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Abstract

The provision of information is an individual entitlement and a prerequisite to enabling children to understand their illness, make choices about their health care and be involved in decision-making processes around these choices. However, limited evidence exists on children's perspectives of information provision while an inpatient in hospital. The aim of this paper is to describe the process of information exchange between health professionals and children in hospital. Informed by an ethnographic design, data were collected using multiple methods, including semi-participant observations, interviews and participatory activities. Forty-nine children aged six to 16 years, with a variety of medical and surgical conditions, admitted to one children's ward at one children's hospital participated in the research. Findings revealed that children encountered a variety of information management experiences. The key message for health professionals is that there is a need to develop child- and family-focussed strategies for assessing children's information needs in order to determine their preferences for information (amount, format, from whom, etc.), to develop a method for gaining an appreciation of parents' and health professionals' beliefs about the optimal amount and type of information to relay to children, and to achieve consensus about who is best placed to transmit this information to children.

Keywords

Children, hospital, information, needs

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Introduction

It is well established that an essential aspect of quality child-centred health care is enabling children to participate in health care consultations and decisions that affect them (Department of Health, 2003; Department of Health, 2010; Department of Health and Children, 2000; Department of Health and Department for Children, Schools and Families, 2009; Donnelly and Kilkelly, 2011; European Association for Children in Hospital, 2002; Kennedy, 2010). The greatest political drive towards listening to children's voices and increasing their participation has stemmed internationally from the Convention on the Rights of the Child (United Nations, 1989: 4). Enhancing child participation and shared decision-making in health care is reliant upon good information (Department of Health, 2010; Donnelly and Kilkelly, 2011). As Hallstrom and Elander (2005: p.235) outlined: 'a prerequisite to be able to participate is to be allowed to do so and to receive information that is adapted to the child's needs and wishes'. The importance of children having routine access to tailored information in a range of readily accessible formats in health care is important for a number of reasons. Under Article 13 of the United Nations (1989) Convention, children have a core right to freedom of expression and 'to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice'. This right is reinforced in many policy documents which emphasise the need for children to have access to the information they want to enable them to understand their illness, to make choices about their care and be involved in decision-making processes (Department of Health, 2010; Department of Health and Department for Children, Schools and Families, 2009). Providing appropriate information to children is important to minimise distress, reduce uncertainty, and enhance coping and recovery times (Jaanieste et al., 2007). Inadequate information provision can lead children to draw inaccurate interpretations and misconceptions, resulting in unnecessary worry, fear and anxiety (Salter and Stallard, 2004; Smith and Callery, 2005). Research on children's views of hospital and health care indicates that children want information (clear, honest, accurate and unambiguous), involvement, consultation and to be listened to (Chapman et al., 2000; Curtis et al., 2004; Garth and Aroni, 2003; Horstman and Bradding, 2002). Yet, there is evidence to suggest that children receive inadequate health care information (Kilkelly and Donnelly, 2006; Smith and Callery, 2005) and are often frustrated with the failure of organisations to share appropriate information with them (Kennedy, 2010). Children experience extreme anxiety and apprehension when admitted to hospital. Fears often relate to the unknown as children try to interpret what is wrong, why they feel unwell and what will happen in hospital (Clift et al., 2007; Wennstrom et al., 2008). Providing children with adequate information is crucial to alleviate these fears and anxieties. While some data exists on information provision to children in outpatient settings and before an impending hospital admission and/or preoperatively (e.g. Buckley and Savage, 2010; Fortier et al., 2009; Gordon et al., 2011; Smith and Callery, 2005), previous research has not investigated the process of information exchange for children while inpatient in hospital.

Aim

This research was part of a larger study aimed at examining the nature of communication for children admitted to a children's hospital setting. The aim of this paper is to describe the process of information exchange between health professionals and children in hospital.

Table 1. Participant demographics.

Demographic	Number
Route of admission	<i>n</i> =49
Emergency department	31
Out-patient department	4
Inter-hospital transfer process	1
Electively (waiting list)	13
Medical conditions	<i>n</i> =15
Asthma	4
Eczema	1
Cystic fibrosis	2
Epilepsy	2
Autoimmune disease	1
Constipation	1
Other (e.g. infections)	4
Surgical conditions	<i>n</i> =34
GIT (e.g. appendectomy)	14
Ophthalmology surgery	4
Orthopaedic surgery	7
ENT (e.g. tonsillectomy)	5
Other (e.g. infections)	4

GIT: Gastro-intestinal Tract; ENT: Ear, Nose and Throat.

