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Children living with long-term conditions and their experiences of partnership in nursing care: an integrative systematic review.

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REVIEW

Children living with long-term conditions and their experiences of partnership in nursing care: An integrative systematic review

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Abstract

Aims and Objective: To describe the experiences of nursing care and partnership nursing as expressed by children living with long-term conditions.

Background: Children with long-term conditions have higher rates of hospitalisations and adverse events in hospital, yet little is known about their experiences of nursing care. How children perceive partnership in care with their families and nurses is of interest in the achievement of safe and effective care

Design: An integrative review following Joanna Briggs Institute protocols for systematic reviews.

Method: An integrative review was chosen following Joanna Briggs Institute protocols for systematic reviews. A total of 5150 articles were screened, with 251 full-text publications reviewed. A total of 21 studies were included, three mixed-method studies and 18 qualitative studies. This review has been reported as per Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Results: Four integrated findings were identified: "Children are aware of their surroundings and needs," "Children value positive communication," "Children want to be recognised as an individual in the triadic relationship, and this can be done through nurses using tailored play;" and "Children seek a shared decision-making process."

Discussion: Children wanted to be seen as an individual in Children and Young People's nursing as well as a child who craves security, fun and comfort, both from their families and nursing staff. Children described observing partnership between nursing staff and parents but felt uninvolved, with some children craving more knowledge and power to better understand their long-term condition.

Relevance to Clinical Practice: Further research is required on how Children and Young People's nursing staff can better support children and empower them to be active members in the shared decision-making process if the child wishes to be involved.

KEYWORDS
child-nurse relationship, children and young people, family centred care, meta-aggregation, nursing, paediatric nursing, partnership, patient and family centred care

1 | INTRODUCTION

There are many children whose lives are built around a childhood experience of illness and long-term conditions, such as asthma, mental health conditions, cancer, and congenital conditions. The complexity of a long-term condition among children means that these children can experience hospitalisation more frequently; and their life may be centred around the need for medication administration, procedures and medical appointments in an effort to improve the quantity and quality of life for themselves and their families (Bell et al., 2020; Srivastava et al., 2016). A long-term condition is defined as an illness, disease or condition that lasts longer than 6 months in duration; and they are intrinsically linked to increased morbidity and mortality (Australian Institute of Health and Welfare (AIHW), 2020; Lambert & Keogh, 2015). Recent statistics from the AIHW (2020) state that 43% of children are diagnosed with at least one long-term condition, with 20% being diagnosed with two or more long-term conditions. Whilst some long-term conditions may only cause minor inconveniences or health discussions, some long-term conditions can have profound impacts on the quality of life for all family members (AIHW, 2020; Lambert & Keogh, 2015). Impacts on quality of life also change within the same subgroup of long-term conditions; an example of this are allergies. Some children may have an allergy that requires limited discussion with health professionals and may not cause a great deal of impact or distress, whereas other children may have allergies that can cause profound impacts on their quality of life, or cause them to develop other long-term conditions, such as asthma (Springston et al., 2010). Legally in Australia, the word 'child' or 'children' is used to describe any person under the age of 18 years old, with 'adolescents' or 'young people' used to describe a child over the age of 12 years old (Australian Government, 2019). Children are usually cared for in paediatric settings and hospitals however some children over the age of 18 may also be cared for in a paediatric setting at the discretion of a medical team depending on their physical or mental ailments (Library of Congress, 2015).

All children who are admitted to hospital must be treated with respect and dignity, and the care preferences and needs of the child are kept central in service delivery (Ekra et al., 2012). Traditionally, particularly before the early 2000s, most adults felt the need to protect children, and these children were viewed being quiet, seen but not heard, and their voices forgotten because the adults surrounding them acted on their behalf to try and ensure that the child receives the best care and treatment possible (Davies & Randall, 2015). Important changes in paediatric health care services were integrated into the Australian healthcare system when The United Nations Convention on the Rights of the Child (UNCRC, 1989) was created which supported the rights of the child to be an active partner in their own care. Article 3 of the Convention clearly states that '*all organisations concerned with children should work towards what is best for each child*' (The United Nations, 1989, p.1). The UNCRC rights influenced how healthcare systems partnered with children and their families and are supported by national accreditation requirements, such as the Charter of Healthcare Rights in Australia (ACSQHC, 2019). To ensure that nurses follow their legal and ethical obligations as set by this legislation, they must form interdependent relationships with both the child and their families in all areas of paediatric healthcare – such as acute hospitals and community settings (Sheehan & Fealy, 2020). Often referred to as 'partnership nursing', this approach is supported by multiple frameworks, most commonly family centred care (FCC) and its newer adapted version, patient and family centred care (PFCC). FCC was the main theoretical framework used in Children and Young People's nursing following health care systems' implementation of the UNCRC and viewed the family as a central to the care provided (Coyne et al., 2018). In the last 10 years, there has been a shift from seeing the family of Children and Young People's nursing as central to the care provided, to PFCC, which acknowledges that the patient and family members are integrated members of the same family, but also unique individuals (Hanson et al., 2017; Institute for Patient and Family Centered Care, 2020). Partnership nursing is a concept term used to describe the unique relationship that exists in Children and Young People's nursing and is defined by five attributes: shared roles and decision-making, parental participation, mutual trust and respect, communication and negotiation (Barratt et al., 2021; Davis et al., 2007; Dennis et al., 2017; O'Connor et al., 2019).

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

- Children and young people can be very aware of their surroundings and health care needs and a lack of communication can make them feel more fearful of the complexities of their healthcare needs.
- Most children wish to have an active role in their own healthcare and shared decision-making process, however it is important to ascertain an individual child's level of involvement.
- Parents provide the most support to their children and nurses who empower parents and children with long-term condition can improve outcomes for the whole family.

The experiences of children living with a long-term condition and their perceptions of health care and partnership nursing have not been well fully described and explored within the existing empirical literature. Previous studies conducted examined children's experiences of partnership in healthcare without the focus on the partnership between children with long-term conditions and nursing (Coyne et al., 2016; Davies & Randall, 2015; Peña & Rojas, 2014; Pritchard Kennedy, 2012). These studies either looked at the children's experiences of health care professionals (HCP) as a whole, instead of exclusively exploring experiences with nursing staff, or did not include children with long-term conditions. Previous research found consistently that children recognised the importance of having an active role in their own health care but were often excluded from the partnership model that existed between their parents and HCP (Davies & Randall, 2015; Pritchard Kennedy, 2012). Children described an awareness of watching the adults surrounding them collaborate and partner together but individually expressed that they were unable to participate in their own care, and were often an observer instead of an active contributor (Davies & Randall, 2015; Coyne et al., 2016). Importantly, the children who did express that they felt like background players in their own care often devalued themselves and their own beliefs of what they felt their health care needs were; and reported increased levels of anxiety and feelings of hopelessness (Davies & Randall, 2015; Peña & Rojas, 2014). However, other children preferred to have no input regarding the decision-making of their care and treatment and wished not to interact with nurses. These children reported that the more knowledge they had about their condition and treatment increased their levels of anxiety and preferred their parents to take on a more in-depth role in the triad partnership model (Peña & Rojas, 2014).

Existing research provides some insights into the challenges that children can experience in trying to establish a participatory role in their own health care. The previous studies (Coyne et al., 2016; Peña & Rojas, 2014; Pritchard Kennedy, 2012) are limited by their focus on two separate dyadic relationships between nurse-child and nurse-parent, which limits examination and understanding of the share participation in a triadic relationship that exists between the child, their parents and nursing staff. Existing reviews (Davies & Randall, 2015; Foster et al., 2013) also have either focused on HCP, which limits our understanding of the distinct nursing role that is contributed; or hospitalised children without the distinction of a diagnosis of a long-term condition, which limits our understanding of the unique needs of this young and vulnerable population. It is therefore timely to understand how children with long-term conditions in hospital perceive the partnership that exists in the child–parent-nurse triad.

2 | AIM

This integrative systematic review addressed the following clinically focussed research questions:

1. How do children with long-term conditions experience partnership nursing with both nursing staff and their parents, when being cared for in a paediatric healthcare service?
2. What are the positive and negative experiences of nursing care in hospital as expressed by children living with a long-term condition?

3 | METHODS

3.1 | Research design

An integrative review (Whittemore & Knafl, 2005) was chosen to describe the known child's experiences of nursing care and ascertain how it linked to the existing partnership triad between the parent, nurse and child living with long-term conditions. This integrated systematic review followed the Joanna Briggs Institute (JBI) protocol for mixed-methods systematic review using a convergent integrated approach to data synthesis and integration (Aromataris & Munn, 2020). The PROSPERO registration number for the review was CRD42021233352 (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=233352).

3.2 | Inclusion criteria

Pre-eligibility screening criteria included:

3.2.1 | Types of studies

Inclusion criteria:

- English language, full-text peer-reviewed studies.
- Quantitative, qualitative and mixed-method studies published between 2010–2021.

Exclusion criteria:

- Editorials, letters, guidelines, opinion papers, literature reviews, systematic or integrated reviews and conference abstracts.

3.2.2 | Types of participants

Inclusion criteria:

- Studies conducted with participants who were being cared for by Children and Young People's nursing services, irrespective of the age of the patient and,
- Participants diagnosed with a long-term condition (irrespective of disease or condition) for longer than 6 months (AIHW, 2020).

Exclusion criteria:

- Studies that focused on the general Children and Young People's patient population, where there was no focus or distinction of children living with long-term conditions.

3.2.3 | Types of outcomes

Inclusion criteria:

- Outcomes that focused primarily on children with long-term conditions and their experiences of nursing care, and the enablers and barriers of a successful triadic relationship between parents, nurses and themselves while receiving nursing care.

Exclusion criteria:

- Studies that focused on the transition from paediatric to adult health care services in the adolescent population which did not include experiences of Children and Young People's nursing care.
- Research that focused on nursing or nurse-led interventions (unless experiences of how the child experienced the intervention were explicitly included).

- Research that focused exclusively on the parent or nurse experiences of triadic partnership.
- Research that focused on the paediatric population in obstetrics or neonatal care.
- Research that did not present data to address the research questions.

3.3 | Search strategy

An initial search of CINAHL was completed to search and identify keywords to inform the search architecture. Keywords were extracted from relevant article titles and abstracts. The search strategy was developed in conjunction with an academic research librarian and with the primary author. The Population, Intervention, Comparison and Outcomes (PICo) mnemonic was used to create the search architecture (Counsell, 1997). The integrative systematic review considered studies that included children living with long-term conditions (P) and their experiences of partnership nursing care (I) when they are receiving Children and Young People's nursing care in the hospital setting (Co).

The keywords used included:

(P) Children, adolescent, youth, child, teenager, kid.
(I) Partnership, partnership nursing, participation, collaboration, negotiation, decision-making, respect, involvement, trust, communication, shared role, shared decision-making, experiences, barriers, facilitators,
(Co) Paediatric, pediatric, paediatric nursing, pediatric nursing, child nursing, children's nursing.

The search was conducted in multiple databases (CINAHL, MEDLINE, PUBMED, PSYCHInfo SCOPUS, Web of Science and Google Scholar). Grey literature was searched (MeDNar and OpenMD.com). Reference lists for all included articles and relevant systematic reviews that were excluded during the screening process were manually searched for additional studies to increase the inclusiveness of the search. Database searches began in November 2020 and concluded in March 2021. An example of the search strategy is provided in Table 1.

The studies found through the search strategy were transferred to Endnote and then into Covidence Systematic Review Software. A long-term condition was defined as an illness, disease or condition that lasts longer than 6 months in duration (AIHW, 2020). A child was defined as any person receiving care from a Children and Young People's nursing service. Studies were included if they were published between 2010–2021 with the underpinning clinical rationale that the FCC framework changed to PFCC in 2010, when a larger focus on the inclusion of children in the triadic partnership become more prevalent (Foster et al., 2013).

3.4 | Study selection

The review process was led by the primary author, who screened all databases and uploaded all relevant citations into Covidence for assessment. Duplicates were removed by the Covidence software. All title and abstracts were screened by the primary author against the inclusion and exclusion criteria and quality checked by the two secondary authors to ensure consistency in the application of the pre-eligibility screening criteria. All three authors involved in the review process were registered nurses, with oncology, paediatric and gerontological clinical expertise, and qualitative and quantitative research experience with a focus on quality and holistic patient care. No previous work of the authors was eligible against the inclusion criteria for this integrative review. Any disagreements were resolved by discussion between all three authors. Full-text reviews were assessed against the inclusion and exclusion criteria. Quality assessments of the included studies were completed by the primary author and checked by the secondary authors. Any concerns regarding the inclusion or exclusion of studies were discussed among all authors. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist (PRISMA) was used, see Appendix S2 for the completed checklist (Moher et al., 2009).

3.5 | Assessment of methodological quality

All studies were critically appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2019). The MMAT is one of

TABLE 1 Example of search architecture in database

Database and date	CINAHL 27/1/2021
Key search terms	Children* or adolescent* or youth or child* or teenager* or kid* Satisfaction* or experience* or perception* or view* or engagement* of thought* or expression* or illustration* Partnership* or "partnership nursing" or participation* or collaboration* or role* or negotiation* or "decision-making" or respect* or involvement* of trust* or communication* or shared roles or "partnership model" or "partnership in care" or "nursing partnership" or "shared decision-making" or "participation in care" MESH Heading (pediatric nursing)
Parameters	Year (2010–2021)
Total search results	642

the only critical appraisal tools that focuses on the quality appraisal of mixed-method studies (Hong et al., 2019). Rather than using separate tools depending on the type of study included, the MMAT allows studies across multiple approaches to be measured by similar quality appraisals, assessing studies on their generic research approach, individual components and mixed methods approach (if used) (Hong et al., 2019). Due to the limited number of studies present in existing literature, all studies were included irrespective of the quality score to describe the current state of the evidence.

3.6 | Data extraction

Data extraction for all studies, regardless of the studies' chosen methodology included: author, year, geographic location, phenomena of interest, study aim, study population, sample size, the rationale for age inclusion or exclusion, methodology, theoretical model, methods, duration, limitations, author notes, key themes and findings relevant. In all studies, quantitative data (descriptive and/or statistical results) relevant to the research questions was extracted. Qualitative data (verbatim findings and illustrations) were extracted. Findings were defined as verbatim statements made by the study's authors. Illustrations were defined as verbatim quotes or drawings from participants in the included studies. All qualitative data was also assigned a level of credibility – unequivocal (evidence beyond reasonable doubt), credible (evidence which is plausible), and not supported (the findings are not supported by data) (Aromataris & Munn, 2020). Qualitative findings that were not supported by an illustration were excluded from the data synthesis and integration in keeping with JBI methods for this review (Aromataris & Munn, 2020).

3.7 | Data transformation

Extraction of quantitative data followed narrative translations of the data and subsequent findings made by the study's authors were formed into qualitised data. This occurred by transforming the quantitative data into a narrative and descriptive interpretation following the JBI approach (Aromataris & Munn, 2020).

3.8 | Data synthesis and integration

All qualitised and qualitative data were pooled using the JBI methodology for mixed-methods systematic review approach (Aromataris & Munn, 2020). All qualitative unequivocal and credible findings were synthesised into categories. Qualitised findings were integrated into the qualitative categories if they applied to the qualitative category. Qualitised findings that did not belong to a qualitative category were synthesised into their own categories. Both the qualitative and qualitised categories were then integrated into synthesised findings, following JBI methodology (Aromataris & Munn, 2020).

3.9 | Findings

A total of 5150 articles were screened through database searches, with 251 full-text publications reviewed. A total of 21 studies were included in the integrative review, see Figure 1 for the PRISMA diagram and reasons for exclusions of studies (Page et al., 2021). Eighteen (18) of the studies included in the review were exclusively qualitative studies, with an additional three studies following a mixed-methods approach. Quality appraisals for the included studies are presented in Table 2. Characteristic demographics of the study are presented in Table 3 (Qualitative studies) and Table 4 (Mixed method studies). An addendum of further characteristics of the included studies is presented in Table S1.

3.10 | Characteristics of the studies

Characteristics of the studies included in the integrative review are presented on Tables 3 and 4, with further information regarding the characteristics of the studies presented in Table S1. The age of participants in the studies varied from 2 years old at recruitment to over the age of 18 years old, but still being cared for and treated in a paediatric health care facility. Two of the included studies did not present any specific age demographics for their participants. All of the included studies, however, did note in their sampling criteria the ages participants needed to be, or be between to be recruited into the study, see Figure 2. More than half of the studies (*n* = 11) looked exclusively at children with a haematology/oncology condition, with the other studies looking at non-specified long-term conditions (*n* = 6), mental health conditions (*n* = 3) and exclusively respiratory conditions (*n* = 1). Only one study (Cheng et al., 2016) looked at the lived experiences of children who identified as Aboriginal (First Nation people), with four studies specifying that they included participants of different ethnic backgrounds (Gibson et al., 2010; Grealish et al., 2013; Nabors & Liddle, 2017; Spratling, 2012). The other 16 studies included in the review did not specify cultural or ethnic backgrounds of their included participants.

