Journal of Pediatric Nursing 63 (2022) 64–71

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Children's voices on their participation and best interests during a hospital stay in Australia

Mandie Foster [a,b,c,*], Angela Afua Quaye [d], Lisa Whitehead [b,e], Inger Kristensson Hallström [d]

[a] Auckland University of Technology, School of Clinical Sciences, Auckland, New Zealand
[b] Edith Cowan University, School of Nursing and Midwifery, Perth, Western Australia, Australia
[c] Perth Children's Hospital, Perth, Western Australia, Australia
[d] Department of Health Science, Faculty of Medicine, Lund University, Box 188, 221 00 Lund, Sweden
[e] Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand

ARTICLE INFO

Article history:
Received 17 September 2021
Revised 4 January 2022
Accepted 5 January 2022

Keywords:
Best interests of the child
Child Centred Care
Decision making
Participation
Children in hospital care

ABSTRACT

Purpose: To explore school-aged children's experiences about their best interests and participation in care during a hospital admission.

Design and methods: A descriptive qualitative design involving in-depth, iterative inductive review of child responses to generate key words that led to identification of categories and themes. The study was guided by the United Nations Convention on the Rights of the Child's definition of the best interests of the child, Bronfenbrenner's bioecological model and a child centred care approach.

Results: Nine school-aged children (5–15 years old) from one children's ward in Australia participated. Analysis yielded thirteen categories, six sub-themes, and three themes: 1) Relationships with parents were positive when they met their children's physical and emotional needs and advocated for them; 2) Relationships with staff were positive when staff created opportunities for children to have a say in their healthcare, and checked in on the children and 3) Seeking familiarity away from home was facilitated when the environment children found themselves in provided them their own space and various forms of entertainment.

Conclusion: School-aged children were able to verbalize what their best interests were and how participation in care could be facilitated in the hospital setting. The inter-relationships of the children with their parents, healthcare professionals, and the immediate environment reflected interactions both within, and between systems.

Research and practice implications: Children in hospital need to be provided with age-appropriate opportunities to participate in shared decision making to support their best interests. Studies that model and evaluate such opportunities are needed.

Introduction

The ability of children to be involved in shared decision making through being listened to, included, protected, and treated as a competent active social agent differs across clinical settings (Carnevale et al., 2021; Foster et al., 2018). Listening to children's voices is vital to install trust, foster respect, autonomy, self-determination, and regard as well as honour social justice and equity (Green et al., 2018; Stålberg et al., 2016; United Nations General Assembly, 1989). The concepts inherent in defining the best interests of a child come from Article 3 of the United Nations Convention on the Rights of the Child (UNCRC) and includes providing all children the right to safety; healthcare; wellbeing; education; family relationships; physical, psychological, and emotional development; identity; freedom of expression; privacy and agency to form their own views and have them heard (Information Commissioners's Office, 2020).

The UNCRC not only seeks to protect children in all areas of society, but also takes a rights approach to children participating in sharing their views on things that are important to them and taking part in decision making related to policy or service delivery, in a manner that is appropriate to their age and development as outlined in Article 12 and 13 of the UNCRC and further defined by the World Vision International (United Nations General Assembly, 1989; World Vision International, 2021). The UNCRC standards were developed by governments, non-governmental organizations, human rights advocates, lawyers, health

* Corresponding author at: Auckland University of Technology, School of Clinical Sciences, Auckland, New Zealand.
E-mail addresses: mandie.foster@aut.ac.nz (M. Foster), angela.afua_quaye@med.lu.se (A.A. Quaye), l.whitehead@ecu.edu.au (L. Whitehead), inger.kristensson_hallstrom@med.lu.se (I.K. Hallström).

https://doi.org/10.1016/j.pedn.2022.01.003
0882-5963/

specialists, social workers, educators, child development experts and religious leaders globally and is the most ratified human rights treaty in history with more than 196 participating countries (UNICEF, 2019, 2021). The UNCRC provides an ethical and legal framework or reference point for the enactment, monitoring, transparency, and solidarity of children's rights universally including the role of society, community, and family to promote and protect children's rights (UNICEF, 2021; United Nations General Assembly, 1989).

However, to date, there is a lack of information on how children's best interests are upheld and expressed in hospitals globally (Carter et al., 2014; Dickinson et al., 2014; Lambert & Glacken, 2011) or how Governments worldwide are promoting the implementation of the UNCRC in legislation, policy, and practice (United Nations General Assembly, 1989; World Health Organization et al., 1986). Despite the present policies, and practice initiatives in place, there continues to be a discourse between what should be and actual practice with a reported disparity in equity of child/youth participation in healthcare settings. Children/youth of all ages and ethnicities need to be viewed as equal citizens and competent advisors in matters that concern them (Coyne & Gallagher, 2011; Coyne & Kirwan, 2012). Including children/youth perspectives in health service planning and evaluation, and in policy and legislative matters, ensures that service delivery is targeted appropriately (rather than relying on adult proxy which may not represent their perspectives) and to support children/young people's agency as well as developing citizenship (Stålberg et al., 2016).

The UNCRC declaration is enacted in clinical practice through models of care including Family Centred Care (FCC), Child Centred Care (CCC) or Child and Family Centred Care (CFCC). The models can facilitate the promotion of children's best interests and participation as active agents (Carnevale et al., 2021; Foster et al., 2013; Foster et al., 2016). The FCC approach views the family as the focus of care where collaboration, negotiation, partnership, and shared decision-making with healthcare professionals is undertaken through the family where the child assumes a passive role (Coyne et al., 2016; Coyne et al., 2018). Within a CCC or CFCC approach, the child is viewed as an active competent agent within their own right and care is planned around the child's self-reported perspective and preferences with the guidance of adults based on the child's competence and capacity within the context of family and community (Coyne et al., 2016; Foster & Shields, 2019). A child's ability, choice, and opportunity to participate in shared decision-making should be viewed as a constant evolving iterative process and be situated for that child's best interest as reported by that child (Carnevale et al., 2021; Coyne et al., 2016; Ford et al., 2018). The literature refers to child friendly hospitals and child healthcare professionals co-designing healthcare initiatives, interventions and research projects with children inclusive of using child self-report tools as a measure of CCC but there is only one published psychometrically validated child self-report tool available (Foster et al., 2019) with most of the literature on children's self-reported healthcare experiences being qualitative designs or reported by adults as proxies (Dijkstra et al., 2006).

