

RESEARCH

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Children's experiences of hospitalization

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Abstract

This article reports on children's experiences of hospitalization. Data were collected via semi-structured interviews with 11 children aged between seven and 14 years from four paediatric units in England. The children identified a range of fears and concerns, which included: separation from parents and family; unfamiliar environment; investigations and treatments; and loss of self-determination. The children's loss of self-determination over personal needs exacerbated their fears and concerns. It needs to be recognized that compliance with hospital routines is a variable, which influences children's reaction to hospitalization. The findings clearly indicate that children need adequate information tailored to their needs, that their views are sought in the planning and delivery of their care and that hospital environments need to be made more child-centred. Interventions designed to reduce children's stress during hospitalization are not only likely to decrease their stress at the time, but also likely to influence how future experiences are appraised and managed.

Keywords anxiety • children • fears • hospitalization • loss of self-determination

Introduction

Ensuring that the views of children are taken into account in matters affecting them is a key principle of the National Service Framework for Children, Young People and Maternity Services – Standards for Hospital Services (Department of Health, 2003). This document emphasizes that hospital services should be child-centred and that children should be consulted and involved in all aspects of their care. Eliciting children's views and documenting their experiences are essential in

providing services that are responsive to their needs. This is particularly important for sick children because their views may not be heard due to illness, developmental status, limited communication abilities or professional attitudes. Although there is a wealth of literature on adults' experiences of hospitalization, there remains a deficit of qualitative data on children's perceptions of hospitalization. Traditionally the adults' view of children's perspectives has been sought, with parents generally acting as proxies for children. However, this situation is rapidly changing as researchers are recognizing increasingly the importance of directly recording children's own perspectives (Carter, 2002; Cohen and Emanuel, 1998; Coyne, 1998; Oldfield and Fowler, 2004). Nonetheless, there remains a deficit of research evidence about children's experiences of hospitalization in relation to their concerns, fears and misconceptions. Furthermore, even less is understood about the manner in which the hospital environment influences children's behaviour.

Background

Generally, hospitalization is a stressful experience for children. Numerous research studies have found that despite age and increased mastery, school-age children have fears and concerns regarding illness and hospitalization. Concerns about pain, mutilation, immobility, separation from significant others, loss of control and disruption have been reported by hospitalized children as potentially stressful (Barnes et al., 1990; Bossert, 1994; McClowry, 1988; Stevens, 1986; Thompson, 1994; Timmerman, 1983). Timmerman (1983) assessed the fears of 16 children aged 10 to 12 years who were having surgery for the first time. Their fears were loss of control, the unknown, pain or discomfort, injections, lagging in school achievement, destruction of body image, separation from significant others, disruption of peer relationships and death. These same fears were reported by 63 children aged 12 to 17 years in Stevens' (1986) study, which suggests that children of all ages may experience a range of fears. Research by Bossert (1994) with 82 hospitalized children aged eight to 11 identified 337 events as stressful, which were reduced to six key areas. These were: intrusive events, physical symptoms, therapeutic interventions, restricted activity, separation and environment. The list of stressful events identified by previous research indicates that children hold many fears about a range of events in hospital. Although these studies are useful, they are quite dated and provide information on the events that children may appraise as stressful. However, this does not mean that all children will appraise the same events as stressful. Furthermore, hospital environments and decor are markedly improved now and more child-orientated than in the past. Therefore, it is important to hear children's experiences of hospitalization in their own words, as this will provide guidance in anticipating the types of events that they may find stressful.

Method

Using the grounded theory method, data were collected through in-depth interviews with 11 children aged 7 to 14 years from four paediatric wards in two hospitals in the south of England. Eight of the 11 children had chronic conditions (asthma, orthopaedic, skin conditions) which meant that they had experienced previous hospitalizations. Three children had acute conditions (cellulitis, constipation, deep vein thrombosis) and had not been in hospital before. This age group was selected because it was anticipated that they would have the cognitive and verbal capacity to participate in the interview process; some research suggests that children aged six and under may find interview situations difficult and provide only yes or no answers (Hetherington and Parke, 1986).

Ethical approval was sought and obtained from the ethics committees responsible for the two hospitals in the study; verbal and written consent was obtained from parents prior to approaching the children. The children were provided with a simplified information sheet and their written consent also was obtained. The children were interviewed on their own in a quiet room within the hospitals to ensure confidentiality. Care was taken to ensure that the interview process would not weary the children; therefore the interviews lasted between 15 and 40 minutes.