The studies included in the review used a variety of methodologies and methods to answer their research questions. Only one study (Livesley & Long, 2013) discussed a theoretical framework used in the paediatric health care setting where the research was conducted, with the framework being FCC (Livesley & Long, 2013). Of the 18 qualitative studies, three studies (Grealish et al., 2013; Manookian et al., 2014; Spratling, 2012) used a phenomenology

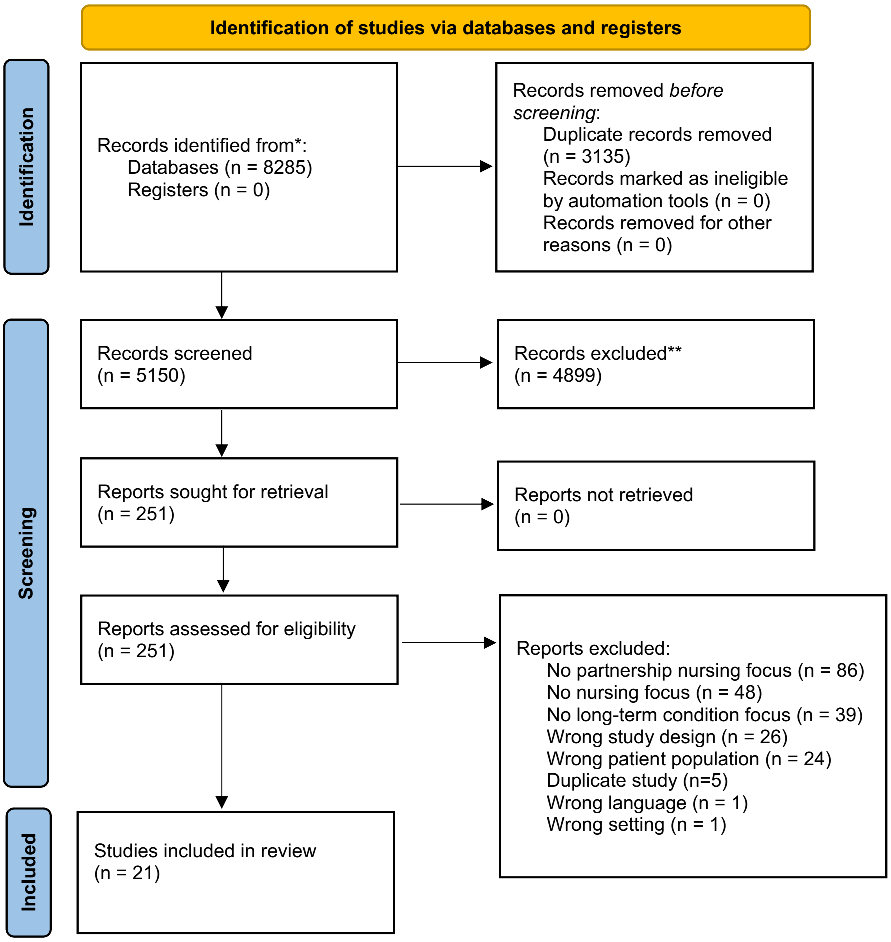

FIGURE 1 PRISMA diagram and reasons for exclusions of studies [Colour figure can be viewed at wileyonlinelibrary.com]

approach, three studies (Lee et al., 2019; Livesley & Long, 2013; Rindstedt & Aronsson, 2012) used an ethnographic approach; one study used a hermeneutic approach (Biering & Jensen, 2010) and one study (Aşikli & Aydin Er, 2020) used a grounded theory approach. One further study (Randall, 2012) used a mosaic approach and encompassed three types of theory in their methodology – phenomenology, ethnography and visual. Most of the studies included in the review (Aşikli & Aydin Er, 2020; Biering & Jensen, 2010; Cheng et al., 2016; Corsano et al., 2015; Darcy et al., 2019; Gibson et al., 2010; Grealish et al., 2013; Lee et al., 2019; Livesley & Long, 2013; Manookian et al., 2014; Montreuil et al., 2015; Nabors & Liddle, 2017; Olsson et al., 2015; Randall, 2012; Spratling, 2012; Xie et al., 2017) used interviews as the main source of collecting data from participants. Five studies (Lee et al., 2019; Livesley & Long, 2013; Montreuil et al., 2015; Randall, 2012; Rindstedt & Aronsson, 2012) also used observations of participant interaction with nursing staff. Some of the included studies also used an artistic medium to collect data, such as art, drawings or play therapy (Çakirer Çalbayram et al., 2018; Gibson et al., 2010; Livesley & Long, 2013; Nabors & Liddle, 2017; Randall, 2012). Two of the mixed-method studies used different methods to collect their data, with one (Sousa Figueiredo et al., 2020) using a questionnaire form and the other using sorting cards (Lapp, 2019).

3.11 | Synthesis and integration of quality data

A total of 90 qualitative findings were extracted from the 21 studies and used in the synthesis and integration of data (Table S1), with an additional 21 findings classified as unsupported and excluded from the synthesis. In the three mixed-method studies, there was a total of eight sections of data collected which were then turned into eight qualitised statements (see Tables S1 and S1). The 90 credible and unequivocal findings and 8 qualitised statements, were then synthesised into categories based on similarities in themes and topics (see Tables S1 and S1). Thirty (30) categories were inductively synthesised (Aromataris & Munn, 2020) from the 90 findings and 8 qualitised statements.

3.12 | Integrated findings

The 30 synthesised categories were aggregated together to create four synthesised findings that explored the child's experiences of nursing, see Table 5. These synthesised findings included "Children are aware of their surroundings and needs," "Children value positive communication," "Children want to be recognised as an individual in the triadic relationship, and this can be done through nurses using tailored play;" and "Children seek a shared decision-making process." Direct quotes from the papers within the synthesised findings are used to illuminate the synthesis for the reader.

3.13 | Integrated finding: Children are aware of their surroundings and needs

The first synthesised finding related to the high level of awareness of children who had a long-term condition. There were six categories that contributed to the first synthesised finding, see Table 5.

Children were aware of the nurse's role and felt that the nurse's role was especially task-orientated (Çakirer Çalbayram et al., 2018). Children across multiple studies associated negative experiences with nurses, when they felt that the nurses role primarily caused pain or discomfort, through difficult or painful procedures (Biering & Jensen, 2010; Çakirer Çalbayram et al., 2018; Nabors & Liddle, 2017). Participants in one study (Darcy et al., 2019) were aware of the changes in their life after a cancer diagnosis and had learned how to cope with a changing physical body due to their disease. Children within multiple studies (Livesley & Long, 2013; Montreuil et al., 2015; Randall, 2012) were aware of their own health care needs due to their long-term condition and described a level of awareness of them, compared to nursing staff who may not of been previously exposed to the child's requirements:

> It's us (the children) who know what our limits are, what we can do … the nurses are not in our situation, sometimes… they can overestimate or underestimate us.
>
> (Montreuil et al., 2015, page 853)

This awareness of their condition and health care needs created feelings of loneliness and hopelessness for children, as they craved the want to be 'normal' and like other children (Manookian et al., 2014; Nabors & Liddle, 2017). They demonstrated awareness of why they were hospitalised but felt isolated due to restrictions in visitors and interactions with children their own age (Nabors & Liddle, 2017). When hospitalised, most children felt aspects of safety and security from their parents and family, and discussed how their parents and family became pillars of support and comfort for them (Cheng et al., 2016; Darcy et al., 2019; Gibson et al., 2010; Nabors & Liddle, 2017; Olsson et al., 2015). Some Children were also aware of the 'unknown' that they may face due to their long-term condition and felt strength from having their parents and family members present during hospitalisation, difficult conversations or treatment procedures (Darcy et al., 2019; Nabors & Liddle, 2017; Olsson et al., 2015). Children across multiple studies displayed awareness at the toll that their long-term condition takes on their parents, and expressed sadness, worry and guilt for their condition causing parental anguish (Gibson et al., 2010; Manookian et al., 2014; Montreuil et al., 2015; Xie et al., 2017).

> They [the nurses] could say, 'Why don't you hold her hand? Mummy was just sitting there not knowing what to do (Harry, 6 years old).
>
> (Gibson et al., 2010, page 1402)

They found their parents to be a great source of comfort and found it difficult when they could not offer the same level of comfort in return, identifying that nurses were an optimal source of comfort for parents (Gibson et al., 2010; Manookian et al., 2014; Montreuil et al., 2015).

3.14 | Integrated finding: Children value positive communication

The second synthesised finding was related to the important elements of communication and how communication styles affected children's feelings of safety and security. There were six categories that contributed to the second synthesised finding, see Table 5.

Children had been previously exposed to positive and negative communication from nurses (Aşikli & Aydin Er, 2020; Montreuil et al., 2015). They expressed positive communication to be 'good' when nurses took their time to know the child and develop rapport with them, such as asking how they were:

> I prefer when the nurse listens to us, then asks us like a few questions, and then, he [the nurse] listens and then, he understands.
>
> (Montreuil et al., 2015, page 853)

Children identified individualised communication as one of the most important aspects of patient–nurse communication (Lapp, 2019; Sousa Figueiredo et al., 2020). Nurses who were able to speak clearly to children about nurse-led interventions and speak using language that children could understand were able to alleviate fear and worry (Biering & Jensen, 2010; Cheng et al., 2016). Some children preferred communication where nurses took time to listen to them and felt that it demonstrated a level of respect that the nurses had for the child, recognising them as more than just a patient (Lapp, 2019). Multiple studies (Gibson et al., 2010; Livesley & Long, 2013; Olsson et al., 2015; Xie et al., 2017) demonstrate that when nurses bypassed children to talk exclusively to their parents, they felt frustrated and ignored:

> The doctor and nurse always provided detailed information about LP [Lumbar puncture] to my parents, but not me. I think I have a right to know about it because I am the one who underwent LP.
>
> (Xie et al., 2017, page 3332)

TABLE 2 Quality appraisal of included studies [Colour table can be viewed at wileyonlinelibrary.com]

Qualitative studies	Aşikli & Aydin Er (2020)	Biering & Jensen (2010)	Cheng et al. (2016)	Corsano et al. (2015)	Darcy et al. (2019)	Gibson et al. (2010)	Grealish et al. (2013)	Lee et al. (2019)
S1. Are there clear research questions?	Y	Y	Y	Y	Y	Y	Y	Y
S2. Do the collected data allow to address the research questions?	Y	Y	Y	Y	Y	Y	Y	Y
1.1 Is the qualitative approach appropriate to answer the research question?	Y	Y	U	U	U	U	Y	Y
1.2 Are the qualitative data collection methods adequate to address the research question?	Y	Y	Y	Y	Y	Y	Y	U
1.3 Are the findings adequately derived from the data?	Y	Y	Y	Y	Y	U	Y	Y
1.4 Is the interpretation of results sufficiently substantiated by the data?	Y	Y	Y	Y	Y	U	Y	Y
1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	Y	Y	Y	U	Y	Y	Y	U

Mixed methods studies	Çakirer Çalbayram et al. (2018)	Figueiredo et al., 2020	Lapp (2019)
S1. Are there clear research questions?	Y	Y	Y
S2. Do the collected data allow to address the research questions?	Y	Y	Y
5.1 Is there adequate rationale for using a mixed methods design to address the research question?	N	Y	N
5.2 Are the different components of the study effectively integrated to answer the research question?	Y	Y	U
5.3 Are the outputs of the integration of qualitative and quantitative components adequately addressed?	U	Y	U
5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	U	U	U
5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	N	U	U

Key

Yes	No	Unsure

Nurses were observed bypassing tasks that children have expressively asked for and this caused frustration in children, who did not understand the mechanics of the nurses' role and were not provided a rationale for why their requests were ignored (Livesley & Long, 2013). Limited communication between nurses and children surrounding their long-term condition and treatment increased levels of fear, worry and helplessness (Manookian et al., 2014; Olsson et al., 2015; Xie et al., 2017). Children in one study were reported to ruminate over their fears and felt unable to start a conversation surrounding their concerns with nursing staff (Manookian et al., 2014).

3.15 | Integrated finding: Children want to be recognised as an individual in the triadic relationship, and this can be done through nurses using tailored play

The third synthesised finding was related to the relationships that exist in the triad between the nurse, child and families (mostly the parents). Eleven categories contributed to the third synthesised finding, see Table 5.

Children valued the relationship that existed between themselves and the nurses taking care of them. They appreciated the

Livesley & Long (2013)	Manookian et al. (2014)	Montreuil et al. (2015)	Nabors & Liddle (2017)	Olsson et al. (2015)	Petronio-Coia & Schwartz-Barcott (2020)	Randall (2012)	Rindstedt & Aronsson (2012)	Spratling (2012)	Xie et al. (2017)
Y	Y	Y	Y	Y	Y	U	N	Y	Y
Y	Y	Y	Y	Y	Y	U	N	Y	Y
Y	Y	U	Y	U	U	Y	N	Y	Y
Y	Y	Y	U	Y	Y	Y	N	Y	Y
Y	Y	Y	U	Y	Y	Y	Y	Y	Y
Y	Y	Y	U	U	Y	Y	Y	Y	Y
Y	Y	Y	U	Y	Y	Y	N	Y	Y

support that they received from nursing staff during difficult times, with the nurses being present or using distraction methods (Aşikli & Aydin Er, 2020; Gibson et al., 2010). Some Children felt that nurses were able to offer excellent education and coping strategies to them that eased the seriousness and fear that they faced during their hospitalisation (Montreuil et al., 2015). They felt it was important that nurses were reliable and didn't over-promise the support that they could provide to the children and their families, as a lack of reliability changed the dynamic of the relationship (Gibson et al., 2010). Children often used words such as "good," "happy,", or "bad" or "angry" to describes nurses, using these words to describe what type of nurses were caring for them and how that nurse enabled/disabled the child to partner with them in the care interaction (Aşikli & Aydin Er, 2020; Corsano et al., 2015; Manookian et al., 2014; Petronio-Coia & Schwartz-Barcott, 2020). Some children made note that not all nurses were happy or interactive and could be angry at the children, with children recognising that not all nurses were the same (Aşikli & Aydin Er, 2020; Olsson et al., 2015; Spratling, 2012):

> For example, we say wait for [my] mother to the nurse while the injection is given to us. The nurse frowns

TABLE 3 Characteristics of qualitative studies

Author/Year	Title	Country	Phenomena of interest	Aim	Methodology	Methods	Number of participants
Aşikli & Aydin Er (2020)	Paediatric oncology patients' definitions of a good physician and good nurse	Turkey	Children with a haematology/ oncology condition	To determine the definitions of a good physician and good nurse provided by elementary school-age oncology patients	Based on grounded theory	Interviews	18 participants
Biering & Jensen (2010)	The concept of patient satisfaction in adolescent psychiatric care: A qualitative study	Iceland	Adolescents with a recent admission to psychiatric care	To develop a better understanding of the concept of patient satisfaction in adolescent psychiatric care by exploring adolescents' perception of psychiatric care and by identifying factors that, from their perspective, contribute to quality of care	Hermeneutic	Interviews	14 participants
Cheng et al. (2016)	The lived experiences of aboriginal adolescent survivors of childhood cancer during the recovering process in Taiwan: A descriptive qualitative research	Taiwan	Aboriginal adolescent survivors of a haematology/ oncology condition	To understand the lived experiences of Taiwanese aboriginal adolescent survivors of childhood cancer in the recovery process	Descriptive	Interviews	11 participants
Corsano et al. (2015)	Speaking about emotional events in hospital: The role of health-care professionals in children emotional experiences	Italy	Children and adolescents with a haematology/ oncology condition	To explore the emotional events experienced by children with the nurses and doctors	None stated by author	Interviews	27 participants
Darcy et al. (2019)	Young children's experiences of living an everyday life with cancer – A three year interview study	Sweden	Children with a haematology /oncology condition	To explore and describe the young child's experience of living an everyday life with cancer	Longitudinal and inductive	Interviews	13 participants
Gibson et al., (2010)	Children and young people's experiences of cancer care: A qualitative research study using participatory methods	United Kingdom	Children and adolescents with a haematology/ oncology condition	To explore children's and young peoples' views of cancer care and to present a conceptual model of communication and information sharing	Exploratory, participatory-based technique	Play activities and interviews	38 participants
Grealish et al. (2013)	Qualitative exploration of empowerment from the perspective of young people with psychosis	United Kingdom	Adolescents who have experienced psychosis	To qualitatively conceptualize empowerment from the perspective of young people aged 14–18 years experiencing psychosis	Interpretive phenomenological analysis	Interview	Nine participants
Lee et al. (2019)	Participation in communication and decisions with regards to nursing care: The role of children	Malaysia	Children with leukemia	To examine the role of children in communication and decisions regarding their nursing care in a paediatric oncology ward in Malaysia	Focused ethnography	Participant observations and interviews	21 participants

TABLE 3 (Continued)

Author/Year	Title	Country	Phenomena of interest	Aim	Methodology	Methods	Number of participants
Livesley & Long (2013)	Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study	United Kingdom	Children with long-term conditions	To establish in a reconnaissance phase effective means and relevant questions to elicit valid data from hospitalised children; to reveal children's subjective interpretations of being hospital in-patients; and to inform future practice, policy and research concerned with hospitalised children	Critical ethnography	Observation, play and interview	15 participants
Manookian et al. (2014)	Children's lived experiences of hematopoietic stem cell transplantation	Iran	Children who underwent HSCT	To discover the lived experiences of children throughout the course of the HSCT process	Interpretive phenomenology	Interviews	Six participants
Montreuil et al. (2015)	Exploring helpful nursing care in paediatric mental health settings: The perceptions of children with suicide risk factors and their parents	Canada	Children with mental health conditions	What are the perceptions of children with suicide-associated risk factors and their parents regarding helpful nursing care in paediatric mental health settings?	Exploratory	Observation and interviews	Five participants
Nabors & Liddle (2017)	Perceptions of hospitalization by children with chronic illnesses and siblings	United States of America	Children with chronic illnesses and their siblings	To understand children's feelings and perceptions of hospitalization through a semi-structured play interview	Not stated	Interviews and play	17 participants
Olsson et al. (2015)	Experiences of teenagers and young adults treated for cancer in Sweden	Sweden	Teenagers and young adults who had been treated for cancer and had finished treatment	To identify aspects of care and the needs that Swedish teenager and young adult stress as important to them during their cancer journey	Not stated	Focus group interviews	21 participants
Petronio-Coia & Schwartz-Barcott (2020)	A description of approachable nurses: An exploratory study, the voice of the hospitalized child	United States of America	Children with a haematology/oncology condition	1. What are children's perceptions of nurses who they see as approachable on an inpatient paediatric oncology unit? 2. How do children describe nurses who they feel are approachable?	Exploratory	Interviews	Seven participants
Randall 2012	Children's regard for nurses and nursing: A mosaic of children's views on community nursing	United Kingdom	Children using community nursing services for longer than 6 months	To elicit children's views of community children's nursing	Mosaic – phenomenology ethnography and visual	Interviews, art groups, and observations	21 participants
Rindstedt & Aronsson (2012)	Children's intent participation in a paediatric community of practice	Sweden	Children with ALL	Not stated	Ethnographic	Observations	Five participants

(Continues)

TABLE 3 (Continued)

Author/Year	Title	Country	Phenomena of interest	Aim	Methodology	Methods	Number of participants
Spratling (2012)	The experiences of medically fragile adolescents who require respiratory assistance	United States of America	Adolescents with respiratory conditions or assistance	To gain an understanding of the perceptions of (1) day-to-day life, (2) how the adolescent with respiratory assistance experiences family, friends and school, (3) how an adolescent perceives their future possibilities and (4) how nurses may help	Interpretive phenomenology	Interviews	11 participants
Xie et al. (2017)	Experience and nursing needs of school-age children undergoing lumbar puncture during the treatment of acute lymphoblastic leukaemia: A descriptive and qualitative study	China	Children with ALL	To describe experiences and nursing needs of school-age Chinese children undergoing lumbar puncture for the treatment of ALL	Descriptive	Interviews	21 participants

Abbreviation: ALL, Acute lymphblastic leukemia; HSCT, hematopoietic stem cell transplantation.

