

Qualitative Study for Designing Peripheral Communication between Hospitalized Children and Their Family Members

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Abstract. This paper describes an effort to develop a new communication supporting environment which engenders a greater sense of social proximity among geographically distributed families, particularly between hospitalized children and their families. We conducted a qualitative study including two in-depth field interviews with in-hospital school teachers and the mother of a hospitalized child. The results from qualitative analysis provided us with insight into the organization of the interactions between the hospitalized child and the family. On the basis of the results, we established a set of design principles and developed four different types of technology prototypes for peripheral communication. The design principles played a splicing role in binding the heterogeneous processes of qualitative research and the development of prototypes. Future works involve the enhancement of design principles and prototypes, and methodological improvements.

Keywords: qualitative research, hospitalized children, peripheral communication, distributed family.

1 Introduction

This paper describes an effort to develop a new communication supporting environment which engenders a greater sense of social proximity among geographically distributed family members, particularly between hospitalized children and their families.

The support system of hospitalized children consists of various resources including a hospital, family, local and in-hospital schools [1-2], and counselors and volunteers, which play significant roles in terms of various aspects of the system (Fig. 1). Children with serious medical conditions may expect certain responses from people and/or services: help with feeling better and managing their lives better, empathic understanding of their situation and no fussing [1]. Parental participation is viewed as a pivotal concept to the provision of high-quality nursing care for children [3]. In particular, interactions between parents and children play a critical role in long-term nursing of a hospitalized child. However, most studies of children with chronic or serious conditions are medically, psychologically, or sociologically orientated [1]; few focus on the perspective of support for family.

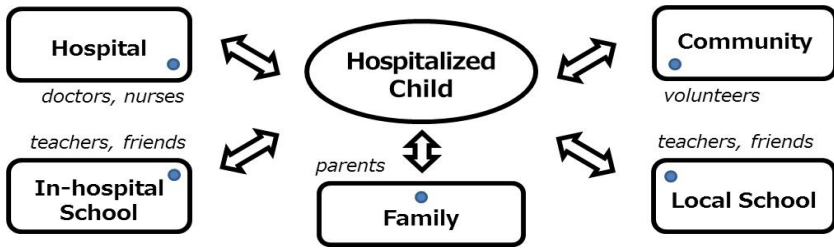


Fig. 1. Support system of hospitalized children

1.1 Peripheral Communications among Family

Family members who live together consciously or unconsciously convey, perceive, and share various types of peripheral information in their everyday lives [4], *e.g.*, cues of tone of voice, singing in the kitchen, the pace of footsteps, doors being slammed shut, light or music leaking through a door, and the aroma of coffee brewing. Each family has an individual style of using these cues to gain awareness of the mood or physical presence of its members. When family members move apart, these cues are no longer shared, which diminishes the sense of close contact the family previously enjoyed. In particular, hospitalized children and their families are provided with very limited opportunities for daily family interactions, resulting in a serious consequences for family members of hospitalized children, particularly for mothers, who sometimes experience serious “separation anxiety.”

1.2 Related Works and Our Approach: Supporting Families Who Live-Apart

Home technologies that aim to assist family members while living apart can be found in human-computer interaction (HCI) area. Efforts include the use of various digital props, for example, internet teapot, family portraits [5], digital décor [6], an augmented planter [7], a jacket for “hug over a distance” [8], and an interactive installation supporting touch over a distance [9] that senses and conveys physical motion and the touch of remote family members. Despite the apparent simplicity of these devices, family members reported emotional affects resulting from their placement in the home.

In this paper, we examine peripheral communication between hospitalized children and their families. We consider an integrated approach that combines qualitative study and the development of a new communication supporting environment. Our process consisted of a field interview, qualitative analysis, establishment of design principles, and development of peripheral communication prototypes.

2 Qualitative Research

To begin with, we conducted two field studies. The *triangulation* of methods and data [10-11] was taken into account. To investigate multiple aspects of the interactions

between hospitalized children and their families on different levels, we adopted a combination of multiple qualitative research methods [12-13] such as semi-structured interviews, participant observation, and questionnaires. The first study addressed in-hospital school teachers, while the second study addressed the mother of a child with repeated long-term hospitalization.

