) but about people not been trained to support these specific needs, this was a relief as we are anxious to keep him at home and (CNS) would have looked at what we want and we sat down to see how we as a family could achieve this between us (Frank)." (Page e86)*	X			F40
Doody, Slevin and Taggart 2018	Intertwined within the CNS approach of working with the child and family was not only the acknowledgement of an individualised plan of care but also the acceptance of the role of the family in the decision-making process. The role was supported, negotiated and encouraged so that family and child could claim ownership of the plans developed and appreciate their real value.	*"She (CNS) will develop and design an individual plan and be at all the meetings to support you, the plan will be done in a way that (child) and us can understand and she will get us all involved in what goes in and deciding what is the best way to do it (Marie)." (Page e86)*	X			F41
Giambra et al. 2014	All of the parents perceived that they had significant expertise in the care of their technology-dependent child. This expertise gave them confidence to communicate openly with the nurses to ensure the best care for their child. Parents who described situations in which they felt there was a lack of shared communication voiced concerns about either their own expertise, the nurse's expertise, or the nurse's perception of parent expertise regarding the care of the child.				X	US7

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			Unequivocal	Credible	Unsupported	
Giambra et al. 2014	Despite years of experience caring for the complex needs of her child, one parent, described a situation in which communication with the nurses did not enhance the care of her child and she felt that her own knowledge must be deficient and her lack of expertise was the reason for the lack of shared communication she experienced.	*"…I'm a passive person … I will say yes and act like I know and really don't …they're so professional that their terms of course aren't going to be like mine. But they are really patient with me." (Page 17)*	X			F42
Giambra et al. 2014	Parents often expressed extreme frustration when their expertise was discounted by the nurses. The parents appreciated nurses who asked for and used their expertise.	*"…Remember that you're a team, so it's not one way or the highway…although you know your child best, there's also the part of the medical team knowing the medical piece." (Page 18)*	X			F43
Giambra et al. 2014	Respect for each other's expertise was described as enhancing communication with the nurses by many of the parents. Without both parent and nurse perception of their own expertise and respect for one another's expertise, shared communication was not possible.				X	US8
Giambra et al. 2014	Every parent interviewed expressed that when they felt they lacked knowledge or expertise about some aspect of their child's care, they asked questions of the nurse. In this way, they showed respect for the nurse's expertise and improved their own understanding and expertise regarding the care of their child. Asking questions was very important from the parents' perspective.				X	US9
Giambra et al. 2014	Some parents described asking questions in order to learn more about the care of their children. This was uncomfortable for some, but they felt it necessary. For other parents it was also a way to verify that the nurses understood what they had communicated about the child's care.	*"When I kept asking the same questions over and over that's when they went in and brought different people to explain it to me until I got it right … and once I did we was all on the same page and it was so much easier." (Page 18)*	X			F44
Giambra et al. 2014	Parents who were less sure of their own expertise, and valued the nurses' expertise tested their knowledge against that of the nurses. An information exchange of this sort could also lead to role negotiation.	*"Just ask a lot of questions … I ask why she's (the nurse) doing it that way, or why we need to do it that way. Or if I'm possibly doing it wrong, just to try to learn." (Page 18)*	X			F45
Giambra et al. 2014	Other parents insisted on having the nurse ask questions of the parent about the child's care. This not only allowed the parent to communicate their expertise to the nurse, it also allowed the parent to determine the expertise of the nurse. Once the expertise of each party was established, dialogue was opened between the parent and nurse and shared communication flourished.	*"Well, upon admission, being admitted into a room, a lot of questions are asked by the nurses just to get to know Tiffany and what her routine is as far as eating. So, there will be some back and forth there between us as parents and the nurse, communicating to how we feed Tiffany." (Page 19)*		X		F46

