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Children's experiences of acute hospitalisation to a paediatric emergency and assessment unit--a qualitative study.

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ABSTRACT

Short stay treatment has become a popular form of care for patients internationally as a strategy to cope with increased demands on health care. In paediatrics this has been found to be a useful strategy that allows diagnostic care and early treatment for sick children. There is little research that considers the perspectives of the children and their experiences of acute the hospitalisation to short stay care facility such as a paediatric emergency and assessment unit (PEAU).

This study explored the experiences of eight children aged 8-10 years. Semi-structured interviews were carried out, to investigate the children's own experiences of being hospitalised in a PEAU.

Thematic content analyses were used.

Three major themes were identified: (1) The children's understanding of disease, treatment and procedures. (2) The children's experiences of healthcare personnel and the PEAU. (3)

Transformation of everyday life into the settings of the hospital.

The children identified the hospital stay as an overall positive experience. The children took part in leisure activities as they would at home and enjoyed time together with their parents whilst in hospital. In their conversations with staff they adapted quickly to professional terms that they did not necessarily understand. They did not differentiate between professionals. Further work should be considered to clarify the consequences of this. This study has provided some limited insight into the child's experiences of acute hospitalisation which should inform nursing care.

Keywords:

Children's Views,

Paediatric,

Interview,

Experiences,

Acute care

INTRODUCTION

In the last decade, with increasing numbers of admissions, reduced length of stay, and increased number of acute referrals (Aitken et al, 2006; Daly et al., 2003)) paediatric acute care has changed (Ogilvie, 2005; Sajjanhar et al., 2009). In response short stay units, such as the paediatric emergency and assessment unit (PEAU) have been developed. This development has the potential to cause negative issues for the children due to the time constraints that limit hospital staff's ability to develop relationships with the children and also that little is known about what short stays mean for the children and how they experience them (Sajjanhar et al., 2009). In paediatric nursing there is an assumption that the child is the focus of the care delivered and that they will be actively involved, where possible, in decisions about their care (Mårtenson, 2009). Previously hospitalisation of children has been found to be a stressful and traumatic experience by many authors (Coyne, 2006; Dowle & Siddall, 2006; Grønseth & Markestad, 2005). Initiatives such as the United Nations Rights of the Child (United Nations 1989), began the quest to ensure children are involved in decision around their healthcare. Since then there have been many attempts to ensure children are listened to (Department for Children, 2004; Department of Health and Children, 2000; Joint Commission Public Policy Initiative, 2001). In searching the literature on hospitalised children's experiences, several studies showed that children were still not being involved in fundamental practices such as decision making that impinge on their care (Clavering & McLaughlin, 2010; Coyne, 2006; Söderbäck et al., 2011). As a result of this there is a growing interest for research on children's own perspective of hospitalisation (Salmela et al., 2010; Söderbäck et al., 2011)

Children are now seen as social, reflective actors instead of passive objects in social structures and processes (Matthews, 2007). Most studies have focused on negative issues such as pain and anxiety of the child (Brewer et al., 2006; Franck et al., 2008 or chronic illness (Griffiths et al 2011)). In

consequence there is a dearth of studies that have a broader perspective on children's experiences of acute hospitalisation. Even though acute hospitalisation is experienced as a serious consequence of illness for the child and their family. This study aims to address this gap.

Purpose of the study

This study investigated the child's perspective of the experiences of acute hospitalisation using a child-centred approach. The aim was to carry out research *with* children rather than *on* children in relation to their experiences of acute hospitalisation event in a PEAU. The study attempts to present an interpretation of the child's view of the experience and provides useful information for the nursing profession in the acute care for children.

Method

Semi-structured interviews (Polit & Beck, 2004) were carried out to capture the children's ideas and explanations of being hospitalised. One pilot interview was performed.

Children that matched the inclusion criteria were identified and the investigator informed of their availability. Once consent had been obtained the interview took place at the hospital or at the child's home depending on the parents and the child's needs. Data were collected during a period of four months between September and December 2009.

As part of the process the children were given the opportunity to draw a picture about their stay at the PEAU which could be used as a starting point and support for explaining their experiences of being hospitalised. Three children did not want to draw, but wished to take part in the study and agreed to be interviewed.