Grounded theory is an appropriate method when little is known about a phenomenon, when the focus is on the process of interaction and one needs to understand behaviour as the participants understand it, learn about their world, learn their interpretation of self in the interaction and share their definitions (Glaser, 1978). All the interviews were audiotaped, transcribed verbatim and analysed concurrently. The data were analysed with the aid of Filemaker Pro 1992, a computer package that creates cards that can be compared and contrasted. The analysis began with coding the data; the codes were compared and then contrasted to form categories which were later merged in order to delimit the core categories.

Results

The children identified a range of concerns and fears about hospitalization which were collated into four categories: separation from family and friends; being in an unfamiliar environment; receiving investigations and treatments; and loss of self-determination (see Table 1).

Separation from family and friends

Hospitalization appeared to cause disruption to the children's lives in that they experienced separation from family and disruption to family routines and everyday activities. The children voiced concerns about being separated from their

Table 1: Children's fears and concerns

Separation from family and friends	Disruption to: <ul style="list-style-type: none"> • family routine • normal activities • peer relationships • school achievement
Being in an unfamiliar environment	Fears of: <ul style="list-style-type: none"> • the unknown • strange environment • professionals Dislikes: <ul style="list-style-type: none"> • noisy ward • bright lights at night • hot environment • inadequate play facilities • food
Receiving investigations and treatments	Fears of: <ul style="list-style-type: none"> • operations • needles • mistakes in treatment • harm to body • mutilation • pain • altered body image • dying
Loss of self-determination:	<ul style="list-style-type: none"> • loss of independence • restricted activities • lacking control over personal needs • lacking control over sleeping and waking time • lacking control over food / meal times • lacking control over timing of procedures

parents and siblings, the home environment and their friends. They reported missing several aspects of their home life in relation to home comforts, atmosphere, their mother's cooking, comfortable beds, their own room, music facilities and pets. For example:

Miss my mum, my dog, my sister, the atmosphere, my own bed, the living room, the telly and the garden. I miss school . . . miss friends at school . . . Like, I'm worried about my schoolwork if I stay too long in hospital. What will happen next?
(Girl aged 13)

Most of the children disliked hospital food. Some complained about the limited choices on the menu in that it seemed to consist mainly of fast food such as chips and burgers, while others disliked the food because it did not resemble home-cooked meals:

The food's awful. It doesn't taste nice . . . You don't get a lot of choice and half the time the stuff's beef . . . I don't eat beef. I ate it until all the stuff about disease. (Boy aged 14)

Hospitalization caused disruption to usual routines such as schooling, sporting activities, contact with friends and planned holidays. The children reported missing events in their everyday life such as social contact at school, playing sport and attending school. Some expressed anxieties about missing school in relation to 'falling behind' with schoolwork, while others appeared to miss the contact they had with their friends. The children's ages ranged from seven to 14 years, which placed them in the pre-pubertal and adolescent stage of life. Relationship with peer group and friendships are particularly important to this age group, therefore it is understandable that the children missed the companionship provided by friends. In one hospital, some children found it difficult to keep themselves occupied due to inadequate play equipment and facilities. Some children had more a positive experience and appeared to cope with disruption by forming friendships with other children on the ward:

When I first came I thought, oh, I was coming into hospital and that's boring . . . but its not as boring as I thought it would be . . . Well, there are people my own age who I can talk to . . . You get to meet new people, 'cause I made a friend the last time I was in here and we're still friends and I go and see her . . . and stuff, and there are games to occupy the time and the time just seems to fly by. (Girl aged 14)

Being in an unfamiliar environment

The unfamiliar setting and uncertainty about treatments seemed to create feelings of anxiety, although most of the children had experienced previous hospitalizations in the past. This suggests that familiarity with the hospital and/or routines may not necessarily eliminate or decrease a child's reaction to hospitalization. Some children reported fears about health professionals and the procedures that they would have to endure. The children's fears seemed to be based on variety of sources, ranging from experiences of visiting relatives in adult hospitals, television programmes, friends and school. For example:

I was worried . . . In the olden days you went into hospital and you lost one of your fingers . . . they would chop your finger . . . they would chop your hand off, right, and bend it like that, they would put this black stuff on and it heats it up and it hurts . . . We got told in a book . . . by our school and I remember it but I can only remember that bit. (Boy aged 7)

This indicates how lack of experience and some information can contribute to misconceptions about hospital which, in turn, leads to a high level of anxiety for some children. The children appeared to lack information on aspects of hospitalization and spoke about obtaining information from a variety of sources including parents, nurses and doctors, observing other children on the ward, books from the local library, medical television programmes and past experiences. Similar strategies have been reported by children ($N = 9$) awaiting planned surgery to meet their information needs (Smith and Callery, 2005).