TABLE 4 Characteristics of mixed methods studies

Author/Year	Title	Country	Phenomena of interest	Aim	Methodology	Methods	Number of participants
Çakirer Çalbayram et al. (2018)	Investigating children's perception of nurses through their drawings	Turkey	Children hospitalised	To examine the drawings of 6-year-old hospitalized children, with an acute or chronic illness, as a projective measure of their perception of nurses	Descriptive	Drawings and statements from children about their drawings	22 participants
Figueiredo et al., 2020	Resilience in adolescents with chronic illness: The nurses' role in its promotion	Portugal	Adolescent with chronic illness	To identify resilience-promoting nursing interventions in adolescents with chronic illness, to assess resilience in adolescents with chronic illness and to establish an association between their level of resilience and the received interventions	Not stated	Questionnaire and scale	32 participants
Lapp (2019)	The patient's voice: Development of an adolescent hospital quality of care survey	United States of America	Adolescents in paediatric hospitals	To develop an adolescent determined hospital quality of care survey	Exploratory descriptive Q-sort methodology	Q-sort methodology sorting cards	60 participants

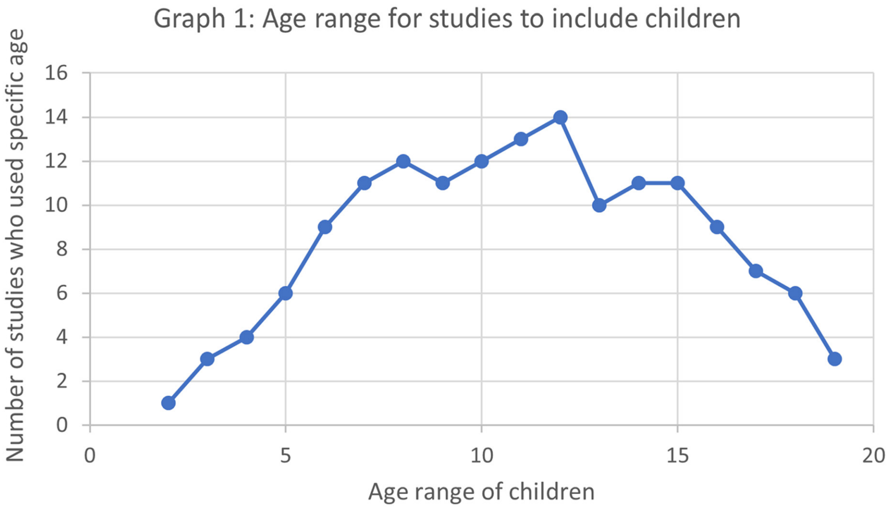

FIGURE 2 Graph represents the number of studies that included a specific age for recruitment of participants and does not represent total volume of children and the age that they participated in the included study [Colour figure can be viewed at wileyonlinelibrary.com]

> and gets angry. This is a bad nurse, but a good nurse tolerates and does not get angry. (Child no. 2, age 9)
>
> (Aşikli & Aydin Er, 2020, page 7)

Children frequently discussed the importance of a fun and happy nurse. Children across multiple studies mentioned enjoyable experiences with nurses who brought fun and happiness to their hospital experiences (Çakirer Çalbayram et al., 2018; Corsano et al., 2015; Darcy et al., 2019; Manookian et al., 2014; Petronio-Coia & Schwartz-Barcott, 2020). They remembered nurses who smiled at them and interacted with them at their own level (Corsano et al., 2015; Manookian et al., 2014; Petronio-Coia & Schwartz-Barcott, 2020). Some children felt that nurses who smiled at them were more welcoming and happier to be caring for them:

> The good memories of nurses will stay in my mind; they are so kind … they always remind me that I am not alone, and they are my friends … sometimes, they play with me or tell stories … when I am sad, they make funny faces (6 year old girl).
>
> (Manookian et al., 2014, page 317)

Children could describe a nurse who was pretending to be happy and smiling, and stated that this fake behaviour flawed the delicate relationship that existed between the child and nurse (Petronio-Coia & Schwartz-Barcott, 2020). According to certain children, nurses who displayed a level of fun and happiness were more approachable. However, this was not the case with all nurses who cared for children in hospital settings, with some children describing nurses as mean and angry, or not having the time to play with them (Çakirer Çalbayram et al., 2018; Petronio-Coia & Schwartz-Barcott, 2020).

When it came to the interactions between nurses and children, children appreciated nurses who treated them as a person and not as a patient. Children wished to be seen as an individual, with different needs and wants compared to other patients in the hospital; and wished nurses to recognise their individuality (Biering & Jensen, 2010; Gibson et al., 2010; Olsson et al., 2015; Spratling, 2012). When it came to communication, children sought nurses to recognise their individuality and tailor how they interacted with the children based on their age and level of development and independence:

> It was very different among the nurse … some treated you really well and some talk[ed] to you as if you were a small child and yes … it was so wrong (Female, 17 years old).
>
> (Olsson et al., 2015, page 578)

When it came to the child-nurse relationship, children frequently pointed out that each nurse displayed different levels of interaction and child centred care (Aşikli & Aydin Er, 2020; Corsano et al., 2015; Spratling, 2012). Children of a variety of ages from 8–17 years old discussed the importance of nurses respecting not only the decision-making and needs of the children, but also of their parents and families (Aşikli & Aydin Er, 2020). This respect demonstrated a level of trust and honesty that bought comfort to children, and without it, children felt that they could not have a solid caring relationship with nursing staff (Aşikli & Aydin Er, 2020; Lapp, 2019).

When it came to the care provided to children by nurses, children craved flexibility and approachability from nursing staff. They wished for tailored nursing care that suited their individual needs and felt frustrated when this was not recognised by nursing staff (Grealish et al., 2013; Spratling, 2012). Older children disliked the rigid and routine structure offered to them based on the nurse's decisions about their health care, and wished that nurses could understand the level of independence that they wished for as they got older (Spratling, 2012). Approachable nurses were those who demonstrated genuine care for the children and were able to tailor the care given to the children to suit the child's individual needs (Grealish et al., 2013; Petronio-Coia & Schwartz-Barcott, 2020). Nurses who were more approachable were described as being more fun and often joked and played with the children, which the children greatly valued and appreciated, for example:

TABLE 5 Synthesis of findings and categories into integrated findings

Findings	Category	Integrated findings
F6, F61, F88, Q2	Children are aware of the nurse's role	Integrated finding: Children are aware of their surroundings and needs
F15, F16, F17, F21	Children are aware of the changes in their life	
F43, F46, F53, F72	Children are aware of their own health care needs	
F31, F48, F54, F84	Children are aware of parental anguish	
F9, F23, F30, F59, F66	Children feel security and safety from their parents and family	
F49, F60	Children feel loneliness due to their long-term condition	
F2, F52	Children value positive communication	Integrated finding: Children value positive communication
F7, F10	Regular communication alleviates fear	
F26, F65, F86	Children want direct communication from nurses	
F29, F50, F67, F82, F83, F85	A lack of communication increases levels of worry	
F44, F45, F47	Children are frustrated with being ignored	
Q3, Q4, Q7, Q8	Nurses need to tailor their communication to suit a person's individual needs	
F1, F5, F33, F70, F90	Children value the child-nurse relationship	Integrated finding: Recognising the child as an individual in the triadic relationship
F8, F32, F64, F77, F78	Children appreciate it when the nurse treats them as a person, not a patient	
F3, F4	Nurses need to respect both the child and family	
F11, F12, F13, F14, F22, F51, F68, F89	Nurses who are fun bring happiness to children	
F34, F80	Nurses need to be flexible in their care to suit individual needs	
F37, F71	Nurses need to be approachable	
F55, F56	Children appreciate the parent-nurse relationship	
F69, F87	Nurses who are fun are more approachable	
F57, F58	Nurses offer children helpful coping strategies	
Q5	Children want a safe and secure environment with their family present to support them	
Q6	Children want to trust the nurses who care for them	
F24, F25	Children enjoy having a role in the decision-making process	Integrated finding: Children seek a shared decision making process
F27, F28, F62, F63	Children want to be informed about their treatment	
F18, F19, F20	Children want a sense of control	
F35, F36, F38	Children value the empowerment that comes from education	
F39, F40, F41, F42	Active participation leads to children being involved in the decision-making	
F73, F74, F75, F76	Children enjoy participating in their own health care needs	
F79, F81	Some children crave independence	

Abbreviations: F1, Finding 1 of qualitative findings; Q1, qualitised finding 1 from quantitative/mixed methods studies.

> Dan drew a picture of this nurses as his favourite and said "He has a big grin and is always happy and funny. I think the perfect nurse should be king, funny, friendly and the opposite of serious."
>
> (Petronio-Coia & Schwartz-Barcott, 2020, p21)

They also discussed the importance of the nurses' presentation when caring for them, stating that scrubs could be intimidating (Aşikli & Aydin Er, 2020; Petronio-Coia & Schwartz-Barcott, 2020; Xie et al., 2017). Children appreciated nurses who took time to make themselves presented and bright, stating that bright colours were less intimidating and allowed the children to be distracted during difficult procedures (Aşikli & Aydin Er, 2020; Xie et al., 2017). In one study as Montreuil et al., (2015) explained, children valued the importance of a strong relationship between the nurse and the parent, as well as the child-nurse relationship. They saw nurses as a support network, not just for themselves, but for their parents who felt heightened levels of fear and stress (Montreuil et al., 2015). Children recognised the importance of information sharing just not between themselves and nurses, but also between their parents and nursing staff (Montreuil et al., 2015).

3.16 | Integrated finding: Children seek a shared decision-making process

The fourth synthesised finding was related to children's seeking to be more involved when it came to their health care needs and the shared decision-making process. The synthesised finding was made of six categories, see Table 5.

Children enjoyed having a role in the decision-making progress and found that active participation in their care increased their level of involvement. They wanted to be included in the decisions regarding procedures and who was allowed to complete their health care procedures, whether it be done by themselves, a parent or a particular nurse (Darcy et al., 2019). Even children as young as three years old demonstrated determination to be included in their own care and be an active participation member:

> I decide which finger to stick and what number to count to. I get to press the button on the lift … don't I mummy? (three year old girl).
>
> (Darcy et al., 2019, p 5)

Children were found to be active or passive participants in their own care. Some children wanted to be actively involved in their own care and wished to collaborate in the decision-making process with their parents and nurses (Darcy et al., 2019; Lee et al., 2019). Observations in two different studies (Lee et al., 2019; Rindstedt & Aronsson, 2012) showed that children who craved to participate took up every opportunity they could to be active participants in their own care. The children in these studies were extremely aware of their health care needs and wished to be a part of the decision-making process regarding health procedures that they needed (Lee et al., 2019; Rindstedt & Aronsson, 2012). Some children with long-term conditions often had repetitive procedures completed in collaboration with their parents and nursing staff, and could easily demonstrate familiarity with the procedures (Rindstedt & Aronsson, 2012). When involved in their own care, children were eager to make decisions, regarding who was completing the procedure or how it was to be done, which turned the procedure from a complex medical procedure to a jovial time where children often played and laughed (Rindstedt & Aronsson, 2012). During observations of medical procedures, children were eager to demonstrate their awareness of their conditions and the procedures and were always attentive to what was occurring around them, asking questions about their condition or procedures (Rindstedt & Aronsson, 2012).

Passive participation occurred when children were relegated to an observer role in their own health care, with parents and nurses discussing the child's health care needs without active involvement of the child (Lee et al., 2019). Some children preferred this route of participation, preferring their parents to shadow and protect them from the health care environment, others trusting that they would be informed of any important decisions by their parents at an appropriate time (Lee et al., 2019). Whilst some children preferred to be a passive participant, a greater number of observations completed in the studies demonstrated that children craved an active participatory role in their health care (Lee et al., 2019; Rindstedt & Aronsson, 2012).

Some children felt that active participation led to a greater sense of control. These children recognised the changes that were occurring in their life and body and wished to be involved in the decision-making progress as it allowed them to gain back some control in a life that had changed dramatically (Darcy et al., 2019). Whilst they did not mention words such as consent or assent in their interviews and observations, children were able to demonstrate their own knowledge of consent, even at a young age:

> Tell me … ask ME if it's OK to lift up my t-shirt (four year old boy).
>
> (Darcy et al., 2019, page 4)

Being informed about their long-term condition and health care needs also impacted the child's sense of control surrounding the changes in their life. Older children felt a lack of information sharing between themselves and nursing staff and felt that as the person experiencing the condition and procedures, they should be more informed about their diagnosis and treatment (Gibson et al., 2010; Olsson et al., 2015). When children were informed about their long-term condition, they felt more confidence and trust in the nursing staff and also in themselves:

> I push my own medicines down the nose tube with (syringe) … Mummy is allowed to watch me (five year old girl).
>
> (Darcy et al., 2019, page 5)

Feeling more in control surrounding their condition and treatment created a sense of empowerment in children. Some children were given a more active voice in their own healthcare and consistently reported that empowerment also came from the information sharing and education that they received from nursing staff, who took the time to clearly ensure that the children understood what was occurring and why:

> They [the nurses] were so good at explaining things, they'd keep explaining things until I understood them, and they didn't use big words.
>
> (Grealish et al., 2013, page 141)

4 | DISCUSSION

This integrative review aimed to synthesise existing literature surrounding how children with long-term conditions experience the nursing care provided to them in the triadic partnerships with nurses and parents. Qualitative and qualitised findings were aggregated into 30 synthesised categories which were then aggregated into four overarching synthesised findings.

In the included studies, a high proportion of studies included children between the ages of 7–12 years of age, with studies exclusively looking at adolescents coming a close second. A high percentage of the studies also came from Western countries, with a lack of diversity and cultures present in the studies, not representing the diversity of cultures and backgrounds found in most countries. This review was completed with the underpinning rationale that a change in Children and Young People's nursing has occurred because of the implementation of FCC to PFCC, allowing the patient (child) to be recognised as a separate and valued entity in partnership nursing care (Frakking et al., 2020). The shift in nursing models may be due to the United Nations Convention on the Rights of the Child, which states that a child has a right to be informed about their own health care and should be able to express their needs and opinions in the decision-making processes (UN General Assembly, 1989).

Children have recognised rights, however legal parental consent is required in most paediatric cases, however gaining children's assent - the child approving the decision ensures that their rights are upheld (Quaye et al., 2019). Nurses often focus first on gaining parental consent before determining if the child is competent enough to be involved in a consent or assent process, rather than seeking the patient's assent or consent initially (Ruhe et al., 2015). It is also unclear what the determining factors are that give nurses insight into whether a child demonstrates appropriate levels of competence to be involved in a consent/assent process (Ruhe et al., 2015; Vaknin & Zisk-Rony, 2011). Patient involvement could be determined by a multitude of interrelating factors, such as the patient's age, their level of competence, the child's own wishes surrounding their level of involvement as well as the parents' wishes. A high proportion of the included studies looked at children between the ages of 7–12 years old, see Figure 2. These children and young people had differing levels of understanding of their conditions, as well as differing levels about the unknown of their diagnosis and how involved they wished to be in their own care. In contrast, the included studies that looked exclusively at children over the age of 12 reported patients wishing to seize more independence and decision-making capabilities, which is consistent with previous research (Coyne et al., 2015). This review has demonstrated that whilst some children are involved in a shared decision-making process, others continue to experience ineffective partnerships in the triad with their nurses and parents.

Children demonstrated an acute awareness of their conditions, treatments and the environment surrounding them. This awareness can lead to feelings of fear and worry, with research elsewhere demonstrating that this fear comes from a lack of communication and information, combined with nurses who do not successfully acknowledge the children's feelings (Coyne & Kirwan, 2012). Nurses were frequently mentioned as 'good' and 'bad,' consistent with broad literature in this field (Clarke, 2022; Coyne & Kirwan, 2012; Peña & Rojas, 2014). As seen in previous research, most children described enabling nurses as happy and fun, and considered their relationship as positive. Children can also have negative experiences and attitudes towards nurses, which is linked to painful medical procedures, lack of quality time and inappropriate communication, consistent with other studies (Clarke, 2022; Coyne & Kirwan, 2012; Peña & Rojas, 2014). The use of narrative constructs by children concerning 'good' and 'bad' nurses, predominantly in relation to the nurse's genuineness of connection and use of light-heartedness, could provide a lens to better understand their experiences and their meaning-making – beyond their illness, to examine their relationships while receiving care (Capurso et al., 2021). It may also provide a useful construct for nursing education, and further research in clinical psychology and child development.

Long-term conditions in children can be complex and cause increased morbidity and mortality (Lambert & Keogh, 2015). The child and parents must navigate a difficult journey to create a new normal following a diagnosis, adapting their behaviours and environments to suit healthcare requirements necessary to the child's quantity and quality of life and at times, survival (Lambert & Keogh, 2015). Children are seen as vulnerable, requiring security and protection from the harsh realities of healthcare and risks associated with complex long-term conditions (Skyrme & Woods, 2018). Vulnerability is seen as inert, with no personalisation and can lead to a lack of inclusivity and partnership between parents, nurses and children (Skyrme & Woods, 2018). Vulnerability should not be seen as incompetence, with many children having the capacity and awareness to participate in decision-making (Skyrme & Woods, 2018). Previous literature has demonstrated that parents wish for more control in their child's healthcare and decision-making, recognising a power imbalance between HCP and parents (Barratt et al., 2021; Reeder & Morris, 2020). Nurse perceptions in the literature highlight that nurses can feel threatened by parents seeking control in the triad partnership, and this can be a barrier to shared decision-making (Barratt et al., 2021; Reeder & Morris, 2020). Current literature suggests the importance of allowing parents to maintain a sense of control, however, there is limited research available on the importance of allowing children to have a sense of control and power in their own healthcare (Skyrme & Woods, 2018). In all models of healthcare, such as Person/Child Centred Care, or PFCC, the child is embedded into the partnership between collaborators, in either consent or assent capacity, depending on their levels of awareness and knowledge.

A young child can be involved in the decision-making of health care decisions, choosing who accompanies them during a procedure or the colour Band-Aid they may use; and older children can choose which arm they want an intravenous cannula in or which side to lie for a lumbar puncture. These decisions are given to adult patients without thought, allowing the patient to feel a sense of control in their own healthcare in whatever capacity is possible. A partnership with both parents and children is a dynamic process that is not static and must constantly be renegotiated according to contextual characteristics, disease progression and childhood development and capacity (De Civita & Dobkin, 2004). Children may be offered minor decision-making power for minor or trivial procedures, however as they mature into young people, they should be involved in decisions that may have lifelong consequences, instead of parents and healthcare professionals making these decisions for them. Fertility treatments, chemotherapy and palliative care are large and heady decisions that may need to be considered during cancer treatment, however paediatric care can often be seen as 'adult-centric,' with adults making these substantial life-changing decisions at the thought of protecting the child, who may need to potentially live with the consequences of the adult's decision for the rest of their life. Preventing children from being involved in their own healthcare can create feelings of worry and fear, and cause prolonged trauma to the child as they attempt to navigate a complex world in the healthcare system (Coyne & Kirwan, 2012). An effective triadic partnership is where the nurse, parent and child work together to establish a plan of care suited to the needs of the child and parent, allowing each party to have a voice in the decision-making process. When the partnership is adult-centric, the child's voice can be lost to the heavy voices of the adults, creating an imbalance of power in the triad, which may cause feelings of frustration and anger as the child matures and craves more power and knowledge over their own health care.

A successful triadic partnership ensures that both the parent and child have the knowledge surrounding a child's long-term condition (Peña & Rojas, 2014). Depending on the child's age and level of maturity, they can be involved in the shared decision-making process, whether it be gaining their assent for medical procedures or choosing which parent they wish to be present during a procedure. Nurses must consider initiating the involvement of children in the partnership instead of waiting for parents to involve their children. Parents can feel a need to protect their children and may not disclose information to their children to protect them to keep them secure and safe (Barratt et al., 2021). Whilst some children would prefer their parents only to disclose what they feel is necessary, other children may wish to have a more active voice in their own care. Parents can also crave power and control over their child's care, especially if the child has been diagnosed with a potentially life-threatening condition (Barratt et al., 2021). This can be viewed as a coping mechanism, as parents adjust to the 'normal' at a time of uncertainty so they may crave power of their lives as they grapple to navigate the complexities of prognosis, treatment and healthcare (Barratt et al., 2021).

Children viewed their parents often as protectors. They often perceived their parents as guards that protected them from the outside world and limited the negative experiences that they were exposed to in an unfamiliar environment, such as the hospital (Clarke, 2022). Surprisingly in this review, nurses were also seen as protectors when the child felt that the parents could not do so. This area of research is extremely limited and further research is needed to understand how children view nurses and parents in terms of meeting their needs for security. The tension in the power dynamic between parents and nurses as protectors warrants further exploration, and how to enable nurses to uphold the rights of both the parent and child. These children may have these long-term conditions for their foreseeable future or their entire life. Teaching parents and families the importance of informed consent and assent early can ensure that in the future, these children have the knowledge and confidence to speak up as adults and ensure that they have a voice that can be heard in their healthcare decision-making processes.