Methods

The study employed an ethnographic processual design described by Boyle (1994: p.170) as 'ethnographies that describe some aspects of social processes'. There are four distinct sub-types: holistic, particularistic, cross-sectional, and ethno-historical. This study was *particularistic* in nature, meaning that an ethnographic approach was applied to processes within a small, isolatable human group.

Participants

Participants (*n*=49) were children (aged six to 16 years) of both genders (22 boys and 27 girls) admitted to hospital through various routes for treatment of a number of different medical and surgical conditions (Table 1). The majority (*n*=40) of participants had a hospital stay of less than seven days.

Procedure

Field work took place over a four-month period in one children's ward. Multiple methods were used to collect data, including: semi-participant observations; informal interviews; participatory activities (i.e. drawing, writing, and stick-a-star quizzes); and documentary evidence (e.g. policies, philosophies, nursing assessment documentation). These methods were not employed in any prescriptive sequence and were often used simultaneously. A topic guide was used to gather data specifically about children's information needs (Table 2). Collectively, the methods helped us to build a comprehensive picture of children's communication needs while in hospital. As it was not

Table 2. Topic guide to explore children's information needs.**Information**

- What sorts of information does the doctor/nurse give you?
- What do they [doctors/nurses] tell/talk to you about?
- What would you like the doctor/nurse to tell/talk to you about?
- Are there things they [doctors/nurses] do not tell you about that you would like to know more about? If yes, what would you like to know more about?

Understanding

- How much of what the doctor/nurse tells you/says to you do you understand?
- What did you not understand?
- What helped you understand?
- How can they [doctors/nurses] make it easier for you to understand?
- If you don't understand, would you tell them [doctors/nurses]?

Asking questions

- Did/do you ask the doctor/nurse questions?
- If yes, what do/did you ask him/her about?
- If no, would you like to ask him/her questions? If so, what about?
- If you wanted to know something, who would you ask?

feasible to employ an electronic recording device on the children's ward, we recorded detailed field notes during and after each visit to the children's ward. Field notes included descriptive accounts of events/interactions observed on the children's ward and paraphrased translations of what children said during informal interviews and while engaging in participatory activities. Consequently, in this paper verbatim quotations from children are not presented. Instead, field note extracts are displayed to illuminate emergent themes (Table 3).

Analysis

Data were analysed using *grounded theorising*; described as a way of working with any sort of data in order to generate and develop ideas (Hammersley and Atkinson, 2007). The constant interplay between data and our ideas crafted a flexible interactive dialogical process. Through this process we deconstructed and reconstructed data using open coding and categorisation. This was performed manually and with the assistance of a computer package (i.e. NUD*IST). The analysis process led to the development of constructs with many different dimensions. In this paper the core themes related to the process of information exchange between children and health professionals are presented (Diagram 1).

Ethics

The study was approved by the Ethics Committees of the hospital study site and affiliated University. Written consent was obtained from parents and written assent from children. As the area of research governance and ethics with children is particularly complex we invested time in securing consent/assent; conducting a risk–benefit analysis and designing age-appropriate assent/information forms and data collection tools (refer to Lambert and Glacken, 2011). Confidentiality was assured. All names cited in this paper are pseudonyms.

Table 3. Field note extracts.

