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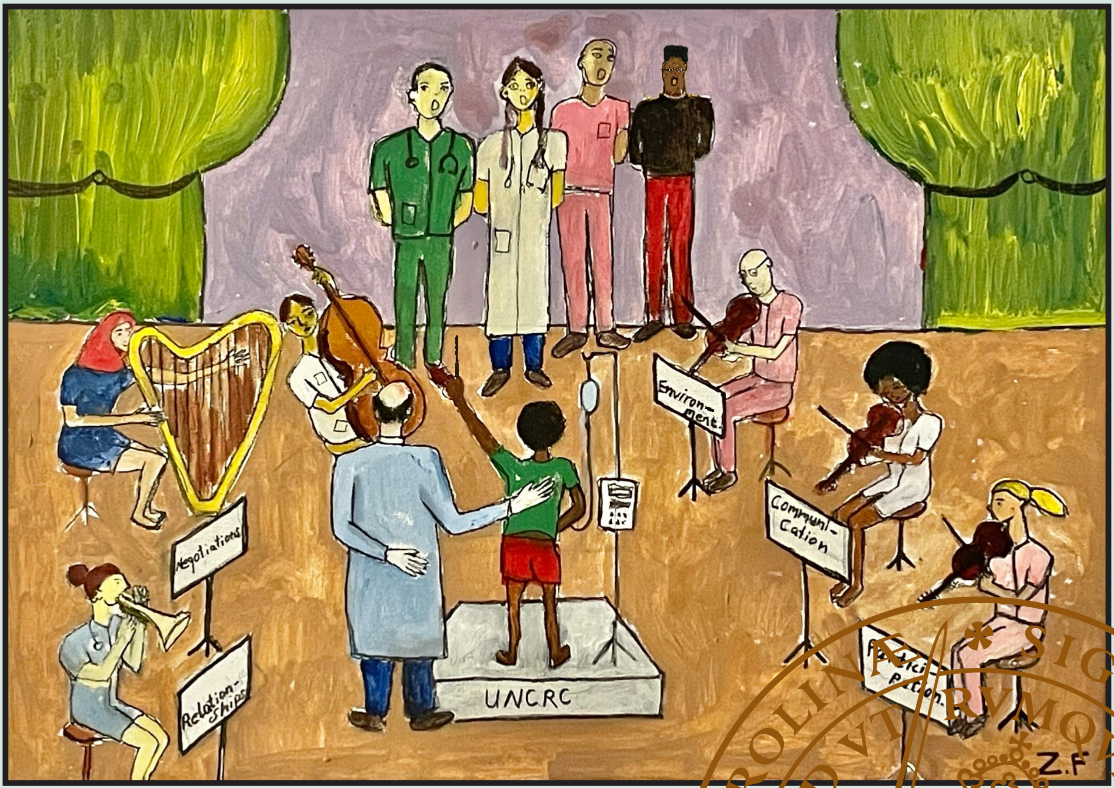

The Child's Best Interests during Hospitalisation -

What does it imply?

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Abstract

The child's best interest has moral foundations in medicine and has existed for decades in the field of paediatrics. Indeed, there are recommendations for the child's best interests to be a primary consideration in all matters that concern the child. However, there is uncertainty in the literature over how the child's best interests may be safeguarded within healthcare.

Aim: The aim of this thesis was to elucidate from various perspectives, the experiences of the child's best interests during hospitalisation.

Methods: A naturalistic paradigm was used, employing qualitative exploratory and qualitative descriptive designs. Data were collected from paediatric units in Sweden and Australia. Thirty-two observations of the interactions between children, their parents and healthcare professionals were graded using the Scale of Degrees of Self-Determination and normative assessments. The same 32 observations were also analysed using inductive content analysis and abductive reasoning. Further, inductive thematic analysis of interviews with nine children, and inductive content analysis of interviews with 16 parents was conducted.

Results: The findings show that interpersonal relationships, an enhancing environment, effective communication, mutual negotiations and collaborations, and active participation are essential to safeguarding the child's best interests during hospitalisation.

Conclusion: The factors involved in safeguarding the child's best interests during hospitalisation are interconnected and nested in a rather complex system and can be further understood using Bronfenbrenner's bioecological model. The child's best interests are context-dependent, situational, flexible, and dependent on all actors involved and actual decisions made. Safeguarding the child's best interests during hospitalisation requires a case-by-case approach and a holistic view of the child, beyond their clinical treatment.

Key words: Best Interest, Child, Parent, Active Participation, Shared Decision-Making, Bioecologal

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This thesis is dedicated to my parents Wesley Kofi Entsieh and Comfort Abena Entsieh

"For there is hope for a tree, if it be cut down,
that it will sprout again and that its shoots will not cease"
Job 14:7

Contents

Abstract

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Abbreviations & General Definitions

AWCH	Association for the Wellbeing of Children in Healthcare
CCC	Child-Centred Care
CHA	Children's Healthcare Australasia
EACH	European Association for Children in Hospitals
FCC	Family-Centred Care
HCA	Healthcare Act
HCP	Healthcare Professional
NBHW	National Board of Health and Welfare
NCC	National Children's Commissioner
NOBAB	Nordiskt Nätverk för barn och ungas rätt och behov inom hälso- och sjukvård (Nordic network for children's rights and needs in healthcare)
SDM	Shared Decision-Making
PPCT	Process-Person-Context-Time
UNCRC	United Nations Convention on the Rights of the Child

Age of Majority	The age at which a person gains the legal status of an adult, usually set at 18 years
Barnombudsmannen	A Swedish government agency that advocates for the rights and needs of children
Best interest	The maximally the good of the individual
Child	All persons under the age of 18 years
Healthcare professional	A provider of healthcare (both treatment and advice) based on formal training and experience.
Parent	Individuals with legal custody of a child

Original Papers

This thesis is based on the following papers:

I Quaye, AA., Coyne, I., Söderbäck, M., & Hallström, I. K. 2019. Children's active participation in decision-making processes during hospitalisation: An observational study. *Journal of Clinical Nursing,* 28:4525–4537.

II Quaye, A. A., Castor, C., Coyne, I., Söderbäck, M., & Hallström, I. K. 2021. How are children's best interests expressed during their hospital visit? - An observational study. *Journal of Clinical Nursing*, 1– 13.

III Foster, M., Quaye, A. A., Whitehead, L. & Hallström, I. K. 2022. Children's voices on their participation and best interests during a hospital stay in Australia. *Journal of Pediatric Nursing*, 63, 64-71.

IV Quaye, A. A., Foster, M., Whitehead, L. & Hallström, I. K. 'I don't remember doctors talking to me like that when I was a kid'- A qualitative study on parent's experiences of their child's best interests during hospitalisation (*Submitted for publication*)

Introduction

Historically, the placement of children in society was a passive one, where children were seen as properties of their parents and were not valued as worthy of having the same rights as adults (Hart, 1991). Children were regarded as having the status of "not-yet knowing", "not-yet capable", and "not-yet adults" (Verhellen, 2015).

However, over recent decades, the plight of children has begun to take centre stage in most western settings through the influence of legislations such as the Universal Declaration of Human Rights and subsequently the United Nations Convention on the Rights of the Child (UNCRC). The UNCRC's definition of a child is '*every human being below the age of 18 years unless under the law applicable to child, majority is attained earlier*" (UNCRC, 1989). The UNCRC reinforces the rights of the child and provides guidelines regarding where to focus to secure the child's best interests in healthcare settings. Since the publication of the UNCRC in 1989, the mandate to safeguard children's rights in all matters concerning them has increasingly been acknowledged internationally (European Association for the Care of Children in Hospital, [EACH], 2016; UNCRC, 1989). Children are social actors who actively co-construct childhood and society (Sommer et al., 2010).

Both a child and the child's perspective are vital when making efforts to safeguard the child's best interests. There is, however, a paucity of research on how to safeguard the child's best interests when they encounter healthcare.

This thesis therefore aims to elucidate from various perspectives, the child's best interests during hospitalisation.

Background

The Child's Best Interests

This principle has its moral foundations in medicine and has existed for decades in the field of pediatrics (Bester, 2019). Article 3 of the UNCRC promotes the child's best interests but does not explicitly define what the best interests of the child entails. Nevertheless, according to Bester (2019) can be defined as "*those things that are needed for a child's well-being*" (p. 120). Buchanan and Brook (1990) further clarify that interests can either be current or future oriented. Current interests are the child's immediate interests like pleasure, desire to be free from pain, suffering, or discomfort, and having normal functioning in life. Future interests include the child's developmental interests. Acting in an individual's best interest has been defined as "*Acting so as to promote maximally the good of the individual*" (Buchanan and Brook, 1990, p. 88).

The principle of the best interest aligns with ethical principles of promoting benefits and avoiding harm. In a healthcare professional (HCP)-patient relationship, it is the core and moral obligation of the HCP to provide care that promotes the health and wellbeing of the patient, in other words the best interests of the patient (World Medical Association, 2013). Whereas the provision of healthcare for adult patients usually involves dyadic HCP-patient interactions that favour patient autonomy, care of children involves triadic interactions of the child-parent-HCP, with children having reduced autonomy (Tates and Meeuwesen, 2001). Parents therefore play an integral role in advocating for their child's best interests. However, situations may arise where the interests of one of these actors are not in conformity with the others. In the instances where the interests of the parents are different from those of their child, it becomes a moral duty for the HCPs to promote those interests that will be beneficial to the child (Buchanan and Brook, 1990; Beauchamp and Childress, 2019).

The best interests of the child can be viewed from various perspectives: from a *care perspective*, *socio-cultural perspective*, *ethical perspective*, and *judicial perspective*. It can be said to be a wider concept that also includes active participation, and shared decision-making. These are elaborated below.

Care Perspective

The two models of care that will be highlighted here, are family-centred care (FCC) and child-centred care (CCC).

Family-Centred Care

This approach to care has been the predominant model of care in paediatric units globally and has been defined as "*care that is planned by the health staff around the whole family, not just the child, and in which all family members are recognised as care recipients*" (Shields et al., 2006). The family is seen as a whole, where interactions of the family members influence each other (Shields et al., 2012). Parents take precedence in the partnerships and collaborations with HCPs over matters concerning their child (Coyne et al., 2016).

Child-Centred Care

This philosophy of care recognises and promotes the child's right to participate in planning and delivery of care that concerns their own health (Coyne et al., 2016). The child, who belongs to a family, is seen as a social actor with their own rights and an active recipient of care. Care is planned in the context of the family and the community and considers the child's perspectives and values. Child-centred care incorporates negotiations between all the actors involved, where the child and their best interests are the focus (Coyne et al., 2016).

Socio-cultural Perspective

Childhood is a socialising process where children grow and develop into unique individuals, who become a part of society. Societal view of children is affected by historical events, cultural norms, and values (Hart, 1991). In turn, socio-cultural perspectives shape the way children are cared for when they encounter healthcare. The child's perspective represents "*the child's own perceptions, experiences, and understanding of their life world*" (Sommer et al., 2010, p.23) whereas child perspective refers to "*direct adult's attention towards an understanding of children's perceptions, experiences and understanding of the world*" (p.22). The main agent in the child's perspective is the child whereas a child perspective is a construction of how the adult as the agent (parents, HCP) views the child. A child's perspective in healthcare situations may enhance opportunities for children to express their views, actively take part in decision-making and may allow care to be tailored to reflect their needs (Coyne et al., 2016). A child perspective wherein the HCP has expert knowledge about care of the sick child, is cognizant about the rights of the child, and understands perceptions, experiences, and actions/attitudes of the child, may further enhance how the child is guided into active participation

(Sommer et al., 2010; Söderbäck, et al., 2011). Thus, both perspectives are vital in care situations involving children. Child-centred care is reinforced when the adult begins to see the child as a competent co-constructor; this results in the child's perspective coming into effect (Sommer et al., 2010; Söderbäck et al., 2011). It is therefore necessary that children are listened to, their wishes, opinions and valuations actively sought, and that they are guided into active participation that leads to increased autonomy, and competence (Rogoff, 1990).

Ethical Perspective

Competence

Beauchamp and Childress (2019) define competence as simply "*the ability to perform a task*" (p.113). The criteria for competence differ from one context to the other and are dependent on the decisions to be made. Competence as explained by Beauchamp and Childress (2019) is therefore relative to decision making. A child's seeming inability to decide in one situation does not mean that child should be judged as being incompetent in another aspect of life. As children grow and develop, their capacities (biological, cognitive, and psychosocial) evolve. Children do not acquire competence by virtue of age alone, but also by events and experiences that shape their response to situations. The levels of competence in an individual can thus be influenced by the context the individual finds themselves in (Beauchamp and Childress, 2019). In the clinical setting, HCPs may need to constantly consider the situation, and assess whether the child is able to perform the task at hand. A child may not be competent enough to know if intervention A would be more effective than intervention B but given an ideal case where adequate information is provided and an enabling environment created for participation, the child may be competent enough to air their opinions and preferences on how the care could proceed (Beauchamp and Childress, 2019).

Autonomy

It is stated in the principle of respect for autonomy by Beauchamp and Childress that "*to respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their values and beliefs*" (Beauchamp and Childress, 2019, p. 104). Autonomous actions in individuals can be identified by the individual's ability to act intentionally with understanding (agency) and do so without any external influence from their surroundings that would otherwise alter their actions (liberty). However, Beauchamp and Childress acknowledge the social nature of individuals and Sedig (2016) brings into focus the family context which patients are a part of. Children's autonomy in the healthcare context may be temporarily constrained by their illness, environment, or actions of parents and HCPs (Beauchamp and Childress, 2019), which when not carefully addressed, may impinge on the expression of the child's best interests. Respect for the child's autonomy obliges HCPs to guide children to freely practise their autonomy whilst partnering with their parents to maximise the net benefits to the child.

Judicial Perspective

The perspectives highlighted above can further be concretised by a judicial perspective which brings into focus various laws, legislations, and policies that aim to foster the best interests of the child. Internationally, the UNCRC is one of the most widely ratified human rights treaties in the world. It was adopted in 1989 to help protect the civil, political, social, economic, and cultural rights of children, since children have a limited autonomy and are more vulnerable to violations of their human rights than adults (Hermerén and Forskningsrådet, 1996; Mapp, 2010).

The UNCRC has since sparked global attention, contributing to a remarkable shift in the value placed on children and how they are perceived in society (Streuli et al., 2011; Webb, et al., 2009). The UNCRC may be used in paediatric practice as a guide to help safeguard the rights and improve experiences of children when they encounter healthcare services. As one of the core guiding principles of the UNCRC and focal point in this thesis, paragraph one in Article 3 states that, "*In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration*" (UNCRC, 1989). A judicial perspective promotes the child's best interests by highlighting the child's right to freely express their views, be listened to, actively participate in shared decision-making and other aspects of their healthcare in a manner that addresses their competence and respects their autonomy (Council of Europe, 2012; UNCRC, 1989).

Shared Decision-Making

Shared Decision-Making (SDM) is not clearly defined in literature. In the paediatric context, SDM can be viewed as an approach to decision-making that promotes collaboration between the child, parent, and HCPs (Lewis et al., 2019; Wijngaarde et al., 2021). In the paediatric healthcare, the process of SDM has not been studied to a greater extent (Malone et al., 2019). Nevertheless, SDM involves multiple processes and is characterised by the development of a partnership between the patient and HCP. In the partnership, the problem is defined (Brand and Stiggelbout 2013), through an information exchange where the options, risks, and benefits of the decision at hand are adequately discussed. Upon discussing recommendations, and checking for understanding of the patient, mutual negotiations are carried out that lead towards an informed decision reflecting the values, preferences, and best interests of the patient in this case, the child (Boland et al., 2019; Brand and Stigeelbout, 2013). Increased patient knowledge and decreased decisional conflict are some of the benefits of SDM (Wyatt et al., 2015).

The processes involved in SDM lie in synergy with active participation, further promoting the child's best interests. However, paediatric SDM is complicated by several factors one of which is the child's evolving capacities. Sickness severity of the child may affect both the child's and parent's willingness or competence to engage in SDM (Angst and Deatrick, 1996). Further complexities in paediatric SDM include the involvement of multiple stakeholders (child, parent, other family or extended family members, and HCPs), who may present competing interests (Boland et al., 2019; Wyatt et al., 2015). Additionally, imbalance of power between HCPs and children, and between children and their parents may not always promote children's inclusion in SDM (Lloyd et al., 2008). HCPs exert power by virtue of their qualifications and training whilst children and their parents are reliant on HCPs to meet their medical needs (Nimmon and Stenfors-Hayes, 2016).

Active Participation

There are varied definitions of "participation" in the literature. In this thesis, the term *active participation* is used which is a multi-layered concept involving several processes where the transfer of information and power allows participants' views to influence decision-making (Franklin and Slopper, 2005; Sinclair 2004). Article 12 of the UNCRC emphasises respect for the child's views whilst Article 13 requires that every child is given the opportunity to freely express their thoughts and opinions, and that they have access to relevant information (UNCRC, 1989). It can then be deduced that the key aspects of active participation are that: the child receives age-appropriate information about the decision to be made, the child's perspectives are prioritised, and that the child's preferences are considered in the decision-making process (UNCRC, 1989, Council of Europe, 2012). Allowing children to actively participate in matters that concern them upholds their legal rights and may improve their positive experiences. Active participation also enhances children's decision-making abilities, helps them develop useful skills for negotiations and debate, as well as empowers them and increases their self-esteem (Council of Europe, 2012; Davies et al., 2019; Sinclair and Franklin, 2000).

Children's and Parents' Experiences of Hospitalization

The period of hospitalisation can be experienced as stressful for children, parents, and the entire family (De Man et al., 2021; Grahn et al., 2016). Research suggests that children's ability to participate in their own healthcare may be influenced by past negative experiences of hospitalization (Khadij et al., 2022, McMurtry et al., 2015). Being in unfamiliar hospital environments may cause children of all ages to experience fear and anxiety (Jepsen et al., 2019; Leibring and Anderzén-Carlsson, 2019). Children also encounter unfamiliar vocabulary and unfamiliar healthcare professionals (Jensen et al., 2012).

Traumatic experiences among children in the healthcare setting may lead to delayed important medical treatment, cause avoidance behaviors, as well as psychological and behavioural difficulties after discharge (Khadij et al., 2022; Lerwick, 2016; Rennick et al., 2014). It has also been documented that parents experience feelings of loss of control when their child is hospitalised. Suddenly, parents must suspend some of their home and work routines to be able to care for their hospitalised child. They become largely dependent on healthcare professionals (Simeone et al., 2018; Wei et al., 2016) and are filled with emotions of fear and anxiety about their child's condition (Dahav and Sjöström-Strand, 2018; Oxley, 2015).

Children's Active Participation in their Healthcare

One of the prominent needs highlighted in research concerning children's encounters with healthcare is that of wanting to actively participate in their care. Most children, irrespective of age and type of diagnosis have the desire to be involved in their healthcare decision-making (Coyne and Gallagher, 2011; Gilljam et al., 2016; Kilkelly and Donelly, 2011; Stålberg et al., 2016a; Vinblad et al., 2019). Additionally, children's active participation in decision-making processes in their healthcare could help increase feelings of preparedness (Coyne, 2008), and might lead to decreased feelings of anxiety. It could also help increase sense of understanding and competence (Angst and Deatrick, 1996), value, and control (Coyne et al., 2014), enhance patient compliance as well as patient reported satisfaction (Hughes et al., 2011). Ultimately, creating opportunities for children to actively participate in decision-making processes during their healthcare may possibly contribute to better care (Stålberg et al., 2016b; Vinblad et al., 2019).

Nevertheless, children continue to experience challenges in being given opportunities to freely express their views and participate actively - as reflected in Article 12 of the UNCRC (Davies et al., 2019). One of the challenges is the occurrence of dyadic communications between parents and HCPs leaving children feeling side-lined (Coyne and Kirwan, 2012; Peña and Rojas, 2014). Another challenge is that barriers exist preventing children's voices from being heard and taken seriously during healthcare encounters (Davies et al., 2019; Lundy, 2007). There are uncertainties among HCPs regarding how to engage children in their care (Coyne, 2008; Harder et al., 2016). The child's age, HCPs' communication strategies, and attitudes of HCPs and parents have also been identified as influencing children's active participation (Davies and Randall, 2015; Runeson et al., 2001).

Parental Participation in their Child's Healthcare

A review by Aarthun and Akerjordet (2014) highlighted varying degrees to which parents participated in their child's healthcare. The review reported that whilst some parents took leading roles in most activities regarding their child's care, others wished to have been involved more. Meanwhile, other parents preferred to take fewer leading roles and leave the responsibility of decision-making to HCPs. Research has shown that parental involvement in their child's care has benefits both to the child and parent (Dowell and Ogles, 2010; Melo et al., 2014; Vasli and Salsali, 2014). However, high levels of parental involvement in their child's care without including the child's perspective may risk side-lining the best interests of the child (Sahlberg et al., 2020).

Child Healthcare Systems

The child healthcare systems in Sweden and Australia are highlighted here. The nature, content and coverage of these services may vary from one country to the other. The healthcare services in both Sweden and Australia are decentralized.

Sweden

In Sweden, organisation and governance of healthcare services occurs at three administrative levels: national, regional, and local. Through the Ministry of Health and Social Affairs (Socialdepartementet), the state takes prime responsibility for overall healthcare policies. These policies are based on three basic principles: i) equal access; ii) care based on need, and iii) cost effectiveness (National Board of Health and Welfare [NBHW], 2019, Annel et al., 2012). The regional and local levels take responsibility for the funding and provision of healthcare services, and thus allocate resources as per need of their immediate populations (Wettergren et al., 2016). Healthcare facilities are both publicly and privately owned, albeit they are all funded through the public sector (Anel et al., 2012).

Children in Sweden make up approximately one fifth of the country's total population – two million of the estimated 10.4 million as at the ending of 2021 (Statistics Authority, 2022). Generally, children who are resident in Sweden receive all healthcare services free of charge, except for prescribed drugs which are bought at subsidised fees (Wettergren et al., 2016). Children may encounter outpatient or inpatient care at regional facilities during periods of ill health. In Sweden, there are several ways in which hospital-based outpatient care services are organised. These include emergency care, scheduled consultations, day care, day surgery, and home-based healthcare (Wettergren et al., 2016). Most hospitals that host paediatric inpatient care units usually have at least two wards, one accommodating new-borns, and the other older children. Child healthcare is usually provided in a team-based approach consisting of a mix of physicians, paediatricians, surgeons, general nurses, paediatric nurses, assistant nurses, district nurses, play therapists, dieticians, psychologists, and physiotherapists (Wettergren et al., 2016).

Australia

The organization and governance of child healthcare services in Australia includes a multi-level approach, where the Australian government, state and territory governments, and local governments have a shared responsibility for the population's health. Public hospitals are funded by the Australian government, and state and territory governments, and are managed by the state and territory governments. Private hospitals are regulated and licensed by the Australian government and state and territory governments but are owned and managed by the private sector (Australian Institute of Health and Welfare, 2016).

Approximately 5.5 million children live in Australia – about one fifth of the total population, which was estimated at 25.7 million in 2021 (Australian Bureau of Statistics, 2022). Provision of child healthcare in Australia is guided by the National Framework for Universal Child and Family Health Services (Australian Health Ministers Advisory Board, 2011). Services are available at no cost, to all children and their families from birth to eight years old. The Framework's vision is to ensure that "*All Australian children benefit from quality universal child and family health services that support their optimal health, development and wellbeing*" (Australian Health Ministers Advisory board, 2011, p. 2). The Framework operates on seven principles: i) Access, ii) Equity, iii) Promotion and prevention, iv) Working in partnerships with families, v) Diversity, vi) Collaboration and continuity, and vii) Evidence-based. The organisation of hospital-based outpatient and inpatient care services in Australia is like that of Sweden. Outpatient care services include emergency care, scheduled consultations, day care, day surgery, and home-based healthcare. Paediatric inpatient care units are usually hosted by hospitals with healthcare services catering for neonates and older children. Child healthcare is provided in a multidisciplinary team environment involving medical practitioners, dentists, nurses, and other allied health practitioners (Queensland Health, 2017).

Children's Rights

Presented here is an overview of children's rights in Sweden's and Australia's child healthcare system. The rights of children from a global perspective will be looked at by means of highlighting core principles of the UNCRC (1989). Sweden and Australia have committed to ameliorating the conditions for children when they encounter healthcare, and these efforts will be looked at internationally through the UNCRC, and nationally through specific policies, legislations, or laws that are at place in each country.

United Nations Convention on the Rights of the Child

The UNCRC is guided by four main principles: i) non-discrimination (Article 2), ii) best interests of the child (Article 3), iii) the child's right to life, survival, and development (Article 6), and iv) the child's right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously (Article 12). Furthermore, there are three main classifications of rights in the UNCRC that can be summarised as pertaining to: i) protection (safeguarding), ii) provision (health) and iii) participation (autonomy) (Clarke, 2015; Webb et al., 2009).