Paediatric research has shown the importance of children being involved in the research processes, allowing researchers to conduct research with children rather than on them (Coyne et al., 2021). The way researchers view children can have a profound influence on how the research is conducted (Coyne et al., 2021). If the researcher views the child as unable to give their views or experiences, valuable data may be missed by the researchers (Coyne et al., 2021). Children see and experience the world differently to adults and this needs to be considered when creating a research process and study design. Most of the studies included in this review used interviews as the main form of research method to collect data. Whilst interviews allow participants to voice their concerns and experiences, they require the participant to be able to express themselves in a manner that the researcher can understand, as well as be able to articulate the necessary depth required concerning the research topic. This factor – that we can only research what we can collect as data - is a limitation of this review examining the experience of children in the triadic partnership. For younger children, those with intellectual disabilities or children traumatised by their experiences, interviews cannot truthfully collect and collate their experiences, with many parents refusing to give consent to interviews given their protective instincts regarding their children (Wyman et al., 2019). For future research, a 'Mosaic' research method may improve inclusivity in the eligibility of paediatric patients in research (Clark, 2001; Coyne et al., 2021), where a range of tools are used in the research, with the children able to choose which method that would prefer to use, such as interviews, drawings, toy play, puppets and journaling (Clark, 2001; Coyne et al., 2021). This approach allows the participant to feel empowered and a member of the research team, rather than just a participant (Coyne et al., 2021). In regards to other limitations of this review, only one study in the included studies (Livesley & Long, 2013) has described the theoretical framework underpinning the research study. This may be due to nursing research being focused on more evidence-based practice compared to having an underpinning nursing theoretical framework to guide research (Younas & Quennell, 2019).

5 | RELEVANCE TO CLINICAL PRACTICE

In this study, children exhibited various experiences of partnership in the care provided to them by parents and nurses. This review has shown the variability in children's beliefs of how involved they should be in the decision-making process, with some children wanting to be heavily involved in all decisions and others preferring their parents to take control. This evidence base is limited by the lack of cultural, medical and methodological diversity in the studies. The small amount of included studies that described the cultures of their participants often had low levels of diverse cultural backgrounds. Over half of the included studies came from haematology/oncology wards, which may not accurately represent the experiences of partnership nursing in children with other long-term conditions. Most of the included studies used interviews as a data collection method which inhibits specific diverse populations of children from research participation. Future research is required on how to best support the development and maintenance of the triadic partnership in Children and Young People's nursing to support children with long-term conditions, parents and nurses. Future research will also need to examine the determining factors in the triadic shared decision-making process and how country-specific legislative and/or governing regulations can support the involvement of children in their own healthcare as well as nursing staff legal and ethical obligations.

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CONFLICTS OF INTEREST

The author had declared no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article

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SUPPORTING INFORMATION

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

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Supplementary tables

Table 1: Characteristics of studies included in review

Author/ Year	**Type of study**	**Setting**	**Rationale for age of children selected**	**Demographic data**	**Sampling technique**	**Data analysis**	**Inclusion criteria**	**Key findings**	**Limitations**
Asikli & Aydin Er (2020)	Qualitative.	Paediatric oncology and haematology services in a Turkish hospital.	Children between 7 – 12 years old are usually comfortable speaking and working with adults and can create purposeful drawings.	11 male participants, seven female participants. Mean age: 9.7 +/- 1.8 years. Disease duration: 15 days to 42 months. Number of hospitalisations: 1 – 16.	Non stated by author.	Thematic analysis.	Children hospitalised between 4th May and 27th November 2017. Children aged 7-12 years who were receiving cancer treatment for at least 1 week.	There were five main themes: Interpersonal relationships, virtues, professional responsibility, security, and individual characteristics.	None stated by author.
Biering & Jensen (2010)	Qualitative.	Psychiatric unit in acute care hospital.	None stated by author.	Six male participants, eight female participants. Ages were 14 years old (n = 1), 15 years old (n = 6) and 17 years old (n =7). Diagnosis: Depression (n = 8), anxiety (n= 3), self-injurious behaviour (n = 8), psychosis (n = 2), anorexia (n = 2), attention deficit hyperactive disorder (n = 4) and social phobias (n = 3). Length of hospitalisation: 6 weeks to 5 months.	Purposive sampling.	Thematic analysis.	None stated by author.	There were 13 main themes: Secure place, isolation from the outside world, activity, tough love and discipline, peer solidarity, self-expression, a person not a patient, consideration, satisfying treatment outcomes, improved mental health, personal development, healing the self and improved family relations.	Author stated: Small sample size, location, and population size of country.
Cheng et al. (2016)	Qualitative.	Medical centre.	None stated by author.	Seven male participants, four female participants. Age of cancer onset 2 – 16 years, (M = 9.4 years) Average length of treatment was 15 mains. Eight participants belonged to the Amis tribe, two belonged to the Taroko tribe and one belonged to the Bunon tribe. Diagnosis: Acute lymphoblastic leukemia (ALL) (n = 3), acute myeloid leukemia (AML) (n = 1), lymphoma (n = 5), hepatoblastoma (n = 1) and brain tumour (n = 1).	Snowball sampling.	Content analysis.	Adolescents between the age of 12 and 18 years old who had been diagnosed with cancer and had finished treatment at least one year ago, who identified as Aboriginals and were able to speak Mandarin.	There were 3 main themes: Roots for resilience, transformation and growth, and impact of traditional tribal rituals on resilience.	Author stated: Participants may not be able to recall past events, recruitment completed in only one setting.

Author/ Year	Type of study	Setting	Rationale for age of children selected	Demographic data	Sampling technique	Data analysis	Inclusion criteria	Key findings	Limitations
Corsano et al. (2015)	Qualitative.	Paediatric haematology and oncology ward.	Authors wanted complex and rich narrations from older children and adolescent as they had greater competence and increase awareness.	12 male participants and 14 female participants. 15 were aged between 6 – 10 years old (M = 7.56; SD = 1.41) and 12 were aged between 11 – 15 years old (M = 12.15, SD = 1.52). Diagnosis: Haematological malignancies (n = 15), solid tumours (n = 4), blood disorders (n = 8).	None stated by author.	Narrative analysis.	All participants were hospitalised for at least 1 week.	There were 5 main themes: Emotional antecedents, emotional and medical terms, participants in the emotional event, behavioural reactions, age, gender and pathology differences.	None stated by author.
Darcy et al. (2019)	Qualitative.	Paediatric haematology and oncology ward.	None stated by author.	Five male participants, nine female participants (One female lost in follow up). Age was 1 years old (n = 3), 2 years old (n=3), 3 years old (n=2), 4 years old (n = 4) and 5 years old (n=1) (Mean not stated). Diagnosis: ALL (n = 9), brain and solid tumours (n = 4).	None stated by author.	Content analysis.	Children between one and six years of age when receiving their first cancer diagnosis, being able to communicate in Swedish and agreeing to participate.	There were 3 main themes: I want to be a child like any other, I need security and control, and I feel lonely and left out.	None stated by author.
Gibson et al., (2010)	Qualitative.	Not stated.	Not stated.	18 male participants and 20 female participants. No ages stated. Ethnic groups: White British (n = 29), White other (n = 2), Mixed – White and Black Caribbean (n = 2), Asian other (n = 2), White Irish (n = 1), Black African (n = 1) and Asian Pakistani (n = 1). Diagnosis: ALL (n= 18), non-Hodgkin's disease (n = 3), Ewing's sarcoma (n = 3), Wilms' tumour (n = 2), osteosarcoma (n = 3), Hodgkin's disease (n = 2), AML (n = 2), neuroblastoma (n = 1), brain tumour (n = 1), Pelvic PNET (n = 1), tumour on outside of lung (n = 1) and cancer of the colon (n = 1). Stage of cancer journey: On treatment (n = 20), at the end of treatment (n = 9) and 6-18 months following successful treatment (n = 9).	Purposive sampling.	Thematic analysis.	Children and adolescents aged 4 – 19 years old in paediatric oncology/ haematology services.	There were six main themes: Children's account of their preferences, play, toys and schoolwork; asking and telling – getting the right balance; worrying about now and the future; the triad of support, and a conceptual model of communication.	Authors note: No children receiving palliative care, small sample size.
Grealish et al. (2013)	Qualitative.	Child and adolescent mental health services.	Not stated.	Five male participants and four female participants (mean age = 16.4 years old). Ethnic groups: White British (n = 8) and Asian (n = 1). All participants (n = 9) had received a diagnosis of a schizophrenia spectrum disorder.	Not stated.	Thematic analysis.	All patients needed to be in recovery stage- defined as a state where they were coping well with their symptoms.	There were six main themes: Individual control and choice versus inflexibility; being listened to, respected and validated; communication, response of services, coping and structure; and quality of relationship and support.	Authors note: One setting for recruitment.
Lee et al. (2019)	Qualitative.	Paediatric oncology ward.	Not stated.	Not stated.	Not stated.	Not stated.	Children diagnosed with leukemia, aged between 7 – 12 years old.	There were two main themes: Child as passive participant and child as active participant.	None stated by author.

Author/ Year	**Type of study**	**Setting**	**Rationale for age of children selected**	**Demographic data**	**Sampling technique**	**Data analysis**	**Inclusion criteria**	**Key findings**	**Limitations**
Livesley & Long (2013)	Qualitative.	Family homes and Nephro-urology ward.	Children older than seven can give accurate accounts of their experiences, impressions and can respond to standard questions and control what they reveal.	Six male participants and 10 female participants. 13 participants had a long-term condition. Age range was between 5- 15 years old (Mean not stated). Reason for admission: Mitrofanoff procedure (n = 3), circumcision (n = 2), epispadias repair (n = 2), urinary tract infection (n = 2), dislodged urinary catheter (n = 1), bladder studies (n = 1), removal of kidney (n = 1), repair of ureter (n = 1), ileostomy (n = 1), abdominal injury (n = 1) and pelvic surgery (n = 1).	Not stated.	Constant comparison.	Children aged between 5 – 16 years old. For phase one – admission in past 18 months. Phase 2 – patients under the care of urology team.	There were four main themes: Transition to patients who are also children, different worlds, child nurse relationship and the challenge: children's voice of competence,	Authors note: Study conducted only on one ward.
Manookian et al. (2014)	Qualitative.	HSCT ward.	Not stated.	3 male participants and 3 female participants between the ages of 6 – 17 years old (Mean not stated). Diagnosis: ALL (n = 2), Thalassemia (n = 2), Hodgkin's disease (n = 1) and chronic myelogenous leukemia (n = 1).	Purposive sampling.	Interpretive analysis.	Children and adolescent aged less than 18 years old, receiving HSCT and able to speak Persian.	There were three major themes: Transplantation rejoicing, deepening of family ties and difficult passage.	Authors note: Children in the study felt weak and tired so interviews were very short. Broad age range.
Montreuil et al. (2015)	Qualitative.	Inpatient mental health services.	Not stated.	One male participant and four female participants aged 11 – 14 years old (Mean not stated). Diagnosis: Anxiety, anorexia/eating disorder, autistic spectrum disorder, psychotic disorder, obsessive compulsive disorder, self-harm, suicidal ideation, and learning difficulties.	Convenience sampling.	Thematic analysis.	English or French speaking children aged 7 -14 years old, receiving treatment for a diagnosed mental health disorder.	There were four main themes: Caring for the child as a special person, caring for the parents, managing the child's illness, creating a therapeutic environment.	Authors note: Small sample size, no fathers or non-parental guardians were recruited. No participants under the age of 11 years old.
Nabors & Liddle (2017)	Qualitative.	Children residing in a Ronald McDonald House.	Not stated.	Nine children between the ages of 3-11 years old (M=6.5 years old), one male participant and eight female participants. Ethnic groups: White (n = 7), Hispanic (n= 1) and Asian (n = 7). Diagnosis: Cancer (n = 3), tracheomalacia/bronchomalacia (n = 2), liver failure (n = 1), pancreatitis (n = 1), mitochondrial disease (n = 1) and brain surgery (n = 1). Eight siblings also participated, between the ages of 3-12 years old.	Not stated.	Thematic analysis.	Not stated.	There were two main themes: Positive themes related to hospitalisation for children with chronic illnesses and siblings; and negative themes related to hospitalisation for children with chronic illnesses and siblings.	Authors note: No questions about anger or guilt, only children were interviewed.

Author/ Year	Type of study	Setting	Rationale for age of children selected	Demographic data	Sampling technique	Data analysis	Inclusion criteria	Key findings	Limitations
Olsson et al. (2015)	Qualitative.	5 adult cancer centres and 2 paediatric cancer centres.	Not stated.	16 male participants and 28 female participants aged between 15 – 31 years old at time of interview (M=21). Diagnosis: ALL (n = 12), sarcoma (n = 12), lymphoma (n =11), testicular cancer (n = 5), brain tumour (n = 2) and gynaecological cancer (n = 2).	Not stated.	Content analysis.	People aged between 15 – 29 years old.	There were four main themes: Personal professional interaction, knowledge and participation; age appropriate environment, and support.	Not stated.
Petronio-Coia & Schwartz-Barcott (2020)	Qualitative.	Paediatric oncology service.	Not stated.	Three male participants and four female participants. All children aged between 8 – 12 years old (Mean not stated). Diagnosis: Osteogenic sarcoma, ALL, non-Hodgkin's lymphoma, t-cell lymphoma and alveolar rhabdomyosarcoma.	Purposeful sampling.	Content analysis.	Not stated.	There were four main themes: Approachable nurses are smiling, and happy, approachable nurses are playful, approachable nurses "talk and listen;" and approachable nurses are creative and competent.	Authors note: Small sample size, all Caucasian participants.
Randall 2012	Qualitative.	Local health service area.	Not stated.	Children aged 5 – 12 years old (Mean not stated). 8 male participants and 12 female participants.	Purposeful sampling.	Content analysis.	Children living in study area with ongoing community nurse care for more than 6 months.	There were four main themes: A continuum of regard for nurses, children with a negative regard, children with positive regard for nurses and context.	Authors note: Some adults only gave consent if they would describe nurse in a positive light.
Rindstedt & Aronsson (2012)	Qualitative.	Oncology clinic.	Not stated.	One male participant and four female participants aged between 2 – 16 years old (Mean not stated). All diagnosed with ALL.	Not stated.	Not stated.	Not stated.	There were four main themes: The child's intent observations and nonverbal uptake, using and understanding medical terminology, assisting the medical staff and advancing to full participation in clinical practices.	Not stated.
Spratling (2012)	Qualitative.	Paediatric outpatient clinic.	Not stated.	Five male participants and six female participants. Mean age 15.6 years old. Ethnic groups: Caucasian (n = 7), African American (n = 2), African American/Caucasian (n = 1) and Hispanic (n = 1). Diagnosis: Muscular dystrophy or atrophy (n = 4), congenital abnormalities (n = 3), Neurofibromatosis (n = 2), Spina bifida (n = 1) and quadriplegia due to injury (n = 1). Respiratory assistance: Tracheostomy (n = 7), mechanical ventilation (n = 4), BiPaP (n =3), and history of a tracheostomy (n = 2).	Purposeful sampling.	Thematic analysis.	Adolescents aged 13 – 18 years old, using a minimum of one medical technology that provided respiratory assistance, tracheostomies mechanical ventilation, on a daily basis for the past 12 months or history of use of technology that provides respiratory assistance on a daily basis in the past 2 years. Able to read and understand English without support from parents.	There were five main themes: 'Get to know me,' 'allow me to be myself,' 'being there for me,' 'no matter what, technology helps,' and 'I am an independent person.'	Authors note: Small sample size, sample selection from a small geographic location and the participants ability to articulate their experiences.

Author/ Year	Type of study	Setting	Rationale for age of children selected	Demographic data	Sampling technique	Data analysis	Inclusion criteria	Key findings	Limitations
Xie et al. (2017)	Qualitative.	Children's hospital.	Not stated.	There were 12 male participants and nine female participants. Age of children between 7 – 12 years old (Mean not stated). Primary school grades were between grade 1 – 6 (Mean not stated).	Not stated.	Content analysis.	Children diagnosed with ALL, were in a stable condition, could read and speak Chinese and had undergone at least one lumbar puncture.	There were three main themes: Complex psychological changes, physical discomfort and Multipolar needs.	Authors note: Only school aged participants recruited.
Çakirer Çalbayram et al. (2018)	Mixed methods.	Children's hospital.	Children can draw human body and they can elaborate pictures.	10 male participants and 12 female participants. All aged 6 years old. 12 participants had chronic conditions; 10 participants had acute conditions.	Not stated.	Content analysis.	6 year old children who were hospitalised for at least 3 days, with no physical, communication or mental conditions affecting their ability to participate.	Unsure.	Authors note: Small sample size, only children hospitalised at time of study were included.
Figueiredo et al. (2020)	Mixed methods.	Children's hospital.	Not stated.	Children and adolescents aged between 10-18 years old (M=15.28 years old). There were 14 male participants and 18 female participants. Diagnosis: Gastrointestinal disorders (n = 13), type 1 diabetes (n = 5), neurological disorders (n = 5), chronic kidney failure (n = 3), cardiorespiratory disease (n = 3), immunological disorders (n = 2) and liver disease (n =1).	Accidental non-probability sampling.	Exploratory factor analysis.	Children hospitalised for at least 3 days who are aged 6, no communication or psychiatric problems, no isolation or infection risks and no disease preventing them from drawing.	One main theme: Resilience in adolescents with chronic illness.	Authors note: Small sample size, small diversity of chronic illnesses under analysis.
Lapp (2019)	Mixed methods.	Children's hospital.	Children can think about abstract concepts from 12 onwards.	Participants aged 12-21 years old (M=16 years old). 24 male participants and 36 female participants. 29 participants had a length of stay less than 3 days and 31 participants had a length of stay greater than 4 days. Of the 60 participants, only 17 had a chronic illness.	Purposeful sampling.	Exploratory factor analysis.	Adolescents diagnosed with a chronic illness at least 3 years ago, minimum of two previous hospital admissions.	There were four main themes: Environment of care domain, physical and psychological comfort domain, dignity and respect domain; and autonomy domain.	Authors note: Only one hospital setting, use of statements only drawn from qualitative studies.