Field Note Extract	Category	Theme
Mary (8 years) stated she would have liked to receive more information about what they [doctors] were going to do when she went down to theatre and also some indication of when she could go home.	Superficial generic information	Type and amount of information
Stephen (11 years) reported that nurses provided him with information about what time he was going to have his operation at, that he would be asleep for about 20 minutes, about how he would feel afterwards and that he would be able to eat and drink after the operation.	Adequate individualised information	
John (13 years) stated that the doctors had explained the operation to his parents and not to him. John did not care that this had happened because he did not really want to be informed. He stated he was extremely sick when he was admitted to hospital and all he wanted to know was that the doctors were going to remove his appendix to make him better.	Readiness and desire for information	
When interacting together and completing the stick-a-star quiz, Shane (13 years) stated that when his father is present health professionals tend to relay information to his father more. Helen (12 years) agreed and relayed to me that when 'they're [parents] not there they tend to tell us [children] more'.	Presence of parents	Flow of information
Katie (12 years), a regular attendee to the children's ward, felt junior doctors, medical students, student nurses and staff nurses would not be able to inform her about her illness or attend to her port-a-cath because they lacked the required knowledge. Katie stated 'students don't know much about your sickness, they don't even know about CF [cystic fibrosis]'.		
Rory (12 years), with no previous hospital experience, expected to receive information directly from the doctor, believing the nurse might not have expert knowledge and consequently give incorrect information. He stated 'they [nurses] don't really give you information . . . they leave it up to the doctor . . . because they [nurses] might get it wrong. The doctor knows more and he should tell you'.	Hierarchy of knowledgeable experts	
Sue (12 years) stated that the nurses can understand the doctor and then the nurses help her understand what the doctors were saying.	Supportive intermediary bodies	
Helen (12 years) stated 'your mother and father can explain to you like simpler'.		
Researcher to Maureen (12 years): 'How did you feel when you were going down to theatre?' Maureen responded: 'Well, just before I went [to theatre] I saw a child coming back [from theatre] crying, so that didn't help'. Freddie (10 years) told me the nurses informed him about what they were doing probably only because he asked them about what they were doing.	Child as active navigator	

(continued)

Table 3. (continued)

Field Note Extract	Category	Theme
Sue (12 years) told me that sometimes the doctors used big words when she needed to go for a blood test such as 'gall stones', 'like is that your kidneys?' and Freddie (10 years) stated that when he was in casualty the doctors were talking about parotid glands and he was thinking 'way hay . . . can ya talk in English please?'	Big mad words	Comprehension of information
Joe (13 years) stated the doctors informed him that it was like an 'elastic band', that the ligaments move the knee case. He said the doctors just described it to him and showed him on his knee. Joe stated that the doctors told him his leg would be like a 'pencil' when they take the cast off, the 'muscles shrink' but this would be only for a day or two then they [muscles] get bigger again.	Developmentally appropriate explanations	