Receiving investigations and treatments

The children voiced a range of fears about investigations and operations in relation to the possibility of harm, mutilation, pain and possible death. They expressed dislike and fears about the possibility of pain associated with receiving injections, blood tests and intrusive procedures:

I don't like blood test things like that . . . I hate the needles and things 'cause . . . I was really good for one yesterday but they don't put the Emla cream on. (Girl aged 9)

Some children recalled previous experiences of pain and were worried about experiencing it again. Some of the children had undergone investigations while others had yet to undergo operations. When the children described the treatment or investigations, they used terms such as 'pushing in', 'drilling in', 'going through me', 'opening up', 'taking out' and 'losing'. These terms indicated feelings of intrusion and loss which implies that children may see invasive medical procedures as the same invasion of privacy and bodily space. For example:

Hmmm. . . I didn't want to come in here. I felt really scared and . . . I don't like when I see people going to the operating room on a table and that . . . 'cause like, when I watch films of someone going in hospital and having an operation, like some people die 'cause of different things and I keep saying I don't want an operation or whatever because I feel that I am going to die, but like quite a few of my friends have had operations, they haven't died though, have they? (Girl aged 11)

The children who required surgical treatment felt worried and scared about the surgical process, such as having to wear a theatre gown, the journey to theatre, waiting in theatre, having the operation and waking up in pain. Concerns were expressed about the potential side-effects of treatment such as altered body image, restricted mobility, dependence on others for help and loss of control. For example:

Well I don't like going to theatre . . . that worries me as well because when I go to theatre I don't like going down on the trolley . . . so they let me go down in my own wheelchair 'cause the trolley frightens me . . . 'cause I don't like to lie down. I like to sit up and watch where I'm going (Girl aged 9)

Some children expressed concerns about altered body image as they spoke about malfunctioning internal organs, infections, skin disorders and abnormal limbs. Some were worried when they had operations that they would appear different from other children and that they may have visible scars or possibly permanent disfigurement. Appearance is very important for teenagers and being left with scars may be seen as a lifelong punishment.

Loss of self-determination

The children experienced some loss of self-determination over meeting personal needs while in hospital, in that they appeared to lack control over matters such as waking time, sleeping time, obtaining food and drinks and using facilities on the ward. The children talked about needing permission or getting permission to perform activities such as getting up, dressing, getting food, using the bathroom, bringing in personal effects, asking questions and leaving the ward. They prefaced their comments with 'allowed to do', which indicated the issue of control. The children reported having to go to sleep at a certain time and being woken at a certain time:

Yeah, I think I'd like to make some decisions, like when I get up or don't get up . . . The nurse said to me the other day, 'Right, we're going to get you out of bed' and I thought, hold on a minute: I don't want to get out of bed, I'm not going to! I mean, they try to understand, but really you're the only one who knows how you feel.
(Girl aged 14)

Children's access to food was limited, as they were not allowed to obtain food or drinks direct from the food trolley or have access to the kitchen. It seemed that simple but important matters were not within their control, rather conditioned by hospital agendas and rules. Similar findings were reported nearly three decades ago by Beuf, who stated that

the simplest acts become regimented in the total institution, thus undermining even further the patient's sense of self-determination. Eating, sleeping, waking and quite often, defecation are functions over which the child loses decision-making powers. (Beuf, 1979: ???)

The children appeared to lack control over their position (bed space) on the ward, as some children reported being physically moved to different bed space or to another ward. Generally, the disruption was inconvenient and appeared to hamper some children's efforts to form friendships with other children. The lack of choice or control over bed space possibly conveyed a sense of powerlessness to the children. This was illustrated by one particular child who, although extremely ill, was moved to a different ward every weekend for five weeks because he was on a 'five-day' ward that closed every weekend.

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It was a lot of bother because I had all the painkiller pumps and things like that . . . I was in a lot of pain and it was a lot of bother moving me onto the wards, so I was getting a bit sick of it because it was sore moving. (Boy aged 13)

There were occasions when children were left waiting for food, medicines, pain relief and procedures and this appeared to cause them upset and discomfort. Some children complained about having to wait for pain relief medication and having to 'shout' for painkillers. For example, one child explained how both he and his mother had to wait a long time before they were admitted because the nurses were not expecting his admission and no bed had been made available.

