

Current Status and Future Tasks on Support for Siblings at the Bereaved Family Gathering

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1. Introduction

Many children pass away in a hospital due to severe illnesses including pediatric cancer, cardiovascular diseases and neonatal diseases. Because of restrictions on visitation, siblings of children who stay in hospital are not allowed to enter the pediatric ward until the terminal period. Consequently, healthcare staff including HPS have few encounters with siblings throughout the time. Though we were concerned about families after they lost their child and left hospital, we did not have any opportunity to hold a grief work with them.

Since the need of grief work for families seemed increasing, doctors, nurses and clinical psychologists came to work together and held gathering evenings twice (once a year) for families who lost their child(ren). In this article, especially gatherings of siblings are mainly reported.

2. Overview of Support for Siblings

We held a family gathering for families that lost their child in our hospital. At the first gathering, we had a group work, an information exchange session, and a concert. During the group work session, we divided families into four and talked about their deceased children and their feelings with healthcare professionals who acted as facilitators in a group. In the second meeting, we had a lecture presentation and an information exchange session. We held a free talk session with healthcare professionals after the lecture presentation. We prepared a room for siblings while their parents were having the group session.

In the room for siblings for the both meetings, we prepared games and some activities so that siblings were able to have fun. Children were encouraged to make handicrafts and play cards with HPS, nurses and volunteer staff. In the second meeting, we held a hospital adventure tour. We went through places where their deceased siblings had often spent time such as a family meeting room, an x-ray room, a hospital school, the building for pediatric outpatients. A cartoon character sticker was placed at each point or a room. Children were given a map and asked to find the sticker during the tour (Pic.1).



Picture 1. Hospital Adventure Tour



Picture 2. Images of a gathering for siblings

3. Result

The number of sibling participation was 18 for the first meeting and 21 for the second one (Table 1). The objective of the 1st meeting was to let the siblings play freely. Children played happily for two hours while their parents were having other sessions. A boy who was attending the meeting was playing alone with his cellular phone and he declined to play with others initially. He, however, gradually joined and played with children his age. When they were about to go home, they talked to each other “let’s meet together again”. His mother told us that he had refused to visit hospital and to watch dramas showing medical scenes since his younger brother died.

At the second meeting, siblings were again encouraged to play in the play-area for siblings while their parents were having their sessions. There were children who attended to the previous meeting and they remembered the previous time and told us “I remember this card game because I played it last time”. There were only two children who participated in the hospital adventure tour this time since other children wanted to stay on a craft-making activity and other activities. During the tour, those participating children were telling us “I remember that XX (the name of their deceased sibling) was here in this hospital”.

While we were walking through the hospital with children, we ran into a mother and her child who also took a tour to see a room where their deceased family member once stayed. The mother was saying to the child “Your sibling was very brave here” with tears. The child seemed a little awkward to see his/her mother crying.

Regarding the play-area for siblings, we received comments from families such as “It was helpful because we were able to attend at our session without concern for our children who were well taken care of in the children’s play-area”. Further, in some cases the communications between families were facilitated through children.

Table 1. The breakdown of the participants

Number of Meetings	Infant	Toddler	5~7 years old	8 years old~
The 1 st Meeting	4	6	6	2
The 2 nd Meeting	2	7	4	8

Unit : (person)

4. Discussion and future tasks

While children are staying in hospital, their siblings are not allowed to visit their sister/brother freely. Consequently, it is considered that siblings are not provided enough opportunities to understand the situations. Especially during the terminal phase of illness when families spend most of their time with their sick children, all family members including siblings need psychological support. Siblings who are not provided enough information may develop distorted or incorrect impressions about hospital and medical care.

Often siblings are allowed to see their brother/sister in hospital only during the terminal phase. The appearance of their brother/sister whom they have seen only sometime ago may have changed dramatically by then. Along with unfamiliar medical apparatus, the sibling may develop negative images including feelings of fear and anxiety toward such situations. A boy who participated in the first meeting also started refusing to see hospitals and medical related dramas after having lost his own brother. It may relate to images that he had developed during his brother's terminal phase. Initially the boy preferred playing alone and seldom responded to us when we invited him for games and handicrafts.

We assumed that his rejection was a sign of his negative feelings toward hospital and healthcare staff. After a while, he joined other children by saying "I want to do the handicraft too". He then started playing with children around the same age as he with a smile on his face. As he played with other children, he spoke more and more. By the end of the day, he was promising with other children "Let's meet here again someday". His change of attitudes during that day indicated that he would be able to come to the next meeting much easier than this time. The objective of both meetings with siblings was to spend good time together and the meeting itself was not to provide any special support to siblings as bereaved relatives. It seemed however, that spending good time in hospital was indeed acting as a kind of grief therapy.

The objectives of the hospital tour of the second meeting were to let participants know places where a deceased sibling spent time, to provide opportunities to have familiar feelings toward hospitals, to lessen their negative feelings of the hospital and to solve questions and misunderstanding about the hospital. One participant lost his/her sibling five years ago. Though the participant was only around 5 years old when his/her sibling passed away, he/she was saying to us "I do remember that XX (the name of the deceased sibling) was staying here". It showed that the certain image or impression of hospital was imprinted on his/her memory.

Families told us about the reasons that they brought their children to the meeting; "we wanted to show our child the place where their deceased sibling had shown their courage to us". It seems that knowing where diseased one had stayed helped siblings to reflect and share their memories of diseased one with other family members and to express their hidden feelings about their loss.

Currently, no matter if it is during the terminal phase or not, support for siblings is not provided. It is however, that the image of hospital definitely has some impact on their lives and memories. They may suffer anxiety and anger toward their experiences and may have difficulties dealing with

such negative feelings. If we allow them to see their siblings more freely and let them spend more time with healthcare staff, it may help them not only to avoid isolation from the situation but also to provide a better image of hospital and healthcare staff. One way to support siblings may be provided continuously through the sibling gathering when we hold the bereaved family gathering.

Gatherings inviting only siblings, meetings that encourage both siblings' and healthcare staffs' participation and some interviews with siblings shall be considered to hold in the future so that siblings can be involved in the situations more during their brother/sister's hospital stay. Regarding hospital tours, requests of siblings / families shall be reflected more and a private tour shall be held depending on cases. With time, we would like to mature the bereaved family gathering that involves siblings and to provide our support as HPS with empathy.

<References>

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