

Exploring Parental Experience at Children's Hospital: Design Recommendations for Their Needs and Wishes

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This study discusses the needs and wishes in relation to parental care experience at children's hospital. Interviews were conducted with 15 parents and nurses based on observation and emotion diary at a children's hospital. Parents of child patients not only care for child patients, but also act as medical communication and information providers. Many of the uninterrupted roles have caused parents to experience physical and emotional difficulties. The findings indicate that three considerations need to be taken in designing product or service for parents in order to deliver better user experience while taking care of child inpatients: comfort, knowing, and emotional experience. Design implications, limitations and further study were discussed as well.

Keywords: *children hospital, child inpatient, parent, emotion, healthcare*

1. Introduction

Hospital is an environment where both patients and health professionals exist for certain amount of time. Hospital is a healing space for patients while a working place for health professionals. Thus, it is important for patients and health professionals to coexist harmoniously in the hospital since they are the main users of the hospital (Alsos and Svanæs, 2011). However, it is unique that in children's hospital, parents of child patients also take care of the patients along with the health professionals, and they even intervene between the patients and health professionals. Because patients who are minors are vulnerable in social, physical, and cognitive ways, parents take a role as supporters.

The study of supporting parents of the patients were limited even though the parents were recognized as important people in the children's hospital. Most studies focus on usage of technology to help treating the patients. Design studies focus on caregiving parents' role as caregivers who takes care of the patients, messengers who report the status of the patients to health professionals, and decision makers as guardians of the patients. Past studies show that the health professionals rely on the parents' opinion about child patients' symptoms and experience (Najman et al., 2001; Shin and White-Traut, 2005; Vehviläinen-Julkunen, 1992). However, the parents and the child patients' evaluation of the healthcare professionals'

function, behavior and experience may be different(Theunissen et al., 1998). The parents and the child patients may recognize various importance according to their symptoms (Tates and Meeuwesen, 2001), and it makes the healthcare professionals difficult to obtain the exact information about the child patients as well as affecting treatment (Suominen et al., 1995). The caregiving parents have a great influence on the child patients since they stay with each other for twenty-four hours a day. We are trying to understand the influence of the parents on the child patients and the health professionals. The purpose of this study is to understand the process of caregiving in the child patients' rooms, and to present means of settling the difficulties for the parents not only to give care, but also to be efficient for themselves.

A previous study illustrated the influence of the parents on treatment of child patients as assistants. According to the study, caregiving parents take efforts in physically, emotionally, and financially, and they are under a lot of pressure (Lu and Cheng, 2013). Montgomery(Montgomery et al., 1985) explains the pressure by categorizing into two groups; objective pressure and subjective pressure. The objective pressure includes physical and financial difficulties through caregiving process while subjective pressure includes emotional response of the caregivers. He determined that the caregivers may be tensed and depressed because of sudden changes of their everyday lives. Products such as monitoring technologies and hearing aids, which are mentioned in treatment of chronic disease, help the caregivers to be aware of the patients and reduce the stress. However, it is hard to find studies to relieve the stress of the caregiving parents. We hope that this study will give positive influence on caregiving parents' health along with child patients and healthcare professionals by decreasing caregiving parents' burden.

Faced with these challenges, our research question becomes;

- How do parents care for children in a children's hospital?
- Who does the parent interact with in hospital life?
- What are the difficulties and wishes of parents in their hospital life?

2. Method

In order to explore needs and wishes of parents as caregiver of their child in the children's hospital, observations and interviews were conducted.

2.1 Interview material

To understand caregiving activities of the parents and the nurses, we asked to write emotion diaries. Emotion diaries include emotion scores, activities, places, needs and wishes (Figure 1). We asked to keep emotion diaries in advance of the interviews, and the interviews were conducted based on the emotion diaries.