2.1 In-Depth Interview 1 (Teachers at an In-Hospital School)

In the first study, we focused on in-hospital school teachers, given their familiarity with a hospitalized child's everyday life and the likelihood that their perspective is different from that of the child's family. The study aimed to determine important clues for interpreting and sensing moods and other various conditions of hospitalized children's everyday lives, including in-hospital school lives, intentionally with the exception of their medical conditions.

Participants. We met two experienced teachers, "A" and "B" (female, in their late 40s and early 50s when interviewed), of an in-hospital school affiliated with the university hospital located in a suburb outside of Tokyo. Both had five years of experience teaching at the in-hospital school in addition to elementary schools.

Method and Research Settings. The research session involved semi-structured interviews [14], a set of questionnaires, in-situ contextual inquiry, and open-ended discussion. The interviews included several topics such as (a) in-hospital school life and its place in the lives of hospitalized children, (b) aspects of everyday life conditions that children avoid displaying to their families, (c) considerations while communicating with children, and (d) clues for recognizing children's emotional state. In addition, we also conducted participant observation [15] during in-hospital classes (a "housecraft" class at the elementary school and an "art" class at the secondary school) to further understand children's everyday lives in a hospital. The session was conducted at an in-hospital school in December, 2009 and lasted for approximately two and a half hours.

2.2 In-Depth Interview 2 (Life Story of a Mother of a Hospitalized Child)

In the second study, we focused on a mother of a child hospitalized on a long-term basis. The second study aimed to understand the life history of a child and the family, including memorable family episodes, and the style of interaction between them, and determine important peripheral communication cues for interpreting and sensing presence, mood, and various conditions of children's everyday life in a hospital and at home, with the exception of their medical conditions.

Participants. The participant "M" was a mother (female, aged 44 when interviewed, full-time housewife) of two children. She lived in a suburb outside of Tokyo with her husband of 17 years and their children. Their first child, "H" (female, aged 14), had a

cardiac disease since birth and had had several long-term hospitalizations. On the other hand, her husband canceled his participation.

Method and Research Settings. Research was divided into three sessions. During the initial session, we emphasized the establishment of a *rapport* with the participant and her partner, the informed consent process, and building a relationship of mutual trust. The second and third sessions involved semi-structured interviews, life story interviews [16-17], a set of questionnaires, and open-ended discussion. The interviews included several topics such as (a) family structure and current situation; (b) a biographical sketch, including memorable events; (c) life story, including her personal experiences of continuously nursing her first child, who suffered from a cardiac disease; and (d) important peripheral communication cues for interpreting and sensing mood, presence, and various conditions of children's everyday lives (with exception of their medical conditions) in a hospital and at home. The sessions were conducted between August and December, 2009 in the living room of her house on an individual basis and lasted for approximately four and a half hours in total.

2.3 Results

All interviews were transcribed into readable narrative texts. First, the transcripts were subdivided into key experiential units (i.e., segments) and encoded with a set of characteristics selected from the established analysis viewpoints. Furthermore, the narrative interviews were interpreted according to the sequence of analysis stages ([13], p.346): (1) analysis of biographical data of the family, (2) sequential analysis of the text and thematic field analysis, (3) reconstruction of the life story (life as told), (4) reconstruction of the case life history (life as lived), (5) detailed analysis of individual textual segments, and (6) contrastive comparison of life history and life story. Table 1 shows an example.

The analysis results obtained from qualitative research provided us with deep insights into the organization of the interactions between the hospitalized child and the family. They indicated that (a) a mother plays a very unique and critical role in the family in terms of long-term nursing, particularly with regard to interactions with a hospitalized child, though she seriously feels isolated at times; (b) the interaction style and relationships among a hospitalized child, the mother, and family had changed during key family events; and (c) rather than vital signs of medical conditions, simple ordinary peripheral cues exchanged among family members, particularly between a mother and her hospitalized child, were important for knowing everyday life events and maintaining their feeling of closely connected. We identified important peripheral cues that a mother used for interpreting moods and various conditions of a hospitalized child and various aspects of a mother's concerns about the everyday life of her child in a hospital and at home.