(Label: N= Number, M= Mean, SD= Standard deviation, PNET = Primitive neuroectodermal tumour, ALL= Acute lymphoblastic leukemia, AML= Acute myeloid leukemia, HSCT = Hematopoietic stem cell transplantation, BiPAP = Bilevel positive airway pressure)

Table 2: Extraction of data of included studies (Qualitative studies)

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Asikli & Aydin Er (2020)	The children cared about the relationship of physician and nurse not only with themselves but also with their families.	"I started to lose my hair. I was very sorry at first but then the nurse here said to me by smiling that my hair will come out when I beat this disease. I was happy. (Child no. 1, age 12)." (Page 6)		X		F1
Asikli & Aydin Er (2020)	The children in this study included statements on the definitions of 'good physicians' and 'good nurses' based on smile, the way they addressed them and how they communicated with them.	"She tells me 'Princess, you're so beautiful today'. She is a good nurse. (Child no. 8, age 7)." (Page 7) "I love my nurse here; she measures my blood pressure and asks 'How are you Dear …' before measuring. (Child no 15, age 7)." (Page 7)	X			F2
Asikli & Aydin Er (2020)	Some of the children stated that the physician and the nurse should treat not only themselves but also their family kindly.	"Nurses are actually good but sometimes they can behave badly. For example, when we walk around the corridor, they could get angry and say us 'go to your room', it is a bad behaviour. Instead, they may ask. (Child no. 3, age 11)." (Page 7) "A bad doctor or nurse shouts out to our mothers and speaks loudly. (Child no. 18, age 8)." (Page 7) "They should play with children, nurses or doctors. For example, hide and seek is a good game. Then we would get along better with them. (Child no. 17, age 9)." (Page 7)	X			F3
Asikli & Aydin Er (2020)	The children stated that they and their family should be treated with respect and tolerance.	"For example, we say wait for [my] mother to the nurse while the injection is given to us. The nurse frowns and gets angry. This is a bad nurse, but a good nurse tolerates and does not get angry. (Child no. 2, age 9)." (Page 7) "I think doctors and nurses should be honest at first. I do not trust anyone who is dishonest. (Child no. 2, age 9)." (Page 7)	X			F4
Asikli & Aydin Er (2020)	The statements of the children about the duties of the physician and the nurse were also included here.	"The doctor's job is to assist the Professor and [to] examine the patients. The duty of the nurse is to establish the vascular access to the patients and to administer drugs. (Child no. 6, age 10)." (Page 8) "The doctor is there to cure the patient. The nurse is there to take care of children and help to doctor. (Child no. 12, age 10)." (Page 8) "I think I would never want to be a nurse in the future. I cannot spare the children and I could not be cutthroat. (Child no.7, age 10)." (Page 8) "We are not a test board. A good nurse should not hurt us very much. (Child no. 16, age 10)." (Page 8) "I love my nurse Mrs … She does not hurt when she takes blood, she finds it in two minutes. I do not get hurt because she gets it right away. (Child no.15, age 7)." (Page 8)			X	US1
Asikli & Aydin Er (2020)	The expressions of children about the use of masks, and hand and body hygiene, which they emphasised.	"The hair should be short; hairs of doctors and nurses should not touch the face of children. (Child no. 12, age 10)." (Page 8) "A good doctor and nurse should [be] dressed clean, [wear a] mask and should tie their hair up. If her hair is messy, she will not be beautiful, hairs can go [into] to the meals we eat. (Child no. 8, age 7)." (Page 8) "A good doctor and nurse should be clean; their nails should be short so that we do not get infected. (Child no. 17, age 9)." (Page 8)			X	US2

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Asikli & Aydin Er (2020)	Children defined a 'good physician' and 'good nurse' with the expression 'who loves children' most frequently. The other definitions of 'good physician' and 'good nurse' mentioned by children under this heading were 'well-kept', 'handsome/beautiful' and 'patriotic.	"Nurses should love children. I don't think they can do their job well if they don't like children. (Child no. 14, age 9)." (Page 9) "(A) Decent nurse is a good nurse. (Child no. 7, age 10)." (Page 9) "The nurse Mrs . . . wears very beautiful makeup and gives me makeup materials. She is a beautiful nurse. Her hair is also beautiful, a good nurse. (Child no. 8, age 7)." (Page 9) "Male nurses must be handsome. A handsome nurse is of course like me. (Child no. 3, age 11)." (Page 9)	X			F5
Biering & Jensen (2010)	This feeling of being sheltered was enhanced by the trust the adolescents felt towards the staff and each other.	"… I learned a lot, and this is a very good place. You experience things you have not experienced before: safety and trust, I learned to trust." (page 5)			X	US3
Biering & Jensen (2010)	They felt they were forced to do something they did not like to do, but the staff thought was good for them and that gave them satisfying results.	(Referring to two of the nursing staff): "They were also quite strict with me and I think that was good for me. So, they were not completely bad? They were bad [grin] but they knew what they were doing. You have to have discipline to get things done." (Page 6)		X		F6
Biering & Jensen (2010)	The adolescents expressed satisfaction with the opportunities and encouragement they received to express their feelings and share painful experiences with peers and caregivers.	"I did not like it (talking to a therapist) much. I did not really get anything out of it. But talking to the nursing staff? It was much better. Why was that? I did not meet my psychologist very often. It is better to talk with those you meet every day." (Page 7)	X			F7
Biering & Jensen (2010)	The adolescents emphasized that they were satisfied when the caregivers treated them with the kind of respect that was manifested in being treated as a person, but not a patient. In the adolescents' view, this informal nature of the patient-staff interaction was the key to the development of a therapeutic relationship as is illuminated in the following excerpt from the interview with participant 2.	". . . you know, you are only people. Well, so? It is of course nice that you are people. It would not be nice if we were only the patients and you only counsellors and nurses. How would it be if it were like this? It would not be nice at all. You cannot connect to people if it is like that." (Page 7)	X			F8
Cheng et al. (2016)	Feeling secure seemed to provide protection and brought courage and confidence to the participants as they faced the unknown of the treatment and disease process.	"Mom accompanied me, took care of me and prayed for me; all these strengths helped me to recover. I felt secured because of her accompany and became less afraid of the treatments. Because of her encouragement, I had confidence to fight cancer. Every time I had lumbar puncture and chemotherapy drugs, mom always prayed for me and stayed with me till I fell asleep, I felt so relieved and less intimidated about chemotherapy." (Page 80)	X			F9

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Cheng et al. (2016)	Through delivery of quality care, provision of necessary information, care and visits of volunteers and other cancer survivors, the participants were afforded opportunities to interact with others and clarify their concerns, which resulted in augmented support and increased confidence toward the outcomes of the treatments.	"During my hospitalization, I was thankful for the nurses. They were willing to accompany me at nights and listen to my complaints. When I couldn't fall asleep, I'd go to nursing station to talk to them. They'd encourage me and showed me inspiring videos to give me confidence." (Page 81)	X			F10
Corsano et al. (2015)	Young patients narrated episodes in which they played and joked with nurses.	"I celebrated my birthday in the hospital, and they (the nurses) sang happy birthday, I got a Barbie and a pair of pyjamas with a penguin." (Page 87)		X		F11
Corsano et al. (2015)	Children also reported pleasant sensations.	"We went to put a dressing on my tummy and the nurse tickled me." (Page 88)		X		F12
Corsano et al. (2015)	In some cases, children said they had never felt sad when they were with the nurses and doctors.	"I always talked and played with them, I never felt sad." (Page 88)		X		F13
Corsano et al. (2015)	Children indicated nurses and doctors as participants in emotional events.	"I felt happy when the nurse played with me on the Play Station, or when another nurse called for pizza in the ward." (Page 89)		X		F14
Darcy et al. (2019)	Shortly after diagnosis and start of treatment the child described feeling like a stranger in an everyday life that was described as utterly changed.	"Now I get help from my Mummy to do pretty much everything, (before) I did it all myself (four-year-old girl)." (Page 4)		X		F15
Darcy et al. (2019)	Eighteen months after diagnosis, the child expressed awareness and of bodily changes which meant that their body was different than others.	"I have thousands of scars now … one here, one here, one here, see? No one else in my class has these (seven-year-old girl)." (Page 4) "Next week I start cortisone treatment again, I'll be a real witch for a while (five year-old girl)." (Page 4)		X		F16
Darcy et al. (2019)	The child now lived a life where cancer did not play a central role for them. However, they were aware that they had experiences of ill-health and hospital.	"Sometimes I want to be sick again … I miss the nurses and I miss the presents (seven year-old girl)." (Page 4)		X		F17
Darcy et al. (2019)	A sense of control was experienced when health care professionals treated the child with respect.	"Tell me … ask ME if it's OK to lift up my t-shirt (four year- old-boy)." (Page 4)	X			F18
Darcy et al. (2019)	The child described experiences of fighting for control and actively striving to make a normal everyday life of the cancer experience.	"Put it on at home (anaesthetic cream) … so that it won't hurt, put on the tape myself (four-year-old girl)." (Page 5)	X			F19
Darcy et al. (2019)	A year after diagnosis the child made a normality of the illness and treatment by incorporating hospital visits and procedures into every day. They now expressed experiencing security and control.	"So I said to the nurse, don't you touch me with your cold hands, warm them up first (four-year-old girl)." (Page 5)	X			F20

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Darcy et al. (2019)	Learning to live with a changed body helped in the striving for normality and the central venous catheter and naso-gastric tubes in particular were expressed as part of themselves.	“No, no, that (NGtube) belongs to me and it's to stay right here (four-year-old girl).” (Page 5)	X			F21
Darcy et al. (2019)	Going to hospital was mostly fun and relaxing, and birthdays and holidays such as Christmas or Midsummer were celebrated there.	“When it was my birthday, the nurses came in here in the morning and sang to me (four year-old girl).” (Page 5)	X			F22
Darcy et al. (2019)	Access to parents for comfort and security continued to be important but parents also became more proficient in giving cancer related care, which led to feelings of control for the child.	“Mummy is the only one on this ward who knows where the tape sits best– I want her to do it (five-year-old girl).” (Page 5)	X			F23
Darcy et al. (2019)	A strong need for control over decision making was expressed by the child both when in contact with hospital services and in their everyday life.	“I decide which finger to stick and what number to count to. I get to press the button on the lift too – don't I Mummy? (three-year-old girl).” (Page 5)	X			F24
Darcy et al. (2019)	It was with a sense of pride and determination they described how they liked treatment related procedures to be carried out and their own participation, as decided by them.	“I push my own medicines down this nose tube with this (syringe) … Mummy is allowed watch me (five-year-old girl).” (Page 5)	X			F25
Gibson et al., 2010)	Older children wanted to be spoken to and given information directly by hospital staff.	‘‘They speak to Mum first, they should talk to me first (John, 12 years old).” (Page 1401)	X			F26
Gibson et al., 2010)	Many older children felt they were not given enough information about their illness and treatment.	‘‘They tell you the medicine will make you better but they don’t tell you how it works’ (Paul, 12 years old).” (Page 1401)	X			F27
Gibson et al., 2010)	Being given information about waiting for treatment was an important issue.	‘‘They could tell me what was going to happen and when it will happen that would help, they just keep you waiting and they don’t tell you why’ (Robert, 9 years old).” (Page 1401)	X			F28
Gibson et al., 2010)	Lack of information made children worry the changes they were experiencing would be permanent.	“I hated the steroids because I couldn’t stop eating. I was worried I was always going to eat like that … I got really fat and I was worried I would stay like that. I think they should warn people about that (Paul, 12 years old).” (Page 1401)	X			F29
Gibson et al., 2010)	For young children, parents were represented as being the most important people when in hospital. Siblings and friends were also important at all ages and many missed seeing them; however, it was important that parents were always present.	‘‘Didn’t like being on my own in a room, it was scary when Mummy had to go’ (Kelly, 6 years old).” (Page 1402) “They give you so much confidence, always being there, helping you. . . they sort of do anything to make you feel comfortable and happy (Shima, 14 years old).” (Page 1402)	X			F30
Gibson et al., 2010)	Children also recognised their parents’ suffering and suggested health professionals make efforts to specifically help parents cope during their children’s treatments.	“They could say, ‘Why don’t you hold her hand?’ Mummy was just sitting there not knowing what to do (Harry, 6 years old).” (Page 1402)		X		F31
Gibson et al., 2010)	They appreciated it when doctors and nurses listened to them, made an effort to get to know them as ‘‘people’’	“They are interested in your social life, your other life, your hospital life and your home life. They just remember what you tell them about (Holly, 13 years old).” (Page 1402)		X		F32

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
	and ‘‘chatted’’ to them about their life. This made them feel ‘‘special’’ and like ‘‘a person and not a patient.’					
Gibson et al., 2010)	It was also important nurses were reliable.	“Sometimes they say they will play a game and then they don’t come back … promised to come back but I knew when it was 8 o’clock she was not coming back (Michael, 7 years old).” (Page 1402)	X			F33
Grealish et al. (2013)	They reported that when staff enforced rule structures, this felt patronizing and inflexible. The quotation below illustrates how participants identified staff responses as blocking their ability to access their own coping mechanisms and a detriment to their own recovery.	“E—when I was at (Y) they wouldn’t let me out for walks that annoyed me and me worse no freedom it was terrible . . . you need to free to do your own things and not treated like a little kid . . . you need power and if you don’t have that you can’t do anything.” (Page 140)		X		F34
Grealish et al. (2013)	Young people specified that feeling in control of their symptoms meant that they felt less confused, more able to ignore auditory hallucinations, less anxious and more able to utilize other coping mechanisms.	“H—it (empowerment) helps to stay in control and just not do it not to do what the voices say.” (Page 140)		X		F35
Grealish et al. (2013)	Participants also noted that if they perceived clinicians not to be listening, they had less confidence that the clinician would know how to help.	“C—Yes that’s it they were always reassuring me and talked in a nice manner. That helps a lot when you are feeling ill. I think when someone listens to you, you get better and more better, they understand me more and what I’m trying to say.” (Page 141)			X	US4
Grealish et al. (2013)	Participant A shows that the need for consistent, clear and accurate information about their treatment, symptoms and services was seen to facilitate feeling empowered.	“A—They were so good at explaining things, they’d keep explaining things until I understood them and they didn’t use big words.” (Page 141)		X		F36
Grealish et al. (2013)	Participant T indicates how he or she felt about discussing symptoms when with a staff member he or she recognized as open to such approaches.	“T—I feel comfy asking them for help I would just go up to them and say can I have help like other places I don’t go to up to them about it I end up being silent.” (Page 141)		X		F37
Grealish et al. (2013)	Participants described a difference between self-acquired coping styles and those which are learned from others. They reported needing clinicians to combine providing support for individual coping styles as well as teaching alternative techniques	“J—Sometimes they haven’t done anything with me about how to cope with the symptoms but at the Unit the nurse she was doing things with me about how to recognise the early warning signs and she did stuff on anger management with me.” (Page 143)		X		F38
Lee et al. 2019	The role of the child as passive participant is conceptualized the situation where the children being overshadowed by their parent or nurses and were least visible within the decisions process.	“Alexis, 11 years, diagnosed with chronic lymphoblastic leukaemia, was admitted for chemotherapy. He was under the care of Alma (the nurse). At his unit, Alexis is sitting on the bed watching TV. Alma (the nurse) comes in and informs his parent, Jenny, that they must transfer to a single room because Alexis is suspected of having an eye infection. Alexis appears distracted by the conversation between Alma and his parent. He stops watching TV and turns to Alma but does not say any words. He seems interested and continues listening to the conversation. Jenny asked, ‘‘How long do we have to be in that room?’’ Alma answered, ‘‘Until the blood culture result is normal, then you will be transferred back to the shared room.’’ Jenny smiles and says, ‘‘Hopefully not long, I don’t like the room because it feels isolated, no friends to chat with.’’ Without a verbal response, Alexis continues observing the conversation between his parent and Alma. Neither Alma nor Jenny involved Alexis in the discussion.” (Page 717)	X			F39

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Lee et al. 2019	Some of the children were not regarded as passive participants in the communication process in terms of being prevented from participating, and rather they took on this role willingly.	"I don't mind, I usually hear what they discussed. I knew it. Even if I don't know, my mum will definitely tell me later on. So, it's okay if nurses do not tell me … and … if I want to know something, I can just ask them … (Emelda, 12 years)." (Page 717)		X		F40
Lee et al. 2019	The role of the child as active participant conceptualizes the situation where the children were most visible within the communication and decisions process. In this situation, children were able to voice out their wishes in the communication process.	"Alexis, 11 years, has a severe mouth ulcer and experiences severe pain. Ann, the nurse in-charge of him, comes in to his unit to commence an IV Morphine infusion for him. Ann told Alexis that she is going to start the medication to ease the pain. However, Jenny (the mother) told the nurse to give the medication after her child takes his breakfast. Alexis appeared in pain and informed the nurse to give the medication straightaway, with the hope that he can eat peacefully after the medication is infused. Jenny, without any objection, just smiles and looks at her son. Ann, without delaying start the infusion as requested by Alexis." (Page 717)		X		F41
Lee et al. 2019	In this scenario, it can be seen that whenever the opportunities were given to the children, they would take the opportunity.	"Albert, 8-year-old boy is under the care of Bella (the nurse). Albert is on nasogastric tube (a narrow bore tube passed into the stomach via the nose) because he refuses oral medicine. In this case, the tube is mainly for the purpose of giving oral medication. He is scheduled for the change of RT. During the removal of the tube, Albert appears calm, he follows Bella's instruction to breath in and out, and he does not struggle or cry. The tube was successfully removed without difficulty. When Bella prepares to reinsert the new tube, Albert starts to cry, and he refuses the reinsertion. He pushes Bella's hand away. Bella, with a firm voice, says: ''If you are willing to take your medication orally, I will not insert the new tube.'' Albert continues crying. Bella repeatedly tells Albert that the RT will not be inserted if he is willing to take his medication by mouth. A bit later, suddenly Albert in a crying tone says: ''I will take the medication by mouth.'' Albert promises to take the medication by mouth. Finally, Bella decides not to reinsert the tube and gives Albert time to take his medication. Before leaving, Bella reminds Albert that she will come back to check if he has taken his medication." (Page 717)		X		F42
Livesley & Long (2013)	The children with more experience of admission to hospital had developed a good understanding of the importance of being admitted to the right ward and this included having confidence in the skills of the ward staff.	''I'd rather stay here [at home rather than go elsewhere than the study ward] It's that they [staff elsewhere] don't know what they're doing … they're not specialised and that …'' (Sarah 15 yrs). (Page 1298)		X		F43
Livesley & Long (2013)	Some children used supportive adults who accompanied them to achieve this in a variety of ways.	''My dad was there, and he was asleep. I couldn't move and I needed a drink. I tried to reach out for his leg, but his leg was pulled in … I was throwing teddies at him.' (Ciara 12 yrs)" (Page 1299)			X	US5
Livesley & Long (2013)	The staff and children worked towards different goals and experienced different realities. The children wanted to be more like other children while the staff were focussed on getting the job done.	"A field entry had recorded Sam shouting 'nurse' repeatedly. Kelvin (12 yrs) also pestered his father. He repeated 'Get her, get her, get her' until his father relented and interrupted a busy nurse. A different strategy was used by Peter (9 yrs) when he insulted his grandmother in frustration at her accepting a staff nurse's advice that his catheter, which he was convinced had been dislodged, was fine. ''You're fat!'' (Peter 9 yrs)" (Page 1299)		X		F44
Livesley & Long (2013)	The children's coping strategies were often disregarded.	"On one occasion, Kelvin suddenly became intensely alert when an agency nurse approached his bed from the side where his urine drainage box hung. He winced. She		X		F45