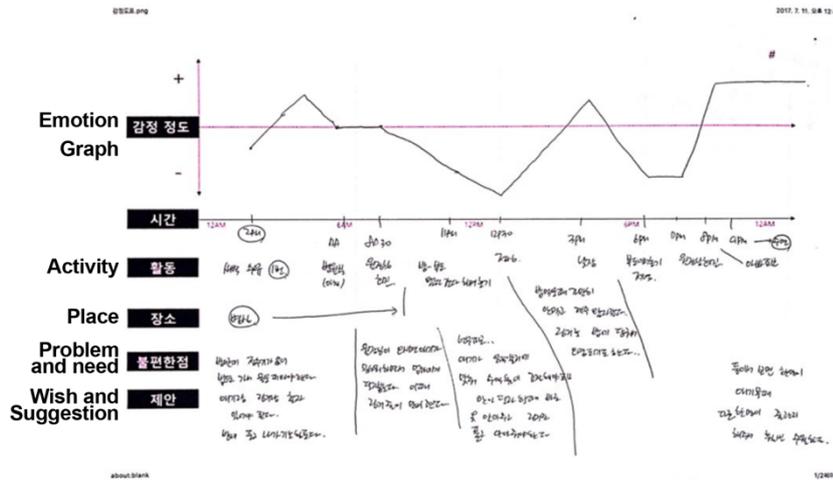


Figure 1. An example of an emotional diary written by the mother of a child inpatient

2.2 Data collection

The observations and interviews were conducted in three children’s hospitals, and three researchers inspected and documented behavioural patterns of parents, their child patients, and the nurses under the hospitals’ permission.

- Observation: Two researchers conducted observations in a common space with accompanying hospital personnel for 4 hours in the morning and afternoon. One person was able to observe one child patient the same as the parent assistant for 16 consecutive hours. Observations were carried out to understand children's hospitals from the viewpoint of the researcher, not the participants. The main focus of observation was the relationship between parents' interaction objects. The most common observation was nursing for children (Figure 2).

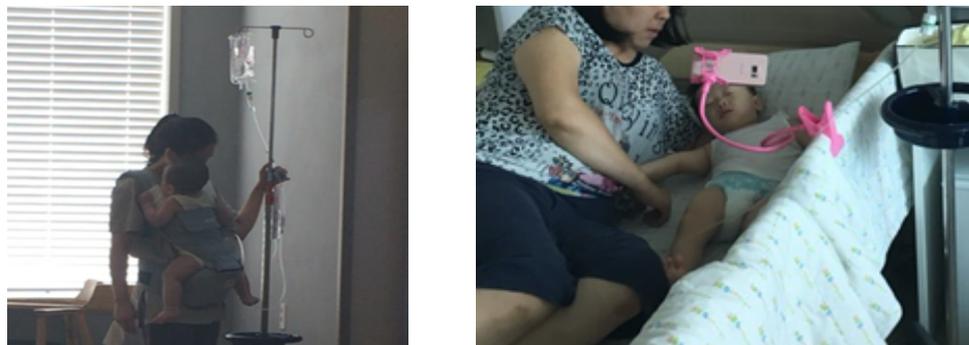


Figure 2. Scenes of daily life of a parent and a child inpatient in the ward

- Interview: The interviewees are recruited from three hospitals, and they are fifteen parents whose children are hospitalized at the time and fifteen pediatric nurses. All of the caregivers are the mothers of the children, and the ages of the children vary from nine months to five years old. The ages of the mothers are from in their late twenties to early thirties. The nurses work in pediatrics department, and the positions vary from new nurses who have three months working experience to chief nurses. Also, the ages of nurses are from mid-twenties to late-forties. Interviews took place inside of the patients’ rooms or nurses’ station, and it took between thirty minutes and one hour. All of the interviews are based on the

parents' emotion diaries and mostly about how their everyday lives have changed since the children were hospitalized, what they do in the patients' rooms, problems and what could be improved (Figure 3).



Figure 3. Scenes of interview with parents and nurses.