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			Unequivocal	Credible	Unsupported	
Giambra et al. 2014	The parents clearly expected the nurse to demonstrate their expertise by answering questions appropriately. They also demanded respect for their own expertise by asking questions of the nurse.				X	US10
Giambra et al. 2014	Parents of technology-dependent children wanted their expertise to be heard. They appreciated being listened to because they felt they had something of value to offer.	*"I want them to listen to me and let me finish what I'm trying to say because if I don't get it all out there right on top of my mind, then I'm leaving something out." (Page 19)*	X			F47
Giambra et al. 2014	Parents became frustrated and felt the care provided by nurses who did not listen was less than optimal.	*"(The nurse) maybe didn't listen to us well enough to consider every aspect of her diabetes." (Page 19)*	X			F48
Giambra et al. 2014	Because the nurses listened, communication was enhanced and what started out to be a serious safety event was subsequently resolved.	*"I felt like the nurses were listening to us and they kept going to the residents." (Page 19)*	X			F49
Giambra et al. 2014	Explaining was used by these parents to impart their knowledge about their child's care and to verify the nurses' understanding of that knowledge.	*"Verbally first, then if they are not quite catching what I'm saying, if I'm not explaining myself right, I'll show them something, and then they can see it and get it." (Page 19)*	X			F50
Giambra et al. 2014	Explaining is tied to asking questions and listening as these two communication acts are necessary for parents to not only explain their child's care but to ensure the nurse understands the care and incorporates it as part of the child's plan of care.	*"That's the first thing I do to communicate his care is I always turn in his medication list and then they go into the system to look and it is never the same. Then, I basically just explain it. Verbally go through everything that it is that he requires, his needs. This past time they asked if it was okay they didn't crush (a medication) if they came up with a different type. And I said actually that is a problem…So, they ended up calling the neurologist and he said crush it. At least they asked." (Page 19)*	X			F51
Giambra et al. 2014	When advocating for their child, the parent communicated with the nurse to ensure their child received safe, correct, and appropriate care. The parents described continuing to advocate for their child until they were confident that they and the nurse both had the same understanding of what the child needed and how best to provide that care.	*"Being a parent, grandparent, we are the children's best advocate." (Page 19)* *"But, yeah there are times when I have felt like I really had to step in and say she's not the property of the hospital, she's my baby, you're not going to do this." (Page 19)*	X			F52
Giambra et al. 2014	Parents also noted that advocacy increased with their perception of their own expertise. Advocacy is entwined with asking questions and listening as well as explaining.	*"I think the more experience you have I think the easier it is to advocate and not question yourself as much." (Page 19)*	X			F53
Giambra et al. 2014	Every parent interviewed described how they verified the nurses' understanding of their child's care. The parents' vigilance is evident in their descriptions of how they know if the nurse understood what they told them.	*"Well, they'll verbalize their understanding of what we're telling them. And then we will visually see if they are doing something right or wrong." (Page19)*	X			F54

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			Unequivocal	Credible	Unsupported	
Giambra et al. 2014	Nearly every parent interviewed stated they always stayed with their child while hospitalized in order to maintain their vigilance. One mother related that she did not even go to the cafeteria if she did not feel confident in the nurse's expertise with her child. Parents felt very responsible for making sure the care their child received was optimal.	*"Well, I always stayed in hospital 24/7 with her. And so I would always be there to describe what our routine at home was." (Page 20)*	X			F55
Giambra et al. 2014	The parents felt ultimately responsible for their child's care however, they recognized that the nurse also had a role to play in that care.	*"In fact, whenever she was hospitalized whatever of her care I could do, I did. I mean, naturally they took her vital signs and did her monitoring but as far as all of her bathing and feeding, you know everything else, I did." (Page 20)*	X			F56
Giambra et al. 2014	The parents expressed appreciation for being asked to be involved in the care of their child.	*"They're (the nurses) just so good about that too, going down the list of what's needed and kind of confirming how much involvement we want them to have." (Page 20)*	X			F57
Giambra et al. 2014	Shared communication apparently results in a high degree of mutual understanding of the child's plan of care from the parent's perspective. When shared communication is not achieved, parents believe they have a different understanding of the plan of care than do the nurses. One parent felt that true shared communication amounted to cohesiveness between the parent and the nurse. Another described shared communication as working hand-in hand with the nurse.	*"I want communication to be more than just a…divulging information at me to a dialogue with me…I just expect you to respect me as a mom and to not just spit information at me but to incorporate me into the care or the communication about my son." (Page 20)*	X			F58
Roscigno 2016	Parents felt that some nurses and other providers working in early acute care places only witnessed the family in the early weeks after the child's injury, when the family is disadvantaged, stressed, and emotional. Parents of children with severe TBI believed this limited perspective gave many nurses a narrow understanding of parents' capacities to eventually manage and adapt to stressors if appropriately supported during this early period. Parents countered that when early acute care nurses could fully appreciate their co-occurring grief with their attempts to be resilient, nurses could then respond in ways that implicitly and explicitly communicated that the family's experiences, knowledge, and perspective were respected.				X	US11
Roscigno 2016	Parents' stories highlighted the importance of creating and implementing a system of caring (coordinated, respectful, inclusive, individualized, and compassionate services for the families), not only individual caring interactions between each nurse and the family.	*"It's not the child, you know, having an injury. No, it's not that. It's, um, it's what you get from everyone else. The support and understanding and the patience … It's just the system itself … instead of somebody being there to help you do this, (sometimes) you're pushing them to do this." (Page 9)*	X			F59

