

Permitted Visits to the ICU or Not—Children and Parents' Experiences

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Abstract

Introduction: Children need intensive care in the first days after open-heart surgery. In some hospitals visits to Intensive Care Units (ICU), are not allowed, even by parents. **Aim:** The study aimed to illuminate the experiences of children and parents regarding permission or not to visit the ICU. **Subjects and Methods:** Twenty children aged between 8 and 15 years with planned open-heart surgery, together with their parents, were chosen consecutively to participate in the study. They were divided into two groups. Group 1, followed the routine with no visits by parents allowed to the ICU. Group 2 were allowed such visits. Data were collected through open interviews with parents and children, following an interview guide. **Results** “Missing” was the overall theme illustrated in the findings, with two major categories; “being seen” and “taking care” being developed. The parents trusted the expert knowledge of the medical staff but Missing was strongly expressed and influenced the feelings within the categories in Group 1. Parents felt they were not seen and the lack of information made them anxious, frightened and feel they were losing control over their parenthood. They asked to see their children only briefly to allay their fears. They knew their children’s needs and thought they could help by taking care of practical issues to improve their well-being. All children in this group felt sad and abandoned. The families in Group 2 felt happy and confident despite not being allowed to stay with children all the time. The parents felt included in their care, which had a positive effect on the children.

Keywords

Parental Participation, Visiting Hours for Parents, Parents' Experiences

1. Introduction

According to the UN Rights of the Child [1] parental participation while the child is in an intensive care unit (ICU) is nowadays mostly welcomed but there are still opposing arguments in some clinics, based on issues of

hygiene and lack of space for parents.

The parent-child relationship is central for the child in all respects and at all ages as has been shown by decades of research [2]-[6]. This essential relationship is supported by allowing parents to take an active part even in the care of newborns who are in hospital, [1] [3] [7] [8].

The ICU, where this study was performed, did not usually allow visits from parents because of the highly technological character of the care. They wanted to protect parents from seeing their children in this environment and a weak postoperative condition. Other reasons were that the ward had insufficient space; parental visits might influence staff activities and issues concerning hygiene and infection control. When a child has open-heart surgery care is provided in an ICU, usually for 3 days. During this time, the children are linked up to various machines, and have chest and lung tubes. Post-operative treatment requires the administration of many sedative drugs together with painkillers that usually affect the children, who can be regarded as more or less unconscious. The obligation to have parents present during these first days needs to be examined. The aim of the study was to illuminate the experiences of children and parents regarding permission or not to visit the ICU.

2. Participants and Method

2.1. Informants

Twenty children, aged 8 - 15 years, scheduled to have open-heart surgery, and one of their parents, were asked to participate in the study. The informants were chosen consecutively the day before surgery.

2.2. Procedures

After obtaining informed consent from parents and children to inclusion in the study the children, with their parents, were divided into two groups. The first group, Group 1, were treated according to the normal hospital routine and had no parental visits. When the last of these patients had left the ICU, Group 2 was brought into the study. In this group parents were allowed to visit their children. During visiting hours the parent had to wear protective clothing, masks, hair covers, boots and gloves, and were told to wash hands when entering the ward. Visits were allowed 2 - 3 times a day each lasting from 45 minutes to one hour.

After informed consent was obtained, ten children and ten parents in each group were interviewed. The first interview with the children was carried out in the ICU when the trachea tube was withdrawn. At the same time the parents were interviewed off the ward. The second interview was performed at the surgical ward the day before discharge from the hospital. Children and parents were interviewed separately. All the parents and children in this study were interviewed in order to explore their experiences of the advantages and disadvantages of visits to the ICU. The interviews that were conducted were qualitative with participants being encouraged to talk freely to allow as much valuable information as possible to be obtained [9]. The opening question was "Have you had any contact with the ward about how your child is doing after the operation? What do you think is good or bad about the regulation of visiting? Do you think your visits are of any help to your child? Supporting question was asked to gain more information, such as "How did you feel about this? Can you explain more?" The interviews lasted about 30 - 45 minutes, were tape-recorded in Vietnamese, transcribed verbatim and then translated into English by the first two authors.