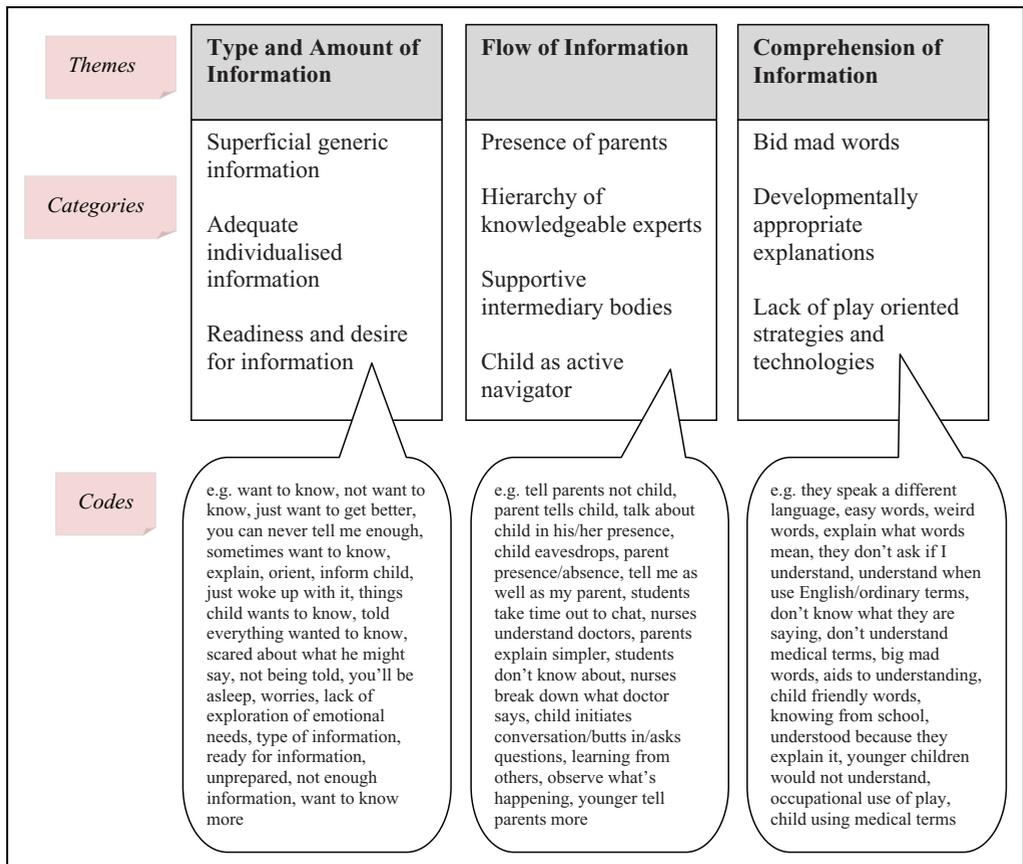


Diagram I Themes, categories and codes.

Findings

Children reported a variety of information-management experiences. Three main themes emerged: 1) type and amount of information exchanged, 2) flow of information, and 3) comprehension of information.

Type and amount of information

Superficial generic information

A number of children felt they were inadequately informed about what was wrong with them, what was happening, or what to expect in relation to hospital and their illness. These children felt the amount of information they received was superficial and generic in nature. For example, children going for surgery reported receiving customary information, such as they needed to have an operation and that they would be asleep for this operation. These children stated they wanted to receive more specific and detailed information about what was actually going to happen in the operating theatre (See Figure 1). Receiving insufficient information resulted in children feeling unprepared and worrying about what was going to happen. In discussing her imminent surgery, Ann (eight years) wondered 'do they cut your eye open?' Supplying children with superficial information meant that they were being communicated with in a stereotypical manner.

Adequate individualised information

Other children spoke about a variety of health professionals (medical and nursing staff, anaesthetists, physiotherapists and radiographers) providing them with information specific to their individual needs. For some children, this included telling them about the operation risks, whereas for others it involved telling them about what might happen in the post-operative period. Providing children with detailed information specific to their needs increased their knowledge, reassured them and enabled them to make sense of what was happening around them. Maureen (12 years) stressed the importance of being told before her operation about the effects of morphine 'because if you are sick after your operation, and don't know why, you might think something is wrong'. Preparing children in advance for what might happen helps to reduce uncertainty and offers them some sense of control. Children in this study were clearly able to articulate what they wanted to be informed about and what they thought other children coming into hospital should be informed about (Table 4).

Readiness and desire for information

A small number of children reported times when they desired not to be informed. The main reasons for this as expressed by children were: being too unwell, scared or afraid about what they would be told; not being bothered about receiving information; and lack of readiness to cope with information provided. These findings have implications for recommending that 'all' children should be directly informed 'at all times'.

Flow of information

Presence of parents

Parental presence, or absence, was influential in determining the directional flow of information between health professionals and children. In situations where parents were present, children

