



## Children's Experiences of Staying in Hospital from the Perspectives of Children and Children's Nurses: A Narrative Review

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### Abstract

**Aim:** This review presents a narrative overview of the existing literature relating to the child's experience of being admitted to hospital from the perspectives of children in hospital and children's nurses who provide the majority of their care.

**Methods:** A narrative review of the literature was undertaken-relevant work was identified through a process of selection using a broad time period, key search terms and a number of appropriate data bases. Data was initially extracted from each study using a data extraction sheet which identified the author(s), date and source of publication, study design, key findings, limitations and recommendations. The extracted data was then added to a summary table and based on this key dominant themes were identified. These provided the foundation for the formulation and the synthesis of a coherent narrative. There were 51 papers included in the review.

**Findings:** The review therefore presents the views of two groups-(1) children who stayed overnight and (2) children's nurses. The main findings of the narrative review are organized thematically. The views of nurses caring for the child in hospital suggest challenges exist within time restraints (to provide care), communication skills and an environment which may isolate and separate the child from their family and other children. The main themes emerging in respect of the hospital experience of children are represented as relating to communication, environment/ward design, play, isolation/separation and the child's relationship with family and children's nursing to be particularly important to the child in hospital.

**Conclusion:** Both hospital ward/environment and children's nurse differ greatly to the child's home and family.

**Keywords:** Children, Sick child, Child, Pediatric, Hospital, Experience, Children's nurse, Nursing care, Child centered.

### Introduction

This review was undertaken as part of an empirical study which led to the award, doctorate in education. The paper is organized as follows: why the study was undertaken, a definition of the process followed by an overview of the literature accessed and a broad analysis of emerging themes. The timeframe covered; the scope of the studies examined; identify theoretical frameworks; the methodologies employed; the core themes identified with noted inconsistencies and overall findings.

A critique of the literature is then broadly presented; it aims to identify gaps and inconsistencies. The material in each section notes the studies which relate to each theme; highlights what they have in common; notes the points of difference and any inconsistencies in respect of findings. The review also tries to account for any differences in terms of the information available from the studies. For example, methodological approaches, differences in conceptualization and outline of synthesis by theme.

### Why the Study Was Undertaken

Children are significant and unique users of healthcare services; this is reflected in the status of the children's nurse and the nature of the training/education they receive. The education of children's nursing

may have consequences such that children may not receive care that takes account of their specific needs. In the context of developments that recognize children as rights holders (UNCRC 1989), including their right to contribute to decision making that affects them, it is important to explore how children experience hospital care, and also the perspectives of those nurses who are charged with delivering that care. Doing so can help inform debates about the nursing profession, and policy decisions that may impact upon the care of children in hospital. The care delivered by the children's nurse may impact on the child's experience of hospital. This review (and subsequent study) has been used to inform the new 2020 under graduate and post graduate pre-registration children's nursing programs at Queen's University, Belfast, Northern Ireland (NI).

### Narrative Literature Review

**Definition, timeframe, methodologies employed and scope of the studies examined:** Whitley et al. [1] defined narrative review as an effort to summarize different primary studies into a comprehensive holistic overview of the topic. Strength then lies in drawing together the diverse understandings of a scholarly research topic [2]. Literature searches were conducted using a number of databases and results assessed for eligibility using specific inclusion/exclusion criteria. Data was initially extracted from each study using a data extraction sheet



which identified the author(s), date and source of publication, study design, key findings, limitations and recommendations. The extracted data was then added to a summary table and based on this key dominant themes were identified. These provided the foundation for the formulation and the synthesis of a coherent narrative. There were 51 papers included in the review.

This review is based on empirical and conceptual work about issues relating to children's experiences of hospital from the perspective of the children and children's nurses for the period 1839-2018. Relevant work was identified through a process of selection using a broad time period, key search terms and a number of appropriate data bases. Literature was sourced in November 2015 using Queen's University Belfast (QUB) online multi search database engine. This method was appropriate to retrieve English language papers around the child's experience of hospital from the perspective of the child and registered children's nurses, as it systematically searched the following databases: Cumulative Index to Nursing and other Allied Health Literature (CINAHL Plus); MEDLINE; PubMed; EMBASE; INTERNURSE; Web of Science; Psych INFO; and Science Direct.

The Database of Abstract and Reviews (DARE) were also searched in an attempt to find systematic or integrated reviews on the topic. In an attempt to source unpublished work, OCLAC dissertation, Index of Thesis, ISI conference proceedings and Cambridge Scientific Abstracts were also searched. Key search words/terms relating to the overarching research question were 'children'; 'sick child'; 'child'; 'pediatric'; 'pediatric'; 'hospital'; 'experience'; 'children's nurse'; 'nursing care' and 'child centered'.

Additional key words identified in publications were considered as each database differed in how it lists a publication. Boolean logic, such as 'AND' and 'OR' were used to combine search terms. A search of reference lists of retrieved papers was also undertaken. Grey literature such as policy and research reports was considered in trying to overcome publication bias. This approach provided a broader view of the literature under review; it did not solely rely on research studies. Duplicate studies were removed at title citation stage of the process. Studies were then either rejected or included at title, abstract or on full paper review regards their relevance to the review question and ultimately the author's doctoral study.