2.3. Analysis

The interviews were analysed using content analysis [10]. The interviews were transcribed as one entire text by one of the authors. Meaning units concerning the aim of this study were identified, condensed and coded. One overall theme was identified. The codes in the next step were developed into sub-categories, divided into main categories. The whole process moved backwards and forwards between the authors until agreement was reached concerning the content. The procedure is described step by step accompanied by quotations to support the findings and ensure validity and reliability. Student's t-test was used to test for possible age-related differences between study group and control group.

2.4. Ethics

The head of the hospital and the local ethics committee in Hanoi, Vietnam gave permission for the study. Par-

participation was voluntary after informed consent had been requested and potential participants were informed that they could withdraw at any time without giving a reason. All information about the subjects is confidential and data were reported in such a way that nobody outside the study would be able to recognize who had said what.

3. Results/Findings

After giving their informed consent twenty children, 11 boys and 9 girls, were included in the study; none refused to participate. The first ten children, Group 1, and their parents followed ordinary hospital routine with no visits allowed. The other ten, Group 2, followed the protocol allowing visits to the ICU and entered the study after Group 1. The children in Group 2 were slightly older, (mean 12.9), compared to Group 1, (mean 12.3), but the difference was not significant ($p > 0.05$). Twenty parents, aged from 31 - 54 years, of the same children were included. **Table 1** shows demographic data concerning both children and parents. Only one father participated, the rest were mothers. However, both parents were involved and had discussed experiences together. Most of the children had been operated on using Suture VSD.

3.1. Interviews

The findings from the interviews are presented below firstly as an overall theme—missing—and then in 2 categories: be seen and taking care. An example of the analysis process is shown in **Table 2**. The content of the interviews, which took place after removal of the chest tubes and those from the day before discharge, are not reported separately since the findings are in agreement.

Table 1. Demographic data for children and parents who participated in the study. Group 1 was not allowed to visit the ICU; Group 2 was allowed (F = female, M = male).

Group	Age child	Sex	Age parent	Sex	Occupation	Surgery
1	11	F	38	F	Farmer	Suture VSD
1	13	M	48	F	Farmer	Suture VSD/Mitral Valve, TV
1	8	M	41	F	Teacher	Suture VSD
1	14	M	38	F	Farmer	Suture VSD/Fallot IV
1	14	F	39	F	Farmer	Fallot
1	14	M	42	F	Farmer	Fallot of Fallot IV
1	12	F	54	F	Worker	Suture VSD
1	15	F	47	F	Farmer	Suture VSD
1	14	F	45	F	Businessman	Suture VSD/TV
1	14	M	35	F	Farmer	Suture VSD/TV
2	15	M	38	F	Farmer	Suture VSD
2	15	F	38	F	Farmer	Suture VSD
2	9	M	38	F	Farmer	Suture VSD
2	11	F	31	M	Worker	Suture VSD
2	13	M	42	F	Staff trade	Suture VSD
2	15	M	38	F	Farmer	Suture VSD/MV
2	12	F	36	F	Saleswoman	Fallot
2	10	F	38	F	Farmer	Suture VSD
2	10	M	43	F	Farmer	Suture VSD
2	13	M	35	F	Farmer	Suture VSD

Table 2. Example of the analysis process, from the condensed meaning units in the text, codes, sub-categories and categories.

Condensed meaning unit	Codes	Sub-categories	Categories	Theme
My mother feeds me, spoon-feeds me with rice soup,	Feeds me	Practical issues	Taking care	Missing
personal hygiene, massages legs and arms, my mother cleans my body. And my mother encourages me. My mother said that “I have to try eating a lot to restore my health soon”. My mother tells stories about my younger sister and my friends, this makes me feel more comfortable.	Personal hygiene Massage			
When my parents are present near me, I feel very happy, when my mother is not present near me, I feel very sad and miss my mother so much.	Encourages me	Wellbeing	Taking care	
Yes, I have noticed,	Tells stories	Taking care		
parents are not allowed to visit. Doctors haven’t noticed me, I do not know anything. I think that hospital should allow parents to visit.		Missing		
I miss so much and a mother is expected to visit. I felt very worried.	Not allowed	No Acceptance	Be seen	
	No information			Be seen
	Miss so much			Missing
	Expect/not allowed			
	Felt worried	Worried		

3.2. Missing

3.2.1. Families Not Allowed Visits

Missing was expressed very strongly. Both parents and children said that they missed each other very much. Parents want to be close their child and vice versa. Missing was interpreted as separation of child and parent in a situation where they thought their child most needed them. The children were used to having their parents close to them, sharing worries and experiences when in hospital. Not seeing each other increased the worry for both parents and children.