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			Unequivocal	Credible	Unsupported	
Roscigno 2016	Parents wanted to motivate nurses to understand the importance of not taking the family's hope away or minimizing what hope meant to them.	*"We went back a number of months (later) just to visit and so (our daughter) could see where she had been and everything … This one nurse who was so funny … I mean he did his job and he was certainly competent technically, but, you know. He was always careful and he'd go, 'Oh, but I don't want to give you any false hope.' And he would say that forever. I'm thinking, I don't care if it's false or true, it makes no difference. So, he walks up and he goes, 'Aren't you the mother of (daughter's name), you know, and I'm standing outside in the hall and I go, 'Yes and that's her.' And his mouth just dropped, I mean truly, he said, 'That can't possibly be!'" (Page 9)*	X			F60
Rescigno 2016	Hailey illustrated how her family noticed and appreciated the way some nurses actively listened to the parents regarding who their daughter was as a person. Nurses then reflected on what might be important to her daughter if she was fully conscious and aware. They showed respect to her daughter as a person, by providing the highest level of personal grooming for her daughter alongside her medical care, even though she was in a coma. Nurses also listened to Hailey's need to be involved in her daughter's care, so nurses found a way to bridge the two needs.	*"They painted her toenails, they painted her fingernails and we had some nurses that were just really, really like almost OCD (obsessive and compulsive) about cleanliness and of course she had blood in her hair and at the time her hair was real, real long. And, um, they just couldn't stand her hair being like that … And they would braid it so it wouldn't get all kinked up … We shaved her legs at one time. They were getting pretty bad. That was after several weeks in ICU. I was like, we've got to do something with this. So the nurse just gave us a razor and said, 'Go to work.'" (Page 10)*	X			F61
Roscigno 2016	Parents described their observations of how various nurses took on differing levels of interpersonal relationships with the parents in order to build a rapport with the family. The levels of interpersonal relationships ranged from acting in a social role and without a deep interpersonal connection to the family ("doing a job"), to a more interpersonal level of support where parents were viewed and treated as unique and equally valued members of the health team.	*"They (nurses) would talk to me just like they would want me to talk to them. They would just look me in the eye and tell me, 'This is exactly what's going on' and, you know, 'We hope' and 'We just don't guarantee' and 'This is what we know', 'This is what we do,' 'this is what we're looking for.' Just you know, 'I've seen some people come in here a lot worse than this and be just fine later on.' 'There's never any reason to give up hope' … (Later, when she was transferred to a medical surgical unit) she had some (nurses) that were just there for their check." (Page 10)*	X			F62
Roscigno 2016	Parents' consistently recognized and appreciated nurses who went beyond the medical tasks expected in their roles.	*"Some people do things because it's a job and they have to do it. Some people do things because they enjoy doing it. It's a job that they want to do. And, of course, that shows in what they do and how they provide care." (Page 10)*	X			F63

Author	Findings	Illustrations (Page number)	Evidence			Label
			Unequivocal	Credible	Unsupported	
Roscigno 2016	Caring-nurse-relationships were described as connected to the family on a human-to-human level. Parents felt that caring nurses recognized parents' competence and empathized how the early acute care system of care inherently disadvantaged the family, so those nurses did whatever they had to in order to mitigate those factors, which decreased the family's workload and stress in being informed and involved in the child's care and decisions. Creating a non-judgmental and accepting environment helped the family to heal from the emotional trauma they were initially exposed to, so that they could build up their resiliency for future roles and responsibilities. This nurse involved the family because she valued that it was the parents' right to participate in their child's care, but she also gave this parent permission to be in control of aspects of the child's care, which decreased the mother's stress and concerns for her own parenting behaviours.	*"I can remember one of the nurses, one of her night nurses…she would try to reassure us about things….I would always be calling her and saying, 'Do this,' 'Do that,' and 'I want this done.' And obviously she had lots of other patients too and at some point I probably said, 'You know, we're probably being overbearing as parents,' and she said, 'Listen,' she said, 'You know, if this were my kid, you, you wouldn't want to be in the same room with me, because I would be there and I would be, you know, making sure this was done and that was done. You know, 'that's what you do as a parent,' so, um, she helped me in any kind of way." (Page 12)*	X			F64
Roscigno 2016	Nursing concern for the family was also demonstrated by attentive attitudes toward changes in the child's medical condition, which should be prevented (seizures, brain storming, increased ICP, etc.) and by showing an appreciation for the family's unique knowledge and involvement in the child's care. Dismissing parents' observations or not being knowledgeable of their meaning or implications (clinical competence), led to a lack of respect for those nurses by parents.				X	US12
Roscigno 2016	Collaboration created a trusting rapport between the nurse and the family.	*"This one nurse was just getting ready to do his lunch, and all of a sudden (my daughter) started—(her) eyes started twitching. And, you know, to us it looked like maybe she was waking up. And so, we're sitting there getting all excited about this, and he (the nurse) says, 'Well, yeah, maybe she's waking up.' And then he left to go to lunch. Well, one of the other nurses that had paid more attention to my daughter and was covering for this other nurse while at lunch said, 'No, I think she's having a seizure'…. I knew she had plenty of assaults already—and I said, 'Nobody's called back. How long do we wait?' So she called them herself. And she got somebody in there right away…. Every time something came up, she'd call the doc and say, 'This is what we need, blah blah blah'—and of course, they (nurses) know so much more in terms of the minute-to-minute things that happen; what to look for and how to monitor everything…. every single one of them takes pride in their work, except perhaps that one nurse who really didn't have care for (our daughter), and thought, "Well, I'll just tell them it's nothing." But we had powerful nurses, and we had powerful advocates." (Page 12)*	X			F65