In an attempt to uncover a more comprehensive body of evidence this review considered all methodologies across a non-limited time period to ensure all similar studies could be considered; the year 1839 was the earliest start date available to the search engine. The focus of the review was primarily on the child's experience of hospital between the ages six and 12 years old with an overnight stay in hospital. The children's nurse perspective of caring for the child in hospital was also sought, retrieved and reviewed. Empirical studies, systematic and integrated reviews in addition to unpublished theses, service evaluations were all deemed relevant to this review.

The underpinning frameworks adopted by similar studies were also of interest to this study. A final search carried out in February 2018 uncovered two additional and pertinent studies which are included in this review. Consulted children around hospital design and their space, and secondly explored the view of the registered nurse when caring for non-English speaking patients in a children's Emergency Department (ED) [3,4]. The scope of literature examined includes empirical studies, reviews, unpublished doctoral theses and service evaluation. Collectively this review aims to provide an insight into the subject under review plus identify any gaps or inconsistencies. Only two of the reviewed studies acknowledged their underpinning framework(s) [5,6]. Both adopt ecological model of human development, and with also adopting theory on communication [6-8].

The focus of this review was primarily on studies that relate to the child's experience of hospital. Where accessible, work which examined the perspective of the children's nurse was also retrieved with a view to representing a more comprehensive insight into children's experiences

of hospital. The review therefore presents the views of two groups. A larger number of researchers sought the view of the child in hospital and those of their parents. The view of the children's nurse was not commonly sought. The initial literature review suggests researchers either focused on a specific population such as children with type one diabetes, chronic illness, the 'good nurse' or a broader exploration of children's experience of being in hospital [9-11]. A qualitative design e.g. ethnography, phenomenology and grounded theory was adopted by a majority of the studies, and generally defended on the basis that it enabled participants to express their perceptions more freely. A small number of studies adopted a quantitative or mixed methods approach.

Sample size consequently varied across studies in relation to their preferred methodological approach. Data collection methods also varied, with many using child participatory approaches; diversity was noted in interview and questionnaire techniques. Methods included observation, interview, sentence completion, diary, play, write and draw, and the use of wishes. Largely all reviewed studies appeared to use appropriate methods to collect their data and address the stated research question. This paper moves to identify the core themes of the literature and noted inconsistencies. This review did not actively seek studies representing the views of parents because the author favoured to seek the views of children, as rights holder and service users. Analysis of literature relating to the perspective of the (children's) nurse is presented next, followed by a review of literature representing the views of the hospitalized child.

#### **Insights from the children's nurse caring for the child in hospital:**

This review found five studies which provide insights into the nursing perspective of caring for children in hospital [4,12-15]. Inconsistencies include a lack of clarity around the terms, 'health professional' and 'nurse'. Hence, it was not always clear if respondents were children's nurses. Furthermore, studies either provided limited or no demographic information on participants. Limited insights were given regarding nursing levels; the skill mix of those registered versus non-registered; child dependencies (level of nursing care required due to a child's medical status/complex health care needs) and the number of children each nurse cared for during a typical shift. The listed variables have the potential to impact upon the child's experience of hospital. A critique of the five studies is next presented in chronological order.

Starting with the earliest, unpublished thesis provides invaluable insights into the social history of pediatric nursing between 1920 and 1970 using 'oral histories'. It offers a retrospective understanding into the culture of the acute hospital and the relationship of pediatric nurses with the children, (family and doctors). A direct quote from sums up findings of the nurse participants during this period [12]. To express a strong sense of value for their work history and are proud of what they achieved. Nursing is seen as a demanding and challenging occupation, to which the system of discipline and hierarchy presented most of the challenges. Nursing was an emotionally rewarding area of work, the nurse participants obtaining most satisfaction from being able to 'nurse the child better'. Nurses cared about the children but failed to realize that the emotional neutrality associated with their professionalism was interpreted by the children as a lack of affection.

A retrospective extract by a children's nurse caring for a child undergoing tonsillectomy aged five or six years during the 1960's, not only provides evidence of the traumatized child in hospital but also the emotional distress and frustration the nurse endured due to the child's experience. If I get upset ignore me because it still upsets me [crying] [pause] then they were taken into theatre and guillotined. Blood everywhere, and then the next poor child was brought onto that table [crying] [pause]. And the child that had had its Tonsils out with its big, red, plastic piny, rubber apron thing, blood running everywhere, going past that child [past the child about to have his or her operation] [crying] because the child that had been operated on was taken into the recovery area [crying] [pause] and I don't know why they could not have taken the returning child another way.....It was a total nightmare and it could have been done so much nicer [12].



Jolley's study was a very significant time period in relation to the historical evolution of children's nursing in the UK [12]. It captured an understanding of what it was like to be a nurse caring for children in hospital and what the experience was like for the child during the period 1920-1970. Although of value, it does not provide a contemporary perspective of the children's nurse caring for children in hospital today. The findings of Coyne whose study sought the view of 12 children's nurses, 11 children and 10 parents about the child's participation in hospital (two hospitals/four wards) complement Jolley's findings. That said, no demographic details were provided. Even though the 12 children's nurse participants were the slighter larger group, only two extracts were used to support the nurse perspective. Coyne published this particular study as two papers the second, solely reports the child respondents' perspective [14,16].

The two children's nurse extracts are presented next. Coyne reports one senior nurse as suggesting some nurses found it difficult to cope with the child who was knowledgeable [14]. She explains: I know that nurses will come out and say oh she's very cocky and she knows everything and sometimes I think the nurses find it difficult that the children know about their condition and know what medicines they are supposed to be taking. I think they feel threatened by these children (Linda, children's nurse).