We were waiting quite a long time . . . in here . . . For the first half hour I don't mind waiting, but it was quite a long time . . . You get used to just sitting doing nothing but my Mum didn't like it . . . you get used to it . . . such are things that you do get used to it. (Boy aged 14)

Some children reported difficulty sleeping due to poor ventilation, bright lights and the noise created by telephones ringing, nurses talking, babies and children crying. Despite these issues, the children spoke about 'getting used to' the adverse aspects within the hospital environment, which indicated adaptation. For example:

I find once I have gone to sleep it's okay, it is not too bad. It's hard if there are younger children in the ward . . . they keep you awake . . . the phone goes during the night but I sleep through it. Yeah, I am getting used to it. (Girl aged 13)

The children also spoke about conforming to the ward routine even though they would have preferred some control over their daily activities in hospital. Although some children clearly had problems with loss of self-determination, nevertheless they spoke about the nurses and doctors in positive terms and listed approachability, kindness and warmth as the qualities that they liked about the nurses. Equally, parents played an important role in ameliorating the negative aspects of hospitalization.

Discussion

It is evident that hospitalization generated a range of fears and concerns for these children. The children's fears about unfamiliar routines, procedures and health professionals indicates the importance of preparatory procedures and pre-admission programmes for children (Ellerton and Merriam, 1994). Children seek order and security in an environment that is alien to them. Therefore, health professionals need to promote a safe environment in the hospital and encourage children to bring in familiar items from home to personalize their bed space. The children disliked disruption to their normal routines and separation from family

and friends. Efforts should be directed towards maximizing the children's continued contact with outside friends, family and school and minimizing the adverse aspects of the hospital environment. The children perceived intrusive procedures, blood tests and pain as particularly threatening and very stressful, which has been reported previously. This indicates the importance of sufficient preparation, age-appropriate explanations and use of relaxation techniques prior to invasive procedures on children.

The children had to 'fit in' with the ward routines and this appeared to cause feelings of frustration and powerlessness for some children. The loss of self-determination seemed to exacerbate some children's fears and anxieties about hospitalization. The importance of control may have been due partly to the children's particular age group; they were in the school-age range, which is seen as a time when children are relatively self-sufficient and striving increasingly for independence. Encouraging children's autonomy is an important element of fostering self-esteem in children of any age, and loss of self-determination may encourage learned helplessness rather than develop autonomy, negatively influencing children's adjustment to their illness and overall welfare. Most wards purport to deliver care according to the child's usual routine, but this may be difficult to achieve on a busy ward with 20 or more patients. Nurses could help by eliciting children's preferences when making decisions about their care so that they feel that they have some control over events in hospital, and where possible, accommodate children's individual preferences. It should be customary practice that children are involved in planning their care, as this will help to alleviate – or at least minimize – fears and anxieties.

For children, hospitalization is a stressful event that is unique to them. A more individualized approach needs to be used in developing interventions that will reduce children's worries and strengthen their coping strategies. Nurses should use questioning, listening and clarifying to gain the perspective of each child. Helping children to express their fears and concerns and responding to those concerns is essential for successful outcomes. Parents can play a significant role; therefore, nurses should provide parents with accurate information so that they can help to relieve children's anxieties. Clearly, any event, even if considered harmless and routine by adults, needs to be explained to children beforehand. Information should not be forced on children who are disinterested, as information-limiting is an effective coping behaviour for some children (Thompson, 1994). Interventions designed to reduce children's stress during hospitalization are not only likely to decrease their stress at the time, but also likely to influence the way that future experiences are appraised and managed.

As seen earlier, the ward environment contained adverse aspects that affected children's experiences of hospitalization. Children particularly disliked the heat, noise levels and bright lights, which has been reported previously (Battrick and Glasper, 2004). It may be suggested that the ward environment and routines are designed for the convenience of the health professionals rather than

for the children. This suggests that ameliorative measures, such as the provision of information or parents' presence, are necessary but not sufficient conditions for the avoidance of distress in children in hospital. Health professionals need to view the ward environment from the child's perspective and take measures to make it more child-centred.

Conclusion

Clearly, children have fears, concerns and misconceptions about hospitalization, which adds to the stress of the experience and has a negative impact on their self-esteem. Intrusive events and medical treatments are obvious sources of stress for hospitalized children, but health professionals may not be aware of other events that are stressful for them, such as disruption to normal routines and loss of self-determination. Nurses need to be sensitive to the emotional and informational needs of children. Good communication between health professionals and children is linked to increased understanding of illness and treatment; this in turn should lead to decreased stress for children and provide the foundation for effective treatment. Hospital environments need to be more child-centered and it is essential that children's views be elicited in the delivery of their care. Children are more likely to be less distressed if their views are heard and they are allowed to participate in their health care. Efforts directed towards these endeavours should contribute to meeting the standards for hospital services for children as outlined in the *National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2003).

Limitations

This research contributes to the knowledge on children's experiences of hospitalization. Its generalizability may be very limited due to the small number of children who participated. Further research is required with a larger sample, broader age span and across cultural groups. The impact of the hospital environment on the psychosocial responses of children requires further investigation.

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