3.2.2. Parents

The parents liked to be present, to share events with the child. “...miss my son so much. I did not know if my son was conscious or unconscious.// I felt very worried, I could not eat anything,... love him so much and miss him”

3.2.3. Children

The children found it strange not to have their parents present, particularly as they had had such a big operation. The ICU was a totally new environment for them, and they missed their parents to be present. “That day, I was... to have heart surgery. I was kept in a blanket to go to the operation. I constantly asked to see my mum but could not see her, I called “Hey, you! Hey, you! Let me see my mum”.

3.2.4. Families Allowed Visits

Parents and children who had been allowed visits did not express feelings of missing despite not being allowed to be present all the time.

3.3. Be Seen

3.3.1. Families Not Allowed Visits

The parents felt they were not seen and included as part of the treatment, and this made them very anxious and

frightened. The children felt abandoned, which also created anxiety and fear. Parents and children lacked information. They felt upset about the regulations and had difficulty accepting them. They felt they were not in control and could not exercise their responsibilities as parents. The subcategories were worries and losing control.

3.3.2. Parents

Parents mostly lacked information about whether their child was safe, they wanted to know what had happened and also worried about whether the staff would be able to take care of their child in the way they were used to. The parents constantly requested information about their child, more than the staff were able to give. Some had not received any information postoperatively. All the worries affected the parents' wellbeing. *"I had no information... until after four days, I telephoned to ask, and then the doctor... let me know. I prayed for my child's safety and that he was treated in a way that would let him recover". "When she wakes up how is she? Does she have pain?... cry...cry"*.

In one case, the doctor telephoned to inform the parents that the operation had been completed and everything had gone well. *"To be informed like this, I felt happy"*.

Parents' acceptance of the rules about no visits differed. They appreciated the work of the medical staff but expressed worries about the child's psychological wellbeing when separated from the parents. If they were allowed to visit their child for 10 - 15 minutes a day, they would feel more secure. *"If mothers were allowed to see their child for a short moment, I think that this will be very good... to let her mother.... be close to her, she is a part of me... crying"*.

A few parents agreed with the regulations because they thought that they were for the good of the child in preventing infections, and keeping the noise level down so that the child was better able to rest.

3.3.3. Children

The children had been informed about the no-visiting rule before the operation but they had not realized that they would feel so helpless without their parents' advocacy. All the children said they felt sad and worried because they needed their mother's caring and cuddles. *"I don't believe in anything. The environment around me consists of... all the injection needle. Feel so frightened... cry... cry"*. The children had problems accepting the rules and were not sure about the information given preoperatively. *"The nurse did not tell the truth. The truth is that the postoperative period for heart surgery is three days, I have to be with my mother"*.

3.3.4. Families Allowed Visits

Parents and children felt they had been included in the treatment and care and they had to be listened to. In their opinion, being with the child was good for both parents and children. The visits made the child and the parent feel happy and more confident. It was good to have somebody in the family to share experiences with. *"When I was allowed to visit her, I felt better, when she saw me, she became very happy". "...when my mother was present near me, I felt more gently, less upset, more calm, more cheerful"*.

3.4. Taking Care

3.4.1. Families Not Allowed Visits

Both parents and children felt they were completely dependent on medical staff administering care and trusted their medical knowledge and experience.

If the parents had been allowed to visit the ICU, they would have taken care to make their child feel happy and comfortable. This was the opinion of both parents and children. They knew how to get the child to feel good. The family experienced the environment as very strange and unknown, and child and parent needed each other.

However, one mother hesitated about her ability to provide care in the ICU, so she had to rely on the professionals caring for her child.

Wellbeing and practical issues were found to be sub-categories.