The nurses in Coyne's study valued the child's involvement in their own care and respected the child as an individual and wanted them to speak out. That said there was a noted lack of agreement on how to determine what that level should be. For instance, according to Coyne, the children's nurse may treat children differently when they present with a mental health related condition or lack capacity. Therefore, the child with physical ill health may be more likely to be involved in the decision making about their own care. For example, Coyne (2006b) [14]. It depends on how old they are...it is difficult to put an age on it....you would have to think are they mentally alert, are they mentally sound, would they be able to do this properly. I'm sure they would especially those that only have something wrong with their body and not mentally (Frances, children's nurse).

Koller et al provides a rare insight from children's healthcare providers (n=8) when caring for children hospitalized in a single room space due to a serious infectious respiratory condition and as a result under extreme infection control procedures. The respondents recounted the negative impact the experience had on them as a professional and on the child. The single room design allowed strict infectious disease measures to be imposed. Koller et al. [13] findings relayed the emotional impact of Severe Acute Respiratory Syndrome (SARS), communication challenges and role changes. The healthcare providers did nurture and act as a short-term substitute family, for example, we're the family for that child, and you know if it had to be my own. I would want someone to be there, so we tried to be in there as much as you can. It's just whatever supportive measures you can give.

Findings did reflect upon the negative emotional effects of isolation due to loneliness. One professional participant described a two-year old boy's experience and how the child changed, 'from initially screaming, crying wanting people there, to almost getting to the point to where he sat in his crib staring out the window. He didn't seem that interested if he was there or not' [13]. Although the participating professionals were not identified by discipline, one respondent sums up the child's experience of hospital from the perspective of a health professional.

I almost cried to a point because it was sad and you would see them as you walked past the door. You know, walk by the hallway and you could hear them. We have monitors down our hallways because of the isolation and everything is closed and you could hear, hear them crying. That was.... the worst [13].

Respondents also noted their Personal Protective Equipment (PPE) could create a sense of unease. As one stated, 'We went in looking like alien's' [13]. This study clearly reported the lines of communication needed to be kept open using a phone communication system. It was

invaluable to the health professional, child and parent as it provided a risk-free mode of communication. It also gave the child access to the outside world i.e. speak with family and friends.

Jackson-Brown and Guvenir [15] also provided valuable insights through their analysis of responses from 13 nurse respondents on caring for children with Learning Disabilities (LD) within the acute hospital setting. The nurses reported experiencing anxiety when admitting a child with LD and to have issues regards the child's level of dependency and the required levels of nursing to meet the child's needs. The nurses did report feeling more prepared for a planned admission, as they were able to read 'the notes' in advance; an extract sums up the experience, we were thrown in the deep end regarding his needs and it can be very difficult to keep an eye on him all the time. He needs constant supervision, which just isn't always possible. However, within the same study one of the two children reported hospital as 'scary, I don't like it'. Challenges on managing the child's behaviour within an acute setting were also reported by the nurse, for example, issues were voiced around the child with intravenous fluids in progress. The thing I found particularly difficult was when he was attached to the intravenous infusion and ...he was zooming off, trying to do other things with the drip stand behind him (nurse) [15].

In relation to the ward environment, the individual room was preferred by the nurse caring the child with learning disabilities, as the main ward was deemed too noisy for the child. Restrictive access to the child in the individual room did not appear to be imposed within this study. In this instance, the child did not appear too confined to their room. It appeared caring for the child with LD presented the nurse with challenges around communication and preferred bed space within the ward. Both appeared to cause the children's nurse anxiety. The findings from Jackson-Brown and Guvenir [15] would suggest the children's nurse to not have the knowledge and skills they required to fully meet the needs of this group of children within an acute hospital setting.

The final study in this group, by Cody et al whose USA study explored the views of 17 registered nurses caring for non-English speaking children within an ED setting (where children do not stay overnight), reported even with adequate resources (interpreter), barriers and challenges did exist. That said, the experience of caring for children who could not speak English was reported to develop the nurse's ability to more effectively care for this group in the future. Once again, study findings suggest nurse education to not fully prepare nurses in meeting the needs of all children in hospital, and in this instance those who were non-English speaking. The nurses in Cody et al study may not be children's nurses, as the USA adopts a generic nursing programme - children's nursing is seen as a post-qualifying specialty. An insight by two of Cody et al. [4] nurse participants are cognizant of the challenges relating to time and communication.

It takes a lot more coordination and practice. It requires extra time as well as good non-verbal skills (participant 1). It usually takes longer since I have to speak slower (participant 16) [4]. In summary, the views of nurses caring for the child in hospital suggest challenges exist within time restraints (to provide care), communication skills and an environment which may isolate and separate the child from their family and other children.

Those studies considered to provide a children's nursing perspective of the child's experience of hospital similar to this study, reported challenges to exist when providing health care to the child and for that care to sometimes negatively impact upon the nurse's health and well-being. Communication challenges existed when children were considered knowledgeable, had a mental health issue or learning disability and for those children who did not speak English. The health professional/nursing participant did appear ill-equipped with the necessary knowledge and skills to adequately care for all types of children in hospital.



The dependency levels of children in hospital and the required levels of nursing needed to meet the child's needs were also highlighted as an area of concern. The use of a bed space was considered positive and negative, with the nurse preferring the child with LD to have a single room as it made the provision of care easier and suited the child more by providing privacy and a reduction in noise level. For others, the single room appeared like a prison cell when used to isolate the child from the outside world. The lived experience of the isolated and distressed child did negatively impact upon the professionals' emotional health and well-being too. With the voice of the children's nurse considered, the review moves next to those studies which provide insights from the child's perspective of being hospitalized.