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
		told him; ‘‘Don’t try to tell me that it hurts if I touch this, because I’ve had the same thing and I know it doesn’t hurt’’ (Agency nurse).” (Page 1299)				
Livesley & Long (2013)	Kelvin’s desire to be more like other children was a strong factor in his acceptance of painful hospital treatment.	“Kelvin’s desire to be more like other children was a strong factor in his acceptance of painful hospital treatment. ‘‘I was trying to get the catheter. . . to not be there, so not to have to have it anymore … Because you can be normal again …’’ (Kelvin 12 yrs). He had endured over 50 surgical procedures, two previous attempts to repair his urethra and bladder neck, and he had travelled, with his father, more than 200 miles to the study ward for a third attempt. He was a knowledgeable patient and knew that his stitches could become infected if they became contaminated with blood or faeces. ‘‘Because the blood can infect it, then I would have to get another operation …’’ (Kelvin 12 yrs,). Having his requests ignored left Kelvin feeling ‘sad’ and that he was ‘not being treated properly’.” (Page 1300)	X			F46
Livesley & Long (2013)	Young children have the capacity to make moral judgments on the nurses that work with them and that they preferred nurses who did things properly and on time.	“Another boy (15 yrs) was lying on his bed and occasionally, he winced. He explained that he was in a lot of pain and that his nurse knew this. He had been waiting for pain relief for at least 30 min. The boy had retreated to his bed and was lying very still in order to manage his pain and derive some comfort. When told that he needed analgesia the staff nurse responsible responded abruptly.” (Page 1300)			X	US6
Livesley & Long (2013)	These children not only spent many hours on their own in their beds, they were witnessed having their individual needs overlooked. However, there were also examples of children that repeatedly shouted, being ignored.	“Sam would often shout for a nurse. On one occasion he was concerned that one of his stents had moved. ‘‘It’s coming out, it’s coming out, it’s coming out’’ (Sam) ‘‘No, it’s not.’’ (Sam’s mother) ‘‘Mum, that’s what it was like last night when it came out. Get a nurse!’’ (Sam) ‘‘Nurse!’’ (Sam). Shahana reassured Sam that the stent was alright. When she left he shouted again. ‘‘Nurse! Nurse! Nurse! Nurse! Nurse!’’ (Sam) Shahana passed by his bed on her way to the treatment room. ‘‘See what I mean, Mum. . . they always say ‘wait a minute’ then they never come.’’ (Sam).” (Page 1300)		X		F47
Manookian et al. 2014	Despite the warmth and love that the children received and expressed, they sometimes experienced deep sorrow when they witnessed their families’ sadness.	“Yesterday, I saw my mother crying behind the window; it was so difficult for me to see the scene . . . when I am sad, she always comes to me and comforts me . . . now it is terrible, as I understand that she is so worried about me and I am not able to do anything to comfort her. (14-year-old boy)” (Page 317)	X			F48
Manookian et al. 2014	The common experience of all children was the feeling of loneliness. All longed for home and their families. They felt alone because of the altered family life.	“I want to be with my sister and play with her … it is so boring here … there is no one to play with … my sister always comes to visit me, but I want to play with her … yesterday, I cried because the nurses didn’t let her stay with me … they always tell me she should go back home, and they don’t let her stay with me for a longer time. (8-year-old girl)” (Page 317)		X		F49
Manookian et al. 2014	Any uncertainty caused adverse psychological effects to the children, such as experiencing a sense of fear, which could be alleviated by correcting and misunderstanding and by giving clear and understandable answers to the	“I was so scared when they told me that they were going to start my transplantation process … I started to cry and felt terrified. My mother took my hand and said that there was nothing to be scared of, but I was so frightened when they inserted the syringe needle into my body … it was a terrible feeling. (10-year-old boy)” (Page 317)	X			F50

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
	children's questions about the illness, treatment, and prognosis	"No one said anything about the process; at first, I thought it was like a surgery, and I was very afraid because I didn't know what was going on, and sometimes I thought it would be a very painful procedure. They should have given me more explanation about the treatment. (14- year-old boy)" (Page 317)				
Manookian et al. 2014	The need for delicate care was explicitly mentioned in the children's stories; most of them described healthcare professionals as kind, caring, and affectionate individuals.	"The good memories of nurses will stay in my mind; they are so kind … they always remind me that I am not alone, and they are my friends … sometimes, they play with me or tell stories … when I am sad, they make funny faces. (6-year-old girl)" (Page 317)	X			F51
Montreuil et al. (2015)	Children reported feeling understood when nurses took the time to get to know them.	"I prefer when the nurse listens to us, then asks us like a few questions, and then, he listens and then, he understands." (Page 853)		X		F52
Montreuil et al. (2015)	Nurses building relationships with children by getting to know them through listening, talking, and trying to understand was identified as an important component of helpful care.	"[The nurses] know about what I say, they understand." (Page 853)			X	US7
Montreuil et al. (2015)	A child described why working with the child to adjust care to the individual's capacities is a helpful strategy.	"It's us [the children] who know what our limits are, what we can do … the nurses are not in our situation, sometimes … they can overestimate or underestimate us." (Page 853)	X			F53
Montreuil et al. (2015)	Helpful nursing for parents and children included the nurses' consistent presence and availability whenever the child needed them. One child contrasted nurses' availability with that of other mental health professionals in an inpatient setting.	"On the other hand, a nurse, if you need to see him, let's say you mention it's very urgent … they will really come right away." (Page 853)			X	US8
Montreuil et al. (2015)	When asked to describe helpful interventions, one child highlighted her nurse's calm communication approach and further explained.	"I'm sure that nurses don't really scream after someone … they say it nicely." (Page 854) "It's maybe not to yell after, but just to warn more calmly, instead of yelling." (Page 854)			X	US9
Montreuil et al. (2015)	One child described how an outpatient nurse's practice of making time for parents was helpful to her mother. The fact that nurses remained available to parents and explicitly made time for them was deemed helpful by both parents and children.	"Well, I'm sure my mom was always a bit sad, like, about my problems. But I think she knew that [the nurse] was always there to help her, to help me." (Page 855)		X		F54
Montreuil et al. (2015)	These are examples of how nurses supported parents through difficult times by being present and attentive to their needs, and sharing information and perspectives in away that parents found comforting.	"Sometimes, my father, he really likes to talk, and sometimes the nurse takes him and they talk for like 15 minutes." (Page 854)		X		F55
Montreuil et al. (2015)	Specifically, parents and children agreed on the importance of nurses keeping parents informed. One child pointed out that she was not always ready to disclose issues directly to her parents, but she wanted them to know.	"Interviewer: You think it would be more helpful if there was more communication between … your nurse and your family? Child: Yes, because … sometimes, when I do something like, bad, or I don't feel well, and the nurses know it … me, I won't say it [to my parents], but I find that in a way it's important that parents know it." (Page 855)	X			F56

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Montreuil et al. (2015)	Through her story, the child exemplified using this strategy to successfully manage symptoms associated with her own mental illness.	“You say like … ‘Oh, I have a headache’ and then you say: ‘Oh, no, I’m gonna throw up,’ but like my thinking [had to] be logical, she would explain that to me … it was really, really good.” (Page 855)			X	US10
Montreuil et al. (2015)	Another intervention that nurses used to help patients learn different coping strategies was distraction from harmful thoughts, as explained by one child.	“When I felt like hurting myself, [my nurse] advised me to stay in the living room and to keep my hands busy, to play cards.” (Page 856)		X		F57
Montreuil et al. (2015)	Similarly, children found it helpful when nurses acknowledged their feelings and helped them by providing specific strategies tailored to the child’s needs.	“Note down what you like to do so that when you’re feeling … stressed out you can just do [those things] to make you feel better.” (Page 856) “Sometimes, it’s hard for me to go to the nurse to ask for help, [so] she told me that, instead of asking directly for help, I could just, for example, sit close to the nursing station, and then she would know that something was going on.” (Page 856)	X			F58
Montreuil et al. (2015)	Adjustments to the social environment were described as ways for nurses to foster relationships between children on the inpatient unit. For instance, one child stated that it would be beneficial to have an introductory activity when a new child joined a unit.	“It would have been fun to have an activity with all the patients, because when we arrive we don’t know anyone, and it’s hard to introduce yourself in the beginning. It would have been fun to have activities to introduce yourself.” (Page 856)			X	US11
Nabors & Liddle (2017)	Children with illnesses reported liking having their parents and siblings close by them or with them while they were in the hospital, and thus siblings were another source of support for patients.	11-year-old Caucasian female patient: “Her mommy (points to the Mommy paper doll) will pretend to be an animal. The Mommy is going to take care of her in her bed.” (Page 1685) 5-year-old Caucasian female patient: [How does each person in the family help the sick person out?] “By doing kind stuff.” [What kind of stuff?] “Like getting water and help them eat.” (Page 1685)		X		F59
Nabors & Liddle (2017)	Doctors and nurses were also viewed as supportive persons and random acts of kindness were reviewed, and these acts of kindness made a positive difference in characters’ lives and emotional states.	6-year-old Caucasian male patient: “What makes the child in the hospital (in his hospital) strong? When a nurse helps them (he pointed to all of the characters in his hospital scenario).” (Page 1685)			X	US12
Nabors & Liddle (2017)	Five of the patients and two of the siblings endorsed sadness. Patients often were sad, because they were confined to bed or to a room and were not able to carry on with their normal lives.	“Well, she can’t move her arm at all with an IV in. Like yesterday, my nose was itchy and I almost knocked myself out because I had an IV in this arm and could not move it and my cast on this arm.” (Page 1866) 11-year-old Caucasian female patient: “Here’s me in the hospital every month. I had to lay in bed and not eat or drink. I had water and Gatorade. I had to try to wait it out. I was always in the hospital and missing field trips. I was sad that I missed out on things my school had. I missed out on being with my friends at school.” (Page 1867) 11-year-old Caucasian female patient: “Because they don’t know what is going to happen to her.” [What do they think is going to happen?] “Anything could happen. No one knows exactly.” (Page 1687) 11-year-old Caucasian female patient: [Do you think she feels lonely?] “Yeah probably.” [Why do you think she feels lonely?]“Because she has to lay in a bed, day after day. She can’t see any of her friends.” (Page 1867) 5-year-old Caucasian female patient: [How do the girls feel?] “Sad. So do their parents.” [Why do they feel sad?] “Because they don’t get to play.” (Page 1867)	X			F60

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
		5-year-old Caucasian female patient: [Do the girls feel scared?] “Yes.” [Why?] “Because they are by themselves.” (Page 1867) 11-year-old Caucasian female patient: “I used to worry a lot because of my pain.” She used to wake up and be scared and worried because she knew it was coming (a pancreatitis attack). (Page 1867)				
Nabors & Liddle (2017)	Three of the patients and two siblings reported not liking doctors or nurses. Not liking doctors and nurses typically had to do with perceiving them as those who administered needle sticks or as persons responsible for painful procedures.	3-year-old Caucasian female patient: “I don’t like nurses and doctors who poke me. They can’t find me here” (Page 1867)		X		F61
Olsson et al. (2015)	Participants highlighted the need for personal meetings with HCP's, which includes; registered nurses, physicians, nurse assistants, play therapists and physiotherapist, particularly professionals who would listen to them, get to know them, and see them as individuals.	“You get a relationship with the nurses. (Male, 16 years)” (Page 577) “Yes, and they make jokes and make you happy and so on. (Male, 17 years)” (Page 577)			X	US13
Olsson et al. (2015)	Participants wanted HCPs to deliver the information on treatment and side effects in a manner that was easily understandable.	“I gained a lot of weight and I had no idea there was going to be such a huge change in my body, it was a shock to me … so I wished they would have been a bit more clear about the side effects. (Male, 17 years)” (Page 578)		X		F62
Olsson et al. (2015)	Regarding knowledge of relationships and sexuality, participants lacked information on the subject and expressed a need for increased discussion.	“One thing I have thought about after my treatment is that I was never informed about … I had testicular cancer … was never informed about how it could affect my sexual ability and so on … that is funny. (Male, 17 years.)” (Page 578)		X		F63
Olsson et al. (2015)	An age-appropriate communication is needed.	“It was very different among the nurse … some treated you really well and some talked to you as if you were a small child and yes … it was so wrong. (Female, 17 years)” (Page 578)	X			F64
Olsson et al. (2015)	They expressed the need, at times, to talk with the physician, with or without relatives. They wanted HCPs to make this routine. Participants described the need for a time-out from relatives now and then.	“If someone asks if you want to talk to the doctor on your own, it is easier to say yes…than to tell your parents to leave. It takes a lot of courage to ask your parents to leave the room. (Female, 18 years)” (Page 579)		X		F65
Olsson et al. (2015)	Teenagers treated at paediatric units used parents in the beginning as protectors and care mediators. They wanted to have someone to support them when they communicated with a physician.	“I remember once when I was at the ICU I couldn't have my parents there. It was the first time since I started treatment and I asked, why can't they be here? (Female, 17 years)” (Page 579)		X		F66
Olsson et al. (2015)	Participants found it difficult to maintain relationships outside the family during treatment and described a need for HCPs to support them by providing information to friends and family.	“The nurses helped me directly with information … that was great, they talked to my teachers and friends at school. That was so good I did not have to do it myself. (Female, 16 years)” (Page 579)	X			F67
Petronio-Coia &	The children in this study recognized that the nurses who were approachable created an environment as one of	Dan commented, “the nurses here smile and make me feel like the hospital is like my home.” (Page 20)	X			F68

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Schwartz-Barcott (2020)	cheer and optimism. Clearly, these children are more likely to approach a nurse who is smiling and happy as they describe this as an open invitation to interact.	Jayson “felt welcomed (on the unit). I felt like I was destined to go there.” (Page 20) Jayson summed this feeling up well as he said, “They would always smile. Always! They were never sad. They never frowned. They were just always happy…that made me feel welcomed and happy to be here.” (Page 20) Riley said “I like to see people with a smile on their face all the time. It makes me feel more comfortable to talk to them and that's what I feel.” (Page 20) As Dan expressed, “I think when a person is smiling, you feel less tense and scared. It makes it easier to talk to them because they seem happy.” (Page 20) Max responded that “always having a smile helps make the kids happier … so it's not like a sad place.” (Page 20) Hobbs noted that the smile needs to be authentic as she described a student nurse who “would try to be too happy and perky and it kinda got a little annoying after a while. They should just be themselves … and not smile all the time because that's annoying.” (Page 20)				
Petronio-Coia & Schwartz-Barcott (2020)	All seven children expressed the feeling of great joy in the hospital when the nurses were “fun and funny” and found these nurses easy to approach. They described the nurses as often telling jokes, “pulling pranks” or just having fun. They forgot that they were in the hospital when they were having fun and laughing.	Riley said that when the nurses make things fun and easier to do like taking medicines it “makes me feel like they care a lot and they want to help you take the medicine.” (Page 20) Riley said “He makes me feel the most comfortable because he's funny. He makes me feel good inside.” (Page 20) Jayson said “He's funny. He would sometimes come in with a syringe with water and squirt it but not at me so I had got a syringe with water and squirted it at him.” (Page 20) Dan drew a picture of this nurse as his favourite and said “He has a big grin and is always happy and funny. I think the perfect nurse should be kind, funny, friendly and the opposite of serious.” (Page 21) Kris said “I like funny people. I don't like people that are kind of boring and they don't really do much stuff and they are kind of grumpy.” (Page 21) Max spoke of another nurse who “would tell stories that are funny” and “his stories were funny and made us smile a lot” (Page 21) Carley liked “fun nurses” who “usually danced to the Lion King songs” in her room. (Page 21)	X			F69
Petronio-Coia & Schwartz-Barcott (2020)	Talking and listening to the child helped to establish a relationship and showed genuine concern that the nurse cared and wanted to help. The children seemed to get a sense that when the nurses took the time to listen to them and “really show they care” by helping with the little things, they felt the nurses truly understood them and how they felt. The children enjoyed talking to nurses with similar interests.	Hobbs mentioned that nurses come in regularly, “they do it a lot, to check in on you and make sure you are doing okay” and they understand that “sometimes you feel lonely because you want to go home even though you know that there are people around you.” (Page 20) Jayson stated that approachable nurses “should always know how the kid is feeling. If the kid is feeling sad, they can help with that. If the kid is happy, they could play a game with them.” (Page 20) According to Hobbs nurses should know “children are not always happy even if they look happy…Like you might not feel good, but you try to like not, not feel good even when you have the medicines that are going to try to help you feel better.” (Page 20) Max said, “it is nice to talk to a nurse who has things in common with me.” (Page 21)	X			F70

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
		Hobbs enjoyed time talking to the nurses because she said it made her feel less lonely and when the nurses talked to her it made her “feel good inside because I am not just their patient, I can talk to them. I am not just a kid in the hospital. I am someone. I can talk to them and they can talk to me.” (Page 21) Max said about his favourite nurse “he'll talk to us and we'll have conversations and when we get admitted, he'll usually, even if he's not our nurse, come from a different pod to say hi.” (Page 21) Kris said “I certainly don't need any nurses coming in that don't really feel like coming in.” (Page 21)				
Petronio-Coia & Schwartz-Barcott (2020)	Nurses who showed they cared by going above and beyond the tasks to complete in a shift were most approachable and easiest to talk to.	“I know the nurses that usually give me the medicine, whenever we come in, and they say hi and when I know the people who are doing anything and they also know some stuff about me, they have conversations with me that aren't awkward and everything” and this “makes the nurse seem more like a friend than a nurse.” (Page 20) Max said “When they are wearing scrubs, I like pictures on it because it shows you a little about them and what they like in their clothes and this is the type of person who would go up to you and start a conversation… that makes them approachable.” (Page 21) Jayson spoke of the “little things” his favourite nurse did to creatively help him. He spoke of hitting his port-a-cath needle into his lunch tray and this nurse took the time to create “a blocker so that when I bumped it, it wouldn't push my needle and I decorated it because I love to do artsy stuff.” (Page 21) Kris described her drawing of the perfect nurse, an imaginative unicorn, as one “who can fly so it can get stuff like medicine really fast.” (Page 21) Carley said she felt safe with the nurse who was able to help her quickly when she was having an allergic reaction to a platelet transfusion and couldn't breathe and then another who she described as “a very good nurse…doing everything perfect for her patients.” (Page 21) Dan was able to acknowledge the importance of competence as he was affected by the lack of it while in the emergency room and said “the only problem with the port is when you go to the ER and I have a new nurse who does not know how to access it. That is a problem.” (Page 21)	X			F71
Randall 2012	The data quoted below shows how some of the children had a positive regard for nurses. These children understood and were able to articulate the reasons they had a nurse visit them.	“PI Why does a nurse come and see you? Nanny To have my needle. PI You have a needle? OK why do you have a needle? Nanny Cause I have growing spurts. PI You have growing spurts. So what does the needle do? Nanny Makes me not grow as quickly. PI Right OK, so is there something, is it a medicine that you have? Nanny Yeah. PI Right OK. Nanny It’s like medicine in the needle.” (Page 95)		X		F72