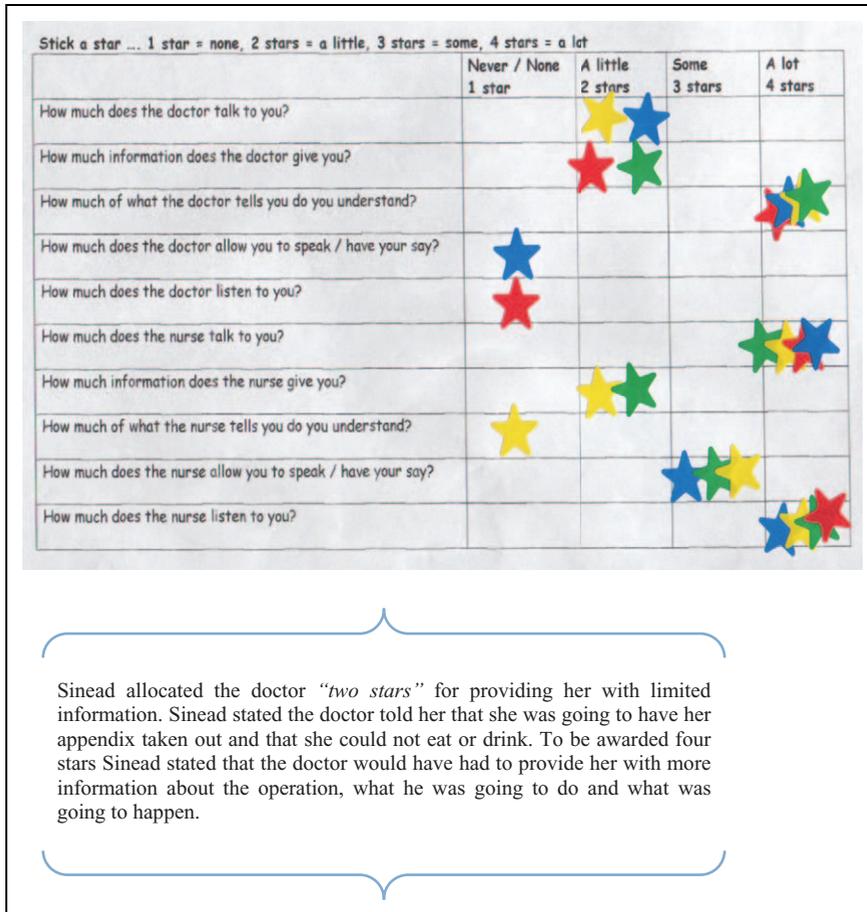


Figure 1. Stick-a-star quiz completed by Sinead (nine years).

reported that they did not receive information directly from health professionals. Instead, health professionals and parents conversed about what was wrong with children in their presence. Children listened to the information being exchanged by eavesdropping, even though at times they acknowledged they did not understand what was been communicated. Other children confirmed that health professionals were more inclined to provide information directly to them when their parents were not present. There were also instances, reported by children, where health professionals would directly relay information to them alongside their parents. Children identified their age as an influential factor in determining whether health professionals informed them directly, or not (i.e. for younger children health professionals would be more likely to communicate directly with parents).

Hierarchy of knowledgeable experts

Children perceived that a hierarchy of knowledgeable health professional experts existed. Children viewed qualified health professionals as superior in their knowledge to in-training health

Table 4. Information children want to know.

Children in hospital want to know . . .	Before admission to hospital children want to know . . .
What is wrong with me?	What do I need to bring to hospital?
What is happening?	<ul style="list-style-type: none"> • Toothbrush and toothpaste • Night-clothes • Slippers
What are you going to do?	What things can you do?
Will it hurt?	<ul style="list-style-type: none"> • The playroom is a fun place • You can get games there [playroom] • You can go to school • The school teacher comes to the ward
Will I have to have an injection?	
What is hospital like?	
What can I do in hospital?	
Are the people nice?	
How will it [illness] affect me?	
Will I get better?	
Will I get an operation?	
How long will the operation take?	
When can I eat [fasting]?	
What can I eat [restricted diet]?	
What medicine is it?	
When can I go home?	

professionals. Senior health professionals were seen as superior to junior health professionals and medical staff superior to nursing staff. Children felt that more senior staff members were less inclined to engage in social conversation, exchanged less information, and their delivery of information was often incomprehensible. Yet, children expected to receive information directly from the medical team, even if this information was incomprehensible. This view of an information hierarchy of knowledgeable health professional experts was not exclusive to children who were regular attendees to the children's ward.

Supportive intermediary bodies

When children did not receive information directly from medical staff they relied upon nursing staff to act as intermediary bodies. Nursing personnel were identified as pivotal, interjecting, assisting and making it easier for children to understand the medical team. Sue (12 years) felt 'nurses know we're not grown up and they break down the big words the doctor uses'. Parents also acted as intermediaries between children and health professionals. Children highlighted that they often sought information from their parents when they did not understand health professionals. A number of children affirmed they preferred to receive information directly from their parents because their parents were able to 'make it [information] simpler'.

Child as active navigator

Some children reported, or were observed, actively seeking information themselves. Children did this by questioning health professionals, their parents, interacting with other children (see Drawing 1) and observing what was going on around them on the ward.

Box 1. Analytic memo: What is not surprising? What is missing?

While it is easy to overlook what is not surprising which was play as being important for children in hospital it was also helpful to consider what was not there. We equate play and its integration into hospital settings as being important for children in hospital. Thus I am not surprised in relation to children wanting to play and reporting being bored if they are not able to play. Yet, despite the fact that there is much documented evidence of the therapeutic use of play and its value as a communication media especially with younger aged children it is something I note to be absent during health professionals engagements with children. Interestingly, it is not that play is absent per se but rather the fact that it is used more as an occupational tool to keep children busy as opposed to an information exchange medium. Moreover, what about technology enhanced play as a medium for information exchange?

