Preparation based on the individualities of children who undergo orthopaedic surgery

— With cooperation from families —

Kazue Goto*

(National Rehabilitation Center for Children with Disabilities)

I. Introduction

Recently, there have been a number of researches and reports on preparation in a paediatric medical field. It is however, important to understand that preparation is carefully practiced with a good understanding of children's medical status, age and cognitive development. Our rehabilitation centre operates surgeries on muscles, tendons and bones, and levels of cognitive development of children who undergo such surgeries vary, depending on the severity of their diseases and developmental disorders. Consequently with the cooperation from parents, different preparation tools based on a childs cognitive level and needs have been developed and been practiced. In this report, the effectiveness of preparation was evaluated from the responses of children and their families.

II. Subject

36 (17 boys and 19 girls) in total out of 180 children, aged between 3 and 17, who underwent orthopaedic surgery in our centre during July 2010 to June 2011.

Medical condition: 15 with cerebral palsy, 5 with spina bifida, 16 with other conditions/symptoms

Method of treatment: muscle release operation - 14 cases; osteotomy - 8 cases ; tendon elongation -5 cases; knee disarticulation - 2 cases; other: 7 cases Intellectual impairment (IQ): Borderline 3, Mild 5, Moderate 3, Severe 1

Speech difficulty: 4 children - able to make sounds but no comprehensive utterance, 2 children - two-word sentence, 2 children - speech difficulty

III. Method

- 1. Preparation (Figure 1.)
 - To explain about preparation to family members and obtain their consent
 - To give the family a handout "Until the day when I-kun can walk 「いっくん 足をな おす日」" and a survey sheet
 - To collect subject's information from family members (regarding how anxious their child appears, the previous medical history, treatments, etc.)
 - Before implementing preparations, let a child select his/her favourite toy/play, and play together
 - (not only to ease the tension of the child but also to get to know the child's levels of development and his/her characteristics)
 - To plan and consult with the family about the preparation based on information provided

- To prepare the followings:
 - A: A handout "Until the day when I-kun can walk"
 - B: Medical play (toys are used)
 - $C\,\dot{\cdot}\, Real$ medical apparatuses are shown and used.
 - Preparation is practiced carefully by considering the child's previous history
 - Evaluate the child after the paly preparation.



Figure 1. Preparation tools

- 2. Evaluation
- Observation: During preparation and when entering the operating room (OR), the Manifest Upset Scale was used which indicates the level of child's anxiety by a score of 1~5, with a score 1 representing the least amount of anxiety, When the child was leaving OR, the Cooperation Scale which indicates cooperative behaviours by a score of 1~5, with a score 5 representing the least cooperative behaviour was used.
- Survey: 4 days after the operation (OP), questionnaires to the child and his/her family were given.

Children were asked about: how much "fun" and/or "tense" they felt about preparation; how much they "understood" and were "motivated"; whether they were satisfied with "contents"; its "necessity".

Parents were asked about: responses of their child towards preparation; "meaning" of preparation; its "contents"; its "necessity".

- 3. Case examples (Figure 2 & 3)
- 1) Case 1: 3 y/o male (Mild Intellectual impairment, delay in language development (twoword sentence), in a wheel chair)

We were told from his parents that the child's language and behaviours were difficult to understand. The handout was used to explain to his mother about operation/treatment procedures, then medical play was practiced to the child in order for him to get used to medical apparatuses. Since he was initially afraid of I-kun doll, his family demonstrated how to play with it and made sure that it was safe to play with. Eventually he started playing with toys and real medical apparatuses in a positive manner.

He used to refuse a blood-pressure measurement, but after playing with a real apparatus and a toy applying it to a doll, to his family and to himself, he started accepting the measurement. Because his family understood the preparation well, we worked together to support his psychological needs.

2) Case 2: 5 y/o male (No intellectual/speech impairment, in a wheel chair)

The handout was used for explaining the operation/treatment procedure to the child's family. The child's status during/after the previous hospitalization and how the family dealt with the previous situation were discussed with his family. To the child, the handout was shown and he was asked to find certain things in photos of the handout. To make him understand his situation, his family emphasized things that he would understand in the story such "oh, it was on TV, too" and "he is just like you" while reading the handout. After that, a medical play was practiced to the child using I-kun doll.