Table 1. Events in “M’s” life history and excerpts from narrative data relevant to the events

	Events in “M’s” life history	Excerpts from narratives on personal experiences relevant to the events
“H’s” birth	<ul style="list-style-type: none"> • The first child “H” was born. • “H” was diagnosed with a serious heart condition at birth and her arterial oxygen saturation was 30. • “H” was immediately moved to a university hospital with “M’s” husband and grandfather. The doctor informed “M’s” husband that the newborn baby might die. • “H” (univ. hospital), “M” (maternity hospital), and her husband (home) suddenly separated. 	<ul style="list-style-type: none"> – “I noticed a newborn nursery where ‘H’ had to lie was silent in the darkness.” – “Papa didn’t tell me what happened with our baby; probably he prevented me from being hurt. But I guessed it because I smelled like disinfectants as my husband came back to me. Usually, I never smelled such things in a maternity hospital.” – “No, no, no... my greatest crisis, that should be the worst time of my life. I was dropped into the depth of unbearable sorrow, at bottom of the hell.”
“H’s” first operation	<ul style="list-style-type: none"> • On the second day, “M” went to the university hospital for “H’s” emergency operation (50% success rate). The doctor said that “H” could die if the blood would spout from the heart. A hospital official advised the parents to call a relative. • When “H” returned to the Pediatric ICU, “M” saw “H’s” entire body covered in tubes. • Thereafter, “M” visited “H” daily for three months. That was the beginning of “M’s” long-term nursing of “H.” 	<ul style="list-style-type: none"> – “The doctor (of the university hospital) showed us a great readiness to care ‘H’. When he gave me strong encouragement, I answered YES in a strong tone. I thought ‘H’ would survive when I saw a smile of nurse.” – “Nurse said me they would be able to care ‘H’ but please take care of me by myself. At first I couldn’t perceive what nurse meant but now I well understand.” – “Actually, I almost did nothing while visiting, but I felt myself pulled by the hair from behind as I left there.” – “Yes, I believe, it’s me who protect ‘H’. I do anything for ‘H’.”
Domiciliary treatment	<ul style="list-style-type: none"> • After leaving the hospital, the parents continued domiciliary treatment for “H” by using a machine for supplying oxygen on a 24-hour basis. “M” or her husband needed to exchange and insert a tube into “H’s” body after every bath. 	<ul style="list-style-type: none"> – “It is business for a baby to cry. But, crying puts a heavy burden on the ‘H’s’ heart. I tried not to let ‘H’ cry as much as possible. Extremely hard.” – “‘H’ couldn’t sleep well when quiet. Perhaps, because she was always surrounded by noises from medical machines.”
“H’s” third operation at two years old	<ul style="list-style-type: none"> • “H” had a third cardiac surgery. • “M” asked the hospital for support for mother-child <i>separation anxiety</i>. “M” was allowed to stay in “H’s” room in the hospital all day for three weeks. “H” bitterly cried as she woke to find herself left alone. The bed was replete with small stuffed toys. • In those days, “M’s” husband was very busy with his work. After work, he would sometimes stop by at the hospital and have supper with “M.” • “M” couldn’t tell her parents about her everyday life with “H.” 	<ul style="list-style-type: none"> – “Prior to the surgery, nurse prompted me to wipe and clean ‘H’s’ body, but I didn’t understand it ... a possible serious situation. – “So, I had to go shopping for groceries quickly while ‘H’ was asleep. I worried during my separation whether ‘H’ was crying, and always wanted to know how things were going with ‘H’.” – “Like a stuffed doll, I’d been with ‘H’ all day long and slept with her in the same bed.” – “I went almost crazy. But, am mom. Became strong afterwards. However, I heard some mothers who went crazy in such a situation.” – “I expected if papa could have heard my story a little more. Honestly, he didn’t support me very much. – I didn’t want to have an advice from parents, but expected them to hear me.”