2.3 Data analysis

All of the recorded interviews were transcribed. We identified the problems from early data analysis among three researchers based on field notes and interview transcripts using Atlas.ti. The early data analysis is about emotion levels of activities which take place in the patients' rooms and when they carry out their tasks. Later on, we discussed about reasons of emotional changes of the parents and the nurses and how it affects their behaviors based on the collected data. Lastly, we created persona of the parents and the nurses based on the analysis to discovered concept of being caregivers as parents and nurses. We also investigated how parents can look out for their personal lives while taking care of their sick children based on the analysis.

3 Results

3.1 Child patients room environment

A child ward is a space where health professionals, child patients, and their families meet and is a space where patients and their families stay. Unlike home, the ward focuses on the efficiency of hospital life and the accessibility of health professionals. For example, the door of a child room has a small window, so nurses can check the situation in the room without opening the door. In the case of the room for one patient, the bed is located in a position visible from the door. Also, in the case of a room for patients, the door has a window. Each patient bed can be divided into curtains, and there is room for a bed next to the patient bed. There is no device provided for the privacy of the protector. Compared with a single room, in the room for children and parents, we can see quiet conversations and children watch videos quietly with their tablet. Because the spacing between beds is narrow and is not soundproof, side patients and parents can easily hear the sickness of child patients and the crying during the treatment process. This seemed to frighten the child patient, and their parents quietly explained the reason to the child patient and comforted him.

Narrow bed space did not cover the activity of child patients (Figure 2). Child patients wanted to get out of the room, and the parents used the IV pole to go around in hospital. In the restroom, child patients play, and child parents contact each other. Nurses have

separated few child patients with a certain virus and educated their parents for fear of cross infection. Child patients and parents who were not separated by the nurses took time to interact and seemed to share the overall story about the children. They shared not only current illnesses, but also past illnesses, treatment processes, etc. Also, they shared insurance treatment methods. They talked about their children's educational problems. The hallway and restroom were also space for child patients and parents of the multi-room to escape from the noise in the room. Parents also went out with a baby to sleep and out of treatment time from other patients in the room. The nurses' room was mainly located in the centre of the ward, and generally, more than one nurse was in the nurses' room. Parents usually visit when they need clothe of child patients, when the IV treatment is over, or when they have additional questions, such as medicine and medical care. There are a telephone and a button connected to the nursing room in the ward, but the parents mainly visited the nurses' room directly.

3.2 Parents' role and emotions in the hospital

Parents continued to care for the child patient by staying near the patient. Parents were close to the child patient for 24hours. The break time for the parents was the nap time of the child and the visit of other family members. Parental activity is to help the child's daily life and supporting therapeutic activities. It is an example of daily activities to help child patient to have a meal and to have a sleep. An example of helping with treatment is medication and communication with health professionals. The parent's responses to emotions were classified as positive and negative (Table 1). Parents played and exercised with children, and visits from other families evoked positive emotions. Classified as positive and negative (Table 1). Parents played and exercised with children, and visited from other families evoked positive emotions. On the other hand, helping to have a meal, go to the bathroom and helping with the healing process evoked negative feelings. Helping a have a meal and going to the bathroom is physically exhausting, the condition of the child patients is not good, and this condition expanded the role of the parents. Parents said it was difficult to control negative emotional expressions of child patients with child patient care. Therapeutic activities are said to be difficult because it is hard for parents to see child illness. Also, parents were not positive about communicating with health professionals. Parents thought the dialogue with the health professionals was formal. Particularly, parents thought that they would take part in the role of the nurses. Parents supported and comforted the emotional difficulties of child patients in the treatment of child patients. Parents said that seeing the pain and suffering of child patients is very hard, although not expressing them to the children.

Table 1 Emotions derived from parents' activities in the children's hospital

Activities with Positive emotion	Activities with Negative emotion
<ul style="list-style-type: none"> • Playing • Exercise such as walking • Family visit 	<ul style="list-style-type: none"> • Taking body temperature • Changing diapers, going to the toilet. • Taking meals • Treatment (surgery) • Round visit by doctors • Changing clothes

4 Discussion

We categorized the results focusing on how the parents took care of their children, and how it affected the parents physically and emotionally. The parents were out of their ordinary lives and gave sensitive care to their children while they communicated with the nurses about treating their children. These activities may make the parents feel difficult physically as well as emotionally.