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Randall 2012	Children with a positive regard for nurses found it difficult to suggest ways in which nursing services could be improved.	PI In your diary you were talking about how when your nurses came and they had real fun with you they tickled you, but when [names CCN] came today she didn't do that, she didn't tickle you didn't play any games with you or [names brother] she pretty much came, gave you your injection, wrote the notes . . . Kelly . . . and went PI and went yeah Kelly because sometimes like the nurses that tickle me like they've been to every single house and I'm like the last one so" (Page 98) "Co-worker 4 Yeah but what about the not so good nurse? Nanny I've never had a not so good nurse. Co-worker 4 . . . You must know what makes a good nurse, so what do you think would make a not so good nurse? Can you think of anything that you wouldn't like? Nanny Well I had a doctor put a needle in me when he said I promise I won't do it, and he did it." (Page 98)			X	US14
Randall 2012	The children with a negative regard appeared to be less involved in the care they received.	"During the observation of Gizmo he was held by his mother while a nasogastric tube was passed. The children were not passive in receiving care, Gizmo wanted the tube put into the same nostril, but was overruled by the nurse (see field notes below). The involvement allowed by adults (parents and nurses) was often restricted for children and this seemed to be especially so for children with a negative regard: CCN ready, suggested Gizmo taken on to Mother's lap, Mother cradles Gizmo restraining his arms as she removes his old tube. CCN suggests different nostril for NG tube. Gizmo upset wants the same side. CCN insists, some explanation, do not want to get sore. Mother restrains Gizmo while tube is inserted, Gizmo very upset crying. States he hates nurse. When over cuddles into Mother. (Field notes observation Gizmo)" (Page 99) "PI How are the ones [the nurses] who come and see you at home different then do you think? Gizmo Don't like them I hate them. PI I know, I know, you said that. Why is that? Gizmo Pulling my tube. PI What about when they come and give wiggly* a drink what's that like? Gizmo The same. PI Yeah [pause]. Gizmo Put that one on as well. PI How do you think they could make it better for you, the nurses? Gizmo By playing. PI By playing a bit more [names CCN] did didn't she? When she came in you were playing doggie, you were hiding in there, yeah. She came and tickled you didn't she? Gizmo She made me laugh. PI Do you remember that? Gizmo She never found me though.			X	US15

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
		PI She did! She was playing a game with you though wasn’t she? Gizmo Yeah, but the idea is to play more games than one game. PI Yeah spend a bit longer with you, would that help mmm . . . Gizmo But not the tube. PI No the tubes do, don’t like the tube, but does the tube make you better? Gizmo Yeah. PI Yeah and it has to be changed doesn’t it? Gizmo I hate it though. (Gizmo: interview after observation)” (Page 100)				
Randall 2012	Children’s position on this continuum of regard for nurses and nursing may be determined by their understanding of their illness and the extent to which adults allow them to be involved in receiving care.	“PI Why do they come and do dressings? Mohammed Because I got poorly skin. PI Poorly skin? How long have you had poorly skin? Mohammed For a hundred years PI Hundred years? Mohammed Since I was born new baby (Mohammed: photo talk diary interview) PI When a nurse comes to see you at home, what happens? Mohammed They don’t come Monday, Tuesday, Wednesday PI What sort of thing happens when they come, what they do? Mohammed Nothing. PI Nothing? Mohammed They just do my dressings. (1st children’s group)” (Page 100)			X	US16
Rindstedt & Aronsson (2012)	Children observe in order to figure out the processes that they later expect to engage in. In many ways, she was thus engaged in intent community participation and informal learning, as an eager and diligent patient.	At the clinic, Elinor, one of the preschool-age children, repeatedly positioned herself as an eager learner. Being an “old-timer” at the unit, she participated intently in what was going on and could anticipate the nurses’ routines. She often knew what was coming next (before it occurred). During the interaction with the hospital staff, she often inquired about what they were doing and why they did things in a particular way. She would, for example, ask why they had not marked the test tubes or the foot of her bed with her name tag. On another occasion, she asked why she had not received a drip (*dropp*) yet. Furthermore, at times she pointed out that there were bubbles in the empty silicon tubes or that the tubes needed untangling. When an assistant nurse measured the urine collection, Elinor would comment on the amount. (Page 329-330) In another episode, another staff member jokingly talked about Elinor’s “princess blood” (Example 5, Line 10). Such joking formats are quite typical for the exchanges with the young patients. Both nurses and doctors routinely made playful or joking comments. (Page 331)	X			F73
Rindstedt & Aronsson (2012)	The nurse conjures up a world of magic (e.g., abracadabra; Lines 3 and 21), turning treatment routines into a more interesting type of event. In all these cases, the little girl responds positively by saying “yes.” She	“Example 2: (Tape I30) Needle procedure. Participants: Ida (I), her mother (M), and the nurse Anna (N). M There, it flew away ((the needle)). I ((Looks at N.))	X			F74

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
	thus explicitly consents to the treatment procedure, showing that patient consent may be feasible even in the case of young children, here a 2-year-old.	N Abracadabra, you're so good ((presses the port lightly with a compress, looks at Ida and the compress)). M Yes. N What a good girl Mummy has. I am hesitant, you know, about whether I should be poking that with something. So, I think you should come back here again very soon. M I don't know when we will be here. N Wait, when did she have her operation? On Wednesday. I Take away the goo ((looks at N)). N Shall we take away the goo? I Yes. N Let's do that then. It's been a week. M ((Laughs)) I Yes ((looks at N)). N Let's see, then. Yes, we'll take away the goo and get you spruced up. I Yes. N Shall we do it? ((Tilts her head to the side, smiles.)) I Yes. N Let's see, then. It still looks a little bruised after the operation. Take away the long abracadabra but (.) my, what a good girl you are. Eh? ((Loosens the bits of tape from the port.)) M ◦Very good◦. N Now it's all gone. And there was a little goo on it. Do you see it? I Yes ((looks at N)). N But now it's going to be nice and clean. (. . .)" (Page 332)				
Rindstedt & Aronsson (2012)	As in the previous example, Ida is permitted to be involved in her own treatment. The children soon show familiarity with medical routines such as the repeated needle procedures.	"Example 3: (Tape I36) Needle procedure. Participants: Ida (I), the nurse Emma (N), the mother (M), and Ida's brother Filip. N Hello (.), hello ((to Filip)). M Do you want to- I Take the window band-aid off ((waves her arms))!∗ M Who is allowed to take it off? I You! N Shall I do it? I No, Mummy ((waves her arms))! M Is Mummy allowed to take it off? Shall we look and see if we can find it (pulls up Ida's top))? No window band-aid here. I The Port-a-Cath." (Page 334) "Example 4: (Tape I31) Participants: the nurse (Peg) is cleaning the silicon tubes hanging from Ida's port. Ida is sitting on her mother's lap, and her brother is standing in the background. N ((Gets another syringe.)) M But you know what this is now, don't you ((referring to a familiar syringe))?		X		F75

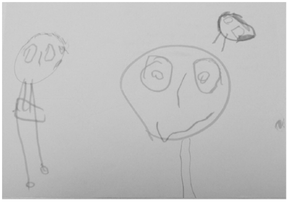
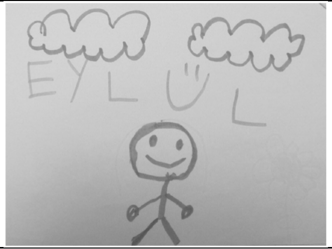
Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
		I Peppari::n. M It’s pepparin. N Peppari::n ((smiling voice, squats in front of Ida)). You are so good. Heparin! ((Smiles)) M Pepparin! ((Laughs, looks at N.)) N Pepparin. That’s right, it’s pepparin ((nods)). M It’s pepparin.” (Page 334)				
Rindstedt & Aronsson (2012)	The children in this study were repeatedly invited to take part in treatment practices. As can be seen, Elinor is willing to be involved and is very much part of the shared treatment endeavour. Moreover, she seizes the opportunity to help out by connecting the test tubes (Line 20), engaging in a collaborative treatment practice.	“Example 5: (Tape E10) Blood tests. Participants: Elinor (E), her mother (M) and father (F), and the novice nurse (Rickard), as well as the experienced nurse (Bengt). Elinor’s mother is sitting on a bed with Elinor lying in her lap. NR (Nurse R) Let’s take this sodium chloride injection. NB (Nurse B) There ((injects into the tube)). NR Okay. Now I’m going to flush it a little. E ((Follows NR with her eyes.)) NB It will be fine. Just wait and see. Go on. It’s going really well. M Mm. NR Yes. NB And now pull up about two or three millimetres. E There’s blood coming ((looks at the tube and syringe)). NB Yes, we got some princess blood. M Can you sit up a little more? E ((Sits up)) M There. E Why do you just have two test tubes? M ((Laughs)) E ((Looks, picks up a test tube.)) NB These are all the tests we usually take, you know. Do you want to hold them? Do you usually put them in? ((Gives the test tubes to E.)) F Mm. E ((Helps to put the test tube in place, looks carefully at what is happening.)) NB Done.” (335- 336)	X			F76
Spratling (2012)	They want nurses to ask them about themselves and get to know them as individuals.	“… be like, more open to you. Like, some nurses they just come and they just take your, you know, information down and they just kinda leave. But if they’re actually engaging a conversation with you and they kinda get to know you a little bit better … I think it helps you get a little bit more comfortable around them.” (Page 2744).		X		F77
Spratling (2012)	Brad said that adolescents should also be able to talk about how they felt about things.	“Try to allow the kids to have some sort of self … like by themselves … let them tell you how they’re feeling …” (Page 2744)			X	US17
Spratling (2012)	Isabelle stated that it was helpful when nurses get to know teens and get to know about things that teens like to do.	“… Ask them questions like, ‘What do you like? What do you like to do for fun?’ and just, you know, just that type of things.’ She considered nurses helpful when they: ‘Mostly do medical stuff … but they can also have fun with you too and taking us to, you know, play games and, you know, something to bond with the patient.” (Page 2744)		X		F78

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Spratling (2012)	The adolescents wanted to be treated as a person, as they viewed themselves, not for their need for respiratory assistance.	"Like you would want to be treated'. She said to nurses: ' … don't treat me like I'm, you know, some little fragile thing. I wanna be normal. Wanna be treated normal … treat them normal. Like, you know, like yourself, like you would want to be treated'. She included: '… I can walk, run, talk and do everything that you can do. I just have a hole in my neck … I'm still able to do things … when you're able and people treat you differently and you just like get special treatment when you don't need it kinda makes you feel low in a way." (Page 2744)	X			F79
Spratling (2012)	The adolescents described receiving special treatment or being treated differently because of their need for respiratory assistance.	"… used to go to school with me and that that was kinda annoying … it was like back in Elementary school but they would like ride the bus with me … like sit in the classroom with me and it was just annoying … 'cus they like, wouldn't be able to go like a hundred feet away from me, or something, not really, but I mean, they basically couldn't let me out of their sight." (Page 2744) "… I really don't prefer to have like a nurse at my side at all times 'cus sort of it makes me feel like I'm being like watched." (Page 2744)	X			F80
Spratling (2012)	The adolescents depended on their respiratory assistance on a daily basis while also actively striving for independence in their lives.	"… I don't have any help with my trach … we always like contact the school nurse and inform them about the trach … we took a bag up there with a copy of all, um, equipment…but I really don't need … I can take care of myself …" (Page 2745)			X	US18
Spratling (2012)	Independence is something of great concern for adolescents but may be even more so for adolescents who require respiratory assistance. They see themselves as being able to take care of themselves without assistance, despite their need for respiratory assistance.	"… I used to have a nurse that went to school with me, so, I don't have that this year. I wanted to be more independent, so I don't really have any help now … I feel like I do well, not having anybody … I'm very independent … And I can do a lot of it on my own." (Page 2745) "… there was one time … in the eighth grade … that my trach accidentally came out but I put it back in myself…they almost called the ambulance but … they didn't have to." (Page 2745)		X		F81
Xie et al. (2017)	Most children have limited knowledge about LP. In fact, children who underwent LP for the first time hardly have any knowledge about the procedure. They think it is awful to undergo such a procedure.	"When the nurse told me that I would have to undergo LP, I thought that it is a surgery, so I was really scared." (Page 3331) "I was so nervous when I heard the word 'lumbar puncture'. It must be very painful because it is 'a puncture.'' (Page 3331) "Dad and mom were not allowed to enter into the procedure room, so they left me there with the medical attendants. When I saw someone wearing white gown and big mask in the room, I became so scared that my whole body started shivering with cold sweat." (Page 3331)			X	US19
Xie et al. (2017)	Children may feel dazed while undergoing LP, and some children described their helpless without companion of their parents.	"A nurse took me into a room and made me lie on a small bed alone, but I did not know what they were going to do with me. I did not know how long I would have to lie on the bed. I also did not know who would perform the procedure." (Page 3331)		X		F82
Xie et al. (2017)	These children felt worried and did not know what to think while undergoing LP.	"Time became so slow when I was lying there, and my mind was completely idle. I didn't know what would happen to me. I thought that some terrible things would occur, and so I was very worried." (Page 3331)	X			F83

Author	Finding	Illustration	Level of evidence			Label
			UE	C	US	
Xie et al. (2017)	They were aware of emotional changes of their parents. They did not wish to cause their parents any further sadness or worry.	"When LP report was ready, a doctor called my mother. Her eyes were red and swollen when she came back, but she said that everything was okay. However, I still did not feel good (shedding tears and sobbing)." (Page 3331)		X		F84
Xie et al. (2017)	Throughout LP, most children wanted healthcare workers to communicate with them actively and enquire about their feelings. They hoped that healthcare workers would give them comfort, explanation, encouragement and praise while undergoing LP.	"While performing LP on me, nobody was talking to me in the room. It was so quiet that I could hear my own heartbeats. I was expecting that the doctor or nurse would chat with me." (Page 3332) "I love the nurse as she seemed like my aunt. She always smiled while telling me what to do. She was there to chat with me when LP was being performed. She even told me stories while performing each session of LP. I felt relaxed and didn't feel much pain while undergoing LP." (Page 3332) "Before administering an injection, I wish the doctor or nurse had told me something. For example, don't move, we are going to start the puncture. It would have eased my anxiety." (Page 3332)		X		F85
Xie et al. (2017)	They wanted the healthcare staff to care about their true feelings and their diseases.	"The doctor and nurse always provided detailed information about LP to my parents, but not me. I think I have a right to know about it because I am the one who underwent LP." (Page 3332)		X		F86
Xie et al. (2017)	Most children hoped the medical staff would not restrict or even ignore them overtly. They were expected to build a relationship of equality and mutual respect with the healthcare staff.	"I had to lie there for six hours, and the nurse only gave me a flat toilet when I wanted to pee. I wish there was a screen to hide myself while peeing. I am a shy pupil studying in the second grade." (Page 3332) "I hope that I could take my Barbie doll with me. I would not have been afraid when I was alone in the procedure room, it would have made me feel safer." (Page 3332)			X	US20
Xie et al. (2017)	Our data showed that different children have different expectations for the environment and healthcare staff performing LP. They wanted a colourful and comfortable hospital environment.	"It would be better if doctors and nurses wore cute gowns. For example, their gowns, caps, and masks could have cartoon characters on them. It would have not made me so scared, the colourful uniforms would have also distracted my attention (laughs)." (Page 3332)		X		F87
Xie et al. (2017)	In this study, we found that 10 children had the need of self-actualisation. These children expected the healthcare staff to appreciate their good performance and help others.	"I didn't move or cry while undergoing LP. I'm very happy that a nurse gave me a light pen as a reward for my good performance during the procedure. I think I'm great. I will show you my prize (laughs)." (Page 3333)			X	US21

(Key: UE= Unequivocal, C= Credible, US= Unsupported, NGtube= Nasogastric tube, TV= Television, RT= Nasogastric tube, IV= Intravenous cannula, ICU= Intensive care unit, HCP= Healthcare professional, PI= Primary investigator, CCN= Community care nurse and LP= Lumbar puncture, F1= Finding 1, US1= Unsupported finding 1)

Table 3: Extraction of qualitative data of included studies (Mixed method studies)

Author	Theme	Finding	Qualitative findings	Level of evidence			Label
				UE	C	US	
Çakirer Çalbayram et al. (2018)	<u>Drawings</u> Majority of the children in the study described nurses as a smiling face.	The child explained the picture she/he drew as "There are two sick kids. One of the kids' head is sick and the other kid has stomach problem. The nurse in the middle is looking after the sicker kid. She is going to look after the kid with head problem later. She is going to make him/her take the pill in her hand. The pill is too bitter." (Page 993).			X		F88
		The sick child drawing himself/herself as the nurse in the picture described the drawing as "Some nurses do not smile at all." (Page 995)			X		F89
		The sick child described his/her drawing as "I have left the hospital and I am picking up flowers to thank my nurse sisters." (Page 997)			X		F90

(Key: UE= Unequivocal, C= Credible, US= Unsupported, F86= Finding 86, US20= Unsupported finding 21)

Table 4: Extraction of quantitative findings

Author	Finding	Quantitative findings	Label	Qualitised statement of quantitative data
Çakirer Çalbayram et al. (2018)	The differences in the drawings involved in the study may be thought to have stemmed from different child-nurse experience relationships and different social environments.	In all drawings: 33.3% used red to draw faces (n=4), 33.3% used yellow to draw faces (n=4) and 33.3% used green to draw faces (n=4). 33.3% drew a hospital figure (n = 4), 25% flower (n = 3), 25% cloud (n = 3), 25% the sun (n = 3), 16.6% drew a tree (n = 2), 8.3% drew a bed (n = 1), 8.3% grass (n = 1), 8.3% house (n = 1). People in the drawings: 83.3% nurses (n=10), 58.3% other people (n=7), 25% the child themselves (n=3) and 4.5% doctors (n=1). No other data is reported.	Q1	The drawings represented the child-nurse relationship and how its variation based on the child themselves
Çakirer Çalbayram et al. (2018)	While determining the duties of nurses, the children in the study also stated the modern roles of nurses, and this is the indication that nursing profession has been progressing in a positive way.	The children with chronic diseases described the duties of nurses as follows: 58.3% as giving injection (n=7), 33.3% as checking blood pressure (n = 4), 33.3% attaching serum (n = 4), 33.3% looking after patients (n = 4), 25% checking body temperature (n = 3), 25% makes medicine (n = 3), 25% examining patients (n = 3), 8.3% described listening to heartbeats (n = 1), 8.3% draws blood (n = 1), 8.3% checks ears (n = 1), 8.3% assists the doctors (n = 1) and 8.3% heals us (n = 1). No other data is reported.	Q2	Children saw the task orientation and variation of nursing duties, however most associated nurses with painful procedures, such as injections.
Figueiredo et al. (2020)	Based on the adolescents' answers, it can be concluded that nurses emphasize the relationship and communication established with the adolescents and their families (confidentiality, respect for complaints, personal preferences and routines, availability to listen to and respond), which are specific nursing care in response to the specific needs of this stage of the life cycle (adolescence) and development.	The results obtained with the List of Resilience-promoting Nursing Interventions (LIER) and the descriptive data analysis revealed that the majority of adolescents mentioned having received sufficient resilience-promoting nursing interventions with a mean of 74.53 (Minimum 53, Maximum 116, SD 12.58). Highest scored answers: 1. The nurse kept our conversations confidential (3.72/4) 2. The nurse considered and took into account my complaint (3.56/4) 3. The nurse respected my preferences, habits, and routines (No score provided) 4.The nurse had a calm, open, and available attitude towards me (No score provided) 5.The nurse answered my questions, even when I did not verbalize them (No score provided)	Q3	Adolescents viewed the most important aspects of nursing was conversations were kept confidential and that nurses considered patient complaints, preferences and habits.
Figueiredo et al. (2020)	The items with the lowest scores among the adolescents fall under the nurses' availability dimension, namely regarding the articulation with the adolescent's school or healthcare centre and the maintenance of contact and communication after hospital discharge.	Lowest scored answers 23. The nurse helped me to analyse what I can and cannot do on my own (No score provided) 24. The nurse guided me to entities or places where I can learn more about my disease (No score provided) 25. The nurse alerted me to erroneous information on social networks and on the internet (or helped me find credible websites) about my illness (No score provided) 26. The nurse guided me to support networks for adolescents with the same disease as me (No score provided) 27. The nurse kept in touch with me after discharge, outside the hospital (No score provided)	Q4	Adolescents viewed the lowest important aspects of nursing as nursing having contact with schools or health centres.