A child's position in society is further influenced by the socio-political and cultural nuances of that country, context, and people closest to the child (Christian, 2017; Moore et al., 2014). Children rely on adults to have their needs met and most children lack decisional rights with their needs being inextricably linked to those of their family and community (Katkin et al., 2017). This is further explained in Bronfenbrener's bioecological model of human development where a child's development is influenced by one's interaction with the environment, biological characteristics (age, gender, appearance, intelligence, skills, perseverance), context and time (Bronfenbrenner, 2004). Time refers to four interacting systems or stages (microsystem, mesosystem, exosystem and macrosystem) that a child moves through with the macrosystem having the greatest impact on a child's psychosocial and emotional development (Bronfenbrenner, 2004). Bronfenbrener's bioecological view on a child's development may allow healthcare professionals to understand the existing support systems in each of the four stages as well as the contextual factors that influence children and their families when they encounter a hospital admission (Gormley & Light, 2021). Research has shown that children and parents undergo various levels of stress when the child becomes ill, and more so when they encounter a hospital admission (Hallström et al., 2002). A bioecological view creates insight into the disruptions experienced by the child when ill, and how that may influence the child's interactions and response to care (Ford et al., 2018). As children and their parents navigate their new environment in hospital, it becomes crucial to meet the psychosocial physical emotional and informational needs of children (Coyne, 2006; Coyne et al., 2006). Meeting the self-reported needs of children can be facilitated by a CCC approach, where a holistic view of children implies recognition of their rights and best interests including the provision of individualised age-appropriate support (Coyne et al., 2016; Ford et al., 2018). This in turn demands a strengthening of the child-parent-healthcare professional relationship, as well as enhanced communication skills among healthcare professionals working with children (Derrington et al., 2018). Relationships created with children and their parents need to be built on trust within an age-appropriate child friendly environment, to further enhance positive experiences, psychological wellbeing, and health outcomes (Dijkstra et al., 2006; Feng et al., 2020; Popejoy et al., 2017).

However, there is a growing concern, that reliance on parental reporting on their child's best interests or hospital experience with children not being provided age-appropriate opportunities to participate or voice their experiences, will overshadow the child's voice and right to be an active social agent (Tates & Meeuwesen, 2001). Whilst some of the literature highlights children's experiences during a hospital admission (Bekken, 2017; Coyne et al., 2014), little research has been conducted to explore children's perceptions about their participation and best interests during hospitalization (Sahlberg et al., 2020).

Aim

To explore school-aged children's experiences about their best interests and participation in care during a hospital admission.

Methods

Design

This study included a descriptive qualitative design guided by Bronfenbrenner's ecological model and a CCC theoretical approach using a face-to-face combined parent-child interview (Braun & Clarke, 2006; Carter et al., 2014; Elliott & Timulak, 2005; Nisha & Michelle, 2017). This article will present the children's self-reported experiences.

Setting

The children's ward is a 37-bed ward that includes a separate ten-bed day unit for day surgery and provides paediatric care in a tertiary setting to over 3000 inpatients in Western Australia every year. The children's ward endorsed a FCC model.

Participants

Through convenience sampling, nine school-aged children (5–15 years of age) within the children's ward were recruited consecutively over seven months from June to December 2019. Children needed to have a basic command of the English language and have provided informed voluntary assent/consent with signed parental consent.

Data collection

The first author introduced herself to the parents and child 12 h following an acute admission or on arrival to the ward for a planned

Table 1
Interview guide.

The child's interaction with parents
What do your parents do when you are in hospital with them?
Do you talk with your parents about how it is for you in hospital?
Are there things that are good in hospital? If so, what?
Are there things that are not so good in hospital? If so, what?
The child's interaction with healthcare personnel
Do staff ask you about how you want things to be in hospital?
If you do not want the staff to do something with you, what happens?
How would you have wished for things to be in hospital if you could decide?
Do you think that you help make decisions about your care in hospital?
Would you have wished to be more involved in how decisions were made regarding your care?
Is there anything else you would like to discuss that I haven't mentioned?

surgical day stay. Planned admissions were sent an invitation to join the study one week prior to their hospital stay. Once recruited into the study, data collection took place between 12 and 72 h for an acute admission and prior to discharge for a planned admission. All interviews were recorded, and demographic data collected included the child's age, ethnicity, gender, and admission type. To ensure authenticity, the parent and child were invited to listen to the recorded interview prior to transcription.

Open-ended questions

The interviews with children included a separate section incorporated into the interview undertaken with parents and were initiated in the hospital at a time that was convenient to the child, family, and staff. The first author asked the child ten open-ended questions that were formulated from the literature (Table 1). The open-ended questions enabled children to talk freely about their hospital experience with their parents' present (Nisha & Michelle, 2017). At the beginning of the interview, the parents were kindly asked not to answer on their child's behalf (Nisha & Michelle, 2017).

Ethical approval

Hospital and university ethics approval were granted where the principles of informed consent, respect, beneficence, integrity, confidentiality, and justice were upheld (Council for International Organizations of Medical Sciences, 2016; Department of Health, 2012; National Health and Medical Research Council, 2018). Informed voluntary child assent and/or signed consent was obtained from all children including signed parental consent.