4.1 Comfort

The parents of child patient stayed at the patient's room day and night caring the child patients which includes cleaning up, feeding the patients, giving baths, giving medicines. The persona demonstrated that patients' everyday life happens in the patients' rooms, and they met with doctors for treatment in addition (Figure 4). P3 said that it is more difficult to care a child patient in the patient's room than at home.

"I do the overall job. My child checks the IV drip, I go to the bathroom together, I help him eat, sleep, I do all about daily life. I cannot help my child live alone. Because playing could not active, so we watch TV or play a board game."(P3)

"I check if fluid drop is fine, and I change diapers. I mostly take care of my kid." (P1)

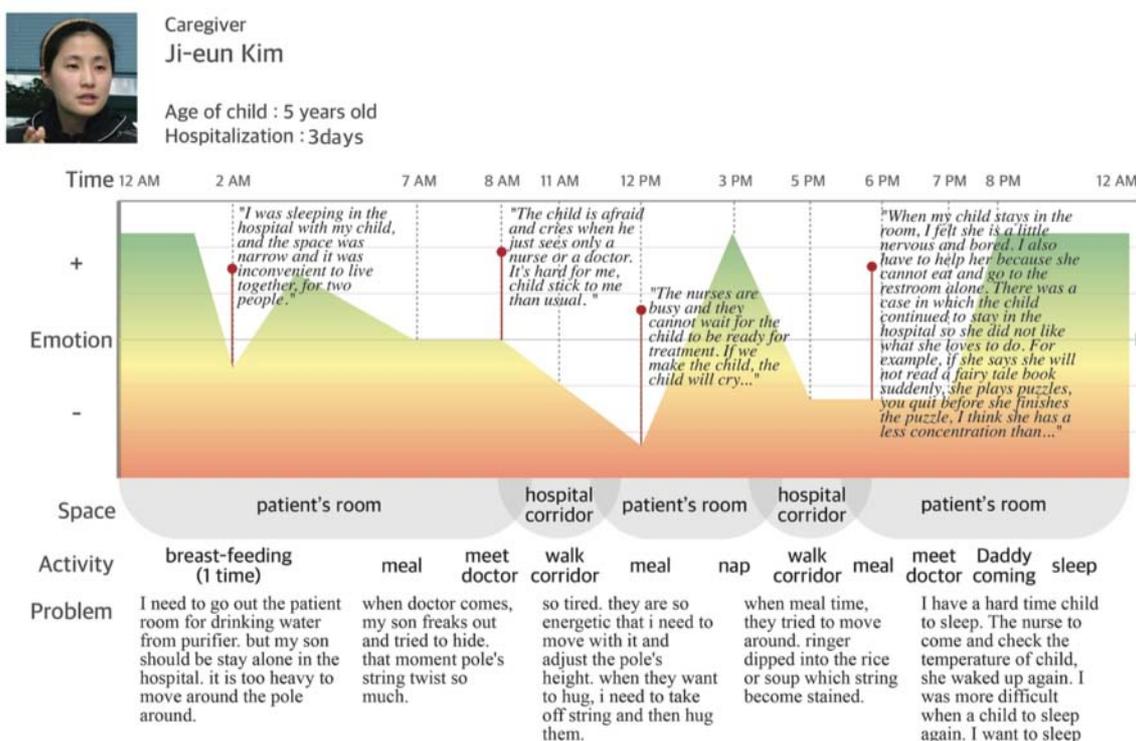


Figure 4. A persona of the mother of a child inpatient

Child patients had hard time adjusting their lives in patients' rooms since they were mostly preschoolers. They were irritated easily and refused food. The parents soothed the child patients to feed them and tried to comfort them emotionally. The parents brought the child patients' favorite toys to comfort and entertain them. Despite of the parents' efforts, the child patients were not themselves. The parents appealed physical fatigue from more energy expenditure than usual, and it may lead to inappropriate parenting. Taking the parents being

the primary interactive people into account, negative interaction of the parents may negatively affect the health of the child patients (Dunning and Giallo, 2012). Also, the parents feel guilty about the inappropriate parenting, and it becomes another stressful factor.