**Insights from the child staying in hospital:** Previous studies such as Carney et al. [18] reported traditionally parents and professionals were asked what they understood about the child's hospital experience. Both UK and International literature suggest a change occurred at the turn of the century, with healthcare providers trying to 'prevent' or 'reduce' the length of hospital stay for children whilst at the same time, improving the environment, communication between the child and health professional, along with parental access.

An integrated review by Coyne [17] which reported on the concerns and fears around illness and hospitalization for children, found children to want to participate and that there are many benefits associated with participation. However, children's participation in decision making may have been 'over sold' by other studies as children actually prefer less involvement. Disquiet was also reported around children's experiences of pain, immobility, disfigurement, separation from significant others, loss of control and disruption to their lives as being all potentially stressful whilst in hospital [19-23]. It was established even short periods of hospitalization can have negative effects on the child, their siblings and family [24-27].

Although a general consensus of existing studies reports the child's experience of hospital as stressful, the child's position appears fluid in reporting both negative and positive views of their experience in hospital (inclusive of the children's nurse). Not dissimilar to the insights of nurses caring for the child in hospital, four broad themes from the child's perspective of hospital emerged from this review. A data extraction sheet was used to identify the dominant themes which were then distilled to key findings and used to construct the narrative. These relate to the following:

- Communication;
- Environment (hospital ward);
- Isolation (individual/side/single room);
- Child relationships with family and nursing.

### Communication

Communication relates to written, verbal and non-verbal, inclusive of the child's right to be silent. A critique of studies and reviews found communication to be pivotal to the child's experience of hospital. For example, a study of 388 children aged seven to 11 years by Pelander and Leino-Kilpi [28] which used sentence completion to gain insights into the child's best and worse experiences of hospital reported worst experiences were around people, feelings, activities and environment. Only 32 of the children reported there to be nothing bad about their experience in hospital (nurses were also deemed positive). Communication was also reported as key to their experience. In line with this finding, Noreña Peña and Juan [29] also reported communication important when determining how nurses communicate 'news' information to hospitalized children.

Using a critical incident technique, data was collected from 30 children aged between eight and 14 years, using participant observation and semi-structured interviews. The analysis yielded three main categories: the children's reaction to the information; nursing staff behaviour as a key aspect in the exchange of information and communication of news as well as children's experience. This study emphasized the need to

promote children's consent and participation in nursing interventions. At the same time period, Fletcher et al. [30] reported the nurse of the future needing to be skilled in non-verbal communication. Not surprisingly, a number of studies have attributed inadequate communication between the child in hospital and the children's nurse to exist [6,14,31-35,16-18,].

For example, Carney et al. [18] who used a questionnaire to seek the views of 213 children aged four to 17 years, before, during and after hospitalization, reported the children cope better with hospital when informed about their care. The communication and information provided by the children's nurse during their initial admission to hospital may then have impacted upon the child's experience of hospital. Two child extracts demonstrate the positive and negative impact of communication on the child's experience of hospital. All the nurses and doctors explained everything what was happening with my arm and it was a lovely visit and I enjoyed it very much.

I was thinking what the nurse and doctor would do to me. I was really scared. The reports of 11 children in hospital by Coyne (2006b) [14] found children to want to be consulted and given information so they could understand their illness, be involved in their care and prepare themselves for procedures. Isabel aged 14 years talked about the consequences of non-inclusion within the children's ward, she states, 'I thought hey I'm the patient here, talk to me, explain what you are going to do'. Further work by Coyne and Kirwin in 2012 [33] reports a lack of effective communication between the children's nurse and child may cause the child to cope and react in different ways. The children were reported as having anxiety, stress, fear and loss of control when receiving care in hospital. The negative experiences were mainly concerned with the need for more information and lack of involvement. The children's perception of their hospital experience, environment and their perspective on the children's nurse may therefore oscillate as a result of inadequate communication.

The children suggested that the health professional (inclusive of the children's nurse) should speak using 'child friendly' language, 'shorter sentences' with some feeling unprepared for procedures and upset when not listened to. They also found it challenging to communicate, as the children's nurse was always busy! Their views on decision making varied, as some children wanted their parent or health professional to make decisions on their behalf. Child extracts from Coyne and Kirwan [33] which seemingly support effective communication as pivotal to the child's experience of hospital are as below, if doctors and nurses work in a children's hospital they should be able to talk to children in a language that children understand (child, 7 years). It is about me, I should be part of the conversation... (Child, 12 years).

Coyne and Kirwan's [33] study was insightful of the change in how children are viewed in research, as the focus on child and young person's wishes and feelings about hospital life were reflective of an understanding by the researchers that they had a right to be heard in respect of decision making. As in other studies, the children's statements and wishes centered on hospital facilities, the views of doctors and nurses, communication, interaction and participating in decision making. Coyne and Kirwan argued that the children's nurse should recognize the benefits and issues that remain around the communication needs of children being met. Interestingly the nursing student, who is not included in staffing numbers (NMC 2010), was reported as having more time for the child in hospital than the Registered Children's Nurse (RNC).