Data analysis

The open-ended questions were analysed iteratively through inductive thematic content analysis by the first and second authors, to ensure rigor (Braun & Clarke, 2006). Researcher reflexivity was disclosed by each researcher at the beginning of the study to limit potential bias. The analysis followed the five phases of thematic analysis as described by Braun and Clarke (2006). Phase 1: The first and second author independently listened to the audio-taped interviews, read through the written transcripts, and took notes. Phase 2: Involved the generation of codes. Phase 3: Data on the phenomenon of the research question were underlined (findings), coded (in vivo coding) and grouped into smaller or larger categories and themes based on similarity of meaning by two independent researchers and then shared with all authors until a consensus was achieved. Phase 4 and 5: The researchers moved between the data and reviewed the codes, categories, and themes multiple times in a repetitive cyclic process iteratively until no new themes or categories were evident and the research team felt the themes portrayed the meaning and significance of the text.

Results

On average interviews with children were completed within six minutes (range 4.25–11.10 min) with the average interview time for the combined parent-child interview being 25 min (range 19.00–36.32 min). One third of the children were five years of age (33%), two thirds were admitted for an acute illness (66%) and all the children were of European ethnicity (100%; Table 2).

The children's responses

The children's responses in relation to their hospital experience generated 239 findings, 13 categories (meeting my physical needs, meeting my emotional needs, protecting me, talking to each other, negotiating and collaborating with me, giving me options, giving me attention, showing me respect, my room, my privacy, my food, watching TV and using the internet, the playroom), six sub-themes (my individual needs, advocacy, having a say, checking in, my own space, my entertainment) and three themes (relationships with my parents, relationships with the staff, seeking familiarity away from home). Children experienced their best interests and ability to participate in care during their hospital stay were met when: parents met their individuals needs and advocated on their behalf, healthcare professionals created opportunities for children to have a say in their healthcare, and checked in on the children, and lastly when the environment they found themselves in provided them their own space and various forms of entertainment. These results are set out in Table 3.

Relationships with my parents

The theme 'relationships with my parents' included the sub-themes 'my individual needs' and 'advocacy' and the categories 'meeting my physical needs', 'meeting my emotional needs', 'protecting me' and 'talking to each other' (Table 3). It describes the child's relationship with their parents, where they experienced their best interests and ability to participate in hospital were met when their parents helped provide for their individual physical and emotional needs including advocating for them when they were less able. The children's physical needs included parents providing pyjamas, shoes, and support during medication regimes *'she tries to stay up when I'm having the puffer and stuff'*, and general well-being *'she asked me if I want anything; like, if I'm eating breakfast and I don't feel good'*. Children also stated their mother was *'good'*, *'helpful'*, *'doing her best'* in *'taking care of me'* and had *'done an amazing job'*. The children's emotional needs were further described as supported by parental presence in sitting by their bed, helping to calm them *'helps calm me down by telling me to breath nice and slowly'*, being patient *'we wait'* and being there no matter what.

> *'…She is there when I need her and also when I don't need her'* (Participant 8, 14 yrs. old).

Children stated that their parents protected them by getting them ready for their hospital admission *'she gets us ready'*, driving them to hospital *'she drives me all the way to here'*, checking in with them *'checking up and making sure I am OK'*, keeping them in hospital *'keeps me in hospital'*, getting medication as needed *'gets a stronger dose of medicine'* and assisting the doctors *'she helps a lot with the doctors'* or seeking assistance on my behalf.

> *'…If the nurse isn't coming straight away, she goes to see if she can get someone talking'* (Participant 9, 14 yrs. old).

The children described that they talked to their parents about *'general stuff'* their *'pain'* and symptoms *'if my tummy is hurting; or if I'm feeling thirsty; or if I'm feeling sick'*, where parents explained certain things

Table 2
School-aged children's demographics.

Child	Gender (female/male)	Age (yrs)	Admission Type (acute/planned)	Findings (number)	Child Interview (minutes)	Child-Parent Interview (minutes)
1	Female	5	Surgical, planned	21	6.00	26.01
2	Male	5	Surgical, planned	12	4.25	36.32
3	Male	5	Medical, acute	15	5.31	23.05
4	Female	6	Medical, acute	13	5.08	23.03
5	Female	11	Medical, acute	55	11.10	31.01
6	Female	12	Surgical, acute	33	5.00	20.00
7	Female	13	Surgical, planned	20	5.11	19.00
8	Male	14	Surgical, acute	42	5.49	31.00
9	Male	14	Medical, acute	28	5.40	30.04

for them *'when we are going somewhere'* and even if the children couldn't explicitly state what they talked about they mentioned that they did talk to each other to some degree.

> *'...Yes, we do'* (Participant 4, 6 yrs. old), *'I can't really remember, I know we do say things'* (Participant 1, 5 yrs. old), *'Yeah, I think I do'* (Participant 5, 11 yrs. old).

Relationships with the staff

The theme 'relationships with the staff' included the sub-themes 'having a say' and 'checking in' and the categories 'negotiating and collaborating with me', 'giving me options', 'giving me attention' and 'showing me respect' (Table 3). The sub-theme 'having a say' included the categories 'negotiating and collaborating with me' and 'giving me options' where children shared that staff negotiated and included them in their care and treatment options as they felt heard *'they ask me for what I want to get done instead of just telling me what to do'*, were able to make decisions *'I get asked if I want, like I get asked to make decisions'* and were provided with options *'they are letting me choose what I want to do; not just telling me straight off'* such as *'they ask me if I want the medicine in tablets or liquid or if I want to use the puffer or if they do the puffer, they give me options'* and *'ask me how I want to get like how I want to get gas or a needle'*. Children revealed that they were not always included in discussions regarding their care *'no I think they like they really tell you what they're going to do'*, and further explaining that if *'stuff'* needed to happen, they would tell the staff how they wanted this to be *'but if it did happen, then probably I would just say, can we do it some different, some other way'*. The children also described that in some situations they were given no options. Children shared that despite negotiation with staff, they were aware that some things had to happen *'some stuff they need to do and I can't really have a say'* like *'surgery'* but they felt reassured that staff would only do something if it was crucial.

Table 3
Inductive thematic analyses of children's responses.