Protection rights pertain to safeguarding the integrity of children, and include the right to life, and the right to be free from maltreatment and exploitation. Provision applies to the very basic elements needed for the child's survival such as food, shelter, and healthcare. Lastly, participation alludes to the child's right to be actively involved in decision-making in all matters concerning the child (Mapp, 2010; Streuli et al., 2011). The rights of children that fall under protection, provision and participation can be viewed as the welfare/needs/best interests of children (Alderson, 2000). Within healthcare, a child's rights perspective assigns responsibility to those in healthcare institutions who encounter children directly and indirectly to consider all rights of children in all decisions concerning children.

Children's Rights in Sweden

Sweden is a member of the European Association for Children in hospitals, (EACH, 2016). EACH established a charter which aims to further strengthen the welfare of all sick children and to promote their rights before, during, and after their encounters with healthcare services (EACH, 2016). In the Nordic Region, Sweden is part of the Nordic Network for Children's rights and needs in healthcare (NOBAB). NOBAB Sweden has a focus to protect and promote the ability of sick children, including those living with disabilities, to develop and grow individually, irrespective of their challenges (NOBAB, 2022).

As part of the strategies to strengthen the rights of children and improve their experiences when they encounter healthcare, Sweden has put in place several laws such as the Health Care Act (HCA) (Government Offices of Sweden: Hälso- och sjukvårdslag, 2017:30), Patient Act (Government Offices of Sweden: Patientlag, 2014:821), and now the UNCRC (Government Offices of Sweden: 2018:1197).

The HCA provides guidelines on how healthcare should be organised and driven, and it also recognises the child's best interests (Government Offices of Sweden: Hälso- och sjukvårdslag, 2017:30). On August 1st, 2021, changes were made to chapter 5 of the HCA, which requires giving extra support to children who find themselves in situations with limited autonomy - for example if a parent dies (Government Offices of Sweden Hälso- och sjukvårdslag, 2017:30).

The Patient Act was enacted in Sweden in 2015 and of particular importance to this thesis are articles three and four. Article three of the Patient Act states that '*When the patient is a child, the child's caregiver also should be given information*'. Article four states that '*The child's perception of the care or treatment should be mapped out as far as possible and recognized according to age and maturity*'.

An evaluation of the implementation of the Patient Act did not include the child's perspective. Moreover, the adult patients' reports from the evaluations indicated no improvements in clinical practice (Swedish Agency for Health and Care Services Analysis, 2017). The UNCRC was incorporated in its entirety as Law in Sweden in 2020 (Government Offices of Sweden, 2018:1197), making it legally binding for all institutions within Sweden that work with children to safeguard children's rights in accordingly. To further keep a check on children's rights, a government agency known as the *Barnombudsmannen* has been established. The prime purpose of the *Barnombudsmannen* is to ensure the protection of children's rights and interests in accordance with the UNCRC.

Children's Rights in Australia

Australia ratified the UNCRC in 1990 and has since then, put into place initiatives to promote children's rights as indicated in the UNCRC.

In 2012, Australian legislation instituted the National Children's Commissioner (NCC) whose main purpose are to monitor how children's rights are being enacted and provide recommendations thereof. However, according to a report by the NCC, there are few laws and policies at the national level aimed specifically at protecting children's rights in Australia. Apart from the activities of the NCC, there is currently no national plan of action or platform from which to push forth children's rights as stipulated in the UNCRC (Australian Human Rights Commission, 2019). The Australian government has instead delegated the responsibility of tailoring activities and services regarding health, education, child protection and youth justice, to the state and territory levels of governance. This then does not compel the national level of governance to implement a broad-based child's rights law (Australian Human Rights Commission, 2019).

Australia has several national health strategies that pertain to healthcare services for children and their families. One such is the Healthy Safe and Thriving: National Strategic Framework for Child and Youth Health, whose focus is on outcomes for children, with a purpose to "*identify the key strategic priorities for child and youth health in Australia for the next ten years*" (Council of Australian Governments Health Council, 2015, p. 4). The National Action Plan for the Health of Children and Young People is a buildup of the Healthy Safe and Thriving and seeks to address priority health needs and inequalities in healthcare for all children and young people in Australia. It aims to achieve this by driving strategic action at the national, jurisdictional, and local levels (Australian Government Ministry of Health, 2019).

Children's Healthcare Australasia (CHA) is a non-profit organisation for children's hospitals and paediatric units in Australia that advocates for the rights of children when they encounter healthcare (CHA, 2022). Similarly, the Association for the Wellbeing of Children in HealthCare (AWCH) is also a non-profit organisation that advocates for the needs of children and their families within the healthcare system (AWCH, 2022).

In 2010, a partnership between CHA and AWCH and other key stakeholders led to the formation of the Charter on the Rights of Children and Young People in Healthcare Services in Australia, with stipulations in the UNCRC as its guideline. The Charter is underpinned by three key principles: i) the child's best interests should be a primary consideration ii) children are to be listened to and taken seriously, and iii) recognition of the family as the fundamental decision-making unit in a child's life. The charter aims to empower children and young people by creating knowledge awareness about their rights, and it also provides guidance for healthcare professionals caring for children (CHA, 2010).

Theoretical Framework

The Bioecological Model

To deepen understanding of the complexities involved in care of a sick child and safeguarding their best interests, Bronfenbrenner's bioecological model and how it relates to the child's best interests in the healthcare setting will be described.

The ecological systems theory (Bronfenbrenner, 1979, Bronfenbrenner and Ceci, 1994), now refined as the bioecological model, was developed by Urie Bronfenbrener, a psychologist. The new model has four components which are interrelated. The components being Process-Person-Context-Time (PPCT) (Bronfenbrenner and Morris, 2006; Bronfenbrenner, 2005; Figure 1). **Process** refers to the dynamic interactions of an individual and the environment they find themselves in. These interactions are referred to as proximal processes, that occur over time and account for the primary mechanisms producing human development (Bronfenbrenner, 2005). The extent to which these proximal processes can influence an individual's development is dependent on the developing individual's characteristics, the environment (both immediate and distant), as well as the time periods within which the proximal processes occur (Bronfenbrenner, 2005). **Person** refers to the developing individual with regards to their biological, cognitive, emotional, and behavioural characteristics. In any given situation, the characteristics that a child brings with them include *demand*, *resource*, and *force* characteristics. *Demand* characteristics refer to age, gender, skin colour or physical appearance - characteristics that act as an immediate stimulus to another person. *Resource* characteristics refer partly to mental and emotional resources such as experience, skills, and intelligence. *Force* characteristics refer to things like differences in temperament, persistence, motivation, etc. **Context** refers to a system of four nested complex layers of the environment: the micro, meso, exo, and macro systems, and the influence that each has on an individual's development.

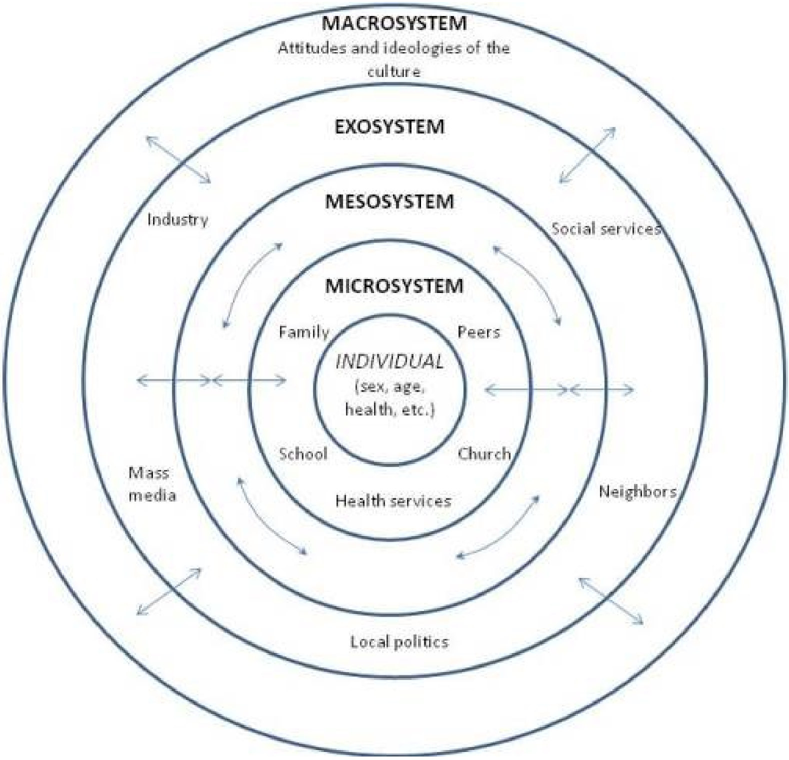


Figure 1. The four nested layers, and reciprocal interactions between a child and their immediate environment in the bioecological model.

The developing individual, in this respect the child, influences, and is influenced by the ongoing interactions within their immediate environment. A microsystem consists of patterns of activities and proximal face-to-face interactions in the child's immediate environment that contribute to a reciprocating influence on the developing child (Bronfenbrenner and Morris, 2006). That the influence is reciprocal indicates that the child is involved as an active social actor and the relationships have bidirectional effects. The interactions between the child and nuclear family forms the microsystem. Not only does the child's immediate environment contain the closest family unit, but also the entire setting in which the child lives. As the child grows older and interacts with more environments, the number of microsystems increases (Paat, 2013). The child-care centre or school, and neighbourhood play area are other microsystems in which the child actively interacts. Interrelations among two or more microsystems in which the child actively participates (i.e., parents interacting with child-care centre personnel), is referred to as the mesosystem. The mesosystem is thus a system of microsystems

(Bronfenbrenner and Ceci, 1994). Moving on, the exosystem refers to social settings in which the child is not involved as an active participant but is still affected by activities of the setting. The parents' workplace, friends and neighbours, extended family, and community health services are all examples of an exosystem. The macrosystem, the outer layer of this nested system comprises cultural values, customs, and laws that govern the entire society. Lastly, **Time** (also referred to as chrono system) encompasses a more holistic aspect; that considers changes occurring over the child's lifetime (Bronfenbrenner and Morris, 2006).

Despite recommendations that *the best interests of the child shall be a primary consideration* in all matters concerning children, little evidence exists on *how* healthcare professionals may safeguard the best interests of the child in daily clinical practice (Waterston and Yilmaz, 2014). Thus, the interrelated projects in this thesis may give further insights into how the child's best interests can be part of knowledge translation for development, evaluations, and implementation in daily clinical practice.

Aims

The overall aim in this thesis was to elucidate from various perspectives, the experiences of the child's best interests during hospitalisation. The four papers in this thesis each had its own specific aims.

- To: explore and describe the child's active participation in daily healthcare practices at children's hospitals. (**Paper I**)
- To: describe ways in which children's best interests were observed to be expressed in paediatric settings during their hospital visit. (**Paper II**)
- To explore school-aged children's experiences about their best interests and participation in care during a hospital admission. (**Paper III**)
- To describe parents' experiences of their child´s best interests during hospitalisation. (**Paper IV**)

Methods

Design

The research design was guided by a naturalistic paradigm where knowledge is socially constructed and emanates from multiple realities. A natural setting refers to an environment as it is in everyday context, free of external manipulation (Lincoln and Guba, 1985).

This thesis consists of Study A and Study B, each of which comprised two parts (Table 1). Paper I took a qualitative exploratory approach. Qualitative exploratory designs are useful when little to no data exist on the phenomena being studied (Rendle et al., 2019). The Scale of Degrees of Self-Determination was used as analytical tool (Hermerén,1996) to assess children's degrees of participation during hospitalisation.

Papers **II**, III, and IV were qualitative descriptive designs (Sandelowski, 2000). Descriptive studies enable comprehensive explanations of the phenomena being studied (Rendle et al., 2019). The analytical approach in Paper II was inductive (Elo and Kyngäs, 2008) and abductive reasoning (Eriksson and Lindström, 1997; Mirza et al., 2014) to gain a deeper understanding of underlying meanings of the child's best interests.

Paper III employed an inductive thematic analytical approach (Braune and Clarke, 2006) for identifying patterns (themes) within the data.

Lastly, in Paper IV inductive content analysis (Lindgren et al., 2020) was used to gain insights into the levels of abstraction and degrees of interpretation with respect to their distinctions and how they relate in forming categories, and themes.

Table 1. Study overview

Study	Design	Sample	Data collection	Analytical Approach	Paper
A (i)	Exploratory qualitative	Children aged 2-17 years from in-and out-patient units with various diagnoses, their parents, and healthcare professionals	Overt, non-participant observations	Scale of Degrees of Self-Determination and Normative assessments	I
(ii)	Descriptive qualitative	Same as above	Same as above	Inductive content analysis and abductive reasoning	II
B (i)	Descriptive qualitative	Children aged 5-14 years old from in-and out-patient units presenting for surgical or acute admissions	Face-to-face parent-child combined interviews	Inductive thematic analysis	III
ii)	Descriptive qualitative	Parents of children aged 2-14 years presenting for surgical or acute admissions	Face-to-face parent-child combined interviews	Inductive content analysis	IV

Setting

Data collection in Study A and Study B occurred in Sweden and in Australia respectively. In Study A, data was collected in the Southern part of Sweden, at one paediatric regional hospital and two paediatric units at a tertiary university hospital, providing services to children. In the three paediatric settings, a total of 14 departments were invited to participate, of which one department declined to participate due to staffing issues and limited resources. Of the 13 that agreed to participate, four functioned as inpatient units, seven as outpatient units, and two served as emergency units. Services provided in the departments covered a range of conditions such as oncology, cardiology, orthopaedics, congenital malformations, surgery, plastic surgery, ear-nose-throat, and ophthalmology. Data in Study B was collected from a paediatric unit at a regional healthcare facility located in Western Australia. The paediatric unit provides care to children up to 16 years. A wide range of medical services including elective general surgery, elective and non-elective orthopaedic surgery and plastic surgery, gastroenterology, neurology, ophthalmology, and ear-nose-throat are provided.

Participants

Children, their parents, and other relatives who accompanied the children to their hospital visits, and the various HCPs who attended to the children.

Children and Parents

The children in Study A were between two and seventeen years old. They had different diagnoses and different types of hospital visit. Accompanying the children during hospitalisation were parents (Study A and Study B), other family relatives (Study A) (Table 2).

Table 2. Demographic characteristics of participants recruited for studies A and B

	Study A (i) & (ii)	**Study B (i)**
Gender		
Girl (N)	18	5
Boy (N)	14	4
Age		
2-6 years	13	4
7-11 years	9	1
12-18 years	19	4
Type of hospital visit		
Outpatient	20	3
Inpatient	12	6
Parents	45	16
Other family relatives	1	0

Healthcare Professionals

In Study A, HCPs observed included assistant nurses, registered nurses, registered nurses with different specializations, physicians, and physicians with different specializations. No demographic information about the HCPs was collected. By default, HCPs were included in the study and had to opt out if they did not wish to participate. Two HCPs opted out of the observations.

Participant Recruitment

Purposive sampling was used in Study A and convenient sampling in Study B. An administrator helped to provide information about upcoming hospital appointments including the child's age, gender, type of diagnosis, type of hospital visit, and time of appointment. This information was accessed ahead of the child's date of appointment.

In Study A, children and their parents were first verbally informed of Study A by the HCP attending to them. The children and their parents/other relatives were then handed an introductory letter in Swedish about the study and those who showed interest informed the attending HCP, who in turn notified the observer of their interest. The observer then handed out detailed participant information letters to the child and parents/ family relative in person. Three types of participant information letters were available: one for children under the age of 15, one for children over the age of 15, and one for the parents/relatives accompanying the children. In the emergency departments recruitment upon arrival was used.

In Study B, children and their parents who presented to the emergency wards were recruited 12 hours following an acute admission whilst those with planned admissions were sent invitations to join the study one week prior to their appointments. Telephone calls were made by the admissions personnel, to inform the children and their parents of the purpose of the study. This was followed by posting information sheets and consent forms. Upon arrival, the children and their parents were introduced to the interviewer, who gave further verbal information about the study.

Data Collection

Study A emanated from one data set collected by means of overt non-participant observations (Liu and Maitlis, 2010). Study B emanated from a second dataset collected by means of face-to-face parent-child combined interviews (Brinkmann and Kvale, 2015; Nisah and Michelle, 2017). The author of this thesis (hereafter observer) collected data relating to Study A whilst another researcher (hereafter interviewer) collected data relating to Study B.

Overt Non-participant Observations

An inspiration for the choice of data collection in Study A, was a study conducted twenty years ago by Runeson et al. (2002). They used overt non-participant observations to investigate children's participation in the decision-making process during hospitalization. Runeson et al. (2002) also focused on identifying and describing children's participation in everyday nursing and medical care during hospitalisation. Overt non-participant observations implied that the aim of the research and role of the observer were known to the children, parents, and HCPs.

The observer, dressed in civilian clothes followed the child and their parents throughout their hospital stay by means of mobile positioning. This means the observer followed and observed interactions occurring among the children, their parents, and HCPs wherever they occurred in the hospital. The observer took a passive role, and only interacted with the participants when the participants initiated it. The observer took 30-minute breaks to record field notes. This was done for observations that took longer than an hour. An observation schedule was used to record the field notes. The field notes were recorded systematically, taking note of the location, who was present during every observed situation, body language of the child, parents, and HCPs, facial expressions, as well as ongoing conversations between the child, parents, and HCPs. Observations ceased when:

- the child fell asleep
- HCPs who did not wish to participate were attending to the child
- the child was in the play therapy
- there was restricted access into rooms for the observer.

Face-to-Face Parent-Child Combined Interviews

In this thesis, the individual interviews were termed as face-face parent-child combined interviews. Though classified as parent-child combined interviews, parents and their child were interviewed separately albeit at the same time, within the hospital premises. Semi-structured interview guides were used (Appendix I). The interviews were tape recorded. During the parents' interviews, some children either sat quietly and listened to the conversations whilst awaiting their turn to be interviewed, or they were preoccupied in play. Parents were offered the opportunity to listen to the audio.

Data Analysis

Transcription of Data

The observer transcribed the field notes from the observations into narrative text. The field notes were written in English whilst conversations occurring between the child, parent, and HCPs were written in Swedish. The conversational text in Swedish was translated into English by the observer and verified by a co-author who was also a native Swedish speaker. The first four observation transcripts were reviewed to inform the next observations. Interview data collected in Study B was transcribed by the interviewer and a research assistant. Analysis of the observational data in Paper I occurred in three steps:

Step 1. Identification of Situations in Nursing and Medical Care

A thorough reading of the transcribed observations as well as field notes was done by the observer. In Step 1, guided by the definition of a situation, identification of everyday nursing and medical care situations was conducted by the observer. In this thesis, a *situation* was defined as "*events occurring between children, and healthcare professionals within the healthcare setting, where decisions about medical and nursing care are made*" (Paper I). All situations not meeting this criterion were excluded (Paper I). Reflections on the questions: "*What is the decision that was made?*" and "*Was the decision made about nursing or medical care?*" enhanced the identification process. Step 1 led to the initial identification of 426 situations which upon joint discussions and reflections with co-authors, led to the removal and collation of situations, resulting into 300 situations.

Step 2. Scale of Degrees of Self-Determination

Developed by Hermerén (1996), active participation in the scale is divided into five levels and it describes various levels of attending to a person's opinions, wishes, and valuations. See Table 3.

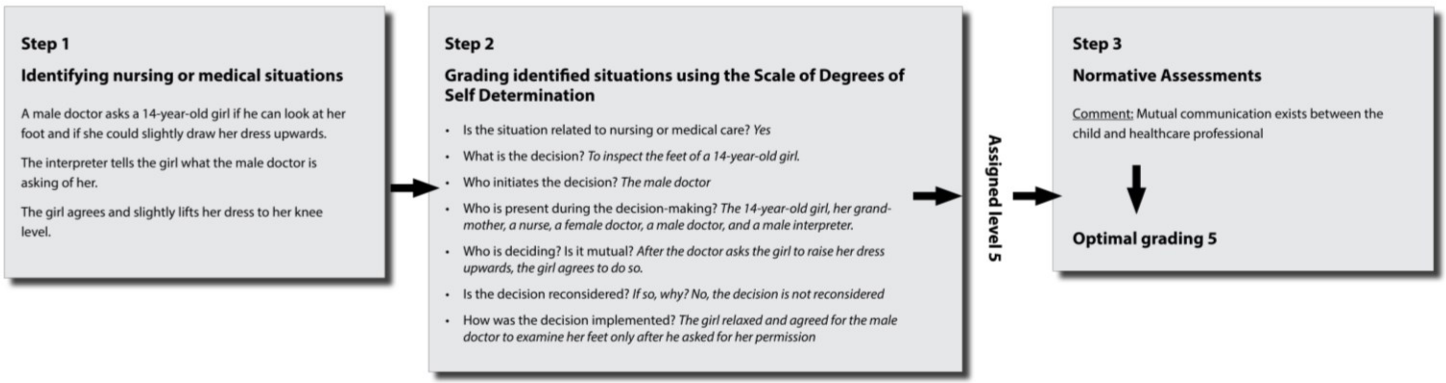
Table 3. Scale of Degrees of Self-Determination

Level 1	A (member of the staff) does not listen to B's (child's) opinions, wishes and valuations.
Level 2	A listens but refuses to discuss the opinions of B with B; no consultation, no two-way communication exists.
Level 3	A communicates with B but does not care about B's answer; B's opinions, wishes and valuations do not influence A's action.
Level 4	A cares about what B says but acts only partly in accordance with B's opinions, wishes and valuations.
Level 5	A acts in accordance with B's opinions, wishes and valuations.

The 300 situations resulting from Step 1 were then subjected to assessments and subsequent grading with the Scale of Degrees of Self-Determination. The assessments were conducted by means of additional questions (Hallström and Elander, 2004) reflected in Step 2 of Figure 2.

Step 3. Normative Assessments

Normative assessments involved comparing actual and optimal participation in the 300 identified situations. These assessments were made in accordance with knowledge of patient characteristics such as the child's age, planned procedures and consideration of alternatives, the situation at hand, decisions made, and how they were carried out. Guiding documents like the UNCRC (UNCRC, 1989), and the Patient Act (Governments Offices of Sweden: Patientlag, 2014:821) were used. The Scale of Degrees of Self-Determination was used to assign optimal levels of active participation to each of the 300 situations.



Step 1

Identifying nursing or medical situations

A male doctor asks a 14-year-old girl if he can look at her foot and if she could slightly draw her dress upwards.

The interpreter tells the girl what the male doctor is asking of her.

The girl agrees and slightly lifts her dress to her knee level.

Step 2

Grading identified situations using the Scale of Degrees of Self Determination

- Is the situation related to nursing or medical care? *Yes*
- What is the decision? *To inspect the feet of a 14-year-old girl.*
- Who initiates the decision? *The male doctor*
- Who is present during the decision-making? *The 14-year-old girl, her grandmother, a nurse, a female doctor, a male doctor, and a male interpreter.*
- Who is deciding? Is it mutual? *After the doctor asks the girl to raise her dress upwards, the girl agrees to do so.*
- Is the decision reconsidered? *If so, why? No, the decision is not reconsidered*
- How was the decision implemented? *The girl relaxed and agreed for the male doctor to examine her feet only after he asked for her permission*

Step 3

Normative Assessments

Comment: Mutual communication exists between the child and healthcare professional

Optimal grading 5

Figure 2. An example showing the analysis process from Step 1 to Step 3.

Inductive Content Analysis and Abductive Reasoning

Analysis of the transcribed observations followed a naïve reading by the author of this thesis and co-authors. Identification, open coding, categorising, and abstraction of observed patterns of the best interests of the child in everyday situations in nursing and medical care followed.

In the identification step, all situations involving any kind of interaction between the child, parent, and HCPs were selected. Selection of the situations was also guided by the questions: "*Were the child's best interests reflected in this situation*?". In the open coding, key words or phrases summarising the content of each identified situation were written down. In the next step, grouping of the situations was done, leading to abstraction of categories. Abduction, which is described as the "*process of generating hypothesis, theories or explanations and precedes deductive and inductive inference*" (Mirza et al., 2014, p.1981) was then used to deepen understanding of the initial categories considering existing literature. Literature was obtained by searching past publications in the databases PubMed, and Cinahl Complete using free search terms: child's best interest, child-Centred care, child's opinion, child(ren)'s competence. Further references were obtained by manual search. A synthesis of seven principles grounded in the resulting literature was conducted by the authors of Paper II and refined into six principles in joint discussions. The principles are shown in Table 4 below. The abstracted categories were further analysed with reference to the six principles, leading to the formulation of main categories.

Table 4. Content of the six priciples used in the analysis

The child receives preparation about what to expect about their care
The child's view is sought about their care
The child's preferences are acknowledge and included
The child indicates how she/he would like the care to be delivered
Parents' actions indicate respect for the child's competence
Healthcare professionals' actions indicate respect for the child's competence

In Paper IV the parent interviews were analysed at the latent level. After a thorough reading of the interview transcripts, the author of this thesis proceeded with the identification of meaning units of relevance to the aim in Paper IV. In a process referred to as condensation, meaning units were shortened by rephrasing and removing repetitive words, with care taken to maintain the core meaning. Thereafter, the meaning units were labelled with codes and discussed in close consultations with the interviewer. The codes were then abstracted directly into sub-themes and themes (Graneheim and Lundman, 2017). Discussions were held with all authors of Paper (III) until a consensus was reached.