3.4.2. Parents

The parents said that they would have been best able to help their child regarding wellbeing and comfort in this stressful situation. The parents felt a strong desire to take care of their child and to be near. *"My son is very young he always wanted his mother present and near him. If he could not see me, he would feel a bit fearful."*

“When I was finally allowed to see my son, we were both in tears. His face was shining with smiles.”

The parents could help with eating and drinking. The child would probably be able to eat better because the mothers knew what the child liked. *“I would help him make the formula, spoon-fed him with his rice soup. He relied on me so I would encourage him to eat better”*. When the child was in pain, they would help with massage and encourage them to feel better. *“If my daughter saw me, she would feel cheerful, this eased the pain”*.

3.4.3. Children

Most children felt satisfied with the care of the medical staff. They helped to feed the child, gave medicine, helped children urinate, sit or lie down.

“Sometimes I woke up at midnight, I could not sleep. A nurse was always present near me and she tried to help me to fall in sleep again. When I felt uncomfortable, the nurse helped me sit up.”

However, some children felt uncomfortable with the care in some respects. Some nurses talked loudly, woke them up several times in the night. They transferred a child from a bed to another without saying why. *“They did not pay attention, bumped my body against a wall, very painful”*.

Some children felt shy when staff of the opposite sex took care of them especially concerning washing their genitals. If their parents had been there they could have helped them. *“I wanted to pee, but could not stand up, my mum was not there to help... I was catheterized and felt very shy.”* The children said they had a lot of pain and worries. Their chest tube hurt them and having a tracheal tube in their mouth was very uncomfortable. The children said that there would be less pain if their parents were allowed to visit. Parents would give body massage or tell them some stories, which would make them feel better.

“When the doctor withdrew two chest tubes at the same time, it was so painful I was so frightened”// “If my mother was there, near me, she would help me reduce the pain. She would make me believe that my close relative was always present, near me”.

3.4.4. Families Allowed Visits

All the parents visited and took care of their children as much as possible. They did not talk about worries, but explained that they tried to encourage their child by being close by and telling stories that made their child feel happier. The parents understood their child’s wishes, what they needed to get a feeling of wellbeing. They understood when their child felt pain and gave massage, but also their presence alone relieved the pain.

“When my child had seen me, and I her, both my child and I felt happy, her pain was relieved”// “I explain to her your dad and mum will help, you will soon be well again”.

A lot of practical things could be handled by the parents, such as feeding, helping to sit up, massaging helping with the prescribed exercises for the airways. Being able to help and participating in the treatment was a very important issue for the parents: *“I make the formula for him to drink”*. *“Helping him to cough to force up phlegm from the throat, I curve the hollow of my hand and clap his right and left lung to force up mucus”*. *“I knew what kind of foods are suitable for my child’s disease and good for her health”*.

Some parents said they did not have much knowledge about how to take care of their child postoperatively. These parents followed strictly the medical staff’s advice about diet, airway protection therapy and personal hygiene.

All the children in this group felt cheerful and happy with the parent’s taking care and helping them to feel well. *“When I felt pain, my parent encouraged me that after the operation finished, all people have pain and you have to try to bear it. Step by step the pain will get better. After several days, you will return to normal”*.

4. Discussion

The present study is aimed at illuminating the experiences of children and parents concerning visits or not to the ICU after the child has had open-heart surgery. Twenty children and their parents, divided into two groups, participated in the study. They shared their experiences of not being allowed or being allowed to visit the ICU. The children ranged in age from 8 - 15 years and were all able to take part in the interviews, regardless of post-operative condition. The interviews were conducted on two occasions, which may strengthen the validity of the study. The qualitative design of the study, as recommended by Krippendorf K [10], made it possible to document the informants’ experiences.

The present study shows that, despite their postoperative condition, affected by painkillers and sedatives, the

children missed having their parents close by to encourage them. They missed them sharing what was happening. This created worries and the children felt abandoned and lacked confidence in the information. According to The Rights of the Child, parental participation is an important aspect in caring [3]-[7]. In the present study, most children believed that if their parents were always close by it made them feel less worried and more confident. The results show the importance of person-centered care principles regarding the participation of parents in supporting the care of children in a good way so as to improve health outcomes [11] [12].