Themes	Sub-Themes	Categories
Relationships with my parents	My individual needs	Meeting my physical needs
		Meeting my emotional needs
	Advocacy	Protecting me
		Talking to each other
Relationships with the staff	Having a Say	Negotiating and collaborating with me
		Giving me options
	Checking in	Giving me attention
		Showing me respect
Seeking familiarity away from home	My own space	My Room
		My Privacy
		My food
	My entertainment	Watching TV and using the internet
		The playroom

> *'...If it is crucial and they need to do it then I just go OK, if it's not crucial they say OK and leave you alone'* (Participant 8, 14 yrs. old).

The sub-theme 'checking in' included the categories 'giving me attention' and 'showing me respect' where children felt their best interests were met when staff showed individualised care by checking in with them on things like their bed *'like how high would you like the bed, how low would you like the bed'*, privacy *'do I want the curtains open or shut'*, television *'do I want the TV on or off, stuff like that'*, warmth *'they ask if I want food and if I need any more blankets, more blankets'*, treatment *'whenever they are doing stuff they ask does that feel OK, is that alright'* and general well-being *'they ask me if I'm feeling OK'*. Children further stated that they would tell the nurses if things were not right.

> *'...Yes, by telling the nurses there are a few wrong things going on, so I want to make some decisions so we can fix them'* (Participant 5, 11 yrs. old).

The children further indicated the nurses and doctors were helpful *'the staff have been very helpful'* and that they weren't *'scared'* which helped them become aware on how to help themselves *'it's in my best interest to just relax and stay here until I get better, relax'* and felt that the staff knew how to care for them *'right care, they know what to do if I have an attack, get the stuff you need'*. Similarly, the children stated that the staff showed them respect by being friendly *'the nurses and doctors always talk to you'*, kind *'they are kind'*, funny *'get your mind off things like before I went into surgery one of the doctors was telling me jokes'*, inclusive *'really inclusive'*, attentive *'really attentive'* and inquisitive about their needs *'they ask me if I feel like it's the best for me'* which helped them feel valued and listened too.

> *'...You know, they were all really nice and listened to me, they make sure my opinion is heard, everything they ask about my opinion they do'* (Participant 1, 5 yrs. old).

Seeking familiarity away from home

The theme 'seeking familiarity away from home' included the sub-themes 'my own space' and 'my entertainment' and the categories 'my room', 'my privacy', 'my food', 'watching TV and using the internet' and 'the playroom' that portrayed the children's interactions with their immediate environment in hospital (Table 3). Upon being admitted, children began seeking familiarity away from home by wanting to have their own space. Having entertainment further enhanced children's ways of adjusting to their new environment. Children were conscious about aspects of their environment, things that made them feel comfortable, and things that could be improved. They revealed their best interests and ability to participate in care were met when certain aspects of their environment included a comfortable room, privacy, food choices, internet, television, and a playroom. Children showed awareness of their environment and they appreciated things in the

environment that made them feel safe. Additionally, they were conscious of missing pieces in the environment and further expressed how they wished things could be improved.

The sub-theme 'my own space' included the categories 'my room', 'my privacy' and 'my food'. This sub-theme highlighted aspects of the hospital environment that children could relate to as their own space. Having their own space helped the children to better navigate their way through their new and unfamiliar surroundings. Children expressed that their space was *'nice'* and *'good'*. Although trying to build a relationship with their new space, some things were experienced as strange.

> *'...You get a bathroom which is good because then if you need to go to the toilet in the night, you can go instead of walking down the hall or something'* (Participant 5, 11 yrs. old).

> *'...Like it's weird sleeping in a different bed that's not yours because its and you know you are at the hospital as well'* (Participant 5, 11 yrs. old).

As part of acquainting themselves to their new environment, children, revealed how important it was for them to have their own rooms, privacy, and food that was enjoyable. 'My room' reflects the rooms in which the children were admitted. In the rooms, children appreciated having interior design features like adjustable beds, as well as architectural aspects like self-contained rooms. At the same time, children expressed wishes for changes in the environment with regards to the interior design. Things like air conditioning units and mini fridges were desired. Better beds for themselves and their parents were also wished for as the children expressed the following about their beds: *'it's really annoying because my pillow just falls down'*. The children also yearned for the showers in their rooms which had a lighter flow, to have a much heavier flow. With regards to the architectural aspects of the environment, children sharing a room with other patients expressed the wish to have two separate bathrooms.

> *'...Maybe if you have like a split room; have like two bathrooms, or something so then you don't have to wait for the other person to finish...'* (Participant 6, 12 yrs. old).

Children were happy to have a variety of food choices and the quality of the food was appreciated. They revealed being served a *'really big breakfast'*, with a variety of things to choose from, such as cereal, fruit, toast, jam and butter. Even though children also wished to have more food options for breakfast, and lunch, overall, they expressed their delight in the food served.

> *'...The food is actually really nice. Yes. I mean, for hospital food ...'* (Participant 9, 14 yrs. old).

Having privacy was cherished by the older children as some children had to share rooms with other patients. They treasured having curtains for privacy when they wanted to change or do other things that they did not want others to see.

> *'...I like how they have the curtains so you can like have privacy. So then like if you just want to get changed you do not have to keep the curtains open or anything. That would be a little bit weird...'* (Participant 6, 12 yrs. old).

The sub-theme 'my entertainment' included the categories 'watching TV and using the internet' and 'the playroom'. Having entertainment whilst admitted in hospital served as an enhancing environment for the children. Watching TV and internet use was a good way for the children to be kept distracted and entertained at the same time. Children who were confined in their rooms and could not move around the hospital surroundings appreciated this service.

> *'...You can watch the TV. You have the Internet. Free WIFI...'* (Participant 5, 11 yrs. old).

Another valued source of entertainment the children talked about was the playroom. The playroom was experienced as one of the favorite things the children liked about their new environment. The children enjoyed looking at the fish in the fish tanks, playing with the available games, as well as other toys displayed for their pleasure. Children showed full awareness of their immediate environment and were able to identify what would enhance their experience. In regard to the playroom, the younger children shared how they wished to have more playroom activities and adventurous playroom environments.