Inductive Thematic Analysis

Analysis followed six phases. In the first phase, the first and second authors of Paper III familiarised themselves with the children's interview transcripts by repeated reading. They noted down their initial impressions of the data. Secondly, initial codes were generalised and in the third phase, themes were sought. The resulting themes were reviewed in joint discussions until consensus was reached in defining and naming the themes in the fourth and fifth phases. In the sixth phase, extracts of the analysis text were presented as quotes in the report.

Preunderstanding

According to Dahlberg et al. (2008), preunderstanding can refer to prior knowledge about a particular phenomenon. In qualitative research, preunderstanding may enhance or limit the understanding and interpretation of data. Dahlberg et al. (2008) highlighted emotional attachment to a phenomenon as well as tradition as possible sources of one's preunderstanding. The author of this thesis has always had a core interest in research concerning children and comes from an up bringing where children are most often assigned passive roles in matters that concern them. The author has an educational background in molecular biology and genetics, as well as in public health, but has no educational or professional experience in nursing. These factors interplay to both facilitate and hinder the author's understanding of the child's best interests when they encounter healthcare. The author's preunderstanding was discussed and reflected upon at regular supervision meetings during the entire research process.

Ethical Considerations

Study A was approved by the Lund Regional Research Ethics Committee (2014/411) whilst Study B was approved by the Hospital and University Ethics approval in Australia (21943). The Helsinki Declaration, (WMA, 2013), General Data Protection

Regulations (GDPR, 2018) and European Code of Conduct for Research Integrity (ALLEA, 2017) were used as benchmarks for conducting the study. All head of departments at the children's hospitals approved the study. Participants were assured of confidentiality and informed of their right to withdraw from the study at any time without this affecting their healthcare.

Autonomy

Autonomy in research must be respected, especially in research involving vulnerable groups like children. Beauchamp and Childress (2019) highlighted that the autonomous individual acts freely in accordance with a self-chosen plan. Posters were put up at strategic places (staff rooms, patient waiting rooms, along corridors, on notice boards), and meetings were held with the HCPs to inform them about the study. Prior to the observations (Study A), and face-to face combined interviews (Study B), the children and their parents were given both oral and written information about the purpose of the study, methods to be used, and risks and benefits of the study. Children were further given age-appropriate information about the study. The children and their parents were given opportunities to ask questions, and time to think and reflect on whether they wished to participate or not. Confidentiality and non-disclosure of participant's identity were assured.

Informed consent refers to a person's comprehension of information (purpose, risks, and benefits) and a voluntary agreement to participate (Beauchamp and Childress, 2019), and is obtained by signing an informed consent. Parents gave their own written consent and children older than 15 years were asked for both written and oral consent. Informed assent is like informed consent, however with informed assent, the child is assessed to have less competence in fully understanding all the risks and benefits at hand (Walker and Doyon, 2001). Children below the age of 15 years gave their informed assent with both their parents required to give written consent on their behalf (Study A). In Study B, only one parent was required to give written consent on their child's behalf. Children who wished not to participate despite their parents' interest, were respected – they did not participate. Healthcare professionals who were not willing to be part of the study could opt out of the study by means of contacting the observer in person, via email, or by telephone call. Contact details of the observer were provided in the posters.

Non-maleficence and Beneficence

The principle of non-maleficence emphasises the need for research to abstain from causing more harm than good towards others. In addition, the principle of beneficence promotes the proliferation of good conducts. The principle, as explained by Beauchamp and Childress (2019) refers to "*a statement of moral obligation to act for the benefit of others*" (p.218). This research may contribute to the current knowledge gap about how to safeguard children's best interests when they encounter healthcare, and in the long run improve service delivery in the paediatric setting. The author of this thesis made efforts to create a good rapport with the children, their parents, and HCPs. Efforts were made to create trust and an environment where the participants would feel safe, and not intimidated by the presence of the author of this thesis. Observing children especially those who had been diagnosed with problems concerning their reproductive organs may have been uncomfortable for the children. Prior to every observation event, children and their parents were asked if they were still comfortable with the presence of the observer. With regards the interviews, children who waited their turn to be interviewed and fell asleep were allowed to do so and were not woken up.

Justice

Beauchamp, and Childress (2019) state that the recruitment of participants should be done in a non-discriminatory way. The use of both purposive, and convenient sampling enabled this research to reach out to all children who attended medical treatment at the study sites, irrespective of age (2-17 years), gender, diagnosis, ethnic background, and type of hospital visit. In addition, the UNCRC also states the importance of including children in all matters that concern them, which allows them to freely express their wishes, valuations, and opinions. Paper III was aimed at directly involving the children by allowing their voices to be heard.

Findings

Both the children and their parents were aware of the complexities involved in safeguarding the child's best interests. They encountered positive and negative aspects during hospitalisation. Patterns that facilitated or obstructed expression of the child's best interests during hospitalisation were identified. Positive experiences facilitated expression of the child's best interests whereas negative experiences obstructed expression of the child's best interests. The facilitators and obstructors are presented under the headings: interpersonal relationships, an enhancing environment, effective communication, importance of mutual negotiations and collaborations, and active participation during hospitalisation. See Figure 3 for an overview of the findings.

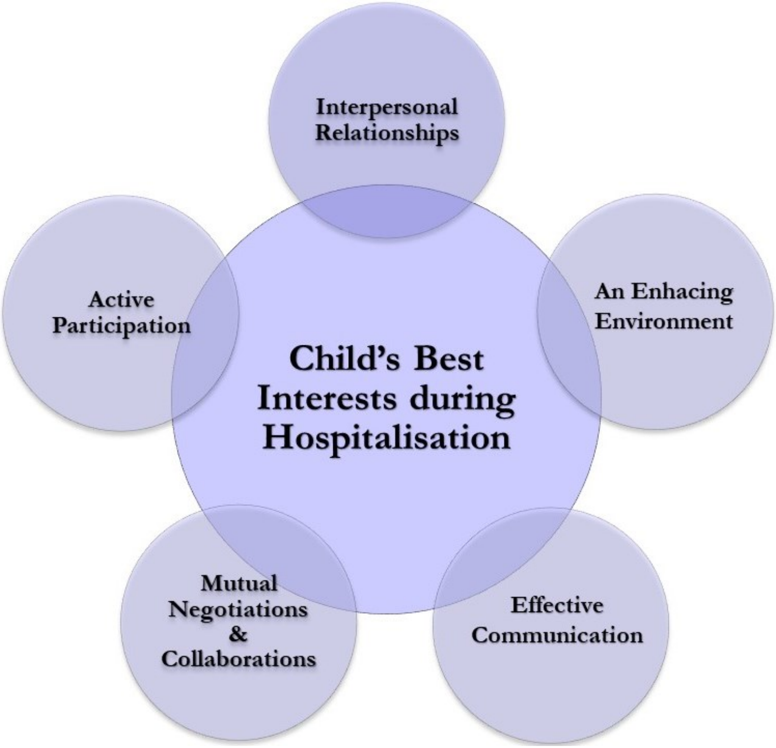


Figure 3. Factors at play in safeguarding the child's best interests during hospitalisation

Interpersonal Relationships

Children (Paper III) and their parents (Paper IV) highlighted a need to have interpersonal relationships with the healthcare professionals and with each other. Interpersonal relationships between the triad occurred in dyads, that is, child-parent, child-HCP, and HCP-parent. The children acknowledged their parents' companionship during hospitalisation. They were happy to be able to chat with their parents, and to have their parents as a source of comfort and protection (Paper III). Likewise, parents were appreciative that their children communicated through them, concerns that they couldn't present to healthcare professionals (Paper IV). The children felt their best interests were met when healthcare professionals constantly checked in on them (Paper III).

Parents expressed a wish for HCPs to try to know their child and develop a relationship with them. It was important to the parents that HCPs took a holistic approach to their child, seeing their child beyond the current illness. They made efforts to help HCPs better understand their child (Paper IV). Parents were aware of the tight schedules of the HCPs, noting that doctors were more distant with the children than the nurses (Paper IV). The children appreciated when the HCPs shared jokes with them whilst undergoing procedures (Paper III). Parents expressed a wish for HCPs to touch base with their child and have conversations beyond the medical context (Paper IV). Parents felt their child's best interests were considered when HCPs interacted with their child in an age-appropriate manner. Such interactions involved HCPs employing various means to distract younger children to gain their co-operation during procedures, for instance. Children were distracted with entertainment such as children's programs airing on television, engaging in child-friendly play, tickling, and placing stickers onto reward certificates (Papers II, III, IV).

An Enhancing Environment

As part of acquainting themselves to their new environment, children sought familiarity while away from home during hospitalisation. They were aware of their physical surroundings. Having a place to temporarily relate to as their own space, helped the children to navigate their new environment. Having their own space, with various aspects of the environment offering them a level of comfortability was a sign to the children that their best interests were forefront. Children cherished having their own rooms, which accorded them a level of privacy. They also highlighted having a variety of food choices and having access to the internet and television (Paper III). The children appreciated having a playroom to go to (Paper III) and their parents shared that it had a calming effect on their child when they were feeling distraught (Paper IV). For the parents, giving the child space during stressful situations, for instance meant that HCPS could avoid rushing into carrying out the planned care. Parents wished HCPs would first assess the child's level of stress and then carry out the planned care when the child felt ready (Paper IV). An enhancing environment also included aspects of a caring and friendly atmosphere. The children (Paper III) and their parents (Paper IV) described the HCPs as being friendly, funny, accommodating, and attentive, among other descriptions. On the other hand, parents highlighted encounters with some HCPs who were more task oriented with their child and did not create a friendly ambience for their child (Paper IV).

Effective Communication

Triadic communications between the child-parent-HCP constituted dyadic communications involving child-parent, child-HCP, and HCP-parent. Children expressed themselves both verbally and non-verbally. Various non-verbal cues (nodding head to indicate an acceptance, moving shoulders up and down, retracting hands, legs, or body away from healthcare personnel or their parents to indicate a refusal, smiling, crying etc.), were used by the children to communicate (Paper I). Effective communication was open, transparent, and tri-directional involving HCP-child, HCP-parent (Papers I, II, III, IV), and parent-child communications (Papers II, III, IV). Situations where a two-way communication occurred between HCPs and the children, and care was planned in accordance with the wishes, opinions, and valuations of the children enhanced observed expressions of the child's best interests (Paper I).

Effective communication for the children and parents implied receiving introductory, preparatory, and sensory information tailored to meet the child's age, and linguistic abilities (Papers II, III, IV). Meeting informational needs of the children and their parents facilitated promotion of the child's best interests. With regards to introductory information, children were curious to know which HCPs would meet them and what their presence entailed in the child's care. Preparatory information referred to situations where children received stepwise information about what procedures they were yet to undergo (Papers II, III, IV). Information about how a procedure would feel (Sensory information) was also observed to be given to the children. To enhance children's understanding when they received preparatory and sensory information, visual aids were used (Paper II).

Situations where HCPs made minimal efforts to communicate with the children and rather communicated via parents as proxy were assessed as not giving prime focus to the child's best interests (Papers I, II, IV). Information was either not provided to children and their parents, or if it was, then no follow-up was made to ensure that the information was well understood (Paper I). Interruptions by the parents during two-way communications between their child and HCPs were observed as not promoting the child's best interests (Paper I, II).

Importance of Mutual Negotiations and Collaborations

For the parents, having mutual negotiations and collaborations mirrored opportunities for their child to exercise their competence and for their child to be supported towards increased autonomy (Paper IV). It was vital for the parents that HCPs actively sought and listened to their child's views, opinions, and valuations and allowed the children to influence how the planned care would be carried out (Papers I III, IV). Mutual negotiations and collaborations among the triad led to compromises in how the planned care was to be implemented albeit with the child's best interests being in prime focus. For instance, children negotiated for more preparatory time for themselves before a procedure could be carried out. Children who regularly attend the hospital were familiar with certain routines and wished not to undergo them. Children who did not have regular appointments similarly wished not to undergo certain routines like temperature, weight, and height checks. Healthcare professionals respected the wishes of these children and suggested the procedures could be done later, despite insistence of the children's parents (Paper II).

Children and their parents experienced down moments in living outside their comfort zone. Both children and their parents experienced uncomfortable events such as sleep deprivation and long wait times. Parents had to conceal their emotions to appear strong for their child (Paper IV). They revealed they had to work together with HCPs to tailor the planned care in accordance with their child's prevailing needs. Parents took advocacy roles and negotiated with HCPs for less invasive procedures to alleviate their child's discomfort (Papers II, III, IV). Parents also took steps to speak up on behalf of their child, when they felt their child's needs were not being met; this was valued by the children (Paper III). In addition, parents questioned things and monitored the care their child received (Paper IV). When HCPs shared different views about a procedure, some took advocacy roles on behalf of the child. Parents valued this, further highlighting that they thought the HCPs who took advocacy roles on their child's behalf had their child's best interests at heart (Paper IV).

Mutual negotiations and collaborations did not always go in line with the child's preferences. In situations where more time went into negotiations with the younger children, parents ran out of patience, opting for the use of restraint, which was not objected by HCPs. Some events such as confinement to one place (Paper III) or restrain

(Papers II & IV) were experienced by both children and their parents as uncomfortable yet at times necessary and in the child's best interests. Restrain or holding was commonly used during procedures such as cleaning wounds resulting from an operation, removing plasters, getting a stitch on the finger, or electrocardiography (Papers I & II).

Active Participation during Hospitalisation

Actions of the children, parents, and HCPs facilitated or obstructed observed expressions of the child's best interests. Assessments of active participation in decision-making using the Scale of Degrees of Self-Determination highlighted that children's active participation was supported in varying degrees by HCPs and parents. Children's active participation in decision-making was mostly at levels four and five and were characterised by situations including medical orders such as taking blood samples or undergoing medical examinations. Levels four and five promoted the child's best interests in that children's opinions were sought and decisions about the care either partially (level four) or wholly (level five) reflected the child's opinions, wishes, and valuations (Paper I).

Facilitation occurred when children actively vocalised their concerns regarding the planned care, and when the HCPs addressed the concerns of the children (Papers I, II, III, IV). Healthcare professionals created opportunities like empowering children (who would need long-term medication beyond hospitalisation) to self-medicate. This was seen by parents as sustainable (Paper IV). Healthcare professionals encouraged the children to engage in minor tasks such as passing on items from trolleys during procedures or taking off plasters and bandages (Paper IV). Healthcare professionals engaged children in their own care by providing the children with alternative forms of taking medicines (tablet or liquid form) (Papers II & III) or allowing them to administer the treatment by themselves under supervision (Paper II).

Other children appeared passive and quietly observed things around them. Children protested care that was given to them, and at times that led to them being restrained (Papers I, II, IV). Additionally, parents occasionally disrupted ongoing conversations between healthcare professionals and their children, to have their own informational needs met. The child's opportunities to participate in their care were hindered when HCPs discontinued the conversations with the children and focused on the parents. However, other HCPs made efforts to engage the children despite parental disruptions (Paper II).

In other situations, efforts were made to engage the children, but decisions made regarding the planned care did not take into consideration the children's preferences (Paper I). Both parents (Paper IV) and the children (Paper III) were aware of the extent to which the child could actively participate in their own care, with parents reflecting on the child's age as one of the limiting factors.

Discussion

General Discussion of the Findings

Bronfenbrenner’s bioecological model is used to deepen the understanding of the complex factors involved in care of a hospitalised child. The findings primarily pertain to the micro and meso systems, and a lesser extent to the exo and macro systems, however, the model may still be used to deepen understanding of the findings. See Figure 4 below.

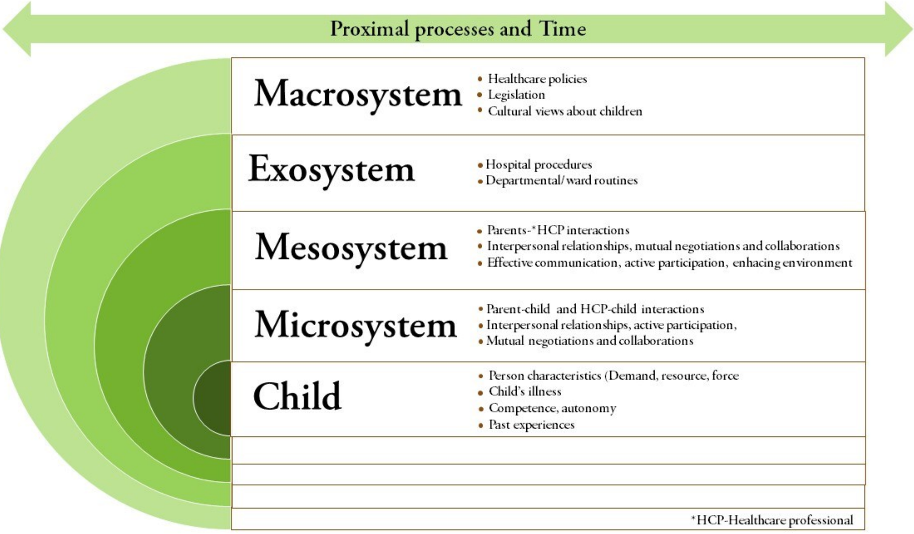


Figure 4. Factors at play in safeguarding the child's best interests

Process

Interpersonal relationships, enhancing environment, effective communication, mutual negotiations and collaborations, and active participation are examples of proximal processes experienced by children and their parents during hospitalisation. These findings account for the interactions between the child and their immediate environment and may contribute to the development of the child's competence and autonomy (Bronfenbrenner and Morris, 2006). Parents experienced their child's best interests were a priority of HCPs when their child was supported towards increased autonomy through these proximal processes. Mutual negotiations, collaborations, and effective communications are components which fit in Shared Decision-Making. Shared Decision-Making in pediatrics is vital for respecting children's autonomy however, literature suggests that SDM is still an emerging trend in paediatrics (Brand and Stiggelbout, 2013; Stiggelbout et al., 201; Wyatt et a., 2015).

The form, power, content, and direction of proximal processes vary systematically as per the characteristics of the developing person, and characteristics of the immediate and remote environment (Bronfenbrenner and Morris, 2006). For instance, it has been shown that HCPs may be reluctant to consider the knowledge and expertise of parents and children due to a shift in the balance of power (Richards et al., 2018; Swallow et al., 2013; Smith et al., 2015). Even though children, parents, and HCPs have varying levels of competence and experiences, they are all experts in their own rights in mutual negotiations. Bronfenbrenner suggests that to be effective, these proximal processes must occur on a regular basis over an extended period, in a reciprocal manner (Bronfenbrenner and Morris, 2006). Engaging children in these proximal processes during hospitalisation and ensuring that children not only get the chance to express their preferences (Segers et al., 2022), but that they are also considered in decision-making (Nordlind et al. 2022) fulfils the legal rights of children as stipulated in Articles 12 and 13 of the UNCRC (Davies et al., 2019; Lundy, 2007). This calls for a need to integrate SDM both in the educational curricula, and daily clinical practice (Malone et al., 2019).

Person

Deducible from the findings is that active participation during hospitalisation was influenced by the actions of the children themselves, their parents, and healthcare professionals. Children either passively observed things, or they vocalised their concerns, which were attended to in varying degrees by HCPs. According to the bioecological model, the personal characteristics of a child at play throughout hospitalisation act as a stimulus to HCPs, thus influencing how the child's best interests are safeguarded. Parental disruptions that relegated children to passive observers, have also been reported in other studies (Van Staa, 2011; Shah et al., 2020; Tran et al., 2022). Allowing children to participate in matters that concern them helps them toward increased autonomy and competence and prepares them for future decision-making as adults (EACH, 2016; Sinclair and Franklin, 2000).

Parents wished for healthcare professionals to have a holistic view of their child beyond the child's current illness, beyond the hospital environment. This finding is comparable to Wood et al. (2018) who also reported the wish among adolescents for healthcare professionals to get to know them and communicate with them beyond the medical context. Healthcare professionals in the study by Grahn et al. (2016) acknowledged the importance of meeting each child as an individual. Being aware of the the person components (i.e., demand, resource, and force) of the child, and how these factors influence the child's competence and willingness to participate in the task at hand might be helpful for healthcare professionals on how to engage children in their own care (Ford et al., 2018).

Context

Microsystem

Positive interpersonal relationships among the triad were valued by the children and their parents and were experienced as fostering the child's best interests. These findings are also mirrored by Loureiro et al. (2021) who reported that children (7- 11 years old) experienced healthcare professionals as friendly. The dynamic nature of interactions (i.e., child-parent, child-healthcare professionals, healthcare professional-parent) can be seen mostly at the micro, but also the mesosystem level of the bioecological model. Since face-to-face interactions in the microsystem have a reciprocating influence on the child (Bronfenbrenner and Morris, 1998), interpersonal relationships formed between children, parents, and healthcare professionals should be encouraged. Yet, developing interpersonal relationships may be constrained by other factors like busy schedules and workloads of healthcare professionals, length of child's hospital stays, continuity of care, severity of illness, and levels of parental or child stress (Marginean et al., 2017).

Seen in the findings are that actions of parents and healthcare professionals around the child may facilitate or hinder expressions of the child's best interests. This is confirmed by assumptions in the microsystem, that there is a reciprocating influence in the interactions between the child and immediate environment (Bronfenbrenner and Morris, 2006). Even though parents had their child's best interests at heart, sometimes what they advocated for was assessed as "second best". This was reflected in situations where restraint proposed by parents was not opposed by healthcare professionals. A critical review by Davies and Randall (2015) asserts that the parental role is a factor that might encourage or impede children's involvement in their own care, which also may lead to unwillingness of HCPs to disprove parental desires. When competing interests arise, HCPs may assume the role of surrogate decision-maker, free of their own and external influence, whilst setting the child as prime focus (Beauchamp and Childress, 2019). According to Söderbäck (2010) HCPs may rely on their professional competence, to guide the child and parents in weighing and understanding the potential benefits versus the potential harm of each alternative. In doing so, promote the decision that maximises the net benefits to the child (Buchannan and Brook, 1990). In the clinical microsystem, the child is an active social agent who directly interacts with their parents and HCPs (Bronfenbrenner, 2005). Proximal processes favour the concept of active participation, and it has been suggested in the bioecological model that for development to occur, the person must engage in an activity.

For the children and their parents, being away from home meant they had to deal with living outside of their usual comfort zones. The microsystem also accounts for the neighbourhood play area, which in the clinical setting would be the playrooms. In this regard, the children were looking for familiarity away from home and they therefore appreciated the playrooms. Their parents shared how the playrooms had a calming effect on their child. This conforms with Bronfenbrenner's suggestions that the symbols in the child's environment should be of the kind that stimulate the child positively (Bronfenbrenner and Morris, 2006). Similarly, Loureiro et al. (2021) reported that the physical environment which included activity rooms and libraries in the inpatient units were most valued by the children. In the findings, an enhancing environment not only referred to the visible and physical features, but also to the ambience and way in which children were received and cared for. Bronfenbrenner's bioecological model highlights that proximal processes include children's interactions with other people, as well as their interactions with the objects and symbols in their environments. Therefore, the hospital environments within which children are cared for need to enhance feelings of safety and security for the child (Gilljam et al., 2016; Lambert et al., 2013).

Mesosystem

In the findings, mutual negotiations and collaborations between parents and HCPs seemed to promote the child's best interests even in situations where children chose to participate less. In a clinical setting, mesosystem reflects interactions between actors of the microsystem where the child was not directly involved but was nevertheless directly affected by these interactions. In the findings, the clinical mesosystem interactions are seen through the HCP-parent partnerships, as well as interactions between different HCPs. The ongoing interactions in the mesosystem equally facilitate or hinder expression of the child's best interests. Based on the findings it may be argued that to some extent, certain interactions in the mesosystem could still be in the child's best interests despite the child not being directly involved. For instance, when parents and healthcare professionals collaborated and worked together to maximise the net benefits to the child. Research shows that depending on the situation at hand, the age of the child and sickness severity, children like it when their parents or HCPs take leading roles in decision-making regarding their healthcare (Boland et al., 2016; Hart et al., 2020). In as much as children wish to be actively involved in their care, they may also seek the engagement of their parents and HCPs (Lipstein, 2013).