Situation: Check the temperature of the child with the ear thermometer

Nurse: I'll try it. It's not scary. Hello? Hello (Nurse put a thermometer on the child's ear)

Child patient: Stay calm while frowning.

Parent: hello (she speaks together), the child is unable to move suddenly by a parent.

Situation: Put an injection on a child patient

Parent: Holding a child and showing a child's favorite video on her mobile phone.

Nurse: Pororo, do you like Eddie? Do you like Pororo? (While talking, looking for blood vessels)

Child patient: he sometimes gave answer but focuses on videos.

"When my child stays in the room, I felt she is a little nervous and bored. I also have to help her because she cannot eat and go to the restroom alone. There was a case in which the child continued to stay in the hospital, so she did not like what she loves to do. For example, if she says she will not read a fairy tale book suddenly, she plays puzzles, you quit before she finishes the puzzle, I think she has a less concentration than..." (P6)

4.2 Knowing

The parents executed two major roles as bridges between the nurses and the child patients: They helped to carry out treatment and report the proceedings to the nurses. First, the parents helped to carry out treatment. Since young child patients were afraid of the treatment, they tended to cry when stethoscope is on their chest, or when taking their temperature. They even refused the nurses to come near by them. In these cases, the parents helped comforting the child patients and hold the child patients to complete the treatment or made a diagnosis

"The child did not like the doctor or the nurse coming. So the child does not like nurses coming to measure the heat, and the child keeps following me ...When the child hides his face, the child often cries." (P7)

The nurses assumed these behaviors are their obligation. However, the parents hoped the nurses to explain the reasons of the treatment before they carried on. They considered that the nurses cared about the patients by heart when the nurses confronted the child patients in person.

"Because patients often have difficulty talking about their condition, parents should be able to observe and tell the story to me, and some parents often do not." (N11)

Secondly, the parents were data collectors of the child patients' experience. They report the pain scale and the interval to nurses when child patients express pain. Even though the child

patients could communicate with language, they mostly revealed their pain with crying, irritation, and uncomfortable gestures. Therefore, the parents knew that their child is in pain, but it was hard to know the exact reason. Most parents assumed the reasons by their instinct. On the contrary, the nurses concluded the reasons by focusing on the patients' biological signs such as frequency and interval of the pain. The different style of accepting the patient' discomfort caused major conflict between the parents and the nurses. The nurses repeatedly mentioned the conflicts.

"Because the children cannot speak, it is difficult for the nurse to determine through the child's crying where the child is uncomfortable, or whether it is just grizzling or hungry. Parents can talk. They can say where is uncomfortable... " (N10)

"I take my child to the restroom, feed him, play with him and put him to bed... I tell the nurse or the doctor how my kid is doing, I take him outside when he wants to play, and I basically do all the work." (P7)

4.3 Emotional experience

The parents went through sudden changes besides the child patients. Since the parents could not overlook other family members who were still at home, they were burdened with more physical chores than usual and financial strain due to leave of absence from their work. However, they said that watching their children suffer is the most difficult thing.

"Adults can express their pain with language, but kids express with crying. So it's hard to know what is wrong. The parents are always anxious. That's why the parents also need consolation." (N2)

The parents plead physical and emotional difficulties. The emotion graph increased temporarily when the parents could take emotional break and then decreased back. It was interesting that the parents relieve their stress by communicating with other parents while walking back and forth the hospital corridor or in the service room.

"When I walk in the hallway or wait for the treatment, I talk to other patients' parents. Why they are hospitalized, or who their doctors are, or if the patients are getting better. I don't have many people to talk to in the patient's room, and I get so much information while talking to them." (P12)

The parents of child patients who were diagnosed with same disease share information and opinion about the process of the treatment. Not only that, they also shared information about medical insurance and other family members. They shared their difficulties, sympathize with each other and control their feelings.