> *'...I would think there would be a nice big playroom and there would be an upstairs where you could like go to a coffee shop and they could give you coffee and tea and everything and there would be a café and a 2-storey house right next to it. And your friends could come and see you with your grandma. Lovely, lovely stickers everywhere and there would be mats, where you could like sit down and have a little snooze...'* (Participant 1, 5 yrs. old).

Discussion

The findings highlight children experienced their best interests and ability to actively participate in care during their hospital stay were met when parents met their individuals needs and advocated on their behalf. In addition, when healthcare professionals created opportunities for children to have a say in their healthcare, and checked in on the children, and lastly when the environment they found themselves in provided them their own space and various forms of entertainment. The inter-relationships of the children with their parents, healthcare professionals, and their immediate environment reflects the interactions both within, and between the nested systems discussed by Bronfenbrenner's bioecological model (Bronfenbrenner, 2004).

Children valued their relationships with their parents, as they relied on their parents to meet their individual physical, psychosocial and emotional needs as self-reported by children. Parents took advocacy roles when their children were less able to, and this was experienced by the children as having their best interests and ability to participate in care met. The former, where parents took advocacy roles and children still felt their needs were met, reinforces aspects of participation where children chose the level at which they wished to participate. Hence, their seemingly non-involvement in a situation may not be interpreted as non-participation (Rogoff et al., 2003). Other studies have reported that participating in shared decision-making on choices of care delivery that may appear minor, gave children a sense of control (Coyne et al., 2014). Sometimes children want their parents (Boland et al., 2016; Coyne et al., 2014) or healthcare professionals (Coyne & Gallagher, 2011; Hart et al., 2020) to take a leading role in decision-making on their behalf. The severity of children's illnesses, and other factors such as culture, age, ability, knowledge on shared decision-making or competency may play a role in children wanting adults to make decisions on their behalf (Boland et al., 2016; Coyne et al., 2014). Children in this study revealed their best interests and ability to participate in care were met when their parents were present as a source of comfort and companionship. Parents and healthcare professionals in hospital made up the microsystem that children interacted with (Bronfenbrenner, 2004). Parental presence and involvement in care of hospitalized children has over the years been recognised as a crucial aspect of care for children in hospital (Jaser, 2011; Melo et al., 2014).

Children also experienced their best interests and ability to participate in care were met when healthcare professionals created opportunities for them to negotiate and collaborate in aspects of care delivery and have a say in matters that concerned them. In addition, children

experienced their best interests were still met even when they could not influence decisions regarding the type of care they were scheduled to receive. Involving children in mutual negotiations (where child, parent, and healthcare professionals contribute to the negotiations with their own perspectives and varying levels of expertise) upholds their rights as emphasized in the UNCRC. This is further in accordance with the principles of a CCC approach. Children in this study recognised that certain care situations, like undergoing surgery, presented little opportunity for them to have a say, as '*things just had to be done*'. These findings are supported by Coyne and Gallagher (2011) where children recognised that decisions regarding their treatment had been predetermined and they had to go by these decisions. In the study by Bekken (2017) children within a rehabilitative setting felt excluded, powerless, depersonalized, and detached during their hospital experience when they were not listened to or included in decisions about their care. It is, however, crucial that decisions are not made over children. Rather, the core elements of participation being that the child receives age-appropriate information, is freely able to express their views and is included in shared decision-making are still availed to every child and that children are supported to participate to a level of their choosing (Council of Europe, 2012). Safeguarding the best interests and participation of children in care requires a constant assessment of the prevailing situation, the child's age and maturity, and their ability to participate in shared decision-making.

Children in this study felt that the healthcare professionals showed them respect, gave them options to choose from, offered them attention and discussed aspects of care that were important to them. Similarly, children in a study by Wood et al. (2018) reported that children valued conversations with healthcare professionals beyond the hospital environment that they were presently situated within (Wood et al., 2018). A holistic view of children beyond their current illness and/or present situation allows healthcare professionals to view the child as a social actor, intertwined in a complex nested system. This further enhances understanding of how these interactions influence the child's response to care and hospital experience (Bronfenbrenner, 2004; Ford et al., 2018). Having conversations with children about matters outside the hospital context, is a way to distract children from procedures. It may also be a way for healthcare professionals to build trust, form quality relationships, and help create a more relaxing ambience for children (Green et al., 2018; Noreña-Peña & Juan, 2011).

Seeking familiarity away from home reflects the self-reported descriptions of children being active participants not only in care delivery, but also concerning the physical aspects of their hospital environment. For children admitted into hospital, the hospital becomes their home away from home and so their comfort in this new environment is vitally important to consider. Children in this study reported awareness of their physical environment and how it influenced their comfort or discomfort in hospital. They were conscious of the beds they slept in, the privacy accorded to them, the food served, the entertainment and playroom available, and many other aspects of the physical environment that were important to them. Feng et al. (2020), reported on child comfort as one of the main factors that mattered most to families who encountered paediatric care. Similarly, Wood et al. (2018) highlighted that a child age-appropriate environment was the main determinant of high-quality care experienced by some children, whilst other children who were acutely ill did not state that their environment was important. In this study, children attempted to navigate their new surroundings and looked for aspects in their new environment which were familiar to them. Experiencing the hospital environment as an unfamiliar situation for children is not unique to this study (Coyne, 2006).

Children in this study expressed a desire to have two separate bathrooms in a patient room that accommodated more than one child, or have curtains for privacy, or wanted to sleep without being disturbed by healthcare professionals. These aspects all point towards what Dijkstra et al. (2006) distinguish as the architectural, interior design and ambient features of a hospital environment. Three aspects of the physical environmental stimuli, architectural (permanent characteristics of a building), interior design (less permanent like furnishings, colours, and artwork) and ambient features (lighting, noise levels, odours, and temperature) play a role in making healthcare facilities, healing environments. A reciprocal relationship exists between a child and their immediate environment (Bronfenbrenner, 2004), and the literature further postulates that the physical environment may influence the healing process and wellbeing of children (Dijkstra et al., 2006; Feng et al., 2020).