Comprehension of information**'Big mad words'**

Just under half of the children in this study reported being unable to understand the information conveyed because of the use of incomprehensible terminology (i.e. 'weird' and 'big mad words') by health professionals. Freddie (10 years) stated that when health professionals were talking, he was thinking 'way hay . . . can ya talk in English please?' Interestingly, some children adopted the medical terminology used by health professionals in their own conversations. However, on probing it emerged that children often lacked understanding of what the terminology meant. This could result in health professionals forming false assumptions of children's level of understanding.

Developmentally appropriate explanations

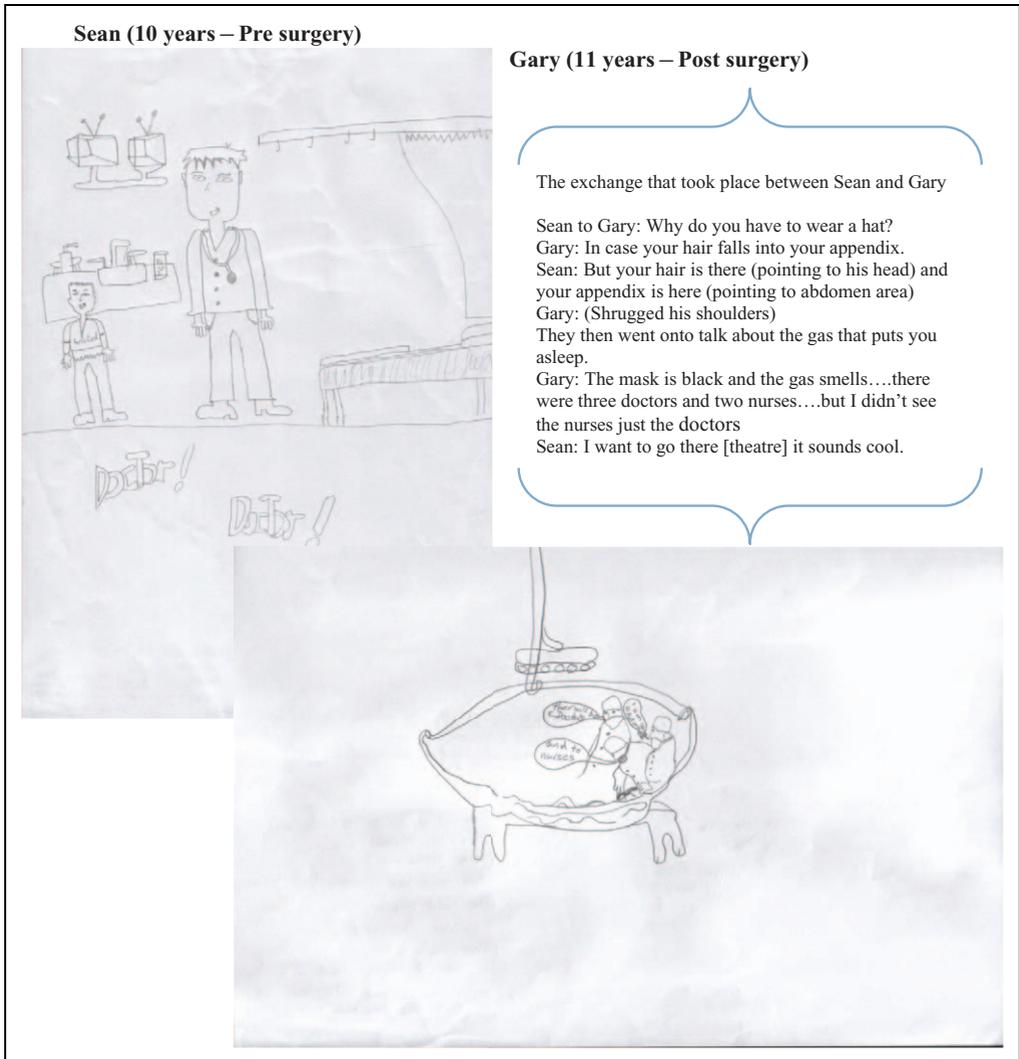
There were many examples of children describing situations where health professionals substituted complex terminology for more easily understandable words using concrete terms, tangible analogies and fantasy/magic.