5 Conclusion

This study demonstrates that the parents of the child patients need to take care of their own physical and emotional health in addition to take care of the child patients. Caregiving the child patients require them to take pause from their everyday life. We would like to discuss the ways to decrease the level of physical labor and support emotional well-being.

5.1 Improve management: Collaborating with healthcare professionals for physical response awareness and supervision

It is important for the parents of the child patients to be aware of the physical responses throughout the treatment process. The child patients have hard time delivering their physical

responses. It is also hard for the parents to interpret the child patients' status from their physical responses. Even though it has been indicated that reporting on symptoms is not objective, it is common for the parents to report the symptoms of the child patients(Theunissen et al., 1998). Severance of communication between the doctors and the patients lower the standard of medical care. We argue to suggest the parents to present evidences of the patients' symptoms to healthcare professionals rather than interpreting the symptoms subjectively. According to the result of this study, the perception of healthcare professionals differed as frequency and expansion of the symptoms varied even with small symptoms. Therefore, the parents should provide sufficient amount of data to the health professionals to help the doctors to make a correct diagnosis. Data can be collected by using real time tracking device(Patel et al., 2012) on the patients, or data collecting interface(Cheng et al., 2012; Weibel et al., 2013).

The conflict between the healthcare professionals and the parents begin from the approach of the symptoms of the child patients. Providing symptom-centered information assist the conflict between the healthcare professionals and the parents (Ammertorp et al., 2005). Even though the healthcare professionals understand the difficulty of the parents in the process of caregiving to their children, it was hard for them to understand emotional difficulties. To diminish the misunderstandings due to asymmetry of information, the healthcare professionals should provide clear information to comfort the parents of the child patients. For example, the healthcare professionals need to provide guidelines when documenting the symptoms. If some kind of templet is given to the parents to categorize types of symptoms such as common symptoms and the symptoms related to the child patients' illness, the communication between the healthcare professionals and the parents would be much easier. Also, the templet would provide the parents what to do when caregiving to ease the parents' anxious minds.

5.2 Sharing: Sharing knowledge and emotion, and dividing tasks

Generally, the parents who take care of the patients in the hospital are easily isolated. It is not considered that the parents gave up their everyday life to take care of their children. The result of this study show that the parents suffer from the labor which is 24 hours. Observing the child patients' symptoms is day and night job.

Physical labor levels were high due to the many roles of the child's mothers, friends, teachers, and therapists in the small house-like room. Sharing the degree of labor in these many roles with other families is a prerequisite for sharing voluntary work with sympathy. You can find opportunities for services at outside of hospital as a variety of activities in child care. Through the expansion of home care services such as cleaning and washing without direct interaction with child patients, sharing work is needed.

Parents should coordinate various aspects of their lives with their personal needs(Strauss et al., 1985). Caring by parents for the child patient is not visible, and the results of the effort are hard to reveal directly to the treatment. Therefore, it is difficult for other families to understand their parents' difficulties. On the other hand, rather than telling difficulties to other families, parents share their feelings with the parents of other children with the same difficulty and discuss stressful situations. Some parents shared information and difficulties through their internet blogs; there are many mother's forum about caring children. Parents were using blogs as a good activity to manage their emotions just by sharing their emotions and empathizing with them(Consolvo et al., 2004; Liu et al., 2011). In this case, we propose that we can expand the cases more easily and make it easier to frequently share the

difficulties of care for child patients and the treatment process by building a system that supports the emotional management of caregiving parents.

It should address the needs of caregiving parents, who play an important role in children hospitals. Parents are especially important because they have a significant impact on the physical condition and psychological condition of the child patient (Homer et al., 1999). Nevertheless, the difficulty of caring child patient by parents is overlooked. We suggest the opportunity to develop management and sharing methods for parents themselves in the study of parental activities in the children hospital. Nevertheless, our research has limitations. As with many qualitative studies, a relatively small number of participants were included, and children patients were excluded because of the difficulty of verbal communication. In the future, we will expand our research results not only to the ward but also to the outpatient children through the study of interaction with children.

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