However, a child's self-reported perspective on how physical stimuli may enhance the healing process of patients, is lacking (Dijkstra et al., 2006). The role that the physical environment in hospitals has in shaping children's experiences and descriptions about their best interests and active participation in shared decision-making requires further investigation. It is integral that children's voices in hospital are actively sought and used to inform and direct both education, theory, research, and clinical practice, thereby improving a child's experience in hospital and overall health outcome (Bekken, 2017; Larsson et al., 2018; Trollvik et al., 2013). These recommendations are further shared by many international child centric clinicians, researchers and academics to direct education, research, and clinical practice (Davies & Randall, 2015; Hayes et al., 2019; Navin & Wasserman, 2019). Actively involving children as co-constructors in interventions aimed at improving their well-being further empowers them and ensures their rights enshrined in the UNCRC are safeguarded (Trollvik et al., 2013).

Methodological considerations

Using inductive thematic analysis as an analytical method offers flexibility with regards to the interpretation of the data. All researchers bring experience and bias to the analytical process. The first author, an experienced paediatric nurse, and data collector for this study and the second author's background in molecular biology and public health will have influenced the analysis. However, the diversity within the team also brings strengths and the group discussions between all the authors allowed for questioning and critique throughout the process of analysis.

Implications for clinical practice

Our findings confirm that a child's self-reported experience on their best interests and participation in shared decision-making in healthcare needs to be viewed from a holistic ecological viewpoint taking into consideration the child's age; competency; illness severity; admission type and psychosocial, emotional, cognitive, and physical, developmental level. Children in hospital need to be provided with transparent fluidic age-appropriate means and opportunities to participate in shared decision-making that is in their best interests as this could influence the child's clinical outcome. The government and healthcare professionals need to be aware of the latest CCC and UNCRC literature, policies, pathways, and legislation to meet the child's self-reported needs in hospital from a multidisciplinary lens.

Implications for future research

Future research with larger representative and inclusive samples (children with disabilities, palliative care, chronic illness and critical care including mental health admissions) to explore how children's self-reported experiences on their best interests and participation in hospital are influenced by the physical environment, resources, policies, guidelines, legislation, acuity, illness typology and UNCRC knowledge from multiple viewpoints (healthcare professionals and parents) and settings is required. Focus groups and purposive sampling to focus on a wider representation of demographic variables, child interviews without parental presence and interpreting the child's non-verbal cues could have provided richer and more detailed data, albeit with a greater time,

ethical consideration, and logistical cost to undertake the study. Future research is required to direct evidence based contextually relevant interventions, initiatives, and policy development to create an inclusive CCC approach that honours the UNCRC to support children's rights to participate in shared decision-making in hospital.

Limitations

Some of the limitations evident in this study were that all respondents were school-aged children, and the admissions were essentially surgical. Whilst the interviews involved open ended questions, children's responses were distinct and short, and this impacted on the depth of the data.

Conclusion

Listening to and allowing children's voices to have influence in shared decision-making not only empowers and safeguards their rights as enshrined in the UNCRC, but also gives invaluable insight to key stakeholders to direct education, theory, research and clinical practice. Documenting children's self-reported experiences about their best interests, needs and participation in hospital is necessary to direct CCC healthcare practices. The relationships that children experience with their parents, and create with healthcare professionals, and the physical environment are vital aspects in meeting their best interests and ability to participate in care during a hospital admission. In further fostering the best interests and participation of children in healthcare, age-appropriate environments need to be co-designed with children.

Funding

This study was supported by the Western Australia Nurses Memorial Trust Grant [SUB/85093]; Australian College of Children, Young People's Nurses Dorothy Clarke Scholarship Grant [26767/6072], and the Childhood Cancer Fund in Sweden [PR2019–0052]. None of the funding sources were involved in this research.

Conflict of interest statement

No conflict of interest has been declared by the author(s).

The authors would like to further confirm that the 'Children's voices on their participation and best interests during a hospital stay in Australia' manuscript is an original research project with Ethics approval that has not been submitted to another journal or been published.

Authorship credit declaration

IKH and AQ conceptualization; MF and LW data curation; MF, AQ, LW and IKH formal analysis; MF, AQ, LW and IKH funding acquisition; MF and LW investigation; IKH and AQ methodology; MF and LW project administration; MF and AQ writing original draft and MF, AQ, LW and IKH review and editing. All authors gave final approval of this version to be published.

Author statement

The authors would like to confirm that the 'Children's voices on their participation and best interests during a hospital stay in Australia' manuscript is an original research project with Ethics approval that has not been submitted to another journal or been published.

Acknowledgments

We would like to acknowledge all the children that participated in this study as well as the funding agencies that made this project possible.

References

Bekken, W. (2017). Decision-making in paediatric rehabilitation: Exploring professional and children's views on decision-making involvement. *Children & Society, 31*(6), 486–496. https://doi.org/10.1111/chso.12218.

Boland, L., McIsaac, D. I., & Lawson, M. L. (2016). Barriers to and facilitators of implementing shared decision making and decision support in a paediatric hospital: A descriptive study. *Paediatrics & Child Health, 21*(3), 17–21.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Bronfenbrenner, U. (2004). *Making human beings human: Bioecological perspectives on human development. Sage.*

Carnevale, F. A., Collin-Vezina, D., Macdonald, M. E., Menard, J., Talwar, V., & Van Praagh, S. (2021). Childhood ethics: An ontological advancement for childhood studies. *Children & Society, 35*(1), 110–124. https://doi.org/10.1111/chso.12406.

Carter, B., Bray, L., Dickinson, A., Edwards, M., & Ford, K. (2014). *Child-centred nursing: Promoting critical thinking.* Sage Publications Inc.