Whilst parents are the focus of the partnerships in FCC, the child is the key and active agent in the partnerships in a CCC approach to care (Coyne, 2016). A CCC approach may enhance microsystem-level kind of interactions for the child, promoting the child's involvement in their care at the level at which they are most comfortable. Healthcare professional-parent partnerships align with stipulations in the UNCRC which mandates parents and state parties to have the child's best interests in all matters concerning them as priority (UNCRC, 1989). There is also a consensus in the literature of the importance of the HCP-parent relationship. This relationship is instrumental in building a good rapport (Callery and Milnes 2012; Vasey et al., 2019; Smith and Kendal, 2018) and may enhance children's positive experiences when they encounter healthcare (Sharkey et al., 2016; Boelsma et al., 2021). The HCP-parent relationship is evident in a FCC approach endorsed by most paediatric institutions around the world (Davies and Randal, 2015). Considering that children have long been side-lined in matters concerning their own care, healthcare professionals need to balance the dyadic relationships (Brand and Stiggelbout, 2013) such that the child's best interests in accordance with articles 3, 12, and 13 of the UNCRC are safeguarded, and that the informational needs of parents are also met (Lewandowska, 2022: Pelentsov and Law, 2015).

Exosystem

Parents complained of long waiting times - a finding similarly reported in other research (Solheim and Garratt, 2013). The clinical exosystem incorporates a much larger social system where the child is not involved but is affected directly by health service delivery, hospital procedures, and routines. Long waiting times may be due to a shortage of healthcare professionals – a problem that may also cause busy schedules and workloads for HCPs which can influence the quality of care and overall patient satisfaction (McMullen and Netland, 2013; Patwardhan et al., 2012). Hospital procedures carried out during night-time meant that children and their parents experienced sleep interruptions. This finding is comparable to those in a systematic review where children and their parents experienced sleep interruptions due to child-related treatments during hospitalisation. Parental sleep interruptions over a long period of time affected parents' abilities to meet their child's needs (Løyland et al., 2020). This calls for the considerations of strategies to enhance children's and parents' positive experiences and to prioritise the child's best interests in all aspects of care.

Macrosystem

Whilst healthcare professionals made efforts to engage the children in their healthcare, they were also observed to communicate with parents as proxy which may not always have facilitated expression of the child's best interests. One possible inference from the latter is that certain historical and culturally constructed views about the status of children might still be prevalent in society (Davies et al., 2019). Other research has also documented healthcare professionals communicating with parents as proxy (Sahlberg et al., 2020). Communications in paediatrics present unique challenges when compared to the traditional adult patient-provider dyadic communications. The triadic communications in paediatrics have a more dynamic nature and requires various communication styles that are age-appropriate and meet the informational needs of both children and their parents (Bray et al., 2019). The macro system is the outer most layer, yet its influence flows down through the rest of the nested systems (Bronfenbrenner and Morris, 2006). How HCPs interact with children during hospitalisation may also reflect cultural views about children that are prevalent in society (Kelly et al., 2012; Davies et al., 2019). It is then vital that paediatric healthcare continues to facilitate at all levels of operations, the integration of children's rights into daily clinical practice (Nordlind et al., 2022). Continued discussions and reflections on children's rights as stated in the UNCRC, healthcare policies and legislations are important.

Time

It was observed that children who had regular healthcare visits wished to opt out of routine checks. However, this was also observed among children with non-regular visits who had routine checks. Children's anxieties of being in a new environment and having to cope with the unfamiliar may have played a role - similarly reported in a review by Jepsen et al. (2019). The period of hospitalisation, where children undergo an ecological transition from being a healthy child to that of an ill child, are examples of events occurring over the child's lifetime. Children experience disruptions in their daily routines in the home and other social interactions with significant others (Ford et al., 2018). Given that unpleasant past experiences may influence children's willingness to be involved in their healthcare (Khadiji et al., 2022; Lerwick, 2016; Noel et al., 2010), it has been suggested that incorporating past painful experiences into preparatory interventions might improve future pain experiences and reduce avoidance behaviours (Pavlova et al., 2020).

Methodological Considerations

Philosophical assumptions were made to inform approaches taken to investigate the phenomenon of the child's best interests. The philosophical underpinnings which informed the basis for the research design are that:

i) reality is multiple and subjective (ontological); therefore, the nature of truth, being children's and their parents' experiences of the child's best interests during hospitalisation, would be varied and not singular.

ii) the inquirer interacts with those being studied; therefore, the epistemological position was that understanding children's and parent's meanings of the child's best interests would require an exploration of their subjective experiences through observations and interviews.

iii) inquiry is value-bound (axiology); therefore, the process of inquiry was influenced by the inquirer's values, choice of paradigm, theory and methods used to guide data collection and subsequent data analysis (Lincoln and Guba, 1985; Guba and Lincoln, 1982).

Trustworthiness

Trustworthiness in qualitative research can be discussed under the concepts: *credibility*, *dependability*, *transferability*, and *conformability* (Lincoln and Guba, 1985). These measures of trustworthiness enable researchers within the qualitative paradigm to reflect on the validity of the findings and whether the chosen strategies and design are reliable.

Credibility in research refers to the confidence of the data and how well the data addresses the intended focus (Lincoln and Guba, 1985). It involves the selection of appropriate methods (i.e., approach to data collection as well as data analysis), and study participants. The thesis focused on elucidating from various perspectives, the experiences of the child's best interests during hospitalisation. It was therefore inevitable that children's hospitals were considered as catchment areas for participant recruitment. Recruiting children from two continents, in a wide age range of two to 17 years old, irrespective of gender, type of diagnosis, type of hospital visit, ethnicity, or religious background enriched the various perspectives of the phenomena under study. Maximum variation may not have been reached since a combination of purposive and convenience sampling was used.

The non-participant observations, despite being time-consuming, enabled the capturing of non-verbal cues, and ongoing day-to-day interactions between the triad that individual or focus group interviews would not have been able to capture (Dahlgren et al., 2007; Taylor et al., 2016). Graneheim and Lundman (2004) identified that the selection of relevant methods of data collection is an important aspect in establishing credibility. The observer, not a native Swedish speaker, may have missed out certain aspects of the language thus leading to loss of information recorded in the field notes. Therefore, one of the co-authors, a native Swedish speaker, went through the observation transcripts to give further guidance. The quality of collected data was enhanced by the systematic and objective taking of field notes which occurred every 30 minutes for observations that lasted longer than an hour. Transcription of field notes was completed prior to the start of a new observation, to avoid recall bias. Since children and their parents were interviewed within the same time - frame, the face-to-face combined parent-child interviews were most appropriate for data collection in Study B. The face-to-face combined parent-child interviews allowed for one-on-one conversations between the interviewer and the participants (Brinkman and Kvale, 2015; Dahlgren et al., 2007). However, a risk remains that the children may not have fully expressed themselves given the presence of their parents. Parents at times, helped their children to express themselves, which may have influenced the findings. The interviewer asked the children follow-up questions to get them to express themselves.

With regards to the choice of data analysis, for Paper I, according to Hermerén, a person who is considered as having reduced autonomy risks having their integrity violated. In this regard, Hermerén formulated the Scale of Degrees of Self-Determination based on ethical principles to provide ways of assessing respect of an individual's integrity (Hermerén,1996). Previous research (Runeson, 2002; Runeson et al., 2000) have used the Scale of Degrees of Self-Determination to assess children's and parent's participation in decision-making during hospitalisation and it was thus deemed as a suitable analytical tool. The scale was developed as a theoretical scale, giving insight into what is *done* by the member of staff, but falls short on describing *how* it is done. This was compensated for by adding critical questions in Step 2 during analysis of observational data in Paper 1. The five grading levels and what each level assesses needs to be discussed and differentiated to avoid difficulties in grading.

Data collected from the observations and the children's interviews has been analysed and interpreted using adult processing abilities. Being an adult, the author's ways to conceptualise information was different from that of a child and it may be argued that the interpretations may not be a true representation of a child's meaning (Nisah and Michelle, 2017). The researcher made great efforts to keep the child's voice in focus throughout the analysis. For instance, in Paper III, the researcher stayed close to the words of the child by referring to healthcare professionals as staff, nurse, or doctor, as the children did. Additionally, joint discussions were regularly held among all the co-authors of Papers I-IV, until agreements of the analysis (how data were labelled and sorted) were reached. Further, representative quotes from the observations (Papers I, II) and interviews (Papers III, IV) were used to assert the findings. The amount of data is also an aspect to consider when discussing credibility (Graneheim and Lundman, 2004). The number of participants leading to Paper III was nine children, with short interview times and few pages of transcript. Sandelowski (1995) indicated that in qualitative research, an adequate sample size should be large enough to capture various experiences, whilst small enough to allow a deeper analysis leading to new and deeper understanding of experiences. Given the complexity of the phenomena under study in this thesis, more children could have been interviewed, since the amount of data needed to address a research question credibly is dependent on quality of data and complexity of research question (Graneheim and Lundman 2004).

Dependability deals with stability of data overtime and decisions made by the researcher during data analysis. Observations and interviews are an evolving process implying that observers and interviewers may acquire new insights into the phenomena under investigation. The discovery of new aspects of the phenomena might influence areas of focus during observations, or the type of follow-up questions asked during interviews (Lincoln and Guba, 1985). In consideration of this, an observation protocol, and semi-structured interview guide were used for data collection in Study A and B respectively. In addition, data collected was constantly reviewed by co-researchers to ensure the observations and interviews adhered to the study aims. Co-authors participated in the analysis of all four Papers, bringing to light multiple subjective perspectives and interpretations of the findings until a consensus was reached (Sandelowski, 1995).

Transferability as a measure of trustworthiness refers to whether the findings of the research in question can be transferred to settings other than the group or population studied. According to Lincoln and Guba (1985), researchers bear the responsibility to provide the reader with the basis that makes it easier for transferability judgments to be made by the reader. Transferability in Studies A and B was facilitated by describing in as much detail as possible, the study context, participant characteristics and their subsequent recruitment, data collection, and analytical processes (Graneheim and Lundman, 2004). The study findings may not be applicable to other cultures because most of the study participants in both Studies A, and B were from developed countries. Moreover, ethnic minorities were not reached. Additionally, though included, children living with intellectual disabilities may have been under-recruited.

Conformability addresses issues to do with objectivity of the findings and resulting interpretations (Lincoln and Guba, 1985). The preunderstanding of the author of this thesis was constantly reflected upon not only during data analysis, but during the entire course of this research. Furthermore, the results from Studies A, and B have been extensively discussed with a multidisciplinary team of researchers in research seminars to help ensure that the findings are free of any personal interests of the researchers (Lincoln and Guba, 1985).

Conclusions and Clinical Implications

The child's best interests during hospitalisation implies having a holistic view of children beyond their current illness. Safeguarding the child's best interests during hospitalisation requires a case-by-case approach because it is context-dependent, situational, flexible, dependent on all actors involved and actual decisions made.

Promoting interpersonal relationships, an enhancing environment, effective communication, mutual negotiations and collaborations, and active participation may enhance opportunities for expressions of the child's best interests during hospitalisation. These factors involved in safeguarding the child's best interests during hospitalisation are interconnected and nested in a rather complex system highlighted in Bronfenbrenner's bioecological model. Therefore, it is important to understand the bioecological influences in the child's environment. This may enhance collaborations between the child, parents, and healthcare professionals, and help to sustain a healthy bioecological system for the child during hospitalisation.

The following clinical recommendations can be deduced from the findings in this thesis:

- Safeguarding the child's best interests during hospitalisation can be enhanced by a bioecological, holistic, and case-by-case approach
- It is essential to have ccontinued establishment and maintenance of an initial good rapport, and the building of trustworthy relationships with children and their parents amidst time constraints
- Continued engagement in discussions of roles and responsibilities and acknowledging expertise of parents and their children as means to enhance collaboration is essential
- Documentation of specific situations in every-day nursing and medical care where the child's best interests were promoted (or not) could be used as teachable moments
- Continued strengthening of the communication skills of healthcare professionals
- Continued creation of knowledge awareness among healthcare professionals, of children's rights as stipulated in the UNCRC

Future Research

The following research areas are proposed:

- Elucidate experiences of the child's best interests during hospitalisation with more presentative samples of children including different diagnosis groups, ethnic minorities, other populations, and other countries.
- Elucidate experiences of the child's best interests during hospitalisation from the perspectives of a multidisciplinary team of healthcare professionals.
- Deepen the understanding of contextual factors across the bioecological model that may influence safeguarding the child's best interests.

Populärvetenskaplig sammanfattning

FN:s konvention om barnets rättigheter är ratificerad av 196 länder. I Sverige infördes konventionen i sin helhet som lag den 1 januari 2020.

Trots rekommendationer om att barnets bästa ska beaktas i alla frågor som rör barn, finns det en osäkerhet hur hälso- och sjukvårdspersonal kan tillvarata barnets bästa under sjukhusvistelse. Målet med denna avhandling var att ur olika perspektiv beskriva hur barnets bästa uttrycks under sjukhusvistelse.

Avhandlingen består av fyra studier med kvalitativ forskningsansats. Datainsamlingen har skett vid fyra olika barnsjukhus i Sverige och Australien. Uri Bronfenbrenners bioekologiska modell har använts som teoretiskt ramverk för att fördjupa förståelse av faktorer som kan påverka barnets bästa under sjukhusvistelse. I Sverige genomfördes 34 icke-deltagande observationer. I Australien intervjuades 16 föräldrar och 9 barn under barnets sjukhusvistelse.

Resultaten belyser att interpersonella relationer, en barnanpassad vårdmiljö, effektiv kommunikation, ömsesidiga förhandlingar och samarbeten samt att stödja barnets aktiva deltagande är betydelsefullt för att tillvarata barnets bästa under sjukhusvistelsen.

För att kunna tillvarata barnets bästa under sjukhusvistelsen krävs att barnets bästa bedöms i varje enskilt fall och tillfälle eftersom bedömningen är kontextberoende och behöver anpassas för den specifika situationen. Likaså är barnets bästa beroende av att alla inblandade aktörer; barn, föräldrar och personal inom hälso- och sjukvård är medvetna om och förstår betydelsen av barnets bästa i den aktuella situationen.

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"*All great achievements require time*". Maya Angelou

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Parent and Child Interview Guide

Purpose of the interviews

To describe the parents' and child's perspective on how the 'child's best interest' is expressed when care is delivered in hospital.

This interview guide has been developed from international guidelines (Brinkmann and Kvale, 2015; Nisah and Michelle, 2017; Dahlgren et al., 2007). Depending on the interactions and flow of information in the interview, not all questions will be asked. The interview will be based on the child and/or parents' experience which will guide the flexibility of questions asked.

Before the interview, the child and their parent will be informed about:

- Purpose of the study.
- That there is no right or wrong answer.
- That there are different experiences and opinions about what the 'child's best interests' are.
- That they can choose not to respond to any question if they feel uncomfortable to answer and they do not need to give a reason as to why they do not wish to answer.
- That the interview will be recorded, if they consent to this.
- That all information will be handled with confidentiality and privacy.
- That the interview will not last longer than one hour.

Possible questions to ask children and their parents

The child's best interest and participation in hospital

- What do you think of when you hear the phrase the 'child's best interest'?
- What does the 'child's best interest' during a hospital stay mean for you?
- **Follow-up question:** Can you explain this?
- How do you perceive that your 'child's best interests' are expressed when you are in hospital with your child.
- **Follow-up question:** Can you give examples
- Can you describe how you have experienced your 'child's best interests' during this hospital stay.
- Can you give examples of when your 'child's best interests' have been met?
- Can you give examples of when your 'child's best interests' have NOT been met?
- **Follow-up question:** Can you describe, express, or explain how?

The child's participation in hospital.

- What do you think of when you hear that the child shall actively participate in his/her own care?
- What do you think of when you hear that the child should actively take part in his/her own care?

- Have you or your child actively taken part in care during this hospital stay?
- **Follow-up question:** Can you give examples when you or your child participated actively in care?
- **Follow-up question:** Can you give examples when you or your child did NOT actively participate in care?
- Do you think children's participation in care should be encouraged? If yes, how? If no, why?
- **Follow-up question:** Can you describe, express, or explain how?

Interaction with healthcare professionals (The child's best interest)

- How do you think your 'child's best interests' were taken into account during this hospital stay?
- **Follow-up question:** Can you give examples?
- When do you think your 'child's best interests' were NOT taken into account during this hospital stay?
- Follow-up question: Can you give examples? Describe what happened?

Interaction with healthcare professionals (Children's participation)

- How do you think your child's participation in care was taken into account by staff during this hospital stay?
- **Follow-up question:** Can you give examples?
- When do you think your child's age and maturity were taken into account by staff during this hospital stay?
- **Follow-up question:** Can you give examples?
- When do you think your 'child's best interests' were NOT taken into consideration by staff during this hospital stay?

  Follow-up question: Can you give examples or describe what happened?

The child's interaction with patients

- 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?
- **Follow-up question:** Can you give examples? Can you tell me more?

The child's interaction with healthcare personnel

- Do staff ask you about how you want things to be in hospital?
- **Follow-up question:** Can you give examples?
- If you do not want the staff to do something with you, what happens?
- **Follow-up question:** Can you give examples?

Parent's interactions with children

- How do you see your role when you are with your child in hospital?
- **Follow-up question:** Can you give examples? Can you tell me more?
- Can you influence how the 'child's best interest' is expressed when your child is in hospital? How?
- **Follow-up question:** Can you give examples?

End of the interview (child)

- 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?
- Thank the child for their participation and contribution to the project

End of interview (parents)

- Do you wish to change anything?
- Do you have any recommendations to staff about how to promote the 'child's best interest' in care?
- Do you have any recommendations to staff about how to facilitate children to participate more in their own care?
- Do you have any recommendations to staff about how to help parents participate more in their child's care?
- Is there anything else you would like to discuss that I haven't mentioned?
- Thank the parent for their participation and contribution to the project

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Paper I

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ORIGINAL ARTICLE

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Children's active participation in decision-making processes during hospitalisation: An observational study

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Abstract

Aims and objectives: The aim was to explore and describe the child's active participation in daily healthcare practice at children's hospital units in Sweden.

Objectives: (a) Identify everyday situations in medical and nursing care that illustrate children's active participation in decision-making, (b) identify various ways of active participation, actual and optimal in situations involving decision-making and (c) explore factors in nursing and medical care that influence children's active participation in decision-making.

Background: Despite active participation being a fundamental right for children, they are not always involved in decision-making processes during their health care. There still remains uncertainty on how to support children to actively participate in decisions concerning their health care.

Design: A qualitative study with overt, nonparticipant observations fulfilling the COREQ checklist criteria.

Methods: Observations of interactions between children aged 2 and 17 years with both acute and chronic conditions, their parents, and healthcare professionals were conducted at three paediatric hospitals in Sweden. The Scale of Degrees of Self Determination was used to grade identified situations. The scale describes five levels of active participation, with level one being the least and level five being the most active level of participation. Normative judgements were also made.

Results: Children's active participation was assessed as being generally at levels four and five. Children demonstrated both verbal and nonverbal ways of communication during decision-making. Findings indicated that children's, parents' and healthcare professional's actions influenced children's active participation in decision-making processes involving healthcare.

Conclusions: Healthcare professionals specialised in paediatrics need to embrace both a child perspective and a child's perspective, plan care incorporating key elements of a child-centred care approach, to ensure children's active participation at a level of their choosing.

Relevance to clinical practice: There is a need for awareness creation to help healthcare professionals facilitate children's active participation in their care and decision-making.

KEYWORDS
child perspective, child-centred care, children, child's perspective, decision-making, healthcare situations, medical care, nonparticipant observations, nursing care, participation

1 | INTRODUCTION

The United Nations Convention on the Rights of the Child (UNCRC, 1989) upholds core values on the rights of a child and defines a child as 'any human being under the age of 18 years unless under the law, applicable to the child, majority is attained earlier'. This study will refer to all persons, including teenagers under the age of 18 years as a child. Both Articles 12 and 13 of the UNCRC highlight the child's right to expression of his/her views and the right to receive information. Despite a child being able to express needs and opinions, decisions about treatment in the healthcare setting are usually made either by healthcare professionals or by the healthcare professionals and parents (Bessell, 2011).

In a Patient Law enacted in Sweden in 2015 (2014:821), the rights of the child as stated in the UNCRC were reinforced. This present research focuses on articles three and four from the Patient Law: 'When the patient is a child the child's caregiver also should be given information', and 'The child's perception to the care or treatment should be mapped out as far as possible and recognized according to age and maturity' (Government Offices of Sweden, 2017). Ensuring that Swedish legislation is written in accordance with the UNCRC, children are treated with respect and their voices are heard, and children's rights are made known to children themselves, parents and all those working with children, are some of the strategies Sweden has incorporated to strengthen the rights of the child in healthcare (Government Offices of Sweden, 2010). Nevertheless, a recent evaluation of the implementation of the Patient Law from an adult perspective showed no improvements in clinical practice. Instead, a reduction in terms of accessibility, information and participation for adults and for caregivers (parents) was reported. Further, in a comparative international analysis of the adult patient's participation in clinical practice, Sweden was found to lag behind compared to Norway, Finland and Denmark (Swedish Agency for Health & Care Services Analysis, 2017).

2 | BACKGROUND

There is no single definition of participation; in this research, the term active participation is used. Active participation is not a one-step scenario. It can be seen as a multilayered concept with many different processes, which imply a transfer of information and power such that the participant's views influence decision-making (Franklin & Sloper, 2005; Sinclair, 2004). Active participation requires that structures are put into place and an enabling environment created where each child is seen as a social actor with unique needs (Council of Europe [CE], 2012). Two aspects of active participation: actual and optimal are referred to in this research. The former implies the current status quo of active participation in daily clinical practice, whilst the latter refers to the acceptable level of active participation with regard to age and maturity of the child, rules and regulations, clinical guidelines, policy documents, etc. There are key elements of active participation embedded in Article 13 of the UNCRC that are integral to this research. These elements are that the child receives relevant information, is given an opportunity to freely express own views, and his/her opinions, wishes and valuations are considered in the process of decision-making (EC, 2014). Healthcare professionals find it challenging to engage children in active participation (Harder, Söderbäck, & Ranheim, 2016). Knowledge from literature reviews shows that very few decisions opposed by children and their parents were reconsidered by the healthcare professionals. In addition, competing factors such as age, gender, communication issues, professional attitude, information offered, previous encounters with healthcare services and psychosocial circumstance were highlighted as factors affecting involvement (Coyne, 2008; Davies & Randall, 2015).

Discourses in research are beginning to look at child-centred care (CCC) as an alternative way of care delivery for the child, since implementation of a family-centred care (FCC) approach has been met with

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

- Children continue to experience obstacles to having their opinions, wishes and valuations heard in healthcare decision-making.
- Some healthcare professionals make a good effort to facilitate children's participation in decision-making, but practice remains variable.
- Healthcare professionals need organisational, social, paediatric and pedagogical competence in how to support and promote children's participation in decision-making and to deliver care that is planned from both a child and a child's perspective.

numerous challenges (Coyne, Murphy, Costello, O'Neill, & Donnellan, 2013; Dall'Oglio et al., 2018; Davies & Randall, 2015; Ladak et al., 2013). Planning care solely through a FCC lens may pose as a hindrance to the rights of the child recognised in the UNCRC. In the CCC approach, the child is the prime focus of care delivery. The child's right to actively participate in healthcare matters are recognised, and care is tailored to reflect the needs and wishes of the child (Coyne, Hallstrom, & Soderback, 2016; Ford et al., 2018; Wimo, Fagerdahl, & Mattsson, 2018). To enhance children's active participation, it requires healthcare professionals to embrace a child perspective, which include attention towards the child's perspective (the child's understanding of the situation) in the healthcare settings (Söderbäck, Coyne, & Harder, 2011; Sommer, Samuelsson, & Hundeide, 2010).

In the follow-up to the implementation of the patient law, an evaluation of how children's best interests are upheld and expressed in hospital settings was absent which is a serious omission (Swedish Agency for Health and Care Services Analysis, 2017). Despite ethical, and pragmatic arguments in favour of supporting children to be active participants in healthcare discourses, there is still uncertainty about how to involve children in active participation (Carlsson, Nygren, & Svedberg, 2018; National Board of Health & Welfare, 2015). Therefore, it is necessary to describe the child's active participation in daily healthcare practice.

3 | OVERALL AIM

The aim was to explore and describe the child's active participation in daily healthcare practices at children's hospitals.

3.1 | Objectives

1. Identify everyday situations in medical and nursing care that illustrate children's active participation in decision-making.
2. Identify various ways of active participation, actual and optimal in situations involving decision-making.
3. Explore factors in nursing and medical care that influence children's active participation in decision-making.

4 | METHODS

4.1 | Research design

In this exploratory qualitative study, overt, nonparticipant observations were used (Creswell & Plano, 2011). In overt nonparticipant observations, participants are fully aware of the researcher's presence, who takes a passive role and only observes the ongoing interactions of the participants (Greig & Taylor, 2001). This research technique provided the opportunity for the first author to observe interactions and to listen to the views expressed by the children, parents and healthcare professionals. Observations is a method that facilitates the capturing of tacit knowledge (nonverbal communications, artefacts, symbols or hidden cultures) that are an integral part of participants' daily lives (Dahlgren, Emmelin, & Winkvist, 2007). The methods adhere to the consolidated criteria for reporting qualitative studies (COREQ; see File S1).