An interview guide (table 1) was developed focusing on issues such as being a patient, interactions between staff and the child, and the environment. These issues were chosen as they have been raised by children in other studies (Coyne, 2006; Forsner et al., 2005). The interviews lasted approximately 20 – 40 minutes and were digitally recorded.

Ethical considerations

The parents were contacted by the primary investigator and informed consent and childhood assent were obtained. There were two different information leaflets one for the children and one for their parents. The child's information leaflet was read aloud to them. A psychologist was available to provide psychosocial and emotional support to children but it was not needed. Prior to this study approval was obtained from the ethics committee of a university college and a university. Approval from the national ethics committee was not necessary in accordance with Danish law

Setting

The project was conducted at a PEAU at a Danish tertiary referral teaching hospital treating acute paediatric patients under the age of 15 years. Children admitted to the unit have vastly different needs and diseases such as breathing difficulties, fever, diarrhoea and vomiting, abdominal pain, seizures and rash, as well more serious illness such as septicemia or meningitis. The length of stay in the PEAU varies from 2 hours up to 16 hours depending on the condition for which the child is being observed. More than 50 percent of the children are discharged within 16 hours, and return to their home with their parents after care and initial treatment. The remaining children are admitted to one of the paediatric wards. It appears that units outside Denmark function similarly (Aitken et al., 2006; Sajjanhar et al., 2009; Najaf-Zadeh et al., 2011)

Participants

The participants were eight to ten years old. This age group was selected as they are considered developmentally able to express themselves for the purpose of a study like this (Allison et al., 2006; Eide & Winger, 2003; Greig et al., 2007; Hoejlund, 2001) Participants were required to be physically and mentally capable of participating and developmentally appropriate for age.

Chronically ill children with previous admissions were excluded due to a possible biased view of their current admission. A total of eight children participated in the study.

Data analysis

A qualitative thematic content analysis was used to analyse the interviews. The content analysis was inspired by Lundman and Graneheim (2008). The interviews were transcribed sequentially in full length. They were read several times to comprehend the content. Meaning units related to the children's experiences were identified, condensed and grouped into categories. The categories were then related to each other and further grouped into themes. The themes were compared to the original transcripts to ensure that those identified were in accordance with the children's expression of their experiences. To enable confidentiality each child was allocated with a number from 1 to 8 which was used to link any comments or statements made to a particular child. To meet the criteria for reliability and validity in this study, a systematic approach and logical methodological coherence was adopted. Notes were made after the interviews. Attempts have been made to carefully describe procedures for data collection, transcriptions and analysis, in order to present the interpretations as clearly as possible. Representative quotations from the transcribed text were chosen as a way to increase the credibility of the results. During the entire process of data collection and analysis each step was discussed with a co-investigator to achieve clarity and consensus, as recommended by Lundman and Graneheim (2008).

RESULTS

Eight children participated (see table 2). The findings derived from the analysis emerged into three major themes;

1. The children's understanding of disease, treatment and procedures

2. The children's experiences of healthcare personnel and the PEAU
3. The children's transformation of everyday life into the space of the hospital

The children's understanding of disease, treatment and procedures

Medical terms were used by the children in relation to their disease during hospitalisation even though they did not always know what these terms meant. The children's understanding of procedures seemed to differ from that of hospital staff. Some of the children (6, 7, 8) spoke of or adopted expressions used by adults such as "Erysipelas" or "a teenage disease." This was exemplified by one girl talking about having "an infection in the lymph's" and when asked what the lymph's were, she answered:

It is something that... it is a little hard to describe (laughing) because I don't know it so well... it is better... it was... if it was my mother she would be able to explain she is an old nurse (6)

The children (2, 5, 8) also used medical terms trying to describe the reason for undergoing different procedures.

Uh, she told me that they, ... when they listened to my pulse rate they said that there was a weak crackle but there was nothing else wrong."(2)

They clearly did not understand what these terms meant in relation to their condition or the reason for their hospital admission. However, the children gave very exact descriptions of their symptoms.

(I=investigator, C=child):

C: It was because I had cystitis

I: Yes, and what is it now that, this is?