3 Designing Prototypes

On the basis of the results of the qualitative study, we established a set of design principles for guiding the development of our new communication supporting environment. The insight into the organization of the interactions between hospitalized children and their families deeply influenced the formulation of the design principles.

3.1 Establishing Design Principles

The following principles were established for designing prototypes which aimed to engender a greater sense of social proximity among geographically distributed family members and improve their emotional well-being.

- Take advantage of familiarity with everyday things [18] and design it with “*periphery*” [19]
- Help the families to remind various scenes of the children’s everyday lives, and help them to engender the feeling of being closely connected
- Emphasize peripheral cues and specific sensory experiences that the children and parents enjoy during their everyday-life experiences [20]
- Focus on the clues for feeling the workings of the children’s lives but avoid directly transmitting vital signs and taking the role as an emergency call.

3.2 Four Types of Prototypes

We designed four different types of prototypes based on the design principles.

Prototype A (“Awake-or-Asleep”). “Awake-or-Asleep” is an accessory for cell-phones, which displays a picture expressing the activity of a hospitalized child and conveys the information to the family at home (Fig.2 - left). It (a) senses the movements of a hospitalized child by using pressure sensors embedded in a child’s bed, and based on the analysis of movements, (b) displays a picture representing the status of whether a child is awake, asleep, or actively moving.

Prototype B (“Did-it-Today”). “Did-it-Today” is a variation of “Peek-a-Drawer” [6], an impressive digital décor by Siio. Its concept and user scenarios inspired us to design “Did-it-Today,” which helps hospitalized children to tell their families about what they did at a hospital that day. When (a) a hospitalized child puts something (*e.g.*, a notebook page or a handcraft a child created that day) into a drawer and closes it, (b) a photograph of the thing is automatically taken, and then (c) the image is transmitted via internet and appears on a small display in the home. We used a paper-mockup version.

Prototype C (“Breathing Toy”). The “Breathing Toy” (Fig.2 - center) is a stuffed doll designed to imitate the movements of human respiration. It (a) captures the motions of respiration of a mother at home by using PVDF-based sensor, (b) translates it

into the sequence of control signals of a precise stepper motor, and digitally controls reciprocal motions of syringes using a linear actuator with a stepper motor, and then (c) reproduces the movements of respiration by pumping a small rubber balloon embedded in a toy and simulates mother's breathing at bedside in a hospital where her child is and vice versa (i.e., from a hospitalized child to the mother at home).

Prototype D (“Touching-a-Breath”). The “Touching-a-Breath” (Fig.2 - right) is a cushion designed to imitate chest movements of human respiration. Similar to the “Breathing Toy,” it (a) captures the motions of respiration, (b) translates it into the control signals for controlling reciprocal motions of syringes using a stepper motor, and (c) reproduces chest movements of respiration by pumping a rubber bladder embedded in a cushion, thus simulating the mother's chest movements at bedside in a hospital, and vice versa (i.e., from a hospitalized child to the mother at home).



Fig. 2. Prototypes of peripheral communication between hospitalized children and their families

3.3 Field Evaluation

The initial field evaluation was performed in March 2010 using four different types of prototypes (from A to D) described in the previous section. One respondent from our previous field study (participant “M,” female, aged 44) participated. Her first child “H” (female, aged 14) was diagnosed with cardiac disease at birth and experienced repeated long-term hospitalizations.