4.2 | Ethical considerations

Ethical approval was granted by Lund Regional Research Ethics Committee (ref 2014/411). Study was conducted in accordance with the Helsinki Declaration (World Medical Association [WMA], 2013) and General Data Protection Regulations (2018). All departmental managers at the children's hospitals approved the study. Participants were assured of confidentiality and informed of their right to withdraw from the study at any time without this affecting their health care.

4.3 | Data collection

4.3.1 | Setting

This exploratory study was conducted over an eight-month period (2017 to 2018), at one paediatric regional hospital and two paediatric units at a tertiary university hospital in the southern part of Sweden. A total of 14 departments were invited to participate and one declined due to limited resources and staffing issues. The departments included four inpatient units, two emergency units and seven outpatient units. The emergency departments, even though under different contextual factors, were chosen to enable the exploration of multiple realities among the participants. Additionally, children admitted to the emergency departments equally have the right to be accorded the important nuances that ensure active participation. The departments included a range of conditions such as congenital malformations, surgery, ears–nose–throat, ophthalmology, plastic surgery, orthopedics, oncology, cardiology and diabetes.

4.3.2 | Participant recruitment

Prior to recruiting participants, the contact details of the respective departmental managers were obtained. Meetings were held with departmental managers to provide information concerning the study. The first and last author took advantage of the departments' daily meetings to meet healthcare professionals and inform them about the study. The first author had a contact person (nurse or a secretary), in each department, to help with obtaining schedules of children due for an appointment at the hospital. This was conducted ahead of the child's date of appointment. Information obtained from the scheduled appointments included the child's age, gender, type of diagnosis, type of hospital visit and time of appointment, to ensure purposeful recruitment. For the emergency departments, children were recruited upon arrival. If the healthcare professionals deemed it suitable, the child and his/her parents were informed about the study. Some children had regular appointments at the children's departments making the healthcare professionals to be well acquainted with them and were in a position to judge whether or not

TABLE 1 Background variables of observed children included in analysis

Gender	
Girl	18
Boy	14
Age range (median age = 8 years)	
2–6 years	13
7–11 years	9
12–18 years	10
Nativity of parents	
Both native Swedish	17
One or two parents born abroad	15
Type of hospital visit	
Outpatient	20
Inpatient	12
Accompanied by	
One parent	16
Both parents	15
Alone	1
Length of hospitalisation	
0–1 hr 59 min	8
2 hr–9 hr 59 min	8
10 hr–23 hr 59 min	0
24 hr–71 hr 59 min	5
72 hr+	11

asking the child to participate would cause them to feel stressed. On the child's admission, the nurse provided a short introductory letter to the child and his/her parents, informing them about the study. If the child and parents showed interest in taking part in the study, the nurse informed the first author. The first author then met with the child and his/her parents either in the waiting room or in patient rooms to provide further information about the study and to obtain their consent. In cases where a child's parents showed interest to participate but the child did not, the child's wishes took precedence and were not recruited. Parents gave their own consent. Assent from children <15 years was obtained, and both their parents were required to give written consent on their behalf. Children ≥15 years were asked for written and oral assent. Age-appropriate information was given to the children. Observations began when written assent was obtained from the child and the child's parents.

4.3.3 | Participants

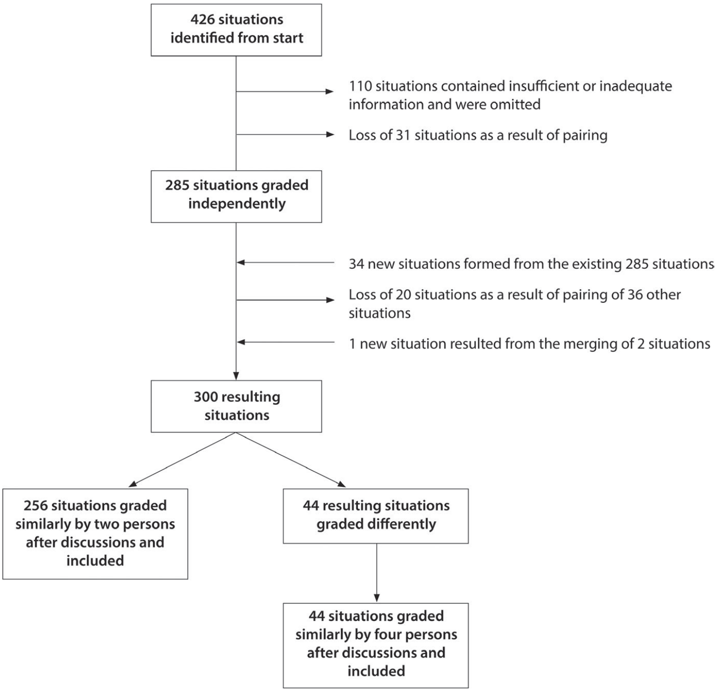
The sample invited to participate were 45 children and their parents. Of these, 11 children (six boys and five girls) and their parents declined to take part. Some children had sensitive conditions (complications with their reproductive organs) and did not wish for the first author to be present during their visit. Some parents of children <15 years were uninterested; others had children with intellectual disabilities and did not want their child to participate. In total, 34 children and their parents were observed. In the analysis, only observations from 32 children were included, as the absent parents of two children did not provide consent. The demographics of the observed children are shown in Table 1.

For reasons of confidentiality, we are not able to provide detailed descriptions of the participants in the study. Children with acute life-threatening diagnosis were excluded. Healthcare professionals who were involved in the care of the children during their hospital stay were eligible to participate. Posters with information about the study were put in all participating departments, to inform healthcare professionals. Indicated in the posters too was that healthcare professionals who did not wish to participate could opt out of the study by either informing the first author in-person, by email or by telephone call. The healthcare professionals from the three children's hospitals caring for children included in the observations agreed to take part, except for two professionals who felt unprepared to participate. No observations of situations involving these two were made. Healthcare professionals observed included general nurses, assistant paediatric nurses, paediatric nurses, specialist children's nurses, doctors, anaesthetists, surgeons, cardiologists, etc.

4.3.4 | Observations

The first author followed the child and his/her parents throughout their hospital visit. Generally, the first author sat near the door, or stood in a corner of the examination room, observing interactions as they occurred. Prior to each observation period, the child and his/her parents were asked if the observations could continue (Runeson, Hallstrom, Elander, & Hermeren, 2002). For visits that lasted more than an hour, the first author took short breaks every 30 min, to record field notes. Field notes included descriptions of any interactions that occurred between the children, their parents, and healthcare professionals (Runeson et al., 2002). Additionally, verbal and nonverbal communications such as participant's body language, description of people present, time and place were recorded in the field notes. The first author's reactions and feelings were also recorded and distinguished from what was observed. The observations conducted in the inpatient units went on for as long as there were interactions occurring between the child, and the healthcare professionals. In outpatient units, the observations were conducted for as long as the child's appointment lasted. The first author withdrew from observing situations if: the child was asleep, or the child was in the play therapy, or there were no further interactions occurring between the child, and healthcare professionals, or the healthcare professionals did not wish to participate, or if there were restrictions as to how far the first author could follow the patient, for example operation theatre, or postoperation recovery rooms. The observations ended when the child was discharged from the hospital. No follow-ups were made. The field notes were then transcribed into English in a narrative text format. The communication interactions between the child, their parents and the

FIGURE 1 The process of identifying everyday situations in medical and nursing care that illustrates children's participation in decision-making



healthcare professionals were transcribed in the Swedish language and later translated into English by the first author. The last author, a native Swedish speaker, verified the translations. After the first four observations, the last author read through the full transcripts to check that observations and content of transcripts were as detailed as needed. Observations ranged from 25 min to 72 hr, with four hours the median length.

4.4 | Data analysis

To identify everyday situations in medical and nursing care that illustrate children's active participation in decision-making, each individual observation, and field notes were read thoroughly by the first author. Any information that might have been omitted during the transcription was added later by the first author. The analysis of the observations followed three steps as described by Runeson et al. (2002).

In this research, we define a situation as 'events occurring between children, and healthcare professionals within the healthcare setting, where decisions about medical and nursing care are made'. A situation was selected if it met both of the following conditions: (a) it contained an event where a decision-making process reflecting nursing or medical care was made, and (b) the child and the healthcare professionals were involved in this decision-making process.

In *step one*, each observation transcript was read through by the first author who identified 426 situations that reflected children's active participation in nursing and medical care. Identifying the situations was enhanced by reflecting on questions like 'What is the decision that was made?' 'Was the decision made about nursing or medical care?' Thereafter, the last author independently went through all identified situations. The two authors reflected upon each identified situation together and discussed if the situation reflected nursing or medical care. During these reflections, 110 situations were omitted. Situations were omitted if:

1. Events in the situation did not reflect any nursing or medical care
2. A medical or nursing decision was made only between the healthcare professionals and the child's parents, excluding the child,
3. A nursing or medical decision was made only between the child and his/her parents, excluding the healthcare professionals,
4. Events were informational, that is, healthcare professionals informing the children of routine activities to engage in, or giving a child information about what the child was going to undergo prior to an operation or medical examination.

The joint discussions and reflections resulted into both the collation and removal of situations that resulted in 300 identified situations (see Figure 1).

TABLE 2 Observed children's active participation in situations distributed in different levels

	Level 1	Level 2	Level 3	Level 4	Level 5
2–6 years	6	12	19	57	70
7–11 years	0	0	8	10	43
12–18 years	6	0	11	17	43
Total	12	12	38	84	156

In *step two*, the Scale of Degrees of Self Determination developed by Hermerén (1996) was used to grade the situations. The scale was developed as a theoretical scale, based on philosophy and ethical principles, to grade ways in which an individual's integrity can be respected. Since it is easy to violate a person's integrity when their autonomy is reduced, Hermeren formulated a principle of integrity 'If one does not respect a person's views, wishes and valuations, one does not respect that person' (Hermerén, 1996, p151). Compared to other scales, this scale was chosen as it (a) can be used for individuals of all ages, (b) can be used to assess an individual's actual participation and the subsequent respect shown for their integrity and (c) has been used in previous research to assess children's and parent's participation in decision-making during hospitalisation (Runeson, 2002; Runeson, Elander, Hermeren, & Kristensson-Hallstrom, 2000;Runeson et al., 2002). The scale divides active participation in decision-making into five levels, and it describes various levels of attending to individual's opinions, wishes and values. The scale, however, only describes what is *done* by the member of staff, but falls short in describing *how* it is done.

1. A (member of the staff) does not listen to B's (child's) opinions, wishes and valuations.
2. A listens but refuses to discuss the opinions of B with B; no consultation, no two-way communication exists.
3. A communicates with B but does not care about B's answer; B's opinions, wishes and valuations do not influence A's action.
4. A cares about what B says but acts only partly in accordance with B's opinions, wishes and valuations.
5. A acts in accordance with B's opinions, wishes and valuations.

In *step three*, each situation was scrutinised and analysed separately by the first, and last authors, in terms of children's degree of active participation. During the grading process, the questions: 'What is the decision?' 'Who initiates the decision?' 'Who is present during this decision-making?' 'Who is deciding? Is it mutual?' 'Is the decision reconsidered? If so why?' 'How was the decision implemented?' were used as guiding questions, to arrive at a grade (Hallstrom & Elander, 2004). Of the 300 situations identified in step one, 256 were graded similarly by the first, and last authors. The remaining 44 situations were graded differently. These 44 situations were further graded independently by the second and third authors. Any disagreements arising from the grading were resolved in joint discussions, where authors returned to the main observation transcripts to get a more comprehensive picture. No situation was omitted as all authors agreed on same grading in the joint discussions. A final of 300 situations were included. Further in the analysis, normative assessments were made in order to gain a deeper understanding and make comparisons of how things are and how things ought to be. Normative assessments were done independently by all four authors. Judgements of what could be an optimal level of active participation was done in accordance with the child's age, maturity, scrutinising the situation observed, looking at the planned procedure and what could have been alternatives, the decision made and being aware of guiding documents as the UNCRC (UNCRC, 1989) and the Swedish Law (Government Offices of Sweden, 2017).

5 | FINDINGS

5.1 | Judgement of children's actual participation in nursing and medical care

The findings show that children's active participation was supported in varying degrees. Level five had the most number of graded situations (156), followed by level four (84), then level three (36) whilst both levels two, and level one, had the same number of graded situations (12). The findings are described below. Examples are given to illustrate each level. Table 2 shows how children's active participation was distributed across the different levels.

5.1.1 | Level one: A (member of the staff) does not listen to B's (child's) opinions, wishes, and valuations

Here, 12 situations were judged as belonging to level one. This level denotes situations where minimal efforts were made by the healthcare professional to communicate directly with the child even if the child was a teenager. This also included children with intellectual disabilities. Communication was solely with the parents. The children's integrity may not have been respected by the fact that some healthcare professionals asked the parents, and not the child, if they could examine their child's body parts. Some children had received medication without being told what they were being given, or underwent routine checks without being told the reason why. Also, use of restraint was not objected by some of the healthcare professionals.

> A doctor attending to a 16-year old child tells the child 'We are thinking of taking some tests that are missing, it is important that we take note of acid in the blood, HB, and things like that'. The doctor turns his eye contact towards the child's father. The doctor and the child's father discuss the child's treatment between the two of them. The child is quiet, listening to the back and forth discussions between the father and the doctor. At the end of their discussion, the doctor shifts eye contacts between the child and the father, telling them the nurses will

> soon come and take the needed tests on the child. He then leaves the room.
>
> (Observation 28)

5.1.2 | Level two: A listens but refuses to discuss the opinions of B with B; no consultation, no two-way communication exists

Also, identified in level two were 12 situations, highlighting situations where both the verbal and nonverbal actions of the children were not considered by some healthcare professionals. Use of restraint during: insertion or removal of an intravenous cannula, lying on a table for an X-ray examination, removal of plasters on various body parts, cleaning operation wounds, taking off clothes, routine examinations, including mouth, nose, ears, were not objected by some healthcare professionals. In some situations, information was not provided to the children nor their parents, and in situations where information was given, minimal efforts were made by the healthcare professionals to check whether the child had understood the information or not.

> A doctor tells the mother of a 2.5 year old child that he wants to examine the child to see how the child is responding to the medicine taken some hours ago. The child sits on the mother's laps. 'Shall we look a little at your body again?' The doctor asks the child. 'I do not want' says the child. He suggests to the mother that the child stands on her laps. The child continues to refuse to be checked. The mother makes her child to stand on her laps. The mother pulls her child's jersey upwards. The doctor quickly checks the child's skin. 'I do not want' the child begins to cry. The child's trousers are pulled downwards by the mother. The doctor holds onto the child's legs. The child screams and begins to kick its legs. The doctor holds onto the child's legs tightly, and examines the legs. He tells the child's mother 'I am satisfied' and he sits down. The child stops crying.
>
> (Observation 34)

5.1.3 | Level three: A communicates with B, but B's opinions, wishes and valuations do not influence the actions of A

Judged as belonging to level three were 36 situations where there was a two-way communication between the healthcare professional and the child. The healthcare professionals made an effort to try and engage the child to participate in their planned care. They also explained procedures to the child and gave information about what was to happen during the examinations. However, despite the healthcare professional's efforts to motivate the children to take part in a planned procedure, the protests of the child against taking part in the procedure did not affect the initial planning, and sometimes use of restraint was not objected. Such situations included finger pricks, cleaning of operation wounds, taking medication, routine measurements including height, weight, temperature and blood pressure, medical examinations.

> An anesthetist is attending to a 2-year old child. 'Hi, I am going to spray a bit more into your nose' he says, showing the child the spray. Upon seeing the spray, the child immediately screams 'no!' looking away from the anesthetist. The child's head is held upright by the mother. The child screams, kicks the legs and wriggles the body. The anesthetist sprays into the child's nose. The child cries bitterly…
>
> (Observation 21)

5.1.4 | Level four: A cares about what B says but acts only partially in accordance with B's opinions, wishes and valuations

Identified here were 84 situations. Of prominence in this level were situations where children voiced their opinions, and there was a two-way communication between the healthcare professionals and the children about the planned care. Situations here were often characterised by medical orders such as undergoing medical examinations or taking blood samples. Sometimes, the children were not in agreement with the planned care, so healthcare professionals tried to find alternative means of delivering the care. The child was encouraged to make partial decisions, but this did not significantly influence the planned care. Sometimes restraint was used here too.

> A 6-year old child is seated on the mother's laps, about to have its finger pricked. The father stands beside them. 'Do you know why you are here today and what we will do?' the nurse attending to the child asks. The child makes a frown on the face saying 'I do not want you to prick my finger'. Both the mother and the nurse laugh. The nurse gently rubs the child's hand and assures the child all will be well. The child is asked to choose which finger to be pricked. The child suggests to count to three before being pricked. When asked to count to three, the child hesitates, shaking the shoulders up and down. The child's mother suggests she will count to three but the child refuses. 'I do not want you to count. I will count' the child angrily says to the mother. 'One, two …' the child counts but hesitates for some seconds. The child seems really scared, breathing in and out very fast. 'Say three!' the father says in a commanding voice. The child looks very tense. Finally the child says 'three'. As the nurse is pricking the finger the child screams out 'aw aw aw' kicking the legs. The father holds the child's legs tightly.
>
> (Observation 2)

5.1.5 | Level five: A acts in accordance with B's wishes, opinions and valuations

There were 156 situations that were graded as level 5. These were situations where children either agreed to the planned care after having received and understood information regarding their upcoming planned care, or the children's integrity was respected and no restraints were used.

> 'Now we shall take some blood tests and later you will get some cortisone' a nurse says to a 10-year old child. 'But I want to sleep now. My head aches' the child complains to the nurse. 'Yes I understand that it hurts, but we must take the test otherwise we will not know what is troubling you. Shall we get some pain killers for you?' the nurse asks. The child, still complaining about the pain, nods the head to indicate a yes. The nurse asks 'Do you want to have it in tablet or liquid form?' The child looks at the father before deciding. The father raises his eyebrows encouraging the child to decide. The child takes a deep breath, telling the nurse 'I want the liquid form'. The nurse goes to bring the medicine, and some water. The child refuses to get the water saying: 'No I want to have the water in my water bottle' The father gets the water bottle from a back pack. The child then drinks the medicine.
>
> (Observation 27)

5.2 | Normative judgements of children's participation

Children's active participation could not be considered as optimal in all of the situations graded at levels one (12 situations), two (12 situations) and three (36 situations). See Table 3. The healthcare professionals could have done more to engage the children in these situations. A total of 73 out of 83 situations judged as belonging to level four were considered as optimal levels of active participation. In most of these situations, the children received information and clarity over things they did not understand, and compromises to planned care were reached. An example was when a child did not wish to lie down for her heart examination as suggested by a doctor. She preferred to sit and the doctor respected her wish. Considered as optimal were 153 out of 157 situations judged as belonging to level five. All possibilities of the children's participation were considered by the healthcare professionals. Nonetheless, four situations judged as belonging to level five were considered as nonoptimal. In these situations, too much responsibility seems to have been placed on the child. For instance, a 6-year-old child decided when and where to have an intravenous cannula removed, or a 14-year-old child was presented with the opportunity to remove an intravenous cannula with the nurse's careful supervision. The 14-year-old child did not seem to be comfortable with this suggestion and requested that the nurse removes the cannula instead.

TABLE 3 Numbers of optimal and nonoptimal situations at each level

Level	Optimal	Nonoptimal	Total (*N* = 300)
1	0	12	12
2	0	12	12
3	0	36	36
4	73	10	83
5	153	4	157

5.3 | Interactions between children, parents and the healthcare professionals with regard to children's active participation in the decision-making process

The actions of children, the parents and the healthcare professionals were the factors that impacted positively or negatively on children's active participation in decision-making.

5.3.1 | The children's actions

The children reacted in different ways to the planned care they were expected to receive and during the decision-making process. Apart from voicing their concerns verbally, children were also observed to communicate and participate using nonverbal cues. The nonverbal cues included: watching curiously with eyes wide open, contemplating on an issue before deciding an action, crying, shaking heads from side to side, moving shoulders up and down, retracting hands, legs or body away from healthcare personnel or their parents to indicate a refusal, nodding head to indicate an acceptance, murmuring words that could not be fully understood, smiling, laughing, making various facial expressions. Most of the nonverbal cues were observed among children aged 2–6 years. The teenagers were more vocal and expressed themselves by speaking up. Some children, by virtue of their personality, appeared more active, asking questions about their planned care and requesting more time before the planned care was administered. Meanwhile, other children appeared passive, observing quietly. The children resisted or protested the care that was given to them. One child expressed he was not interested in receiving information that was being given to him, as it had been repeated at previous visits.

5.3.2 | The parents' actions

In some situations, some parents were more involved in the decision-making process than their child. Some parents were at times unsupportive of their child's actions as they did not request for alternative solutions to painful and unpleasant procedures that their child was expected to undergo. This was seen in situations judged as belonging to levels one, and two. For some children with parents from other countries, the parents tried to liaise with the child in their language. When children did not comply with an examination, some parents sometimes raised their voices against their child and also indicated to their child that they were sad. Sometimes, some parents lost their patience, restrained the child and urged the healthcare professional to just proceed with the planned care. Other parents protected their child from a painful procedure by asking for alternative solutions for their child. Conversely, in other situations, some parent's requests on behalf of their child were not met. For instance, in one situation no provision was made for a child to meet with the surgeon prior to the surgery despite parents' vocalisations.

5.3.3 | Healthcare professional's actions

In some situations, there was minimal effort from the healthcare professional to involve the child in discussions which they had with parents. This was true even for children who were observed to have a reserved personality. When some parents suggested restraint of their child, threatened or raised their voices against their child, some healthcare professionals did not act in favour of the child. Other healthcare professionals had to juggle their time taking care of other patients and sometimes this infringed on the extent to which they would engage children into active participation. Two examples are given below where the same child is engaged differently by two healthcare professionals.

> A 3.5 year old child is about to undergo an EKG examination. A nurse attending to the child says 'Shall we put the tubes again?' The child refuses by shaking the head from side to side. The nurse tries to convince the child but the child still refuses. The nurse receives a call on her work phone. She excuses herself and leaves the room.
>
> (Observation 11)

In other situations, the healthcare professionals made real efforts to engage the children in decision-making. They tried to create a trusting environment for the children to open up and participate freely. Children scheduled for a surgery were shown pictures of procedures they would undergo and medical equipment they should expect to see. Some healthcare professionals played games with the children and used dolls to describe to the children what would happen to them.

> Another nurse in the room walks closer to the 3.5 years old child. Holding the electrodes, she says to the child 'Does H know colors?' The child nods the head. 'Really? Ok where should we put the yellow tube then' the nurse says in a child-like voice. The child smiles shyly, putting a finger in the mouth. 'Shall we put it on the nose?' The nurse asks the child. The child shakes the head from side to side, smiling. The nurse makes a sad face. 'aww aww where shall we put it then?'. The child laughs. The child points at its own chest. 'Shall we put it there?' The nurse asks the child. The child nods the head. The nurse sticks one of the electrodes on the child's chest. The nurse continues asking the child where to place the rest of the coloured electrodes. The child seems to be enjoying the game. Before the child realises it, all the electrodes have been placed in their rightful positions.
>
> (Observation 11)

6 | DISCUSSION

The findings reveal that children's active participation varied and was seen most evident at levels four and five. Active participation was both optimal and nonoptimal. Children's way of communication during decision-making was both verbal and nonverbal. The actions of children, the parents and the healthcare professionals were the factors that impacted positively or negatively on children's active participation in decision-making.

6.1 | Children's actual and optimal participation

The grading and normative judgements reveal that there were no elements of optimal participation observed in levels one, two nor three. This was seen across all the age groups, including children with intellectual disabilities. These findings are not in accordance with elements of the UNCRC, nor the patient law enacted in Sweden, which all emphasise children's rights to freely express themselves and for their views to be given due weight in accordance with age and maturity (Government Offices of Sweden, 2017; UNCRC, 1989). One may reflect that some of the healthcare professionals may not be fully aware of the patient law and what it entails of them. It could also be that healthcare professionals are aware of the patient law, but may have uncertainties as to how to engage children to actively participate in decisions concerning their health care. Healthcare professionals may need managerial support on how to support the rights of the child in daily clinical practice. It has been suggested by the Swedish Society of Nursing (2014) that up to 60% of nurses within child and adolescent healthcare lack specialist training. Children in Sweden are cared for by a mix of healthcare professionals who both have, and who lack specialised skills and experience in childcare. This may have an influence on how children are cared for, and thus, their active participation. However, this does not exclude organisational factors of the children's services.

In level three participation, children were communicated with; yet, decisions made in the long run may not indicate that some of the healthcare professionals reconsidered opposed decisions. Healthcare professionals in the study by Carlsson et al. (2018) were of the view that children's active participation in the healthcare context was limited and that children could only decide in trivial matters such as deciding which arm the cannula could be inserted, but had little say on the planned treatment. Research by Stålberg, Sandberg, and Söderbäck, (2015) suggests that children as young as three years old are able to communicate their health and treatment needs as well as opinions. Nevertheless, despite the evidence, children are still rarely consulted with or included in discourses pertaining to their own health at a desirable level (Carlsson et al., 2018; Coyne, 2008; Coyne, Amory, Kiernan, & Gibson, 2014).