C: And it was such a thing with... I can feel it in a way when I have cystitis

I: Yes

C: By that, that I like... uh, when I pee then it stings, it kind of hurts and I cannot get it all out (5)

The children illustrated their different perceptions and subsequent lack of knowledge about their treatment when talking about it. This was illustrated by two children (2 & 4) who talked about inhalation treatment with a nebulizer due to asthma:

”It is that it blew a kind of water such medical dust up into my nose” (2)

“Yes... I got... they had such a beaker with a tube that went outside where it blew dust into my head” (4)

Almost all children talked about pain in relation to blood sampling even though they were not directly asked about blood sampling or if it was painful. When asked "could you tell me some more about what this blood sampling is?" the children focused on their experience that having blood taken did not hurt them. All but one child said that it did not hurt and that they had an anesthetic cream or a “magic plaster” as the children called it.

The children’s experiences of the healthcare personnel and the PEAU

The children generally focused on the positive things that happened during their stay. Getting positive attention and being the centre of attention seemed to make the children feel important. Many of the children did not differentiate between the different healthcare personnel and talked about the staff as a homogenous group. Information given by staff was also addressed by the children, but not linked to a specific group. Some children felt that staff did not address them directly and identified this as being overlooked.

A boy (1) talked about driving a bus (a three-seater that transports patients inside the hospital) as being fun. The experiences that children talked about were not necessarily related to care or treatment. Being in hospital also gave the children a space where it was all right to relax. Another boy (2) said that no one came and reminded him that he had to do his homework. A girl (5) wrote

on her drawing “Goodbye, it was fun.” When asked to elaborate on this she said (5): “it was not fun, it was more like nice.” “Nice” with the paintings on the windows and “nice” that the children were given a drawing that they could paint themselves. So the children focused on the positive things such as the child friendly environment.

The children (4, 3, 7) talked about participating in staff teachings as expressed by one boy:

“I have been teaching someone to become nurses [...] It was such a thing where they examine me and then they should try to guess which disease I had...” (4)

A common theme was that the children were the center of attention and in some cases they knew why they were at the hospital where as the medical student did not.

The staff were talked about as one group by the children. The children often used “they” when referring to nurses and other hospital staff members. The children spoke about them as a group of people illustrated here by one girl who expressed that she (8) “...cannot stand those in white clothes” and when asked who wears white clothes she answered: “... physicians and such things.” Although when asked to identify specifically who the children were talking about it was clear that they were aware there were doctors and nurses involved in their care, but they did not differentiate between them.

The children’s comments were not linked to a specific healthcare group but some of the children (2, 5, 7) talked about how the staff talked to their parents and not to them: “They talked mostly with my mother and father” (5). Another talked about how: “they talked about adult stuff” (2). This was, however, not experienced by all of the children. Some children expressed that the staff did talk to them and “that they were nice” (8) as one girl (8) expressed: “they were nice and said welcome and shook hands all the time.” Other children (1, 2, 4) stated that the staff did talk to them about different things such as:

“They said that they should examine me and such things in my lungs and that they should take some samples and that I should have medicine and a mask” (4)

The children’s transformation of everyday life into the space of the hospital

The children appeared to quickly adapt to their environment and enjoyed similar activities to those they engaged in when at home, enjoying the bonus for some children of time alone with their parent.

The children talked about how they had the opportunity to do whatever they wanted in play activities. Those that were creatively minded in their spare time at home did the same in the hospital when they were given an opportunity to do creative things, such as drawing. One girl (6) talked about watching a movie in after-school programs and at home with her siblings. This girl also watched movies at the hospital. The children expressed that they could play games, read books, watch television or spend time with their parents.

Some children enjoyed the added bonus of time alone with parents, as expressed by a boy (4): “... well we have been having a good time and stuff like that, been drinking lemonade.” The activities included reading stories as expressed by a child (5): “I was told stories – it was my mother who read a story aloud to me.” Another boy (3) talked about him watching a movie with his mother or as expressed by a boy (4) “just being together with my mother.” Time without any expectations may even have felt like an oasis from their everyday life at home as one boy (2) expressed it: “... no one to remind you about homework ... I could have time off.”

DISCUSSION

The children’s understanding of disease, treatment and procedures

The children’s descriptions of procedures revealed interesting findings e.g. when talking about some of the procedures the children’s experiences seemed to differ from that of paediatric nurses an experience that might lead to misunderstandings. The children used terms without understanding them and did not try to find out what the terms actually meant. This can result in the child

continuing to have misconceptions about areas of their care such as the example of the children using a nebuliser (2,4). These children had been hospitalised for less than 16 hours. They appeared to quickly adapt and use similar terms as the hospital staff but may have a different understanding of the terms. Because of this different understanding the child will continue interpret activities with their lack of understanding differently to the reality without a full and understandable explanation. It is important that hospital staff members ensure their communication is understood by the children. This is further supported by other studies that have shown that children do not always feel they are informed about such areas as procedures (Birks et al., 2006; Coyne et al., 2006; Runeson et al, 2002).