The session was conducted individually in the living room of her house in a suburb outside of Tokyo, Japan. In this field session, we used mockup versions of the “Awake-or-Asleep” and “Did-it-Today,” and workable prototypes of the “Breathing Toy” and “Touching-a-Breath.” The “Breathing Toy” and “Touching-a-Breath” were installed in their living spaces. Because of network limitation, we used a stand-alone version. Following an introductory component, including informed consent, we demonstrated each prototype along a user scenario, and then, the participant was asked to evaluate each prototype after using it for some time. The interview involved an interactive semi-structured interview, completion of a questionnaire (ratings), and an open-ended discussion. In addition, the participants were asked to think aloud about their feelings and thoughts while trying and evaluating. The interview contained several topics, for example, the potential for (a) softening feelings of tension, anxiety,

and loneliness of a mother; (b) stimulating feeling of being with the child and feeling love for the child and life of the child; (c) feeling pleasant or being bored following long-term usage; (d) matching the actual situation. The session lasted for approximately two and a half hours in total.

Results and Discussions. An excerpt from the participant's verbal responses to each prototype obtained during the evaluation session is included in Table 2.

Table 2. Comments on the prototypes obtained from the evaluation session

Proto type	Verbal data obtained while trying and evaluating prototypes
A	"I was anxious while I had to go for shopping or laundry, about if 'H' cried." "If I know 'H's' situation in the in-hospital school or her mental condition beforehand, we can talk more smoothly when meeting a child." "In the case (of emergency), a cell-phone will be most helpful."
B	"I am glad that I can see she struggles in the things other than the disease." "This seems to be more helpful in a case of children with cancers. They usually have a long hospitalization. Or in a case that a hospital is far from their houses."
C	"I always minded how 'H' was awake, eating or sleeping in the hospital. If the toy changed its movement, I would probably wish to know the reason why." "For me, the person is better than a thing. I'll go there to see her, actually!"
D	(After burying her face in the cushion and tasting its movements slowly for a while) "It's nice... it seems I'm with my child... Oh, 'H' (she called for the name of H)." "If I hear from a nurse that 'H' sleeps well using it, I don't mind wearing a belt of a sensor."

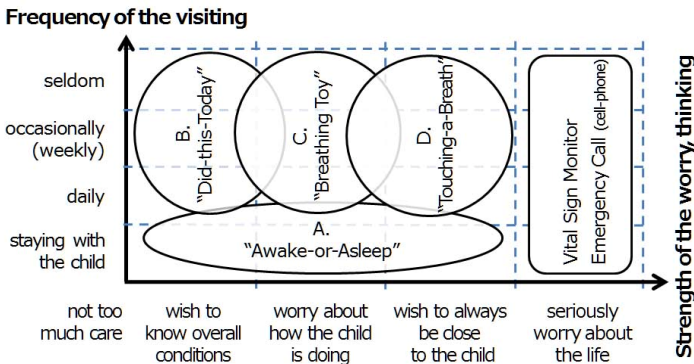


Fig. 3. Individual prototype matches different situations of a hospitalized child and the family

The participant indicated positive responses for this type of communication-supporting environment and, provided the most positive response to the "Touching-a-Breath" that emphasized tangible communication through touch. The results suggested that individual prototypes are appropriate for different situations (Fig. 3). There was not

one prototype that was appropriate in every situation. For example, “Awake-or-Asleep” seemed helpful in situations in which families stayed at the hospital with their child.

4 Concluding Remarks

The present paper presented an integrated approach that combined a qualitative study and development of a new communication supporting environment for geographically distributed family members, particularly between hospitalized children and their families. Our process consisted of field interviews, qualitative analysis, establishment of design principles, and development of peripheral communication prototypes.

Two in-depth field interviews were conducted for both in-hospital school teachers and the mother of a child hospitalized on a long-term basis. The qualitative analysis provided us with deep insights into the organization of the interactions between a hospitalized child and the family. On the basis of the analysis results, we established a set of design principles and developed four prototypes of different types of peripheral communication. In our initial field evaluation, the participant provided the most positive response for “Touching-a-Breath,” which emphasized tangible communication. The design principles played an essential role of splicing heterogeneous processes of qualitative study and the development of technology prototypes.

Our future research involves further field studies, including evaluations, enhancement of prototypes, improvements of quality in qualitative research [11], and refinement of the design principles. There still exists a *gulf* between the outcome of qualitative research and basis for the design of user experiences [20]. Our challenges involve methodological enhancements to bridge this gap in the research and design.

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