Some older children linked their increased understanding directly to their schooling.

Both younger (six to 11 years) and older (12–16 years) children expressed difficulty with understanding words used by health professionals. Simple explanations helped children of all ages understand better and comprehend what was happening; thereby facilitating their inclusion in the communication process.

Lack of play-oriented strategies and technology

There were few instances observed and/or reported by children of the purposeful use of play activities (any kind) and/or technologies such as game consoles to facilitate information provision (Box 1).



Drawing 1 Sean and Gary learning from each other.

Sean (10 years – Pre-surgery).

Gary (11 years – Post-surgery).

Discussion

This study, which reports on children's information needs while inpatient in hospital, complements previous studies which explored the information needs of children pre-hospitalisation/pre-operatively (e.g. Buckley and Savage, 2010; Smith and Callery, 2005). Using a larger sample size ($n = 49$) and a wider age range (six to 16 years) we integrated observational data with informal interviews and participatory techniques to gather data over time throughout the child's hospital stay. Many of our findings mirror those of the previously cited authors; however, differences were

also noted. One key question to emerge was whose role and responsibility it is, and who is best placed, to relay information to children about their health care condition/treatments and what is happening to them.

Although child participants identified a range of health professionals who provided them with various types of information, children expected to receive information directly from the doctor as they perceived the doctor to be the knowledgeable expert. Children distinguished the nurse as an *intermediary body* transmitting information to them (when the doctor neglected to do so), and/or translating what the doctor had said (when the doctor had used medical terminology not understandable to them). Children seemed to perceive that the nurse would not have the expert knowledge required and consequently may not be in a position to give correct information. Such a perception might have been formed by the children as a consequence of their experiences of nurses delegating information provision to doctors. Nursing staff were observed frequently telling children 'we'll have to wait to see what the doctor says' or 'let's ask the doctor when he comes'. Yet, it was evident that children frequently did not understand what the doctors were telling them and held the view that nurses, because of their ability to perceive them as a child, were more likely to use child-friendly language to inform them of events/activities. Parents held a similar instrumental *intermediary* role, whereby they retold the children what the doctor had said to them in a manner their child would comprehend. These findings lend support to previous reports that in general children find it easier to understand nurses and children frequently rely on their parents to act as *communication brokers* and *mediators* to reinforce and translate information provided to them by health professionals (Buford, 2005; Kilkelly and Donnelly, 2006; Lewis et al., 2007; Young et al., 2003). This may explain why children do not possess particularly strong objections to health professionals communicating with and informing their parents about their condition/progress. Despite this, children still respected and valued receiving information directly from health professionals.

Children expressed diversity in the amount and type of information health professionals relayed to them, ranging from adequate individualised information to insufficient superficial information. A possible reason why health professionals might be calculated in the amount and type of information they share directly with children may be a perception that it is the parents' responsibility. For instance, in previous research undertaken with children with chronic and life threatening illness, many parents highlighted that they preferred to receive information first, before their child (Ellis and Leventhal, 1993; Young et al., 2003). This enabled parents to act as gatekeepers and filter the information that was given to their child. Another possible explanation why some health professionals chose to only provide children with limited superficial explanations may be related to their concern about upsetting or overwhelming children if they provided too detailed information (Bluebond-Langner, 1978; Ellis and Leventhal, 1993; Young et al., 2003). While there may be many plausible explanations for filtering the amount and type of information given to children, it neglects children's right to information. Notwithstanding this, however, perhaps the important thing is that someone informs the child. However, while parents are an important information source for their children, it should not be an excuse for health professionals not to provide children with adequate developmental and age-appropriate information. Indeed, parents might not always be best placed to prepare their child because they are sometimes unsure of what will happen themselves (Smith and Callery, 2005). Findings here support Buford's (2005) study, which found that not only did children want information, but they expected this information to come directly from health professionals. Parents believe that it is important for health professionals to communicate directly with children (Buford, 2005; Callery and Milnes, 2012). Yet, in support of other studies