Author	Finding	Quantitative findings	Label	Qualitised statement of quantitative data
		28. The nurse provided me with a means of communication to contact them. (No score provided) 29. the nurse contacted or had a direct relationship with my school or health centre (1.25/4)		
Lapp (2019)	Environment of care domain No findings reported.	Most important to least important (No other data provided): 1. Clean room. 2. Having family stay. 3. Comfort of your room. Friendly staff. Staff easy to talk to.	Q5	Adolescents viewed having a clean environment with family around as most important.
Lapp (2019)	Physical and psychological comfort domain Trust in the nurse scored utmost and far higher than that of other items in the physical and psychological domain. This finding is interesting given that adolescents are poised ready to move to the adult healthcare world and trust has been determined as the most important quality of care theme in the adult population surveys.	Most important to least important (No other data provided): 1. Trust in your nurse to take care of you. 2. Nurses wash/foam hands/keep you safe from germs. Skill of nurse taking your blood. 4. Nurse gave you medicine when needed. 5. Nurse truthful about things done to you that would hurt. Doctors wash/foam hands/keep you safe from germs.	Q6	Adolescents believed the most important aspect in nursing care was placing trust in nursing staff to take care of them and keep them safe.
Lapp (2019)	Dignity and respect domain No findings reported.	Most important to least important (No other data provided): 1. Doctor listens to you. 2. Doctor clearly told you what would happen to you. Nurse listens to you. Nurse respects your privacy. 5. Nurse clearly told you what would happen to you. Being told what your medicine was for. Understood what your doctor said.	Q7	Adolescents believed the most important aspect in nursing care was that nurses listened and respects patients.
Lapp (2019)	Autonomy domain Adolescents with chronic illnesses may have experienced multiple hospitalizations and often have extensive knowledge of their health status, and what works better for them. Therefore, they may want to contribute suggestions more, feel validated for those suggestions, and feel more engaged with the course of their treatment and care.	Most important to least important (No other data provided): 1. You felt able to tell the doctor what was wrong. 2. You felt able to ask the doctor to explain what was said. 3. You felt able to ask the nurse to explain what was said. 4. You felt able to tell nurse how much you hurt. 5. You felt able to ask questions. Questions about you directed to you/not just parents.	Q8	Adolescents believed the most important aspect in nursing care was that nursing were able to explain what was said in medical discussions.

(Key: Q1= Quantitative finding 1, N= Number, SD= Standard deviation)

Table 5: Synthesis of qualitative findings into categories.

Label	Finding	Category
F1	The children cared about the relationship of physician and nurse not only with themselves but also with their families.	Children value the child-nurse relationship.
F2	The children in this study included statements on the definitions of 'good physicians' and 'good nurses' based on smile, the way they addressed them and how they communicated with them.	Children value positive communication.
F3	Some of the children stated that the physician and the nurse should treat not only themselves but also their family kindly.	Nurses need to respect both the child and family.
F4	The children stated that they and their family should be treated with respect and tolerance.	Nurses need to respect both the child and family.
F5	Children defined a 'good physician' and 'good nurse' with the expression 'who loves children' most frequently. The other definitions of 'good physician' and 'good nurse' mentioned by children under this heading were 'well-kept', 'handsome/beautiful' and 'patriotic.	Children value the child-nurse relationship.
F6	They felt they were forced to do something they did not like to do, but the staff thought was good for them and that gave them satisfying results.	Children are aware of the nurses role.
F7	The adolescents expressed satisfaction with the opportunities and encouragement they received to express their feelings and share painful experiences with peers and caregivers.	Regular communication alleviates fears.
F8	The adolescents emphasized that they were satisfied when the caregivers treated them with the kind of respect that was manifested in being treated as a person, but not a patient. In the adolescents' view, this informal nature of the patient-staff interaction was the key to the development of a therapeutic relationship as is illuminated in the following excerpt from the interview with participant 2.	Children appreciate it when the nurse treats them as a person, not a patient.
F9	Feeling secure seemed to provide protection and brought courage and confidence to the participants as they faced the unknown of the treatment and disease process.	Children feel security and safety from their parents and family.
F10	Through delivery of quality care, provision of necessary information, care and visits of volunteers and other cancer survivors, the participants were afforded opportunities to interact with others and clarify their concerns, which resulted in augmented support and increased confidence toward the outcomes of the treatments.	Regular communication alleviates fears.
F11	Young patients narrated episodes in which they played and joked with nurses.	Nurses who are fun bring happiness to children.
F12	Children also reported pleasant sensations.	Nurses who are fun bring happiness to children.
F13	In some cases, children said they had never felt sad when they were with the nurses and doctors.	Nurses who are fun bring happiness to children.
F14	Children indicated nurses and doctors as participants in emotional events.	Nurses who are fun bring happiness to children.
F15	Shortly after diagnosis and start of treatment the child described feeling like a stranger in an everyday life that was described as utterly changed.	Children are aware of the changes in their life.
F16	Eighteen months after diagnosis, the child expressed awareness and of bodily changes which meant that their body was different than others.	Children are aware of the changes in their life.
F17	The child now lived a life where cancer did not play a central role for them. However, they were aware that they had experiences of ill-health and hospital.	Children are aware of the changes in their life.
F18	A sense of control was experienced when health care professionals treated the child with respect.	Children want a sense of control.
F19	The child described experiences of fighting for control and actively striving to make a normal everyday life of the cancer experience.	Children want a sense of control.
F20	A year after diagnosis the child made a normality of the illness and treatment by incorporating hospital visits and procedures into every day. They now expressed experiencing security and control.	Children want a sense of control.
F21	Learning to live with a changed body helped in the striving for normality and the central venous catheter and naso-gastric tubes in particular were expressed as part of themselves.	Children are aware of the changes in their life.

Label	Finding	Category
F22	Going to hospital was mostly fun and relaxing, and birthdays and holidays such as Christmas or Midsummer were celebrated there.	Nurses who are fun bring happiness to children.
F23	Access to parents for comfort and security continued to be important but parents also became more proficient in giving cancer related care, which led to feelings of control for the child.	Children feel security and safety from their parents and family.
F24	A strong need for control over decision making was expressed by the child both when in contact with hospital services and in their everyday life.	Children enjoy having a role in the decision making process.
F25	It was with a sense of pride and determination they described how they liked treatment related procedures to be carried out and their own participation, as decided by them.	Children enjoy having a role in the decision making process.
F26	Older children wanted to be spoken to and given information directly by hospital staff.	Children want direct communication from nurses.
F27	Many older children felt they were not given enough information about their illness and treatment.	Children wanted to be informed about their treatment.
F28	Being given information about waiting for treatment was an important issue.	Children wanted to be informed about their treatment.
F29	Lack of information made children worry the changes they were experiencing would be permanent.	A lack of communication increases levels of worry.
F30	For young children, parents were represented as being the most important people when in hospital. Siblings and friends were also important at all ages and many missed seeing them; however, it was important that parents were always present.	Children feel security and safety from their parents and family.
F31	Children also recognised their parents’ suffering and suggested health professionals make efforts to specifically help parents cope during their children’s treatments.	Children are aware of parental anguish.
F32	They appreciated it when doctors and nurses listened to them, made an effort to get to know them as ‘‘people’’ and ‘‘chatted’’ to them about their life. This made them feel ‘‘special’’ and like ‘‘a person and not a patient.’	Children appreciate it when the nurse treats them as a person, not a patient.
F33	It was also important nurses were reliable.	Children value the child-nurse relationship.
F34	They reported that when staff enforced rule structures, this felt patronizing and inflexible. The quotation below illustrates how participants identified staff responses as blocking their ability to access their own coping mechanisms and a detriment to their own recovery.	Nurses need to be flexible in their care to suit individual needs.
F35	Young people specified that feeling in control of their symptoms meant that they felt less confused, more able to ignore auditory hallucinations, less anxious and more able to utilize other coping mechanisms.	Children value the empowerment that comes from education.
F36	Participant A shows that the need for consistent, clear and accurate information about their treatment, symptoms and services was seen to facilitate feeling empowered.	Children value the empowerment that comes from education.
F37	Participant T indicates how he or she felt about discussing symptoms when with a staff member he or she recognized as open to such approaches.	Nurses need to be approachable.
F38	Participants described a difference between self-acquired coping styles and those which are learned from others. They reported needing clinicians to combine providing support for individual coping styles as well as teaching alternative techniques	Children value the empowerment that comes from education.
F39	The role of the child as passive participant is conceptualized the situation where the children being overshadowed by their parent or nurses and were least visible within the decisions process.	Active participation leads to children being involved in the decision making.
F40	Some of the children were not regarded as passive participants in the communication process in terms of being prevented from participating, and rather they took on this role willingly.	Active participation leads to children being involved in the decision making.

Label	Finding	Category
F41	The role of the child as active participant conceptualizes the situation where the children were most visible within the communication and decisions process. In this situation, children were able to voice out their wishes in the communication process.	Active participation leads to children being involved in the decision making.
F42	In this scenario, it can be seen that whenever the opportunities were given to the children, they would take the opportunity.	Active participation leads to children being involved in the decision making.
F43	The children with more experience of admission to hospital had developed a good understanding of the importance of being admitted to the right ward and this included having confidence in the skills of the ward staff.	Children are aware of their own health care needs.
F44	The staff and children worked towards different goals and experienced different realities. The children wanted to be more like other children while the staff were focussed on getting the job done.	Children are frustrated with being ignored.
F45	The children's coping strategies were often disregarded.	Children are frustrated with being ignored.
F46	Kelvin's desire to be more like other children was a strong factor in his acceptance of painful hospital treatment.	Children are aware of their own health care needs.
F47	These children not only spent many hours on their own in their beds, they were witnessed having their individual needs overlooked. However, there were also examples of children that repeatedly shouted, being ignored.	Children are frustrated with being ignored.
F48	Despite the warmth and love that the children received and expressed, they sometimes experienced deep sorrow when they witnessed their families' sadness.	Children are aware of parental anguish.
F49	The common experience of all children was the feeling of loneliness. All longed for home and their families. They felt alone because of the altered family life.	Children feel loneliness due to their long-term condition.
F50	Any uncertainty caused adverse psychological effects to the children, such as experiencing a sense of fear, which could be alleviated by correcting and misunderstanding and by giving clear and understandable answers to the children's questions about the illness, treatment, and prognosis	A lack of communication increases levels of worry.
F51	The need for delicate care was explicitly mentioned in the children's stories; most of them described healthcare professionals as kind, caring, and affectionate individuals.	Nurses who are fun bring happiness to children.
F52	Children reported feeling understood when nurses took the time to get to know them.	Children value positive communication.
F53	A child described why working with the child to adjust care to the individual's capacities is a helpful strategy.	Children are aware of their own health care needs.
F54	One child described how an outpatient nurse's practice of making time for parents was helpful to her mother. The fact that nurses remained available to parents and explicitly made time for them was deemed helpful by both parents and children.	Children are aware of parental anguish.
F55	These are examples of how nurses supported parents through difficult times by being present and attentive to their needs, and sharing information and perspectives in away that parents found comforting.	Children appreciate the parent-nurse relationship.
F56	Specifically, parents and children agreed on the importance of nurses keeping parents informed. One child pointed out that she was not always ready to disclose issues directly to her parents, but she wanted them to know.	Children appreciate the parent-nurse relationship.
F57	Another intervention that nurses used to help patients learn different coping strategies was distraction from harmful thoughts, as explained by one child.	Nurses offer children helpful coping strategies.
F58	Similarly, children found it helpful when nurses acknowledged their feelings and helped them by providing specific strategies tailored to the child's needs.	Nurses offer children helpful coping strategies.
F59	Children with illnesses reported liking having their parents and siblings close by them or with them while they were in the hospital, and thus siblings were another source of support for patients.	Children feel security and safety from their parents and family.
F60	Five of the patients and two of the siblings endorsed sadness. Patients often were sad, because they were confined to bed or to a room and were not able to carry on with their normal lives.	Children feel loneliness due to their long-term condition.
F61	Three of the patients and two siblings reported not liking doctors or nurses. Not liking doctors and nurses typically had to do with perceiving them as those who administered needle sticks or as persons responsible for painful procedures.	Children are aware of the nurses role.

Label	Finding	Category
F62	Participants wanted HCP's to deliver the information on treatment and side effects in a manner that was easily understandable.	Children wanted to be informed about their treatment.
F63	Regarding knowledge of relationships and sexuality, participants lacked information on the subject and expressed a need for increased discussion.	Children wanted to be informed about their treatment.
F64	An age-appropriate communication is needed.	Children appreciate it when the nurse treats them as a person, not a patient.
F65	They expressed the need, at times, to talk with the physician, with or without relatives. They wanted HCPs to make this routine. Participants described the need for a time-out from relatives now and then.	Children want direct communication from nurses.
F66	Teenagers treated at paediatric units used parents in the beginning as protectors and care mediators. They wanted to have someone to support them when they communicated with a physician.	Children feel security and safety from their parents and family.
F67	Participants found it difficult to maintain relationships outside the family during treatment and described a need for HCPs to support them by providing information to friends and family.	A lack of communication increases levels of worry.
F68	The children in this study recognized that the nurses who were approachable created an environment as one of cheer and optimism. Clearly, these children are more likely to approach a nurse who is smiling and happy as they describe this as an open invitation to interact.	Nurses who are fun bring happiness to children.
F69	All seven children expressed the feeling of great joy in the hospital when the nurses were "fun and funny" and found these nurses easy to approach. They described the nurses as often telling jokes, "pulling pranks" or just having fun. They forgot that they were in the hospital when they were having fun and laughing.	Nurses who are fun are more approachable.
F70	Talking and listening to the child helped to establish a relationship and showed genuine concern that the nurse cared and wanted to help. The children seemed to get a sense that when the nurses took the time to listen to them and "really show they care" by helping with the little things, they felt the nurses truly understood them and how they felt. The children enjoyed talking to nurses with similar interests.	Children value the child-nurse relationship.
F71	Nurses who showed they cared by going above and beyond the tasks to complete in a shift were most approachable and easiest to talk to.	Nurses need to be approachable.
F72	The data quoted below shows how some of the children had a positive regard for nurses. These children understood and were able to articulate the reasons they had a nurse visit them.	Children are aware of their own health care needs.
F73	Children observe in order to figure out the processes that they later expect to engage in. In many ways, she was thus engaged in intent community participation and informal learning, as an eager and diligent patient.	Children enjoy participating in their health care needs.
F74	The nurse conjures up a world of magic (e.g., abracadabra; Lines 3 and 21), turning treatment routines into a more interesting type of event. In all these cases, the little girl responds positively by saying "yes." She thus explicitly consents to the treatment procedure, showing that patient consent may be feasible even in the case of young children, here a 2-year-old.	Children enjoy participating in their health care needs.
F75	As in the previous example, Ida is permitted to be involved in her own treatment. The children soon show familiarity with medical routines such as the repeated needle procedures.	Children enjoy participating in their health care needs.
F76	The children in this study were repeatedly invited to take part in treatment practices. As can be seen, Elinor is willing to be involved and is very much part of the shared treatment endeavour. Moreover, she seizes the opportunity to help out by connecting the test tubes (Line 20), engaging in a collaborative treatment practice.	Children enjoy participating in their health care needs.
F77	They want nurses to ask them about themselves and get to know them as individuals.	Children appreciate it when the nurse treats them as a person, not a patient.
F78	Isabelle stated that it was helpful when nurses get to know teens and get to know about things that teens like to do.	Children appreciate it when the nurse treats them as a person, not a patient.

Label	Finding	Category
F79	The adolescents wanted to be treated as a person, as they viewed themselves, not for their need for respiratory assistance.	Some children crave independence.
F80	The adolescents described receiving special treatment or being treated differently because of their need for respiratory assistance.	Nurses need to be flexible in their care to suit individual needs.
F81	Independence is something of great concern for adolescents but may be even more so for adolescents who require respiratory assistance. They see themselves as being able to take care of themselves without assistance, despite their need for respiratory assistance.	Some children crave independence.
F82	Children may feel dazed while undergoing LP, and some children described their helpless without companion of their parents.	A lack of communication increases levels of worry.
F83	These children felt worried and did not know what to think while undergoing LP.	A lack of communication increases levels of worry.
F84	They were aware of emotional changes of their parents. They did not wish to cause their parents any further sadness or worry.	Children are aware of parental anguish.
F85	Throughout LP, most children wanted healthcare workers to communicate with them actively and enquire about their feelings. They hoped that healthcare workers would give them comfort, explanation, encouragement and praise while undergoing LP.	A lack of communication increases levels of worry.
F86	They wanted the healthcare staff to care about their true feelings and their diseases.	Children want direct communication from nurses.
F87	Our data showed that different children have different expectations for the environment and healthcare staff performing LP. They wanted a colourful and comfortable hospital environment.	Nurses who are fun are more approachable.
F88	The child explained the picture she/he drew as “There are two sick kids. One of the kids’ head is sick and the other kid has stomach problem. The nurse in the middle is looking after the sicker kid. She is going to look after the kid with head problem later. She is going to make him/her take the pill in her hand. The pill is too bitter.” (Page 993).	Children are aware of the nurses role.
F89	The sick child drawing himself/herself as the nurse in the picture described the drawing as “Some nurses do not smile at all.” (Page 995)	Nurses who are fun bring happiness to children.
F90	The sick child described his/her drawing as “I have left the hospital and I am picking up flowers to thank my nurse sisters.” (Page 997)	Children value the child-nurse relationship.

(Key: F1=Finding 1)

Table 6: Synthesis of qualitised findings into categories.

Label	Qualitised finding	Category
Q1	The drawings represented the child-nurse relationship and how its variation based on the child themselves	
Q2	Children saw the task orientation and variation of nursing duties, however most associated nurses with painful procedures, such as injections.	Children are aware of the nurses role.
Q3	Adolescents viewed the most important aspects of nursing was conversations were kept confidential and that nurses considered patient complaints, preferences and habits.	Nurses need to tailor their communication to suit a person's individual needs.
Q4	Adolescents viewed the lowest important aspects of nursing as nursing having contact with schools or health centres.	Nurses need to tailor their communication to suit a person's individual needs.
Q5	Adolescents viewed having a clean environment with family around as most important.	Children want a safe and secure environment with their family present to support them.
Q6	Adolescents believed the most important aspect in nursing care was placing trust in nursing staff to take care of them and keep them safe.	Children want to trust the nurses who care for them.
Q7	Adolescents believed the most important aspect in nursing care was that nurses listened and respects patients.	Nurses need to tailor their communication to suit a person's individual needs.
Q8	Adolescents believed the most important aspect in nursing care was that nursing were able to explain what was said in medical discussions.	Nurses need to tailor their communication to suit a person's individual needs.

(Key: Q1=Qualitised finding 1)

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 2
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 4
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 5 / 22
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5/6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 23

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Page 24-26
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	NA
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Supplementary table 1
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 24-26
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 27
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 13-15
	23b	Discuss any limitations of the evidence included in the review.	Page 13-15
	23c	Discuss any limitations of the review processes used.	Page 13-15
	23d	Discuss implications of the results for practice, policy, and future research.	Page 15
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 4
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 4
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	NA
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary Tables

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

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