Author	Findings	Illustrations (Page number)	Evidence			Label
			Unequivocal	Credible	Unsupported	
Roscigno 2016	Parents often felt they were entirely or mostly responsible to protect their child from injury because nursing staffing and the child's room assignment on these wards were not perceived to take these safety needs into account, or the nurses did not seem to be knowledgeable about the care of this population.	*"When we were leaving ICU to go up to the floor…it was really disconcerting to me, seeing (my daughter) not getting that immediate care (she needed), you know. Like, she would have a neuro storm, and her temperature would be going up, up, up, up, and well, it wasn't their time to check on the patients, so they weren't coming and seeing what was going on. And so I would alert them, and they were like, "Oh, yeah, well, I'm going to be getting off the shift, so the next nurse will have to do it"….It seemed like they weren't prepared for that level of care needed, for these acute patients—I mean, I guess. That's how it felt. And it went on and on, you know (chuckles), every day." (Page 13)*	X			F66
Roscigno 2016	The need for nurses to allow parents to get involved in the care of the child.	*"You just sit and watch your child, and (normally) you do all you can to help them, but then when certain things like this happen, you can't do anything to help them because either you don't have the expertise, or you know, it requires something else. So, it was just, it was painful." (Page 13)*	X			F67
Roscigno 2016	The nurses gave anticipatory guidance to the parents to prepare them in how to get involved in the care of the child. By preparing parents ahead of time, the parents could be empowered to be able to get their information needs met and to become involved in the decision-making process for their child as they wished.	*"They (nurses) did a good job understanding (our complete needs), but now that we look back, we didn't understand (all that was going on at that time) like they said, which was probably a good thing. I'm not sure whether we tuned it out? I remember the nurse in there kept saying, 'No matter what, don't leave them (physicians), just keep pressing, pressing, pressing for information and keep pushing for information.' She kept telling me that and she made us sit down and eat." (Page 13)*	X			F68

(Label coding note: P1= Parent 1, F1 = finding 1, US1: Unsupported finding 1, CNS= Clinical nurse specialist, ICU= Intensive care unit, MDT= Multidisciplinary team for example). Evidence is allocated to a category based on quality level of finding: **Unequivocal** (findings accompanied by an illustration that is beyond reasonable doubt and; therefore not open to challenge), **credible** (findings accompanied by an illustration lacking clear association with it and therefore open to challenge) and n**ot supported** (findings are not supported by the data)

Table 2: Findings associated with facilitators and barriers to partnership.

Facilitators to partnership	Label	Finding
	F5	Having a reference nurse with extensive experience of the child gives parents piece of mind
	F14	Parents value nurses’ expertise, availability and responsiveness
	F24	The key to caring is when the nurse knows the child and family and the child and family know the nurse
	F28	Nurses who are flexible in the care they offer
	F36	Nurses bring plans together that would otherwise be fragmented, disjointed and open to failure
	F37	Nurses who use their knowledge and expertise to support the family in an appropriate manner
	F47	Parents feel appreciated when they are listened to because they want their expertise heard
	F60	Nurses who do not minimise a parent’s need for hope
	F63	Nurses who go beyond medical needs in the care of children
Barriers to partnership	Label	Finding
	F16	Some parents choose to limit their contact with nurses
	F17	Conflict occurs when there is limited collaboration
	F31	Parents feel a lack of future preparation in the care of their child
	F42	Communication which is not individualised or appropriate
	F43	Parents feel frustrated when their expertise is discounted by nurses
	F48	Parents feel frustrated and felt the care provided to be less than optimal when nurses did not listen to them
	F66	Parents feel a need to protect their child when they do not perceive nurses to be knowledgeable

(Label coding note: F1 = Finding 1 of data extraction. All findings have a quality score of credible or unequivocal)

Supplementary File 1: Guidelines for systematic reviews and meta-analyses (PRISMA checklist)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	6
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	1,6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6,7

Checklist from Moher, D., et al. (2009). "Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement." PLoS Med **6**(7): e1000097.