'A nurse child relationship', at theme from a doctoral study by Joan Livesley and Long which reported that even though the researcher did not recruit children's nurses to their study, their methodological approach included 100 hours of observation which captured the voice of the child and children's nurse. Livesley and Long's study which was undertaken in two phases reported the child and children's nurse as 'living in differing worlds' when in hospital. An extract from an episode of nursing care on a children's ward with Kelvin aged 12 years



and children's nurse Mary, reinforced the importance of the child's voice being heard. In it Mary complained that Kelvin had been particularly difficult, describing him as 'stropky' and almost shouting at him, as he requested 'his pad' be changed [34].

Mary was appalled when she discovered Kelvin's experience of hospital (unknown to Mary) comprised of over 50 surgical procedures. Kelvin was also reported as being knowledgeable and aware that his stitches could become infected if they became contaminated with blood or faeces. He explains, because the blood can infect it, then I would have to get another operation... (Kelvin, 12 years). Having his request ignored left Kelvin feeling 'sad', and aware he was 'not being treated properly'. Mary then explained, I knew that the patient was coming and... I was just a bit stressed about that... I know that he does need to know what we're doing... (Mary, nurse).

The relationship between Mary and Kelvin suggests Mary, the children's nurse knew Kelvin as a patient, but not as a person. Mary's reflections were noted as representing the need for nurses to have sufficient time (to fully care), therein making the life of hospitalized children a little more tolerable. Children's nurses were represented as having considerable influence in determining the child's experience of hospital.

Shilling et al provided a unique synthesis of qualitative studies which reported the voice of disabled children when admitted to hospital. Their review reported on the importance of communication between the child, parent and staff in decision-making on matters that affect the disabled child. Notably, Shilling et al found little differences in the responses of able bodied and disabled children, with both reporting negative experiences of staying in hospital. Their findings were based on methods of data extraction and synthesis where each study was independently reviewed by two of the authors, themed and then integrated into a thematic framework and finally re-reviewed against the framework. This review also appraised the papers reviewed by Shilling et al [35]. For example Franklin and Sloper [36].

As noted previously, Livesley and Long [34] who used an ethnographic approach, observed children in an English hospital as struggling for their competence to be recognized and their voice heard. This was demonstrated both through what they said and in their non-verbal behaviour, such as 'turning away' and 'being silent'. The child was therefore not seen as an equal partner in their care, and for that reason had to rely on an adult. In the absence of an adult, the child was reported to receive basic health care from the children's nurse. Ciara aged 12 years, desperate to get her dad's attention resorted to throwing things, she explains. My dad was there, and he was asleep. I couldn't move and I needed a drink. I tried to reach out for his leg, but his leg was pulled in... I was throwing teddies at him.

As stated, communication appears key to the child's experience of hospital. Their rationale for doing so was because of its impartiality and non-aligned status to a specific population, setting and/or criteria. This study reported healthcare professionals/nurses as categorizing the child in hospital when wanting their healthcare needs met, as either a passive bystander or active participant. The child as a passive bystander who is quiet and shy, in the absence of a parent, may receive less nursing intervention/ basic care. Their voice was also reported as challenging by the children's nurse.

That said if a child assumes the passive bystander position in the presence of their parent, this often results in the health professional and parent conversing about the child in their presence, with the child listening in the background. The child's position also had significant implications for the level and nature of communication a health care worker had with them. The active participant on the other hand would vigorously seek their health needs being met. The healthcare workers' response was to interact directly with them (either in the presence or absence of their parent), listen to them and give them an opportunity to ask questions. In reality though, children may move from one position to the other. Corsano et al. [37] similarly explored the hospitalized

children's representations of their relationship with nurses and doctors during the same time period.

Carney et al. [18] whose study elicits the experiences from children as young as four years old found preparation for hospital essential in reducing anxiety and alleviating of negative perceptions (16.2% of participants in their study mention anxiety as a theme). Children again appeared to cope better with hospital when informed. The communication and information provided by the children's nurse during their initial admission to hospital may therefore impact upon the child's experience of hospital. The children who were prepared for hospital were mainly positive, with the younger child reporting they preferred their parent to be with them during their stay in the hospital environment similar to communication, the ward environment was reported as pertinent to the child's hospital experience [5,6,17,18,30,33-35,38,39,]. Studies are categorized in respect of the 'differing views'. The term, environment within the context of this review and study, relates to the ward setting in a hospital where children receive inpatient healthcare. The terms 'single room', 'individual room' and 'side room' were used interchangeably in the literature-the differing terms were not confusing.

A broad view by Fletcher et al. [30] which used write and draw, reported the issues relating to children admitted to the hospital environment as being scared or worried, and fear of the unknown. Concerns after admission to hospital related to the care environment, social needs, and individual/personal needs and requirements. The child's space was reported by Silav Utkan's [3] to be of great importance to the child in hospital, as it can make them feel either safe or unsafe. Schalkers et al. [40] poignantly titled their study to echo the need for personal space-[I would like] a place to be alone, other than the toilet.

Unfortunately, the child's healthcare services in the UK cannot always ensure a child can remain in the same bed space during their stay in hospital. A child may be allocated a bed space in an individual room, bay of four to six bed/cot spaces or within a long ward with 10 (approximately) bed spaces, known as a 'Nightingale ward'. Allocation and reallocation of a child's bed space is usually undertaken by the ward manager/nurse in charge using their professional judgement based on the individual health needs of each child in the ward. The child's personal space within the ward environment includes a bed or cot to sit and sleep in plus a locker in which to keep their personal belongings (RCN 2014).