Highlighted also in this study is that children reacted to various situations in the healthcare setting both through verbal and nonverbal cues. Yet, it appeared that not all nonverbal cues made by the children triggered the desired reactions from some of the healthcare professionals. Stålberg, Sandberg, Larsson, Coyne, and Soderback (2017) also reported on a number of nonverbal cues expressed by children in the healthcare setting. In other research, by Wimo et al. (2018), they argued that the phenomenon of participation must be redefined to include nonverbal bodily actions. Having a child perspective would imply that the healthcare professionals couple their knowledge of what the planned care entails in a specific situation, with the attention and motivation to understand what the child's perceptions, experiences and actions in that specific situation might be (Sommer et al., 2010). This in turn may enhance the healthcare professional's understanding and interpretation of a child's actions in a particular situation and what alternatives to offer the child. Embracing a CCC approach means that healthcare professionals recognise the child as a social being capable of taking part in situations within its own competence (Ford et al., 2018; Söderbäck et al., 2011; Wimo et al., 2018). The child belongs to a family, of which the child is the key agent in the partnerships. Information-sharing involving the child would then require that the child is included, and duly guided by an adult with opportunity to increase competence, whilst taking care not to only have a child perspective (Coyne et al., 2016).

The findings in this present study indicate that children's active participation across all the ages was seen more at levels four and five. The healthcare professionals involved in these situations might have been more proficient on how to facilitate the individual child's active participation. This is to be welcomed because active participation forms a crucial preparatory foundation for children to make decisions in the future (Runeson et al., 2002; Sinclair & Franklin, 2000). Children's active participation in decisions regarding their own treatment has been associated with decreased anxiety, increased sense of value and control, improvements in their psychological and physical recovery from surgery, more rapid recovery; increased cooperation with procedures, and improved perceptions of treatment services (Walker & Doyon, 2001).

Despite level five being considered as the best level of active participation, there were situations judged as belonging to level five, but not having an optimal level of participation. Some healthcare professionals seemed to actively engage the child by supporting the child to decide beyond what was deemed as optimal. In the case of the 14-year-old child who was to remove a cannula, some could argue that a child of this age could still be able to remove a cannula with careful supervision from the healthcare professional. In this particular situation, the child experienced it as a huge responsibility and could not control the situation. Beauchamp and Childress (2013) indicate that competence, which is the ‘the ability to perform a task’ is relative to the decision to be made and is situation based. In determining a child's competence, healthcare professionals need to carefully consider the child's age, illness, maturity and situation.

6.2 | Factors affecting children's active participation

Children's, parents’ and healthcare professional's actions were observed as factors that influenced children's active participation. Of children who seemed passive and not to ‘actively’ participate despite efforts from the healthcare professional, Rogoff, Paradise, Mejía-Arauz, Correa-Chavez, and Maricela Angelillo (2003) caution that one should be careful not to judge these children as not actively engaging in participation. On the contrary, children who prefer to participate by simply observing a situation can still be seen as active and skilled learners. This is where the ability of healthcare professionals to understand and interpret nonverbal cues of children becomes crucial. Children learn nuances of a situation by observing, and when they are presented with the same or similar situation next time, they are able to use their previous experience from one situation, to either engage or disengage themselves from the next situation. Lave and Wenger (1991) identify this as situated learning, where both verbal and nonverbal expressions demonstrate experiences of learning in previous situations. This is important because a negative or positive situation in which a child was once involved in, will influence their experiences and skills in the healthcare setting. A negative event may lead to a child's withdrawal or unwillingness to actively participate in a situation, whilst a positive event may lead to motivation and engagement in a situation. With age and maturity, children become capable to reason as they gradually develop a better understanding of their environment and situations (Walker & Doyon, 2001). A child's refusal to take part in a particular treatment plan should be taken seriously and the child should be seen as being rational and competent in his/her own means.

Some parents either protected their child from painful procedures by asking for alternative solutions, or sometimes other parents resorted to the use of restraint during various medical procedures, which some of the healthcare professionals did not object. Similar findings have been reported in other research (Coyne, 2008). With reference to use of restraint, one then questions what role healthcare professionals ought to play when parents suggest actions that might not always be in the child's best interest. Healthcare professionals can assume the role of surrogate decision-maker, having a commitment to the incompetent patient's interests, free of conflicts of interest and free of controlling influence by those who might not act in the patient's best interest (Beauchamp & Childress, 2013). Also, healthcare professionals have a legal responsibility to ensure that the rights, dignity and safety of children are upheld during their hospital stay. Therefore, the use of restraint (forceful physical restraint of children by their parents so that a medical procedure can be undertaken) may be considered as a violation of the child's basic right to physical and psychological protection during their hospital stay (European Association for Children in Hospital [EACH], 2018). Others have argued for the use of restraint to protect a patient. If restraint is to be considered as a way of protecting the patient, then it should be seen as a separate treatment, presented as an alternative form of care. It has to be done with the patient's consent/knowledge. Conversely, research in paediatrics has suggested that restraint may be associated with speech and language problems, a negative self-image, fear of a procedure, distrust of medical care and post-traumatic stress disorder (Brenner, 2007; McGrath, Forrester, Fox-Young, & Huff, 2002). Guidelines such as the 'safe sedation of children undergoing therapeutic procedures' from the Scottish Intercollegiate Guidelines network calls restraint during a medical procedure that is not lifesaving as unacceptable (EACH, 2018).

There were some situations where the child was supported to decide beyond what was deemed as optimal. This may indicate a lack of communication by some of the healthcare professionals with the child, on the options available and limitations during the decision-making process. An alternative explanation could be that the presence of a child's parents may have influenced the extent to which the child could be given limitations by some of the healthcare professionals. Results from a review by Coyne (2008) indicated that there were high levels of uncertainty among healthcare professionals, of the extent to which children should be included in decision-making. Having children's opinions to reflect in decisions made may imply that healthcare professionals relinquish to a certain level, their authority to the children. Nonetheless, it has been suggested by Coyne (2008) that this may make healthcare professionals feel threatened to deal with children who are well empowered to challenge them. Professional competence (at organisational, social and pedagogical levels) in care situations is thus inevitable. According to Söderbäck (2010), organisational competence entails the ability to create an enabling environment for the child, whilst being time conscious. Social skills require the aptitude to facilitate a two-way communication with the child. Pedagogical competence demands that information, preparation and implementation of activities reflect the child's competence, its needs and its rights to protection and participation (Söderbäck, 2010).

6.3 | Strengths and limitations

Trustworthiness in this study was enhanced by triangulation of data collection. Participants with varying diagnoses, age, ethnicity and gender were recruited. All observations were conducted by the first author, hence enhancing consistency in data collection. Detailed observation descriptions lead to richness of data, producing more than 300 situations to analyse. Data analysis was conducted by all four authors. The first author, not having any nursing or medical background, was able to take an impartial role when interacting with the healthcare professionals, the children and the parents. Prior to the research, the first author had never met or known any of the study participants, nor worked in any of the environments nor had any children treated in any of the children's hospitals and departments included in the research.

The first author, not having had a level of preunderstanding as a healthcare professional, might be seen as a limitation. Nevertheless, throughout data collection and analysis, guidance was given by the other three authors who are educated in paediatrics, have experience of working in the area and are familiar with the daily routines of the departments. The first author, not a native Swedish speaker, may have missed out certain nuances of the language, leading to loss of information in the observations. Observations were captured in field notes; hence, the first author depended mainly on recall and written notes. To overcome this challenge, being well informed of a patient's condition prior to an observation played an important role. Field notes were written immediately or after short breaks to reduce recall bias, but no matter how detailed descriptions of observations are, much still remains invisible. With experience in conducting observations, the last author was able to review observations and give guidance. Due to the explorative nature of our method design, we did not include the following in our analysis: variability in level of participation across units, differences in departmental contextual factors, and whether or not the same healthcare professionals were observed interacting with more than one child. The first author tried to establish a relation with the children and their parents before the observations which may have influenced the children's and parents' behaviour. Likewise, healthcare professionals could have altered their actions, leading to false impressions for the first author to note, but with time, they all appeared to become at ease with the first author's presence and resumed their natural behaviour.

7 | CONCLUSION

Active participation can be said to occur at different levels, and factors that influence active participation include the child's, parents' and healthcare professional's actions. Daily clinical practice in children's hospital units does not fully fulfil the requirements of the Swedish patient law. Managerial support in daily clinical practice is needed for healthcare professionals to emulate professional competence, for key elements of active participation (a. Receiving relevant information, b. being given an opportunity to freely express own views, c. consideration of opinions, wishes and valuations in the process of decision-making) to be availed to children. Care delivery for the child needs to be planned by professionals specialised in paediatrics, with both a child perspective and a child's perspective, planning care with core elements of a child-centred care approach. Future research could focus on combining observations with interviews of children, their parents and healthcare professionals to gain a deeper understanding of their experiences of the child's active participation in their own health care.

8 | RELEVANCE TO CLINICAL PRACTICE

When children are actively involved in decision-making in their health care, they are usually better informed, thereby facilitating and benefiting the work of the healthcare professionals. There remains a need for interventions aimed at educating healthcare professionals on children's rights and how they can facilitate children's active participation based on the child's needs and competence.

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CONFLICT OF INTEREST

The authors do not have any conflicts of interest to declare.

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SUPPORTING INFORMATION

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

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ORIGINAL ARTICLE

How are children’s best interests expressed during their hospital visit?—An observational study

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Abstract

Aims and objectives: To describe ways in which children's best interests were observed to be expressed in paediatric settings during their hospital visit.

Background: The best interests of the child are embodied in national and international legal systems, although the definition remains problematic. The child's limited autonomy mandates duty bearers to have both a child perspective and the child's perspective when considering what the best interest of the child entails in care situations.

Design: A qualitative descriptive study with overt, non-participant observations fulfilling the COREQ criteria.

Methods: Thirty-two observations of interactions between children aged 2 to 17 years with both acute and chronic conditions, their parents and healthcare professionals were conducted at three paediatric hospitals in Sweden. Inductive and abductive reasoning were used in the content analysis of data, which followed the identification, coding, categorising and abstraction of observed patterns of the best interest of the child.

Results: Findings reveal facilitating and obstructing factors for the child's best interests to be safeguarded in healthcare situations. Children were guided in or hindered from exercising their competence. The observations showed a variation in actions taken by both parents and healthcare professionals to safeguard the best interests of the child.

Conclusions: Determining the best interest of the child requires a case-by-case basis, as it is context-dependent, situational, flexible and dependent on all actors involved and actual decisions made.

Relevance to clinical practice: Healthcare professionals’ actions can facilitate or obstruct observed expressions of the child's best interest. It is essential to enhance healthcare professionals’ communication skills, knowledge awareness and continuing education about the rights of children receiving healthcare services. Reflections and discussions on how to protect the best interests of children may help healthcare professionals to uphold children's best interest in daily clinical practice.

KEYWORDS
best interest, child rights, child-centred care, child's perspective, hospitalisation, mutual negotiation, observation

1 | INTRODUCTION

The best interest of the child is one of the four core tenets of the 1989 United Nations Convention on the Rights of the Child (UNCRC). Article 3, states that, '*In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration*' (UNCRC, 1989). In accordance with the UNCRC definition of child, all persons under the age of 18 will be referred to as a child in this study. Interests are defined as 'those *things that are needed for a child's wellbeing*' (Bester, 2019, p.120), and best interest is defined as *'acting so as to promote maximally the good of the individual'* (Buchanan & Brook, 1990, p.88). Interests may be current or future oriented. Current interests include the child's immediate interests (wanting pleasure, desires to be free from harm and discomfort, and normal functioning) whereas future-oriented interests refer to developmental interests of the child (Buchanan & Brook, 1990) Values codified in the declarations of the World Medical Association International Code of Medical Ethics guide healthcare professionals with the moral obligation to ensure the best interests of their patients in all care situations (World Medical Association [WMA], 2013).

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

- It has been shown by this research that there are both facilitating and obstructing aspects to the observed expressions of the child's best interests. Children's ability to exercise their influence in care was largely dependent on the actions of parents and healthcare professionals.
- Giving child-focused preparatory information, acknowledging the child's influence, and striving to respect the child's abilities facilitate observed expressions of the child's best interests.
- Determining the best interests of the child requires a case-by-case basis, as it is context-dependent, situational, flexible, dependent on all the actors involved at a particular moment, and actual decisions made. Fulfilling the best interests of the child focuses on creating an environment for the child's opinions, views, and valuations to be expressed alongside those of parents and healthcare professionals in mutual negotiations with a reinforcement of communication skills among healthcare professionals.

2 | BACKGROUND

The best interest standard is an integral aspect in the moral foundations of medicine (Bester, 2019). In the patient-provider relationship, the moral commitments of the provider, henceforth referred to as healthcare professionals, include promoting the health, well-being and rights of their patients (World Medical Association [WMA], 2013) and not less so when the patient is a child (Buchanan and Brook, 1990). The best interests of the child can be looked at from the child's perspective, which gives insights into the child's perceptions and experiences of their reality whilst the child perspective reflects the adult's understanding of children's perceptions (Sommer et al., 2010). The best interests of the child can also be understood through the lenses of child-centred care (CCC), a philosophy of care that places the interests of children at the core of care planning and delivery (Coyne et al., 2014). Underpinning the best interest standard in CCC is an acknowledgement of the competing interests of parents and healthcare professionals to those of children, and to determine which interests promote the net benefit for the child (Buchanan and Brook, 1990). This presupposes that opportunities are created for children to express themselves and be listened to (Carter et al., 2014). The best interest standard accords a central focus on the individual's current and future-oriented interests and this resonates with CCC, which offers a holistic view of children beyond their current illness (Ford et al., 2018).

The holistic view of children can further be appreciated by insights from Bronfenbrenner's bioecological model, which affirms the central placement of an individual, in this case, the child. The developing child is at the centre in interactions with its environment, consisting of five layers: the *micro*, *meso*, *exo*, *macro* and *chrono* systems (Bronfenbrenner 1979. Care of sick children involves emotionally and practically complex situations. These may induce various kinds of emotional responses such as fear (Leibring & Anderzén-Carlsson, 2019) and anxiety (Anderzén-Carlsson, Sörlie, & Kihlgren, 2012; Delvecchio et al., 2019). The family unit, which is part of the child's immediate environment (microsystem) in the bioecological model, plays an important role as the child undergoes an ecological transition from the micro to the exosystem. As the child navigates through and interacts with an unfamiliar environment in the healthcare setting (the exosystem), the parents are the first source of comfort and safety for the child (Delvecchio et al., 2019; Salmela et al., 2011). Knowing their child, parents play an integral role in their child's care, aiming to maximise opportunities that foster the best interests of their children. At times, parental views of what is best for their child may not always 'be best' for the child and so professional guidance of healthcare professionals is crucial (Coyne & Harder, 2011).

When children encounter healthcare, the attitudes and practices within the healthcare setting reflect the societal view of children (Carter et al., 2014). The needs of children in healthcare are also governed by legislation and laws (macrosystem) that aim to protect the interests of children. On January 1, 2020, the UNCRC was incorporated into national law in Sweden (2018:1197, Government Offices of Sweden, 2017). This complement and reinforces the Swedish Patient Act (Patientlagen 2014:821 [The Patient Act], 2014) which also emphasises the child's best interests. Thus, paediatric institutions have a legal duty to uphold the best interests of the child. A report by the Barnombudsmannen (2020) states that a child's right perspective in all affairs concerning children needs to be strengthened. Previous research has usually employed interviews to elicit children's voices (Anderzén-Carlsson et al., 2012; Coyne, 2006; Coyne et al., 2014; Leibring & Anderzén-Carlsson, 2019). However, observed interactions of children, parents, and healthcare professionals on how to uphold the child's best interests are less explored. There is a dearth of evidence on how the best interests of the child may be upheld in daily clinical practice (Waterston & Yilmaz, 2014) and an exploration of situations within medical and nursing care involving children, their parents and healthcare professionals may provide valuable insights in this current knowledge gap.

3 | OVERALL AIM

To describe ways in which children's best interests were observed to be expressed in paediatric settings during their hospital visit.

Specific objectives

1. To identify and describe everyday situations in medical and nursing care that illustrate ways in which the child's best interests are expressed during the child's hospital visit.
2. To identify and describe aspects of everyday medical and nursing care that facilitate or obstruct the expression of the child's best interests during their hospital visit.

4 | METHODS

4.1 | Design

This research employed a qualitative descriptive design (Sandelowski, 2000) that has its philosophical orientation in naturalistic inquiry. Data were collected by means of overt non-participant observations (Neuman, 2014). Inductive (Elo & Kyngäs, 2008) and abductive reasoning (Ericksson et al., 1997, Mirza et al., 2014) were used in the content analysis of data. The methods adhered to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) (see Supplementary File 1). A detailed description of the study setting, participants and their recruitment, and the conducting of observations is provided elsewhere (Quaye et al., 2019).

4.2 | Data collection

4.2.1 | Setting

Data collection occurred over a period of eight months from 2017 to 2018. Observation sites included one paediatric regional hospital and two paediatric units at a tertiary university hospital in [country name]. Fourteen departments received an invitation to participate, with one declining due to limited resources and staffing. The departments, which included nine outpatient units (two of which were emergency units), and four inpatient units, cared for a range of conditions including orthopaedics, oncology, cardiology, diabetes, congenital malformations, surgery, plastic surgery, ear-nose-throat and ophthalmology.

4.2.2 | Participants and participant recruitment

To enable exploration of multiple realities among participants and to enhance maximum variation, children aged 2–17 years, with different diagnoses and hospital admissions were recruited, along with their parents. Six boys and five girls, along with their parents, declined to participate in the study. Reasons ranged from disinterest in the study, to sensitive diagnosis of the children which the child did not want to be observed during consultations, and parents not wanting their child with an intellectual disability to participate. Healthcare professionals observed included registered general nurses, assistant nurses and physicians, all with various levels of specialisation. The first author obtained the schedules of children who were yet to attend their healthcare appointments at the respective participating departments. Upon the child's admission, the attending nurse provided the child and parents with a short introductory letter about the study. Children and their parents who showed an interest in participating in the study informed the attending nurse, who then informed the first author. The first author then took contact with and gave age-appropriate information to interested parents and their children. Observations began when written assent and consent were obtained from both children and their parents. Healthcare professionals received information about the study through briefing sessions and posters displayed on notice boards in all the participating departments, and they were given the opportunity to opt out of study participation. Background information of the observed children is shown in Table 1.

4.2.3 | Observations

The first author followed 32 children and their parents throughout their hospital visit. The observer sat near the door, or stood in a corner of the examination room, observing everyday medical and nursing care including verbal and nonverbal interactions between the children, the healthcare professionals and their parents. Observations ranged from 25 minutes to 72 hours, with four hours

TABLE 1 Background variables of observed children included in analysis (N = 32)

Gender (n)	
Girl	18
Boy	14
Age range (median age = 8 years)	
2–6 years	13
7–11 years	9
12–18 years	10
Reason for admission	
Abdominal, stomach, kidney and reproductive organ problems	12
Surgery for heart operation	5
Infection	6
Sleeping problems	2
Respiratory problems	1
Diabetes and cancer	3
Knee problems	1
Allergy	1
Blood disease	1
Type of hospital visit	
Outpatient	20
Inpatient	12
Length of hospitalisation	
0-1 hr 59 min	8
2 hr–9 hr 59 min	8
10 hr–23 hr 59 min	0
24 hr–71 hr 59 min	5
72 hr+	11

being the median length. The first author took 30-minute short breaks to record field notes for observations that lasted longer than an hour. Observations discontinued when no interactions occurred involving the children and healthcare professionals, or when the child was in play therapy, or asleep, or healthcare professionals attending to a child being observed had opted out of the study, or places with entry restrictions for the observer. Data collection consisted of field notes written by the observer during each observation and transcribed into English in narrative text format.

4.3 | Data analysis

Inductive reasoning in the content analysis was chosen because there is a dearth of evidence on how the best interests of the child may be upheld in daily clinical practice. This analytical approach involved identifying, coding, categorising and abstraction of observed patterns of the best interests of the child. Figure 1 shows the flowchart of the analytical process. (Elo & Kyngäs, 2008). **Step 1:** A naïve reading of the observation texts was done by the first, second and last authors to get new and deeper insights into the observations. The first author read thirty-two individual transcribed observations and field notes. The last author read 90% of the observation transcripts and the second author read 20% of the observation transcripts. **Step 2:** the first author identified 548 situations that reflected any kind of interactions between the child, healthcare professional and the parents. In **Step 3**, situations were examined in relation to the question: '*Was the child's best interest reflected in this situation*?' and situations containing inadequate information were omitted. Open coding of key events in each identified situation was done independently by the first, second and last authors, and verified in joint discussions. **Step 4**: Categories emerged by the rigorous examination of the identified situations and their possible meanings, by the first author and verified in joint discussions with the second and last authors. **Step 5:** An abductive reasoning was then employed, to connect the initial findings to what is written in literature. A search of past research was therefore conducted. Key references (Coyne et al., 2014; Runeson, Hallstrom, Elander, & Hermeren, 2002a; Quaye et al., 2019) found by means of manual search were identified. Reference lists of key articles were searched for further relevant studies. Searches were also conducted in the databases CINAHL Complete and PubMed using the free search terms: best interest, child's opinion, child(ren)'s competence, child-centred care. From the retrieved articles, seven principles grounded in the literature were developed and joint discussions among all authors led to refinement of the seven principles into six principles. The numbering of the principles (shown in Table 2) does not follow any order of hierarchy. **Step 6**: The categories were discussed in relation to the six principles. Facilitators and obstructors in each category were noted. The six principles were used as a guide in grouping the categories into main categories.

4.4 | Ethical considerations

The Lund Regional Research Ethics Committee (ref 2014/411) approved the study. The Helsinki Declaration, (WMA, 2013), The European Code of Conduct for Research Integrity (ALLEA, 2017) and General Data Protection Regulations (GDPR, 2018) were adhered to in the study. All heads of departments at the Children's Hospitals approved the study. Participants were assured of confidentiality (non-disclosure of their real names and diagnosis details) and informed of their right to withdraw from the study at any time without this affecting their healthcare.