Christian, B. (2017). Translational research: The intersection between sociocultural and environmental factors and the health of children and families. *Journal of Pediatric Nursing, 37*, 127–131. https://doi.org/10.1016/j.pedn.2017.09.013.

Council for International Organisations of Medical Sciences (2016). International ethical guidelines for health-related research involving humans. *Geneva*, 1–119.

Council of Europe (2012). *Participation of children and young people under the age of 18.*

Coyne, I. (2006). Children's experiences of hospitalization. *Journal of Child Health Care, 10*(4), 326–336. https://doi.org/10.1177/1367493506067884.

Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision making: Children,adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing, 18*, 273–280. https://doi.org/10.1016/j.ejon.2014.01.006.

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing, 20*, 2334–2343. https://doi.org/10.1111/j.1365-2702.2010.03582.x.

Coyne, I., Hallstrom, I., & Soderback, M. (2016). Reframing the focus from a family centred to a child centred care approach for children's healthcare. *Journal of Child Health Care*, 1–9. https://doi.org/10.1177/1367493516642744.

Coyne, I., Hayes, E., Gallagher, P., & Regan, G. (2006). *Giving children a voice: Investigation of children's experiences of participation in consultation and decision making in Irish hospitals.* The Stationary Office.

Coyne, I., Holmström, I., & Söderbäck, M. (2018). Centeredness in healthcare: A concept synthesis of family-centered care, person-centered care and child-centered care. *Journal of Pediatric Nursing, 42*, 45–56. https://doi.org/10.1016/j.pedn.2018.07.001.

Coyne, I., & Kirwan, L. (2012). Ascertaining children's wishes and feelings about hospital life. *Journal of Child Health Care, 16*(3), 293–304. https://doi.org/10.1177/1367493512443905.

Davies, A., & Randall, D. (2015). Perceptions of children's participation in their healthcare: A critical review. *Issues in Comprehensive Pediatric Nursing, 38*(3), 202–221. https://doi.org/10.3109/01460862.2015.1063740.

Department of Health (2012). *WA Health research governance policy and procedures.* Perth: Research Development Unit, Department of Health.

Derrington, S. F., Paquette, E., & Johnson, K. A. (2018). Cross-cultural interactions and shared decision-making. *Pediatrics, 142*, 187–192. https://doi.org/10.1542/peds.2018-0516J.

Dickinson, A., Wrapson, W., & Water, T. (2014). Children's voices in public hospital healthcare delivery: Intention as opposed to practice. *The New Zealand Medical Journal, 127*(1405), 24–31.

Dijkstra, K., Pieterse, M., & Pruyn, A. (2006). Physical environmental stimuli that turn healthcare facilities into healing environments through psychologically mediated effects: Systematic review. *Journal of Advanced Nursing, 56*(2), 166–181. https://doi.org/10.1111/j.1365-2648.2006.03990.x.

Elliott, R., & Timulak, L. (2005). Descriptive and interpretive approaches to qualitative research. *A handbook of research methods for clinical and health psychology* (pp. 147–159). Oxford University Press.

Feng, J. Y., Toomey, S. L., Elliott, M. N., Zaslavsky, A. M., Onorato, S. E., & Schuster, M. A. (2020). Factors associated with family experience in pediatric inpatient care. *Pediatrics, 145*(3). https://doi.org/10.1542/peds.2019-1264.

Ford, K., Campbell, S., Carter, B., & Earwaker, L. (2018). The concept of child-centered care in healthcare: A scoping review protocol. *Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, 16*(4), 845–851. https://doi.org/10.11124/JBISRIR-2017-003464.

Foster, M., & Shields, L. (2019). Bridging the child and family centred care gap: Therapeutic conversations with children and families. *Comprehensive Child and Adolescent Nursing, 1-8.* https://doi.org/10.1080/24694193.2018.1559257.

Foster, M., Whitehead, L., & Arabiat, D. (2019). Development and validation of the needs of children questionnaire: An instrument to measure children's self-reported needs in hospital. *Journal of Advanced Nursing, 75*, 2246–2258. https://doi.org/10.1111/jan.14099.

Foster, M., Whitehead, L., Arabiat, D., & Frost, L. (2018). Parents' and staff perceptions of parental needs during a child's hospital admission: An Australian study. *Journal of Pediatric Nursing, Online., 43*, e2–e9. https://doi.org/10.1016/j.pedn.2018.06.013.

Foster, M., Whitehead, L., & Maybee, P. (2016). The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centered care within a pediatric critical care setting: A synthesis of quantitative research [article]. *Journal of Family Nursing, 22*(1), 6–73. https://doi.org/10.1177/1074840715618193.

Foster, M., Whitehead, L., Maybee, P., & Cullens, V. (2013). The parents', hospitalized child's and health care providers' perception and experiences of family centred care within a