The child may also have a bed table and chair. Their 'bed space' may be a single or double room (side room) with ensuite toileting facilities, or a dedicated bed space within the ward where children share toileting facilities. Lambert et al. [41] on investigating the perspectives of 55 children aged five to eight years around their social space in hospital (inclusive of inpatients) found young children want a diverse range of age, gender and developmentally appropriate leisure and entertainment facilities which were integrated within the environment. The children wanted to be socially connected when in hospital. Today's technology can help children connect with home, school and wider world. Coyne and Kirwan [33] and Marcinowicz et al. [42] also reported a lack of play facilities.

A review by Coad and Shaw [43] reported children and young people want more say in the planning and development of appropriate hospital and community health services. A more recent non-UK descriptive study by Silav Utkan [3] which consulted children (number of participants' unreported) around hospital design and their space using crayons and paper to draw how they would like their bedroom to be in hospital, reported their findings using three pictures. The children's drawings similarly reported a need to be able to communicate with the outside world. In addition to the usual items found within a child's bedroom such as bed, table and chair, participants also drew a computer and television. Children also reflected their own personalities and desires in the pictures they drew. Other included items were picture frames, books, CD's and toys.



The concept of a personal area was important for the older child (young person). Their space more often included shelves, drawers and cupboards for their own items; they also wanted to arrange the items themselves. The child's view of their hospital bedroom was that it should also be a place to talk with their visiting friends. An area of interest was noted in that medical devices and related materials were not included in the pictures. The ward environment also central in Livesley and Long [34] reported children (n=9) to find the children's nurse as having the power to provide or withhold toys. Lambert et al. [44] study also reported on the value of an array of activities as it helped create an environment that would relieve boredom, offer choice, control and a less sense of isolation for the child. The use of technology was also thought to be positive for the child socially, as it could connect them while in hospital and externally to home, school and beyond.

Batterick and Glasper [38] used a retrospective quantitative approach to seek the child's view of hospital; the children's ward was reported to not meet their needs. Just over half (52%) of child participants (n=213) mentioned the physical environment as well as: food, television, video and games. Findings related to the children's physical surroundings (again highlighting the environment as a central theme within the child's experience of hospital).

### Physical and Social Environment

Negative physical aspects were reported by the children around the food, their inability to watch television/videos, play games, beds, theatre gowns, equipment, noise, temperature and smell. Their need for having their 'own space' was highlighted by references to the child's own locker, bed and a need for privacy. The social aspect of the environment related to positive interactions with other children. The children were equally aware of their space. For example, some kids were friendly; the playroom is a good idea' the adolescent area was good. It helped me have privacy [18].

Edwards also signified the 'environment' to be an important factor in the child's experience of hospital. Aspects pertinent to the environment are summarized by Edwards as follows [5]:

- Feelings associated with the hospital setting;
- Being a different and unfamiliar environment;
- Experiencing loneliness, isolation and disconnection;
- Restoring equilibrium;
- Fear of the unknown and undergoing treatment.

Edwards collected their data through unstructured participatory observation and semi-structured interviews alongside a variety of methods and activity-based approaches [5]. This study found the child's experience of hospital to be disruptive and to produce feelings of powerlessness and uncertainty. This was experienced due to a complex variety of factors, situations and people impacting upon their experiences. The children and young people were diverse in terms of age, experience of being in hospital and illness, with some being acutely ill and others having long term chronic illness. Like Lambert et al. [6] both qualitative studies suggested children to find the hospital very different to the child's home environment.

The amenities available to the children in hospital were explored by Marcinowicz et al. [42] from the perspective of 22 hospitalized children aged 10-16 years (and their parents), who were all interviewed in the hospital's school room. From the children's perspective, the possibility to spend their free time in an interesting way was important; examples of the child's views were, there's a day room here. We have different games and we play...And there's a library, also great. You can use the computer and borrow games (Boy, age 11). I especially liked the day when the hospital teachers performed a [theatrical] play and were reciting rhymes. It was very funny. It was good fun and nice. Something was going on, it wasn't so boring (Girl, age 14). From the

older children's perspective, privacy was mentioned in the context of safety.

Security is most important. To feel secure in the hospital...I don't mean that I feel insecure but for example I'm not afraid to say that I need a bedpan. I mean it's important to ask for help and know they will actually help you (Girl, age 14). Marcinowicz et al. [42] reported humour and fun to be important to hospitalized children. Likewise, Coyne and Kirwan [33] reported inadequate play facilities as one of the reasons for children's dissatisfaction with the hospital and health-care professionals. A discussion paper by Ford et al. [45] which declared 'being in hospital is not normal', reported on the role of play for the child in hospital as, Play is important. It is important to children's social, physical and emotional development and to their sense of well-being and sense of themselves. The paper now presents the next broad theme of isolation from the child's perspective of hospital.

### Isolation of the Child in Hospital

Isolation within the context of the child in hospital relates to the child's separation from their family (parent/guardian), visitors (those dear to them) and the other children admitted to the ward. Both Edwards and Carney et al. [5,18] reported on the negative impact of separation from family and friends. Similarly, Coyne (2006a) [16] also raised concerns around the separation from family and friends, as an issue for children, reports the magnitude of separation as clearly illustrated by one young person aged 13, who when asked what she missed from her home life states, Miss my mum, my dog, my sister, the atmosphere, my own bed, the living room, the telly and the garden. I miss school...miss my friends at school.... Like, I'm worried about my schoolwork if I stay too long in hospital. What will happen next?