5 | RESULTS

Findings are presented according to factors that facilitate or obstruct expression of the child's best interests in healthcare situations, under three main categories: giving child-focused preparatory information, acknowledging the child's influence, and striving to achieve a balance, and eight categories. The main categories are presented in bold text whilst the categories are italicised. Observations indicated

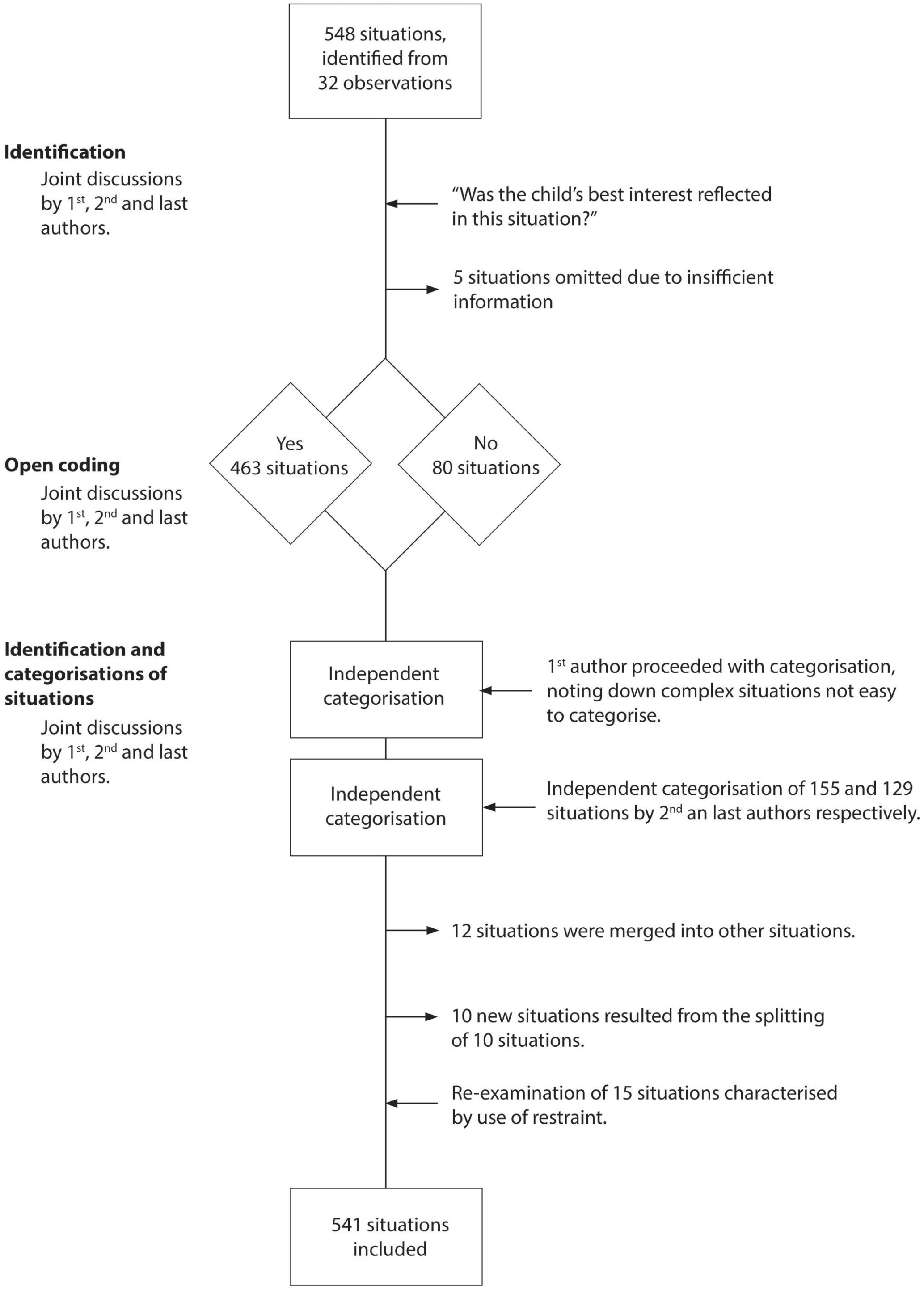

FIGURE 1 The process of identifying and categorising everyday situations in nursing and medical care that illustrate the child's best interests

TABLE 2 Content and references to the six principles used in the analysis

Content of principles	Literature references
1. The child receives preparation about what to expect about their care	Hallström et al., 2002, Runeson et al., 2002a, Coyne et al., 2014, Måtenson et al., 2007, Davis and Randall, 2015
2. The child's view is sought about their care	Hallström et al., 2002, Runeson et al., 2002b, Stålberg et al., 2016, Coyne, 2006
3. The child's preferences are acknowledged and included	Coyne, 2008, Coyne et al., 2014, Runeson et al., 2002b, Söderbäck, 2012, Davis and Randall, 2015
4. The child indicates how she/he would like the care to be delivered	Onugha & Finlay, 2012, Davis and Randall, 2015, Schalkers et al., 2015
5. Parents' actions indicate respect for the child's competence	Quaye et al., 2019, Alderson, 2006
6. Healthcare professionals' actions indicate respect for the child's competence	Quaye et al., 2019, Alderson, 2006

TABLE 3 Categories and main categories of observed expressions of the best interest of the child

Main categories	Giving child-focused preparatory information	Acknowledging the child's influence	Striving to respect the child's abilities
Categories	Giving introductory information	Actively seeking child's views	Relinquishing protectiveness over child
	Giving preparatory information	Creating space for the child's influence	Engaging the child despite parental disruptions
	Giving sensory information		Balancing benefits against unintentional harms

that children in this study could be guided in or hindered from exercising their competence in care situations. The observations showed a variation in actions among both parents and healthcare professionals to safeguard the best interests of the child. Results are supplemented with descriptions of situations from the field notes. Table 3 below gives an overview of the categories and main categories.

5.1 | Giving child-focused preparatory information

Reflected in this category are situations where children either received or did not receive preparation tailored to meet their informational needs. The former acted as facilitators enabling the expression of children's best interests, whilst the latter presented as obstructors to expression of the child's best interests. Information exchange was a prominent aspect throughout interactions between the children, their parents and healthcare professionals. Verbal information given to children was observed to be introductory, preparatory and sensory in nature. Receiving or not receiving such information facilitated or obstructed observed ways of expressing the child's best interest. Creating time prior to a procedure, to explain things to the children and their parents, and following up with the children to see whether they understood what was explained to them enhanced observed expressions of the child's best interests. Not creating time to give necessary information to children before procedures presented as obstructors.

5.1.1 | Facilitators

Introductory information from healthcare professionals about who they were and what role they would play during the child's hospital visit was given to children. Children and their parents also got the opportunity to introduce themselves to the healthcare professionals. *Preparatory information* was given to children prior to undergoing surgery, an examination, treatment or length of hospital stay. Children also received *sensory information* about what a particular treatment they were yet to undergo would feel like. In certain instances, healthcare professionals employed the use of visual aids, to help the child see instruments that would be used in his/her care.

> An assistant nurse attends a 4-year-old child who is going through routine checks prior to an operation the following day. The children's nurse shows the child a blood pressure (BP) kit. 'Have you seen this?' the children's nurse asks the child. The child shakes its head from side to side…The children's nurse explains to the child, 'We will put this on your arm and then pump air into it, and it will feel tight around your arm and then relaxed and then tight again, and relaxed. Are you ok with that?' The child nods its head…
>
> *(A14)*

5.1.2 | Obstructions

Challenges arose when there was a communication barrier in terms of language despite the presence of an interpreter or when children did not receive information prior to a procedure. In the example below, information about treatment alternatives was discussed with the parents and not with the child.

> A 4.5-year-old child and parents are being attended to by a nurse. The nurse discusses treatment options for the child with the parents of the child. The nurse maintains eye contact with the child's parents, informing them of the treatment alternatives. The child sits quietly, turning its head back and forth, looking at whoever is talking…
>
> *(A3)*

5.2 | Acknowledging the child's influence

This alludes to situations where healthcare professionals were observed to either *actively seek the child's views* about their care, or not. Seeking the child's views entailed paying attention to the child's interests and thereupon *creating space for the child's influence*. Observations showed that creating space for the child's influence also meant that the child's preferences and interests were given due consideration. This led to a compromise in how the planned care could proceed with the child's interests at the centre of the care planning. However, not actively seeking the child's views in matters concerning their care presented as obstructors.

5.2.1 | Facilitators

Prior to undergoing routine checks or procedures requiring blood samples, children's views were actively sought by the attending healthcare professionals. During a procedure, healthcare professionals constantly asked the children how they felt. In one situation, a 14-year-old child expressed feeling immense pain after a cannula insertion. The healthcare professionals removed the cannula and inserted it on a different arm. Older children were sometimes given the opportunity to choose if they wanted to administer the treatment by themselves, prick themselves or remove a cannula with the healthcare professionals' supervision. Children either indicated they preferred not to do so or agreed.

> An assistant nurse is about to give painkillers to a 9-year-old child. 'Can you sit up? You will have to drink the medicine', the assistant nurse tells the child. The child sits up in the bed. The assistant nurse holds up the medicine in a syringe and asks the child, 'Do you want me to hold it for you as you drink, or do you want to hold it for yourself?' The child looks at the mother. The mother gestures with a nod of her head. 'I can hold it', the child responds. The assistant nurse then gives the medicine to the child…
>
> (A7)

Creating space for the child's influence was further observed in situations where children were given alternatives to choose from, and their preferences were respected. Non-frequent attenders did not want to undergo routine checks for weight, height and temperature. Similarly, children who were in frequent contact with healthcare were too familiar with certain aspects of care that they wished not to take part in. Even when parents insisted that their child should undergo an assessment, the healthcare professionals respected the child's wish when they judged that this could be done later. Children were consulted about their parents being present and carrying out some aspects of their care. Also acting as facilitators are situations where children's initiatives to make their wishes known were acknowledged. For example, when children negotiated for more time to ready themselves before a blood test. During procedures, children were curious, wanting also to listen to their own heartbeat, see their own weight or height. In some situations, healthcare professionals reorganised their work and waited for the child to finish when she/her was preoccupied with a play activity. At other times, children determined that the healthcare professionals could proceed with the care.

> 'Are you ready?' a nurse asks a 14-year-old child prior to a cannula insertion a second time… 'I am not ready, but it would take an eternity if we were to wait for me so just proceed', the child responds. 'I hope we will succeed this time', the nurse says. 'Please stop saying that. It makes me more nervous', the child responds immediately. 'Oh sorry', the nurse immediately apologises…
>
> *(A18)*

5.2.2 | Obstructions

At times, children were not presented with opportunities to negotiate their readiness before the planned care could be carried out. Children's views were not actively sought, nor could they exercise their influence.

> A 14-year-old child's feet are about to be examined by a doctor. The doctor squats by the child's side. Without asking the child, the doctor lifts the child's clothes slightly upwards. The child immediately pulls its legs backwards. The child's eyes are wide open. Eyebrows are raised. A nurse standing by purses her lips. Another doctor standing next to the nurse purses her lips and her eyes open wide. The child's grandmother looks at the child. There is a slight moment of silence…
>
> (A4)

In addition, the feelings of children who seemed upset after undergoing stressful procedures were sometimes observed not to be given due attention by the parents or the healthcare professionals. In a situation after a procedure with the use of restraint was over, the healthcare professional said to the child, 'You are really good' The child spoke out saying, 'I am upset'. The child's mother responded saying, 'But it wasn't so scary' and gave him a hug. The mother and child continued talking whilst the healthcare professional prepared to leave the room.

5.3 | Striving to respect the child's abilities

Efforts were made by parents and healthcare professionals to respect the child's abilities. In the case of parents, *relinquishing protectiveness over the child* implied that parents allowed their child to exercise their competence under guidance that would not obstruct expression of the child's best interest. At the same time, healthcare professionals also had to strike a balance in ways of *engaging the child despite parental disruptions*. Healthcare professionals made efforts to continuously include children in discussions in situations where parental involvement risked obstructing the child's best interest. In complex situations, *balancing benefits against unintentional harms* meant unpleasant experiences for the child to undergo. In 15 situations, restraint or holding of the child was used to prevent the child from moving so that the care could proceed.

5.3.1 | Facilitators

Parents requested treatment alternatives for their child or asked for more time to be taken to explain a planned procedure to their child. Parents also helped children feel more secure about undergoing a procedure by going through it themselves, such as standing in front of an X-ray machine or pretending to drink medicine. At times, in the absence of the healthcare professional, children complained to their parents about painful procedures, and their parents encouraged them to talk about it with the healthcare professionals. For children with a long-term condition, parents actively took part in their care and helped to administer medication to their children by themselves. The parents allowed conversations to occur between their child and healthcare professionals, without much interruption.

> A doctor attends to an 8-year-old child admitted to the children's hospital prior to an operation. 'OK, now I want to know some things, [child's name]. Do you have pain in your stomach?' the doctor asks. The child looks at the father without responding to the question. The father tells the child 'It's not a trick question, [child's name]. You can answer it…'
>
> (A6)

Healthcare professionals strove to strike a balance upon meeting children and their parents, by affirming the child's presence. Healthcare professionals brought themselves to the level of the younger children by leaning or squatting down to talk to them and continued to actively engage children in conversations about their healthcare, despite disruptions from parents. Also observed is that outcomes of a situation with the same child were different and to a greater extent dependent on the approaches of the healthcare professionals. Engaging younger children in age-appropriate and playful manners facilitated opportunities for children to co-operate. At times, healthcare professionals advocated on behalf of the child. Once, parents of a child suggested the healthcare professionals proceed with attending to their child whilst the child was eating, but the healthcare professional insisted seeing the child afterwards. Healthcare professionals made efforts to respect the child's abilities by attending to the child first, as shown below.

> A 15-year-old child is about to be physically examined by a doctor. 'Ok I will look a little at your stomach', the doctor suggests after asking the child a series of questions. 'OK', the child responds. The child lies in the bed. 'Bend your knees and lay down your arms', the doctor tells the child, while helping the child to put its legs in an upright position. She examines the child's stomach using her hands, massaging various parts and asks the child if it hurts. When the doctor is done with the physical examinations, she informs the child, 'It feels normal in your stomach and I can say that it is nothing acute…'
>
> *(A29)*

5.3.2 | Obstructions

Situations also presented insights of parents constantly interrupting conversations between their child and the healthcare professional, either to have their own informational needs met or to answer questions on behalf of their child. At times, this led to older children being passive and not being able to take part in ongoing discussions. Balancing benefits against unintentional harms could result in the use of restraint when younger children took longer to co-operate with a planned care, and parents lost their patience. The use of restraint was not objected to by the healthcare professionals. Restraint was commonly used observed in situations such as taking a capillary blood sample, undergoing EKG and X-ray examinations, cleaning of wounds from an operation and removal of plasters.

> A 6-year-old child is going to have an operation wound examined by two nurses. The mother and nurses, standing on either side of the bed, try for a while to convince the child to let the nurses have a look. The child refuses. The child covers its body with a blanket and continues to prevent the nurses from pulling it down. After a while, the mother grabs her child's hands. She tells the nurses to go ahead. The nurses immediately pull down the blanket. The child shouts, 'No! No, mum, no!' The child wriggles on the bed in protest. The nurses pull down the child's clothes. They carefully examine the wound…
>
> (A5)

Findings demonstrated that, at times, greetings were exchanged among healthcare professionals and parents whilst children were not greeted. During discussions, disruptions from the parents caused healthcare professionals to continue the rest of the conversations with the parents and the child was side-lined. In consultations, parental views were sought more than those of children.

6 | DISCUSSION

This study found that there were both facilitating and obstructing aspects to the observed expressions of the child's best interests. Children's ability to exercise their influence in care was largely dependent on the actions of parents and healthcare professionals.

In this study, children receiving introductory, preparatory and sensory information about their upcoming care facilitated observed expressions of the child's best interest. Observations revealed that children were keen to know who would meet them, what would happen to them, how procedures, treatments or examinations would feel, and this reflects their current interests. Bray, Appleton, & Sharpe (2019) also highlight these three types of information children deemed important to receive. Not receiving child-focussed preparatory information appeared to obstruct expression of the child's best interests. Lack of information has been reported as one of many probable causes of fear as children navigate through the unfamiliar environment of the healthcare setting (exosystem) (Salmela et al., 2011). During the ecological transition to an unfamiliar environment, children's inadequate understanding of certain procedures may further exacerbate their fears (Salmela et al., 2011) thus meeting their informational needs is inevitable. In the present study, creating time to prepare children, explaining things to them, and following up on their understanding of what was explained to them was observed to enhance children's knowledge of their new situation. Research shows that meeting the informational needs of children makes them feel valued and less anxious (Coyne & Gallagher, 2011; Stålberg et al., 2016), has a positive effect on their experiences of clinical procedures (Gordon et al., 2011), and ensures their rights to seek, receive and impart information from a child's right perspective as recommended in Article 13 by the UNCRC.

In the observations, acknowledging the child's influence reinforces placing the interests of children at the centre of care planning as stipulated by a child-centred care (CCC) approach. Allowing children to exercise their influence as seen in the findings, further mirrors respect for the child's competence (*ability to perform a task*) as defined by Beauchamp and Childress (2019, p112). The child is then guided through relevant actions by the adults, to increased competence (Coyne, Hallström & Söderbäck, 2016; Ford et al., 2018), an aspect that Davies et al., (2019) point out may be one of the most challenging assumptions to overcome. It challenges the historical placement of children where an asymmetric position existed between the children and adults, and children did not enjoy equal value and rights as adults (Davies et al., 2019). Since children interact with numerous changing environments, Bronfenbrenner's theory emphasises understanding children in these environments. Findings in this study reveal that parents and healthcare professionals made efforts to facilitate observed expressions of the child's best interests. Actively seeking the views of children, as seen from the observations, shows that children's roles as co-constructors are recognised. Planning care whilst being aware of children's interests ensures that their unique perspectives are brought to light, and care can be tailored to maximise the net benefits for the children. At times, children's views in this study were actively sought, and they were given opportunities to have influence over how the planned care could proceed. This is in synergy with a CCC approach to care planning, empowers children and makes them feel recognised. These findings support previous research (Coyne, 2006) which show that children felt they were respected as persons when their opinions were sought, and they were not just instructed on what to do. Striving to respect the child's abilities in care situations in the observations highlights the efforts of parents and healthcare professionals to balance benefits against harm in care situations. This could further be emulated in care situations, as it shows the child's role as an active agent in the partnerships and that a holistic view of the child as stressed by a CCC approach, is recognised (Coyne, 2016).

In our observations, obstructions to expression of the best interests of the child arose when competent children were hindered from exercising their rights in healthcare situations. Instances where striking a balance in the triadic interactions presented as an obstruction are seen in situations where healthcare professionals directed questions about children to their parents or discussed results of an examination with the parents instead of the child. These findings are in congruence with earlier research where parents were a proxy in consultations between their child and the healthcare professionals (Coyne & Gallagher, 2011; Sahlberg, karlsson & Darcy, 2020). At the same time, other research has discussed the challenges in striking a balance between protecting the child from too much information and acting in the best interests of the child (Martin et al., 2019). Our identified situations revealed the communication about expectations and responsibilities for the child, parent and healthcare professionals was missing, as also found by Coyne, (2015). Lack of open tailored communication involving the child, parents and healthcare professionals could lead to negative experiences of healthcare for the sick child (Coyne, 2006). In our study, balancing benefits against potential harms at times led to the use of restraint, or children being side-lined in discussions about the ongoing care. A review by Bray et al., (2015) also shows the use of holding/restraint during procedures involving children in several studies. Limited knowledge in national guidelines for procedures with use of physical holding/restraint was reported by healthcare professionals and that they also experience challenges in balancing benefits against unintentional harms where holding/restraint is concerned (Bray, Carter, & Snodin, 2016, Bray et al., 2019). Sahlberg et al., (2020) report similar findings to ours, where parents limited the opportunities for their child to be heard.

6.1 | Mutual negotiations

The complexities involved in the care of children may pose challenges for healthcare professionals to uphold the child's best interests. To promote the child's best interests, healthcare professionals could take the responsibility to initiate/encourage mutual negotiations involving the child, parents and healthcare professionals. In mutual negotiations, the child, parents and healthcare professionals are all experts in their own rights, albeit with varying levels of competence and experiences (Harder et al., 2013; Rogoff, 1990). The approach of mutual negotiations seems not to be commonly used in clinical practice (Harder et al., 2013), even though negotiations are often a daily part of children's interactions in the home, and other environments (Rogoff, 1990). Harder et al., (2013) posit that encouraging negotiations improves children's autonomy and competence when they interact with people in new environments. When competing interests of the actors involved arise, a more holistic view of the child and situation as supported by CCC and the bioecological approaches may enhance understanding. An ecological view would allow understanding of the child's immediate support system (microsystem) such as the disruptions the child and parents are facing and how this could be affecting their coping strategies and response to care. From a CCC perspective, the important questions are finding out what the current and future interests of the child (child's perspective), parents, and healthcare professionals (child perspective) are, and how may the healthcare professionals engage the child and parents, and together weigh the competing interests against alternatives, reaching a compromise that promotes the best interests of the child. Inclusion of both the child's perspective and a child perspective is crucial in the mutual negotiations (Söderbäck et al., 2011). When parental views of what may be good for the child risk causing more harm than good, such as situations where restraint is suggested by parents, healthcare professionals should advocate on behalf of the child, with a child's rights perspective (Waterston & Yilmaz, 2014).

6.2 | Methodological considerations

Qualitative descriptive studies allow researchers to stay close to their data and offer a broad description of observed facts about the phenomenon under study, in everyday language (Sandelowski, 2000). The use of overt, non-participant observations (Neuman, 2014) enabled the first author to visibly observe the ongoing interactions between children of different age and with different diagnoses, their parents and healthcare professionals in the hospital setting. However, the behaviour and actions of the participants may have been influenced by the presence of an observer. Observation is a technique that facilitates the capturing of tacit knowledge (non-verbal communication, artefacts, symbols or hidden cultures) that are an integral part of participants' daily lives (Dahlgren, Emmelin, & Winkvist, 2007). The trustworthiness of the observational data was enhanced by rigorous approaches to the sampling of participants, systematic and objective taking of field notes, and data analysis leading to over 500 situations identified and analysed.

An inductive approach was chosen because scientific knowledge about how the child's best interest can be upheld in the paediatric setting is fragmented (Elo & Kyngäs, 2008). Abductive reasoning enhances the development of scientific knowledge by enabling the perception and understanding of underlying meanings of a phenomenon (Ericksson et al., 1997). The use of the six principles refers to the abductive reasoning in the analysis and connects the results with Articles 3 (best interest), 12 (respect of child's views) and 13 (freedom of expression) of the UNCRC (1989). The six principles need to be developed further for use in situations involving holding/restraint to also reflect the child and parent's consent, and where informational needs of parents were met. Having their informational requests met enables parents to have some level of control during this stressful period of having a sick child (Hallström et al., 2002), and therefore, this could be considered in accordance with the Patient Act in Sweden (Patient Act, 2014) when determining the child's best interests.

The first author has an educational background in molecular biology and public health, which may have presented a risk in under- or overestimation of observed situations, and subsequent analysis. As a strength, it allowed the first author a level of naivety in data collection and analysis. The second, fourth and last authors had expert knowledge and experience, having worked as paediatric nurses and researchers in the Swedish healthcare system. The third authors' professional background and international perspective, and the different pre-understanding of all the authors added credibility to the study.

7 | CONCLUSION

The study offers a new understanding of what aspects of medical and nursing care may facilitate or obstruct expression of the best interests of the child. The former should be encouraged in paediatric care and the latter should be discussed and reflected upon for alternative solutions. The best interests of the child (Article 3) are interwoven into all the other rights of the child in the UNCRC, which also needs to be taken into consideration when determining what is best for the child (Degol & Dinku, 2011). Determining the best interests of the child requires a case-by-case basis, as it is context-dependent, situational, flexible, dependent on all the actors involved at a particular moment, and actual decisions made. Mutual negotiations involving the child, parents and healthcare professionals should be encouraged, as negotiations help increase the child's competence. It may be suggested that different values and experiences of children, their parents and healthcare professionals could present diversity in safeguarding the child's best interests (Bowyer, 2016; Dan, 2018), thus possibly accounting for variations in expressions of the best interests of the child. Therefore, future research should focus on examining whether various levels of specialisation among healthcare professionals play a role in facilitating expression of the child's best interests. Further observations coupled with interviews of children, their parents and healthcare professionals may give a deeper understanding of their perceptions and experiences of the best interests of the child.

8 | RELEVANCE TO CLINICAL PRACTICE

A continued creation of knowledge awareness of what the rights of children are when children encounter healthcare services is important. Fulfilling the best interests of the child focuses on creating an environment for the child's opinions, views and valuations to be expressed alongside those of parents and healthcare professionals in mutual negotiations with a reinforcement of communication skills among healthcare professionals. Developing the six principles further, in accordance with the various guidelines for paediatric clinical practice, may (i) direct courses of action; (ii) help set priorities; and (iii) provide new insights to healthcare professionals on areas to focus on when optimising the best interests of the child in care situations. Reflections and discussions on how to protect the best interests of the child may help healthcare professionals incorporate the UNCRC into daily clinical practice.

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CONFLICT OF INTEREST

The authors do not have any conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

The first author participated in the study design, ethical approval application, data collection, analysis and drafting of the manuscript. The second author participated in data analysis, reviewed the manuscript, as well as co-supervision. The third, and fourth authors participated in study design, data analysis and reviewed the manuscript. The last author participated in the study design, ethical approval application, data collection, data analysis, reviewed the manuscript and supervision. All authors read and approved the final manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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Paper III

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

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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

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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 bioeological 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 microsystem 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.

> *'…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

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

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.

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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.

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Paper IV

‘I don't remember doctors talking to me like that when I was a kid’- A qualitative study on parents’ experiences of their child’s best interests during hospitalization

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Abstract

There is a paucity of literature on parents’ experiences of their child’s *best interests* when they engage with the healthcare system. This study aims to explore parents’ experiences of their child´s best interests during hospitalization. A descriptive qualitative inductive design using face-to-face parent-child combined interviews, analyzed by latent content analysis. Sixteen parents recruited from a tertiary hospital in Western Australia were interviewed. Collaboration, development of trustworthy relationships, and effective communication are essential in shaping parents’ experiences of their child’s best interests during hospitalization.

Key words: Parents’ experiences, child’s best interest, child centered care, bioecological model, hospitalization

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Introduction

Patient experiences are a valuable source of evidence to inform planning, delivery, and evaluation of healthcare services (Lygre et al., 2020). Parents and legal guardians are recognized as proxy-decision makers/representatives of their children until their child attains the age of majority to fully represent themselves (Aarthun and Akerjordet, 2014). In this article, "parents" is used to refer to individuals with legal custody of a child. Articles 3 and 18 of the United Nations Convention on the Rights of the Child (UNCRC) emphasize that prioritizing the child's best interests should be a primary concern of parents and state parties (UNCRC, 1989). The best interests of the child can be elucidated from the child's perspective and a child perspective. The former represents children's understanding and experiences; highlighted in their own self-reported narratives (Foster et al., 2022; Sommer et al., 2010; Stålberg et al., 2016). The latter is defined as adults' understanding of children's experiences (Sommer et al., 2010). Delivery of pediatric care worldwide, has mainly been shaped by a family-centered care (FCC) approach where the entire family unit is the care recipient (Shields et al., 2012). However, concerns have been raised over effectiveness of FCC, and that it may overshadow the child's perspective (Uniacke et al., 2018). A child centered care (CCC) approach prioritizes needs of children in the context of the family and recognizes children as active recipients of care (Coyne et al., 2016; Foster and Shields, 2020). A CCC approach reinforces the best interests of the child and is beginning to permeate day-to-day healthcare delivery within pediatric clinical practice in Western settings (Coyne 2014, Ford et al., 2018, Foster et al., 2019).