Some of the children talked in a negative way about the possibility of pain associated with having blood samples taken, but most of them said that it did not hurt. This seems to be in contrast to the findings by Coyne (2006) and Forsner et al.(2005) where the experience of illness concerned pain. One reason could be that the children could pretend to be unaffected by having blood samples taken. By doing this they meet the expectations of how you are supposed to act as a patient (Hoejlund, 2001). The children did seem very sincere when talking about the blood samples and having tried it they might have experienced that in fact it did not hurt, contrary to what they thought or were told.

The children's experiences of the healthcare personnel and the PEAU

Interestingly the children did not seem to distinguish between the different hospital staff groups and spoke about staff as one group. The child meets many different health care professionals with different functions and different roles during a hospitalisation and is assumed to have different expectations of these staff. But it would appear for the children in this study there was no differentiation between categories of staff that for them staff are staff, regardless of their education and title.

Many children were focused on being the center of attention and on getting positive attention. The children talked about the positive and exciting experiences when elaborating on their encounter with the PEAU. Getting positive attention has also been described by Forsner et al (2005), reporting how the children enjoyed playing with their toys and getting visits and gifts. Being the centre of attention might also give the children a feeling of control, shown by Coyne (2006) and Forsner et al. (2005). These studies revealed that clinical procedures were a key issue for children as they expressed fears and concerns in relation to these and negative aspects of their hospitalisation were also a consideration (Coyne, 2006; Forsner et al., 2005). This study challenges those findings and the understanding of children's experiences of hospitalisation.

The children's transformation of everyday life into the space of the hospital

The analysis showed how the children tried to bring activities from their everyday life into the hospital setting. The children could be viewed as trying to bring order to an environment that was unknown to them as described by Horstman and Bradding (2002) and Lorentsen (1997). In this study the children expressed that they had an opportunity to do different activities with their parents and that it was nice to have their parents present and appreciated having one of their parents to themselves. This has also been described as important in other studies (Coyne, 2006; Forsner et al., 2005; Runeson et al., 2002).

Limitations of this study

This study was conceived to contribute to the knowledge of children's experiences of acute hospitalisation. It was not the authors intention to be able to generalize the findings of the study. As a qualitative study the analysis was preoccupied on discovering coherence and how this coherence manifested itself in different ways and in this way made the findings transferable into similar settings and contexts.

The analysis showed that there did not seem to be a difference between the interviews that took place at the children's homes and at the hospital concerning the topics discussed. The use of drawings as a focus to the interview worked well with the children who used them. There were no apparent differences between the children who made drawings and the children who did not. Other methods such as combining the interviews with observations could have strengthened this study.

CONCLUSION

This study has provided some further insight into the child's experiences of acute hospitalisation and their ability to take an active role in their care decisions. Even though international literature and textbook's for nursing describe that hospitalisation of children can be traumatic and stressful this study has shown this might not always be the case, which might in part be due to changes in approaches to the hospitalisation of children. Overall children identified a positive experience when asked about their stay in hospital. They highlighted that they enjoyed being the centre of attention as well as having increased attention from their parents. This study has shown that children may not understand medical terms that are used but use them themselves. From this finding health professionals should be aware that children can give accurate information to them about their condition or symptoms but that the response to this should be modified to ensure that the child understands the terminology used. The study provides new knowledge to nurses about children's experiences of acute hospitalisation; knowledge that informs paediatric care and should give reason for reflection. Because of this hospital staff need to be aware of their pre-conceptions when talking to children about treatment and procedures etc., and that they should listen to the children's experiences and ensure the children understand information presented. It is important to ascertain the child's level of understanding which this study has shown may not be as reliable as it first appears.

Further research is needed, including children in a broader age span so that different aspects of hospitalisation can be examined in relation to what is valued as important by different age groups. It would also be relevant to combine interviews with observation studies and carry out follow-up to investigate any lasting effect of these identified areas in terms of the child's perception of hospitalisation.

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