With isolation/separation presented in a broader sense, Austin et al. [46] published a review of the child's experience of being cared for in a single room (side ward). The 16 papers showed a paucity of child specific studies, therefore a firm conclusion about how children experience isolation could not be drawn. That said, the review did report 'children appeared more concerned with the separation from their family than the possibility of acquiring an infection'.

In relation to practice the review proposed children's nurses have a pivotal role in caring for children in isolation by; keeping families well informed; ensuring isolation policies are adhered to; spotting behavioural and emotional cues and ensuring adequate input from play specialists and education. They also recommended the use of technology to relieve boredom. For example, isolation in a side room is non-negotiable if the child has an infectious disease or high risk to infection as result of their illness or treatment. Additional criteria include constant observation i.e. positioned in a bay or main ward near the nurses' station for optimal viewing.

As stated previously, although not considered as true isolation, a positive finding was reported by Jackson Brown and Guvenir [15] where one child reported 'I don't like it outside (on the ward). I like my room'. Their study reported many of the parents, nurses and children found the experience in hospital was made easier for the child with a learning disability if their given space was an individual room.

### Relationships with Nursing and Family (When in Hospital)

Relationships between the hospitalized child and the children's nurse are considered first, followed by an overview of findings relating to the relationship between the child and their family. Jolley's summing up the child's experience during the period 1920-1970 as a negative experience [12]. Jolley states, It is found that the child participants tended to be traumatized by their hospital experiences. The cause of this trauma is found to be the way in which nurses practiced according to a scientific and professional paradigm. Unwittingly, this last resulted in the nurses being perceived by the child participants as lacking in affection or emotional 'care' for them as children. Many of the



participants remain confused and troubled by this aspect of their experience.

Jolley stated most of the participants reported the nurses as being busy and associated this with the routine nature of the work. An extract by a child in hospital in 1934 aged four to five years provides an insight into their relationship with a nurse [12]. I can't remember anybody sitting by my bedside, everything seemed to be [pause] so straight, so erect, so blue and white [pause]. I probably didn't know the word at the time but 'starch', you know everything, nothing was unruffled, everything was so upright and clean and straight and so proper I suppose. But the one bit of kindness was [Name] but I really think I was just another patient [to her].

Robinson's review of 31 studies between 2000 and 2009 on the CYP's view of health professionals in England succinctly found the CYP to not only want the health professional to be familiar, accessible and available, but be informed, competent and to provide them with information [47]. They also wanted the professional to be a good communicator, to participate in their care, uphold both their privacy and confidentiality and to demonstrate acceptance and empathy. These qualities were similarly reported in two studies in 2009 by Moules and by Brady [48,31].

Schmidt et al. [49] reported child participant narratives to include 'she used kind words', 'they were nice to me', 'they were happy and helpful'. This qualitative study undertaken in the USA reflects the views of 65 children who all 'reported positive feelings about nurses'. Most indicated that although they were sometimes fearful of their nurses they helped alleviate their fears. This study reinforces the power of positive communication in meeting the needs of the child in hospital. Does it relate to the fact that the researchers were nurses, their methodological approach, cultural differences or a healthcare system/non-NHS which valued nurses who were given time to care?

The 2009 study by Brady in Ireland, sought the views of 22 children aged seven to 12 years on their understandings of the good nurse. This study reports communication to be a vital component of a positive hospital experience for the child. Brady reported the good nurse should use terms of endearment, as it was important to the child and made them feel special. The children also appreciated being praised for being brave during unpleasant procedures [31]. This was in contrast to a qualitative study by Woolhead et al. [50] (n=74) where being overfamiliar with older patients was seen as disrespectful. John age 12 explains, 'She calls me sweetie pie.

Randall and Hill [51] in a later study reported the findings of children and young people as describing a good nurse as having, 'A professional persona and the ability to connect with them, delivering timely and effective care and being respectful of the children's dignity'. Rush and Cook's [52] study findings concur, reporting good communication, respectful attitudes, and nurses' attributes and behaviour (i.e. looking smart) as important to children in hospital. The attributes were significant in respect of the child's experience because they preferred the nurse to act as a professional rather than a friend or surrogate family member. The children wanted the nurse to be nice to them and respect their view.

The study by Marcinowicz et al. [42] referred to previously, also explore the child's perceptions of the nurse. Here 'the nurse' was not defined as a children's nurse. It reported qualities, behaviour, and tone of the nurse's voice as well as their verbal and nonverbal communication patterns as being key to the child's experience of hospital. Qualities for the best nurses were given as simple statements- 'being nice', 'pleasant', 'friendly', 'familiar', 'entertaining' while they cared for them and 'gentle' when are carrying out procedures. The tone of voice and non-verbal behaviour used by the nurse was also reported as important to the child. Extracts include, the ideal behavior of a nurse is when she is talking with a nice, calm voice (Boy, age 12). They look at you so grimly, so angrily, as if you were disturbing them or something like that (Girl, age 14).

Brady's study appeared to have equally clear views between the good and bad nurse; similar to other studies the child was represented as wanting the nurse to like them and for their family to be involved in the care provision [31]. The children also reported needing their parents close by them when they were in hospital. Carney et al. [18] concur in reporting continuity with care-givers as most important for younger children; the children in Carney's study also wanted their parent to be present. Bjork et al. [53] also reported children as wanting to be involved in decision-making on their care and as needing to have a good relationship with healthcare staff.