(e.g. Boylan, 2004; Fortier et al., 2009; Garth and Aroni, 2003; Gibson, 2005; Wennstrom et al., 2008), a small number of the child participants in this study preferred not to be informed. As Lewis et al. (2007) reported, sometimes children want their parents to protect them and are happy when communication is directed to parents because of the fear of hearing bad news or distressing information. Children's choices of not wanting to hear bad or distressing information has implications for their ability to make decisions about their care. Greater sensitivity by health professionals and parents in assisting children to identify their fears and concerns and assessing children's specific information needs would assist in identifying what specific information children would like to receive, or not; thereby ensuring that information provision could be tailored accordingly. Ultimately, this would result in care that would be truly based on each individual child's needs. While we can only make assumptions about the reasons health care professionals share information in a particular fashion with children, what is clear is that there needs to be a quality standard developed by health care professionals, parents and children regarding the provision of information. The standard development process could help clarify each cohort's expectations of each other in relation to information giving/receiving and resolve role ambiguity in the information exchange process. Support for this recommendation is heightened by Callery and Milnes's (2012) revelation that the negotiation of roles in parent-child-nurse interactions was not discussed and consequently conflicts arose over different beliefs about what role children, parents and practitioners should assume.

The proposed development of a quality standard should include the construction of an information management strategy to ensure health care information would be actively accessible to children of all developmental ages and capabilities. Child participants perceived their age to be influential in whether they were directly informed by health professionals and the degree to which they were able to understand the information exchanged. Older children believed they were informed more and understood more, partially as a consequence of their schooling. Yet, some older children (12–16 years) also highlighted that simple explanations helped them understand better and feel included. Children's descriptions of 'big mad words' correspond with Kilkelly and Donnelly's (2006) Irish and international (Kilkelly, 2011) findings that overly technical language leads to ineffective communication. Donaldson (1978: p.18) postulated that the 'better you know something, the more risk there is of behaving egocentrically in relation to your knowledge'. Health professionals often become so familiar with the everyday routine use of their medical discourse that they do not realise the extent of its unfamiliarity to their patients (Stevenson et al., 2004). This can act as an exclusionary method inhibiting the patient's ability to understand and respond (Sieh and Brentin, 1997). One way to overcome this problem is for health professionals to ask the child what he/she has heard, thereby checking the child's interpretation and understanding of what was said. This validation is an important yet often neglected part of the trans-circular model of communication. Child participants relayed examples of developmentally appropriate explanations given by health professionals. There is much anecdotal literature which suggests that effectively communicating with children requires finding an appropriate way to take account of each child's development stage and maturity level (Chesterfield, 1992; Jolly, 1981; May, 1999; Parish, 1986; Thompson, 1991). Data from this study drew attention to the fact that play activities were predominantly utilised as diversionary and occupational tools as opposed to therapeutic 'informative' interventions. It is argued that, perhaps, alternative modes of communication consistent with modern technologies are required to enable health professionals to more effectively deliver information to children (e.g. Dragone et al., 2002; Moulton et al., 2009). Moreover, with the current drive to enhance child agency, many technologies have the potential to place children as active seekers, rather than passive recipients, of information.

Inbuilt scaffolding can guide children through task completion and information acquisition and allow each child to work at his/her own level and pace.

Conclusion

The provision of information is an individual entitlement and prerequisite for children's participation in health care decisions. Yet, the type and amount of information children want varies according to their individual needs and desires for information. This creates a great challenge for health professionals because explanations must be tailored to each child's need, including their preference to remain uninformed. To do this, we need to develop child- and family-focussed strategies for assessing children's information needs, to determine children's individual preferences for involvement and information, and parents' and health professionals' beliefs about the optimal amount and type of information to relay to children at any given point in time; including negotiation of who is best placed to transmit this information to children. Within triadic interactions (i.e. child–parent–health professional) the dynamics are increasingly complex, and in order to remain consistent with the United Nations Convention on the Rights of Children (UNCRC), an emphasis is needed on children's right to information and involvement in decisions that affect them, health professionals' duty to care and parents' responsibility to protect children and act in their best interests. This presents a dilemma for health professionals and parents of deciphering when it is appropriate to adopt a protective stance (e.g. through filtering or withholding information from children) and/or a more participatory stance (e.g. involving and relaying detailed information to children) when relaying health care information to children. Opening tripartite dialogue and establishing quality standard processes will assist with interpreting Article 13 (right to information), in conjunction with Article 3 (best interests) and Article 5 (right to guidance from adults) of the UNCRC, thus ensuring children are provided with appropriate information tailored to their individual needs, evolving capacities and agency (Lundy, 2007).

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