The benefits the child receives from parental presence during hospitalization are well documented. If a parent gives the child love and security, the hospitalization will be less frightening [13]. According to their websites, many paediatric ICUs now welcome parents to be there 24 hours a day [14]. However, there are still some which do not allow visits or restrict visiting hours. As long as the wards are too narrow to allow space for parents to stay all the time, visiting hours should be offered. We could see from this study that visits of some hours per day reduce the stress for children and parents alike; all the families allowed visiting were satisfied.

The hospitalization of a child is also stressful for the parents. Stressful factors include uncertainty over the child's illness and recovery, concern about the information given, and disruption of their usual parental role. Parents may experience fear, guilt, distress, or anxiety. They can believe that they are in a weak position because of being in an unfamiliar environment, and they may believe they will lose control and independence. This confirms the findings from Kristensson-Hallström's study in a surgical ward [15].

The parents in the present study felt they were not seen, did not receive the information they had expected which made them worried, anxious and frightened. The loss of control hindered them in taking their responsibility as parents.

Our study confirms the findings in other studies that the hospitalization of children is also stressful for parents. Stressful factors include uncertainty over their child's illness and recovery, concern about the information given, and disruption of their usual parental role. Parents may experience fear, guilt, distress, or anxiety. They may believe that they are in a weak position by being in an unfamiliar environment, and they may believe they will lose control and independence, which confirm findings from Kristensson-Hallström's study in a surgical ward [15].

A lot of studies show the importance of parents being present near their child [3]-[8] [15]-[23]. The views of parents are important in the care of sick children, because they have both the legal and emotional responsibility for the child's welfare [1] [5]. Parents usually give the child emotional support and act as a bridge between the child and the hospital staff [5]. The members of a family know each other, and usually know what to do for the child's wellbeing. In a vulnerable situation, such as being in an ICU post-operatively, a child needs a close relative as an advocate, to express their needs, as has been found by other authors [1] [3] [5].

The parents in the present study wanted to participate in the care, to help their children with practical issues, to support and comfort them so that they could feel well. The children missed their parents being near, helping them and were too shy to receive help from the staff. This finding was quite similar to those in a study about parent participation on a pediatric surgical ward [24]. Children's integrity was affected and it was shown that children found it harmful, stressful, and frightening.

Most parents in the group who were not allowed to visit thought that there was no substitute for their care when their child has just undergone heart surgery. They wanted to take care of their children's daily needs in the same ways as the parents who were allowed to visit. In a study from Hong Kong by Wah Lam [6] parents' experiences of participating in the care of their hospitalized child was that there was no fixed rule regarding whether parents should or should not participate in childcare. While parents were staying with their child, it was natural for them to provide the usual day-to-day care of their child, but if they did not, none of the staff asked for them to be there [6]. Research by Darbyshire (1994) and Neill (1996) has also confirmed similar findings [19] [20]. The parents felt that their care and constant presence made their child feel good. In the Hong Kong study it was shown that parents' participation in their child's care took the form of providing individualized care, ensuring adequate child monitoring, and meeting the emotional needs of both child and parents [6]. From the parents' description of their experiences of childcare, it was found that they had a strong desire to participate, which was in line with some previous studies [6] [20] [21]. The Platt Report [16] strongly recommended that mothers be admitted with their children and that parents be allowed to visit and help as much as possible with the care of their child. Since then parent participation in the care of a hospitalized child has been viewed as beneficial for both the child and the parents. This was proposed by UNICEF and ratified in many countries around the world including Vietnam [1].

All the parents in the group who were allowed to visit their child from the first day said that when they were with their child they took on as much care as possible. Studies identifying parental needs when a child is in an ICU have shown that parents need to be able to see their child frequently and to receive adequate information [22] [23]. A few accepted the rules of the ICU and trusted the staff to know best.

5. Conclusions

Findings from this study stress the importance of parent participation in supporting their children while in a surgical ICU after open-heart surgery.

Separation of child and parent creates anxiety, worry and loss of control for the child and the family. If parents are allowed to visit at least some hours a day they feel included, able to help with practical issues, and to encourage and comfort their child.

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