Batterick and Gasper [38] in their study of 50 children used a questionnaire to capture the views of both children and their careers over a period in hospital, found participants reporting that the children's voice was not always accurately heard. The reason for this was attributed to the fact that parents, acting on behalf of their children, often completed questionnaires intended to access the views of the child. The young people in their study was represented as rightly wanting their voice heard but as having had their voice compromised by the acts of their parent(s).

The 2004 audit similar to Carney et al. [18] found dependence on adult careers to occur even when children wanted to be consulted. An alternative view was reported by 12-year-old Ciara in Livesley and Long's study [34]. In this instance, Ciara preferred to seek her dad's attention to get a drink; she chose to not use her right of voice. Ciara's account supports Lambert et al. [6] findings which reported the nurse to view the developing child in hospital to move along a continuum where they may act in an opposing manner. For example, Ciara may alter from being a passive participant to an active participant within the communication process of healthcare.

Interestingly, a study by Aldiss et al.[54] reports upon a hospitalized child (Amy) being asked who she would tell if she needs something and her parents were not present, she responds by saying, she would tell the nurse. When asked if she would tell a doctor, Amy replies, "No, never", however Amy's rationale for no, to asking the doctor is, "If I talk to so many people they'll think I'm silly". In this scenario the children's nurse was represented as non-judgemental. This child's report reinforces the view that the child and adult differ in their perception of the world, here the child appears less developed psychologically and emotionally and lacks confidence in competently dealing with the situation. However, adults with learning disabilities and mental health issues also struggle with social situations.

Jackson Brown and Guvenir found of the 13 families giving their views only two children with learning disability participated. Views related to carer anxiety, preparedness for admission difficulties managing the child's behaviour, ward environment and individual/side room. The two children stated they were scared and nervous about being in the open ward and a single room was preferred over the open ward environment. The main issue for staff in Jackson Brown and Guvenir's [15] study was the child's behavior.

Interestingly, supporting and managing the child while on the ward mostly fell to the carer/parent and not the nurse. The children, their careers and nursing staff all reported anxiety around the child's admission, with nursing staff feeling more prepared than parents for a planned admission as they could read the notes. Nurses in Jackson Brown and Guvenir's [15] study sum up their experiences. We were thrown in the deep end regarding his needs [nurse]. It can be very difficult to keep an eye on him all the time. He needs constant supervision, which just isn't always possible (nurse). Parallel to the nursing views was the view of one of the two children who described the hospital as 'scary. I don't like it'.

The findings from the 11 children aged 11 to 14 years in Randall and Hill's [48] study in 2012 were not aimed to generate new understanding but to improve an undergraduate children's nursing curriculum. The participants were found to view the nurse as a female



who dresses differently to the doctor and as someone who was there to look after them '24/7' but not to diagnose. The latter was seen as the doctor's job. One child stated to want 'the nurse to tuck you into bed and give you a kiss', suggesting that the nurse was seen as acting in place of a parent. Finally, the children in this study wanted the Health Professional (HP) to have a good relationship with them and to demonstrate empathy and acceptance as a person [51].

Whilst children appeared to mostly want their parent to be with them in hospital and want recognition as a rights holder, they sometimes wanted their parent to act on their behalf when in hospital. The parent was also reported to act as the child's advocate when not asked for by the child. With the child's view of the children's nurse overall a positive one, their experience of staying in hospital could be improved in relation to communication and environment.

## Conclusion

In summary, this narrative review presents the findings of previous empirical studies relating to the child's experience of hospital from the perspectives of hospitalized children and children's nurses who are charged with their care. It notes that whilst most of the work accessed employs qualitative methods, it is for the most part descriptive with very few studies drawing on a conceptual framework to guide their study. Narrative methodology enabled the process of selection using a broad time period, key search terms and a number of appropriate data bases. Data was then successfully extracted from each study using a data extraction sheet which identified the author(s), date and source of publication, study design, key findings, limitations and recommendations. The extracted data when added to a summary table enabled the author to identify key dominant themes, which provided the foundation for the formulation and the synthesis of a coherent narrative.

This approach was commended by the external examiners at the author's doctoral viva voce; the two UK Professors in Children's Nursing supported this approach over a systematic review as it provided a broader insight into what research had been undertaken, methodologies, findings plus identification of the gaps in the literature. It also informed the empirical study around its theoretical framework, method of data collection and development of the research questions for the children's nurse participants.

Child participant research questions and data collection tool were co-developed with a Child Research Advisory Group (CRAG) of primary school children. The main findings of the narrative review are organized thematically and the main themes emerging in respect of the hospital experience of children are represented as relating to communication, environment/ ward design, play, isolation/separation and the child's relationship with family and children's nursing to be particularly important to the child in hospital.

The small number of studies presenting the perspective of the children's nurse suggests a deficit exists in their knowledge and skills to effectively care for all children staying overnight in hospital. Educational deficits for children's nurses caring for children in hospital were around child development, those who were knowledgeable about their illness and for those children with mental health and learning disabilities. Challenges also exist around time restraints (to provide care), the health and well-being of the nurse and an environment that meets the needs of the child and children's nurse.

## Recommendations

As stated, the narrative approach adopted by this review was found to be appropriate for this research study. It did however identify a limited number of studies which included the view of the children's nurse alongside little or no demographic information, or as to why children's nurses select children's nursing. None of the studies which focused on children's nurses highlighted the lack of other professionals to work

with the nurses: psychologists, volunteers, etc. A gap seemed to also exist around life-threatening situations where the narrative aspects of children might have also been of interest. Further research is therefore recommended within the noted areas. Nurse education also needs to consider the noted deficits when writing new programs.

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