paediatric critical care setting: A meta-synthesis of qualitative research. *Journal of Family Nursing, 19*(4), 431–468. https://doi.org/10.1177/1074840713496317.
Gormley, J., & Light, J. (2021). Child–parent–provider interactions of a child with complex communication needs in an inpatient rehabilitation facility: A pilot study. *American Journal of Speech-Language Pathology, 30*(1), 105–118. https://doi.org/10.1044/2020_AJSLP-20-00031.
Green, L. M. C., Friend, A. J., Bardgett, R. J. M., & Darling, J. C. (2018). Including children and young people in assessments: A practical guide. *Archives of Disease Children Education and Practice, 103*(5), 267–273. https://doi.org/10.1136/archdischild-2017-313368.
Hallström, I., Runeson, I., & Elander, G. (2002). An observational study of the level at which parents participate in decisions during their child's hospitalization. *Nursing Ethics, 9*(2), 203–214. https://doi.org/10.1191/0969733002ne499oa.
Hart, R. I., Cameron, D. A., Cowie, F. J., Harden, J., Heaney, N. B., Rankin, D., ... Lawton, J. (2020). The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: A qualitative study involving adolescents and young adults with cancer and their caregivers. *BMC Health Services Research, 20*(1), 25. https://doi.org/10.1186/s12913-019-4851-1.
Hayes, D., Edbrooke-Childs, J., Town, R., Wolpert, M., & Midgley, N. (2019). Barriers and facilitators to shared decision making in child and youth mental health: Clinician perspectives using the theoretical domains framework. *European Child & Adolescent Psychiatry, 28*(5), 655–666. https://doi.org/10.1007/s00787-018-1230-0.
Information Commissioners's Office (2020). Best interests of the child. https://ico.org.uk/for-organisations/guide-to-data-protection/ico-codes-of-practice/age-appropriate-design-a-code-of-practice-for-online-services/1-best-interests-of-the-child/.
Jaser, S. S. (2011). Family interaction in pediatric diabetes. *Current Diabetes Reports, 11*(6), 480–485 https://doi.org/10.1007%2Fs11892-011-0222-y.
Katkin, J., Kressly, S., Edwards, A., Perrin, J., Kraft, C., Richerson, J., Tieder, J., & Wall, L. (2017). Guiding principles for team-based pediatric care. *Pediatrics, 140*(2), Article e20171489.. https://doi.org/10.1542/peds.2017-1489.
Lambert, V., & Glacken, M. (2011). Engaging with children in research. *Nursing Ethics, 18*, 781–801. http://nej.sagepub.com/content/18/6/781.full.pdf.
Larsson, I., Staland-Nyman, C., Svedberg, P., Nygren, J., & Carlsson, I. (2018). Children and young people's participation in developing interventions in health and well-being: A scoping review. *BMC Health Services Research, 18*, 507. https://doi.org/10.1186/s12913-018-3219-2.
Mello, E., Ferreira, P., Lima, R., & Mello, D. (2014). The involvement of parents in the healthcare provided to hospitalzed children. *Revista Latino-Americana de Enfermagem, 22*(3), 432–439 06/01https://doi.org/10.1590/0104-1169.3308.2434.
Moore, T., McDonald, M., & McHugh-Dillon, H. (2014). Early childhood development and the social determinants of health inequities: A review of the evidence. https://www.rch.org.au/uploadedFiles/Main/Content/ccch/151014_Evidence-review-early-childhood-development-and-the-social-determinants-of-health-inequities_Sept2015.pdf.
National Health and Medical Research Council (2018). *Australian Code for Responsible Conduct of Research.* Canberra: The National Health and Medical Research Council, the Australian Research Council and Universities Australia.
Navin, M. C., & Wasserman, J. A. (2019). Capacity for preferences and pediatric assent implications for pediatric practice. *The Hastings Center Report, 49*(1), 43–51. https://doi.org/10.1002/hast.980.
Nisha, D., & Michelle, O. R. (2017). *Interviewing children and young people for research.* Sage Publications. https://www-doi-org.ezproxy.ecu.edu.au/10.4135/9781526419439.
Noreña-Peña, A., & Juan, L. (2011). The experience of hospitalized children regarding their interactions with nursing professionals. *Revista Latino-Americana de Enfermagem, 19*(6), 1429–1436. https://doi.org/10.1590/S0104-11692011000600021.
Popejoy, E., Pollock, K., Almack, K., Manning, J. C., & Johnston, B. (2017). Decision-making and future planning for children with life-limiting conditions: A qualitative systematic review and thematic synthesis. *Child: Care, Health and Development, 43*(5), 627–644. https://doi.org/10.1111/cch.12461.
Rogoff, B., Paradise, R., Mejía-Arauz, R., Correa-Chavez, M., & Maricela Angelillo, C. (2003). Firsthand learning through intent participation. *Annual Review of Psychology, 54*(1), 175–203. https://doi.org/10.1146/annurev.psych.54.101601.145118.
Sahlberg, S., Karlsson, K., & Darcy, L. (2020). Children's rights as law in Sweden–every health-care encounter needs to meet the child's needs. *Health Expectations, 23*, 860–869. https://doi.org/10.1111/hex.13060.
Stålberg, A., Sandberg, A., Söderbäck, M., & Larsson, T. (2016). The child's perspective as a guiding principle: Young children as co-designers in the design of an interactive application meant to facilitate participation in healthcare situations. *Journal of Biomedical Informatics, 61*, 149–158. https://doi.org/10.1016/j.jbi.2016.03.024.
Tates, K., & Meeuwesen, L. (2001). Doctor-parent-child communication: A (re)view of the literature. *Social Science & Medicine, 52*(6), 839–851. https://doi.org/10.1016/s0277-9536(00)00193-3.
Trollvik, A., Eriksson, B. G., Hummelvoll, J. K., & Ringsberg, K. C. (2013). Children's participation and experiential reflections using co-operative inquiry for developing a learning programme for children with asthma. *Action Research, 11*(1), 31–51. https://doi.org/10.1177/1476750312467834.
UNICEF (2019). A simplified version of the United Nations Convention on the Rights of the Child. https://www.unicef.org.au/Upload/UNICEF/Media/Our%20work/childfriendlycrc.pdf.
UNICEF (2021). Frequently asked questions on the United Nations Convention on the Rights of Child. https://www.unicef.org/child-rights-convention/frequently-asked-questions.
United Nations General Assembly (1989). Convention on the rights of the child. United Nations. https://en.wikipedia.org/wiki/Convention_on_the_Rights_of_the_Child.
Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., & Wray, J. (2018). Eliciting the experiences of the adolescent-parent dyad following critical care admission: A pilot study. *European Journal of Pediatrics, 177*(5), 747–752. https://doi.org/10.1007%2Fs00431-018-3117-y.
World Health Organization et al (1986). *Ottawa charter for health promotion. An international conference on health promotion. Ottawa, Ontario.*
World Vision International (2021). Defining child participation. https://www.wvi.org/sites/default/files/Defining%20Child%20Participation.pdf.