Bronfenbrenner's bioecological model provides insight of factors that influence the child's psychosocial and emotional development. For instance, within the microsystem is the child's home environment reported as the most influential factor (Bronfenbrenner, 2004). The macro system level includes societal views of children, and legislation such as the UNCRC (UNCRC, 1989). Hospitalization for in-patient care is recognized globally, as stressful, and sometimes a life changing event (Ari et al., 2019; Claridge et al., 2020; Nassery and Landgren, 2019). During hospitalization, the hospital environment becomes part of that child's microsystem where interactions among the child, parents, and healthcare professionals become of paramount importance to ensure that the child's best interests are well represented (Ford et al., 2018).

Determining the child's best interests in a hospital setting will ideally involve combined views of children, parents, and healthcare professionals (Quaye et al., 2021). Children's self-reported experiences of their best interests during hospitalization have been explored in previous research (Foster et al., 2019, 2022). However, there is a paucity of literature on parents' experiences of their child's *best interests* when they engage with pediatric healthcare systems. Highlighting these experiences may provide valuable information to inform pediatric practice, through the facilitation of the co-production of personalised care, and with a CCC approach and UNCRC principles (Aarthun et al., 2019; Carter et al., 2014; Dickinson et al., 2014; UNCRC, 1989).

Aim

To describe parents' experiences of their child´s best interests during hospitalization.

Methods

Design

A descriptive qualitative inductive design using face-to-face parent-child combined interviews (Carter et al., 2014; Elliott and Timulak, 2005; Nisha and Michelle, 2017). Qualitative content analysis was undertaken which focused on the subject, context and emphasized variation to enable a condensed description of the phenomenon under study (Graneheim et al., 2017; Lindgren et al., 2020) This article presents parents' experiences. Data on the children's experiences have been previously reported (Foster et al., 2022).

Participants and participant recruitment

Parents were recruited from a tertiary hospital in Western Australia, which provides services to over 3,000 children annually. One week prior to the child´s planned admission, parents were sent invitation letters by the second author with information about the study. Those who presented as an acute admission were recruited on the ward. Inclusion criteria were that parents needed to have a basic command of the English language and have provided informed voluntary signed consent. Through convenience sampling the second author reached out to parents of 41 children. Of this, 16 parents (all European ethnicity) of children (eight girls and seven boys) aged two to 14 years old agreed to participate. Most admissions were acute (80%) and reason for admissions included medical, surgical and/or complications associated with a chronic illness. Data collection took place over seven months from June - December 2019. Interviews were conducted between 12-72 hours post admission and prior to discharge. Reasons for non-participation included children being discharged prior to scheduled interviews or declining to participate.

Data collection

The parent-child interviews were conducted within the hospital premises at a time most convenient for parents, their child, and the healthcare professionals. An interview guide with open-ended questions formulated from the literature was used (Dahlgren et al., 2007). Topics covered included: the child's best interests, the child's participation, and interaction with parents and healthcare professionals during hospitalization. Thirteen mothers and one father were interviewed individually, whilst one mother and father were interviewed together. Thereafter, parents were given the opportunity to listen to their recording before transcription and advise the researcher of any changes, of which none of them wished to listen to the recordings therefore no changes were made to the content of the interviews. The interviews ranged in length from 16 to 36 minutes.

Data Analysis

Data were analysed at the latent level. All interviews were transcribed verbatim by a research assistant and verified by the second author. The first and second authors listened to and read through each transcript to become further immersed in the data. Thereafter, the first author proceeded to identify meaning units of relevance to this study with a focus on data relating to the parents. The meaning units were then condensed to reduce the text whilst maintaining the core meaning. Condensed meaning units were then labelled with codes which were close to the original text and at low levels of abstraction and interpretation. Constant comparison of codes was conducted by the first and second authors, carefully examining similarities and differences in the data. According to Lindgren et al. (2020), data deemed rich enables abstraction of codes directly into sub-themes. Sub-themes were abstracted and pooled to form themes, independently by the first author. Discussions were held between the first and second authors multiple times, to compare, contrast and refine sub-themes, themes, and the main theme. Further discussions on the whole analytical process were held with the third and fourth authors until a consensus was reached (Table 1). The analytical process was iterative, involving back-and-forth examination of meaning units and interview transcripts, in line with the study aim.

Table 1. An example of inductive content analysis of parents' experiences of their child´s best interests during hospitalization

Meaning units	Condensed meaning units	Codes	Sub-Theme	Theme
I think it's when they can come in and you are complete strangers but look at the bigger picture and look at trying as quickly and as fast as possible to gauge a bit of info about your child and their personality type and then really work that care around that type of personality to keep their best interests at the forefront	Healthcare professionals can look at the bigger picture despite being strangers with children, and trying as quickly as possible, to gauge information about the child and their personality and work the care around the child's personality to keep their best interest at the fore front	Knowing my child	Seeing my child beyond current illness	Tailoring care to reflect my child's needs
Maybe come back in, in you know an hour's time and try something again, you know, maybe just back off a little bit, leave her alone, give her some time.	Mother's opinion is for healthcare professionals to give child some time by backing off a little and leaving her alone	Giving my child space		

Ethical approval

Both the hospital and university ethics committees approved this study. Permission was obtained from parents for the interviews to be recorded. Parents were reminded that information they shared would be treated confidentially and that they had the right to cease participation in the study without any impact on the care of their child.

Results

Analysis yielded 50 codes, 10 sub-themes, three themes, and one main theme (Table 2). The main theme 'A balancing act of collaborating and developing trustworthy relationships through effective communication during care situations' included three themes: i) Supporting my child to attain increased autonomy, ii) Tailoring care to reflect my child's needs, and iii) Encountering ups and downs.

Table 2. Summary of the themes generated through inductive analysis of parents' experiences of their child's best interests during hospitalization

Sub-themes	Themes	Main theme
Respecting my child's integrity Age-appropriate interactions with my child Creating opportunities for my child's active participation Open transparent communication	Supporting my child to attain increased autonomy	A balancing act of collaborating and developing trustworthy relationships through effective communication during care situations
Shared responsibilities Seeing my child beyond current illness Advocating on my child's behalf	Tailoring care to reflect my child's needs	
Living outside our comfort zone Positive care encounters Short comings in care received	Encountering ups and downs	

A balancing act of collaborating and developing trustworthy relationships through effective communication during care situations.

This main theme collated parents' active and passive experiences of their child's best interests during hospitalization. The former refers to parents' actions and inputs to facilitate care in their child's best interests. The latter allude to their observations of actions of healthcare professionals, as well as of their children. Parents found themselves in situations requiring a balancing act of collaborating with their child, and healthcare professionals, to achieve intended outcomes in their child's best interests. Navigating their new environment and the healthcare system, parents depended on developing and maintaining effective communication. Effective communication was described as open and transparent communication comprising tri-directional communication involving healthcare professional-parent, healthcare professional-child, and parent-child communication. Effective communication enhanced the development of relationships between the triad, described as trustworthy.

Supporting my child to attain increased autonomy

This implied healthcare professionals interacted with the child in an age-appropriate manner that showed respect for the child's integrity. Additionally, this meant healthcare professionals created opportunities for the child to be actively involved in their own care. This was further enhanced by occurrence of open transparent communication between the child, parent, and healthcare professionals.

Respecting my child's integrity

For parents, respect for their child's integrity was inferred through the attempts by healthcare professionals to seek their child's opinions on aspects of care. This included seeking the child's opinion when decisions needed to be made, how their child felt about an impending procedure and how to move forward with future care situations, including preferences for route of medication delivery and food. It meant healthcare professionals sought the child's permission prior to conducting any examinations or treatments that were invasive:

> "They always asked for his permission and he said yes." (Parent of 3-year-old boy)

Respecting the child's integrity also entailed ensuring protection of their child's privacy. For parents whose child was pubescence, the child's preference to have a healthcare professional of the same gender as theirs or conducting routine checks without their child having to take their clothes off, was appreciated. Parents felt that the value of their child was being acknowledged when their child was given a voice and allowed to freely express their opinions. Parents were impressed and often surprised at how healthcare professionals talked to their child. Reflecting on societal changes, parents recalled their experiences as being different:

> "It's really good that times are changing, and we are actually talking with children as well and involving them in what's happening to them" (Parent of 14-year-old boy).

Age-appropriate interactions with my child

Parents shared that healthcare professionals took their child's age and maturity into consideration, and this shaped the nature of the interactions between healthcare professionals and their child. In other situations, parents felt their teenage child was "babied" by healthcare professionals. Age-appropriate interactions included intentional selection of words and how healthcare professionals talked with children:

> "When putting her needle, he [nurse] sat there, talked her through the whole thing. When he put it [needle] called it a straw, alleviated the 'n' word. Sung her a song, which I thought was nice. Just spoke through a calm voice, gave a high five after" (Parent of 6-year-old girl).

Distracting children in an age-appropriate manner was described in relation to how healthcare professionals worked things out with distressed children, to gain their co-operation. Approaches included tickling, placing stickers onto reward certificates, engaging children in child-friendly play, having entertainment available such as a children's television channel and providing children with play activities to keep them distracted.

Creating opportunities for my child's participation

Supporting the child to engage in their own care was a crucial element in safeguarding the child's best interests. Creating opportunities for the child's participation meant that healthcare professionals encouraged the child to engage in tasks that were not too demanding for them. Minor tasks encompassed activities such as helping to take off plasters and bandages, having the child pass items from trolleys during procedures, and disposing of used items like cups or plasters. Parents saw education to self-medicate by healthcare professionals, as empowering and sustainable, especially when the child had a long-term illness and would need to continue with medication post discharge:

> "There's going to be times where she needs to self-medicate. To arm her with tools to be able to do it herself and do it properly to make sure she's breathing in the medicine, is really important." (Parent of 11-year-old girl)

As much as parents wished for their child to participate more fully in their care, they were equally aware of factors that could limit this, such as the age of the child, the specific situation at hand and actions of healthcare professionals, which may limit the extent of their child's participation:

> "it depends on how old the child [is]. She's at three and a half years old. I assume older kids is easier for them to listen to instructions and follow through. But she's three and a half; So how to get them actively participate at this age?" (Parent of 3-year-old girl)

Nevertheless, parents still shared a wish for healthcare professionals to make ongoing efforts to engage their child in care. They believed that supporting their child's participation in their own care created a sense of control, helped their child relax, and reduced distress and worry. Parents believed that the engagement of their child in their care also facilitated the child's wider engagement with healthcare professionals, adherence to planned care and enhanced the number of positive experiences with healthcare delivery.

Open transparent communication

Parents believed that the use of communication styles in accordance with the child's linguistic and developmental levels by healthcare professionals were at the core of developing open transparent communication. Parents described triadic communication during care situations as necessary and important. During healthcare professional-child communication, parents valued healthcare professionals' engaging with their child without using parents as proxy. Open transparent communication also implied a stepwise explanation of procedures given to their child, to enhance the child's understanding of what upcoming care entailed. Sometimes parents felt that their child had no voice in matters that concerned them where healthcare professionals communicated with the parent instead of making attempts to communicate directly with their child. Having open and transparent communication allowed for sensitive issues to be explored and for the child's concerns to be discussed:

> "Making sure that everything is explained and it's on their level so that they can understand, and it helps ease the stress a little bit off them" (Parent of 3-year-old girl)

Parents valued communication between themselves and their child and this enabled their child to share their feelings, experiences, and ask questions that they didn't feel they could ask healthcare professionals. Open and transparent communication with healthcare professionals further augmented the parents' and the child's trust in healthcare professionals. There were, however, times when parents encountered a breakdown in communication with healthcare professionals. Parents said this occurred when they were not given enough information about upcoming procedures, what would happen next, what roles were expected of them, or when parents and children did not make efforts to communicate with healthcare professionals:

> "Some parents and children would get that white coat syndrome and just think to shut off completely, they don't really communicate, and it becomes very clinical" (Parent of 2.5-year-old girl)

Tailoring care to reflect my child's needs

Distinguished in this theme are symbiotic efforts made by parents and healthcare professionals to provide personalized care that catered for the child's prevailing needs, suggesting a sharing of responsibilities among the triad. Parents emphasized a need for healthcare professionals to see their child beyond the current illness, to allow healthcare professionals to know their child better from a holistic lens and implement planned care in accordance with the child's preferences. Parents described adopting several advocacy roles orchestrated by them on their child's behalf.

Shared responsibilities

Shared responsibilities meant the child, parents, and healthcare professionals worked together as a team to maximize outcomes in the best interests of the child. Whilst parents attended to the daily basic needs of their child which encompassed feeding, bathing, dressing, nappy changes, and mobilization; healthcare professionals predominantly carried out the pharmacological aspects of care. At times, parents were allowed by healthcare professionals to administer medication to their children, but this was under supervision. Parents appreciated receiving expert guidance and care for their child. Frequent checks on children by healthcare professionals suggested to parents their child's needs were at the forefront of care delivery. Getting help from friends and other extended family members to care for children left at home enabled parents to channel their efforts towards promoting the best interests of the hospitalized child. Shared responsibilities also inferred that in certain acute situations, parents had to give healthcare professionals space, and allow them to make quick and necessary decisions during critical times, without parental interference:

> "When we first came in it was the emergency, which I stood back and just let them do what they needed to do to get us stable" (Parent of 11-year-old girl).

Seeing my child beyond the current illness

Fundamental was the parents' wishes for healthcare professionals to see their child as an individual and not be defined by their current illness. Healthcare professionals needed to take a personal interest in knowing more about their child's temperament, likes and dislikes in addition to the medical information required. Parents described how they made efforts to help healthcare professionals better understand their child's needs and create a good rapport with their child. In addition, parents articulated a wish for healthcare professionals to "*touch base*" directly with their child, instead of using them as proxy:

> "Look at the bigger picture and look at trying as quickly and as fast as possible to gauge a bit of info about your child and their personality type and then really work that care around that type of personality to keep their best interests at the forefront" (Parent of 2.5-year-old girl)

Giving the child space during stressful situations implied not rushing to implement planned care when children were distressed. Parents felt it was necessary for healthcare professionals to first gauge the stress levels of their child, give the child some breathing space to process all that was going to happen, and then return after a while to continue with the planned care:

> "Maybe come back in an hour's time and try something again, just back off a little bit, leave her alone, give her some time" (Parent of 6-year-old girl)

Advocating on my child's behalf

Parents sought to help alleviate discomfort experienced by their child during hospitalization. When parents assessed that their child's best interests were not being honored, they intervened by advocating on their child's behalf. Advocacy roles included monitoring and questioning aspects of care and speaking on their child's behalf. Parents described initiating discussions with healthcare professionals to further understand the significance and need for certain invasive procedures. Parents described the child's best interests as pivotal when the plan of care was weighed up against alternative diagnostic tests and procedures to promote the child's best interests and wishes. Of importance to parents was that their child's comfort was ensured:

> "They were querying possibly another blood test but to me, the trauma and what it's going to do to her… It's too high for me to agree for that to happen" (Parent of 2.5-year-old girl).

Encountering ups and downs

Parents described experiencing 'ups' and 'downs. The 'ups' of their child's hospital stay were defined by positive care encounters with healthcare professionals and the delivery of care. They met healthcare professionals who maintained a level of professionalism whilst interacting in an age-appropriate manner with their child. 'Downs' were described as short comings in care delivery, and the parents wished for improvements. In navigating the ups and downs of their new environment, parents experienced living outside their usual comfort zone but described this as necessary to secure their child's best interests.

Living outside our comfort zone

Parents made sacrifices to support their child's best interests. Parents and their child wanted to be as close as possible to each other especially when the child felt scared at night. This was not always possible, and parents grappled with feelings of losing control due to sleep deprivation and their child's sleepless nights. Parents went through a roller coaster of emotions which they concealed to appear strong for their child. At times the child had to endure uncomfortable situations, for example being held or the use of physical restraint were described as sometimes unavoidable, yet necessary and in the child's best interests. It was vital for parents to have a place they could relate/connect with as their own space. Parents were aware that stress in the short term was for the greater good, indicating that they grasped the complexity involved in safeguarding their child's best interests during hospitalization:

> "He is obviously feeling frustrated that he was stuck in hospital and that he was going through all this stuff, all because he needed medicine. But then you have to try and explain it to him that his best interests are to be in there to get his leg fixed" (Parent of 3-year-old boy).

Positive care encounters

Overall, parents described themselves as content with the care received. Positive interactions were marked by a friendly and calm demeanor when healthcare professionals talked with their child. Parents appreciated how health care professionals interacted with their children. Healthcare professionals were described as welcoming, accommodating, considerate, helpful, putting in their best efforts, and having exceeded the parents' expectations:

> "*Every single person* [healthcare professional] is good. [healthcare professional] has dotted the I's and cross the T's. They have gone above and beyond" (Parent of 6-year-old girl)

Availability of a playroom was described as instrumental in supporting their child's best interests. Parents shared that their children felt calm and more relaxed in the playroom:

> "Once he got up here [playroom] and he could see the toys he relaxed a bit more. Down there is a different story…Once he saw the toys in this colourful room the fish kind of calmed him down" (Parent of 3-year-old boy)

Shortcomings in care received

Parents grappled with variation between healthcare professionals, in relation to how their child's best interests were brought into focus. In some situations, detailed explanations were given to the child and parents, whilst other times the information provided was not clear. Parents experienced that when healthcare professionals shared different views amongst each other, some stepped up to advocate on their behalf, for example for less invasive procedures to be undertaken:

> "Another nurse stepped in and said, let's try another less invasive way. I feel that she in that situation, had my child's best interests more at the forefront than the other person" (Parent of 2.5-year-old girl).

Doctors were described as more distant compared to nurses. Long wait times associated with admission, consultation, receiving medication, undergoing examination and procedures, led to parents feeling agitated and exhausted. Some healthcare professionals were described as task orientated and parents did not feel that their child's best interests were safeguarded:

> "This is my job. I've got a job to do. I'm going to do it without any regard for the child herself with no care for A she's just a job" (Parent of 6-year-old girl)

Discussion

Collaboration was recognized by parents in this study as fundamental to the tailoring of care to meet their child's individual needs. The process of collaboration calls for mutual negotiations (Quaye et al., 2021) of distinct roles and responsibilities to be played by the triad. In this study, parents and healthcare professionals worked together and depended on each other symbiotically to provide nursing and medical care. The process of collaboration has been described as evolving overtime from a professionally dominated encounter to a collaborative one (Swallow et al., 2013). However, healthcare professionals may be reluctant to take into consideration parental and child knowledge and expertise because of an implied shift in the balance of power (Swallow et al., 2013, Smith et al., 2015). The value of parent-healthcare professional collaboration aligns with UNCRC stipulations which require parents and state parties to prioritize the child's best interests in all matters concerning the child (UNCRC, 1989). However, the primacy of the child as an *active* agent in the alliance between the parent-healthcare professional collaboration must not be lost (Bronfenbrenner, 2004; Coyne et al., 2016). To safeguard the child's best interests, collaboration requires healthcare professionals not only to draw on their professional expertise, but also acknowledge and work alongside children and parents as partners (Coyne, 2016; Oulton et al., 2020; Quaye et al., 2021).

Parents in this study wanted healthcare professionals to develop interpersonal relationships with their child and expressed wishes for healthcare professionals to look at the 'bigger picture' during interactions. Respecting the child's integrity, getting to know the child at a more personal level-beyond the medical context and giving the child space were seen as fundamental to promoting the child's best interests. These are consistent with delivery of care within the CCC approach (Coyne et al., 2016) and are supported by Bronfenbrenner's bioecological model in relation to the importance of understanding personal characteristics and capacities of the child as an individual (Rosa and Tudge, 2013). Healthcare professionals may incorporate these insights to collaborate with parents and children to help sustain a healthy bioecological system for the child during hospitalization (Ford et al., 2018). In this study, bioecological transitions (changes in roles and settings throughout the life of a developing individual) (Bronfenbrenner and Ceci, 1994; Rosa and Tudge, 2013) were coupled with experiences such as parents and their children living outside their comfort zone. Parents experienced sleep deprivation or concealed their own feelings to appear strong for their child. Nassery and Landgren (2019) also found poor sleep quality among parents of hospitalized children. Developing trustworthy relationships between parents and healthcare professionals may have a positive impact on children's experiences with healthcare (Boelsma et al., 2021; Sharkey et al., 2016) However, the nature and quality of relationships developed between parents and healthcare professionals may be influenced by length of hospital stay, busy schedules and workloads of healthcare professionals, levels of parental or child stress, continuity of care provision, and severity of illness (Coyne, 2008; Mărginean et al., 2017). It is crucial that healthcare professionals strive to create rapport with children and parents from their first encounter and consistently build rapport in subsequent encounters (Sharkey et al., 2014).

The capacity to collaborate and establish and/develop trustworthy relationships in this study, hinged on effective communication which occurred at three levels. Communication was experienced as effective when it was open, transparent, and in accordance with the child's cognitive and linguistic developmental milestones. Effective communication has been discussed as a fundamental aspect to enhance patients' health literacy (Brach et al., 2017; Agency for Healthcare Research and Quality, 2020) and it provides healthcare professionals deeper acumen into patients' symptoms, perspectives, and preferences (Street, 2016). Effective communication for parents in this study also encompassed the provision of age-appropriate information to children. Parents of children with and without communication difficulties expressed a need for adequate communication with healthcare professionals. The experience of unmet communicational needs among parents with hospitalized children is corroborated in previous research. Hemsley et al. (2013) reported that parents of children with communication difficulties felt that their child was vulnerable and more likely to be ignored during interactions with healthcare professionals. Further, parents have highlighted more generally, inadequacies in the provision of, and access to, information for their children (Bray et al., 2019). Parents in this study felt that effective communication was impacted by an imbalance in power that stymied communication. These findings bring into focus the persistence of traditional imbalance of power between parents and healthcare professionals (Reeder et al., 2021) and are comparable to Carlsson et al. (2016) who reported feelings of inferiority among parents that hindered them from voicing their concerns to healthcare professionals. In accordance with UNCRC, it is an obligation for pediatric healthcare institutions to make information accessible, understandable and that children and their parents can utilize information for the benefit of the child's best interest (Brach et al., 2017).

The findings of this study provide evidence of the influence of legislation promoting child's rights such as the UNCRC, and societal changes in the view of children and reinforce the principles of a CCC approach where care needs to be planned within the context of family with the child as an active care recipient.

Implications for practice

Providers of pediatric healthcare are encouraged to:

- Engage in discussions on the roles and responsibilities of parents and their children and acknowledge their expertise to enhance collaboration.
- Establish effective means of communication tailored to meet the child's developmental and linguistic milestones.
- Establish a good rapport and build trustworthy relationships with children and their parents amidst time constraints.
- Approach the planning and delivery of pediatric healthcare with a holistic bioecological view of children, beyond their current illness.

Strengths and Limitations

Trustworthiness in this study was enhanced through the team approach to data collection and analysis. The second author conducted the interviews, and the first author conducted data analysis in consultation with all authors. Most of the admissions were acute (80%) thus it may be argued that child and parental levels of stress may have influenced the depth and quality of the interviews. This was taken into consideration and all interviews were conducted 12-72 hours post admission or before discharge. Of the 14 interviews, only one child was living with a disability therefore parents of children living with disability are not fully represented in this study. Most of the children were adolescents, their parents were of European ethnicity and only two fathers were interviewed. The interviews were short, on average 26 minutes which may have narrowed scope of the data.

Conclusion

This study demonstrated that collaboration, development of trustworthy relationships and effective communication are integral aspects of healthcare delivery and essential in shaping parents' positive experiences of their child's best interests during hospitalization. Tailoring communication and interaction styles in accordance with the child's age, maturity, illness severity, emotional, cognitive, and physical developmental levels are vital in the development of effective communication. Future research needs to focus on healthcare professionals' perceptions of the child's best interests during hospitalization.

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Supplementary materials

The data used in this study contains sensitive information about the study participants and they did not provide consent for public data sharing.

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

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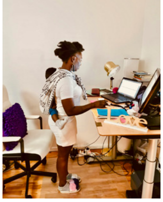
About the author

I was born in Ghana West Africa, but I grew up in Zambia, since the age of three. I undertook my undergraduate education in Molecular Biology and Genetics at The University of Zambia. Thereafter, I was awarded a scholarship by the Swedish Institute to pursue my Master of Science with major in Public Health at Lund University, Sweden. I then proceeded to pursue my doctoral education with the Child and Family Health research group, Department of Health Sciences, Faculty of Medicine, Lund University.



Recommendations exist for the child's best interests to be a primary consideration in all matters that concern them. However, there is uncertainty in literature on how children's best interests may be safeguarded when they encounter healthcare. The overall aim in this thesis was to elucidate from various perspectives, the experiences of the child's best interests during hospitalisation.

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