3) Case 3: 10 y/o fem (No intellectual/speech difficulty, in a wheel chair)

We came to know that this 10 year-old girl was talking with her friends about her forthcoming operation rather than with her family. We suggested her, therefore, practicing medical play with other children in order to reinforce the information and correct it when necessary. During the medical play, questions addressed the girl such as "what do you do in this situation?" were sometimes answered by other children and they were advising each other. Her family said "we are encouraged to see children of similar ages of my daughter having such positive attitudes toward operations".

4) Case 4: 10 y/o fem (No intellectual/speech difficulty, not able to run but can walk)

Both the girl and her family had severe anxiety and the girl was once hospitalized because of an anxiety attack. Since several anxiety behaviours were shown from her parents regarding her operation, the procedure of the operation and how to manage certain situations after the operation were discussed thoroughly. After a consultation with a psychologist, taboo words and things that would happen to the girl during the operation were discussed and determined with her parents. Since her parents requested medical play, it was practiced based on the surgical procedure. The parents said "It was great to experience the preparation because both our daughter and we were really worried. Though we aren't sure if every child shall read the handout, we think it is necessary to discuss and consult regarding a surgical procedure".

5) Case 5: 7 y/o fem (moderately intellectually-impaired, speech difficulty (babbling), in a wheel chair)

The parents told their daughter "you will sleep over to treat your legs" and couldn't tell her about the upcoming surgery. Using a doll and practicing a simulation of the surgery in front of the operation room were suggested to the parents since they mentioned that they usually used a visual method when they explained to their daughter. The parents were also given information on possible pain and other difficulties that the girl would experience after the surgery.

After the surgery, we received a comment from the parents; "Our daughter entered the operation room with no panic and we were able to wait until she came out without unnecessary anxiety. We were well prepared by knowing what would happen after the surgery".

6) Case 6: 6 y/o fem (No intellectual/speech difficulty, not able to run but walk due to motor weakness in limbs)

4 days after an operation, the girl was hospitalized where no parent was allowed to sleep over. She had severe separation anxiety and seldom smiled and was often sobbing. Sensory plays were used to reduce her stress. Since the girl had great pain during her treatment, a medical play was practiced for several times. She was repeatedly playing with bandages and disinfectant. She was saying to a doll "you don't like it" "Don't cry, well, it's OK to cry but stay still" by which she expressed her feelings and released her stresses.

Her parents were informed their daughter's behaviours during the play. It was suggested that they observe what the girl said during her play at home. They were also encouraged to praise her efforts towards the treatment. In addition, parents were encouraged to tell us anything that they did not understand.



Figure 2. During preparation

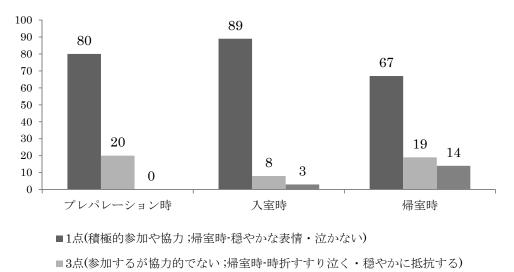


Figure 3. Playing

IV.Result

Information on children who were going to undergo an operation was collected regarding the following: the level of anxiety, the level of understanding, the way they normally receive information, his/her medical history. The method of preparation, including detailed contents and taboo wording, was carefully planned with children's families. Information was gathered through behaviour, observation and interviews, and then considered, Consequently appropriate preparation that matched a child's need was more likely to be practiced, with it came a deepened understanding of preparation in the families. As a result, psychological support for children was properly provided with their families.

As for the evaluation of behaviour observation regarding the said 36 subjects, 80% of them participated in a positive manner. 89% indicated a cooperative attitude when he/she was entering the operation room (OR). When a child was leaving the operation room, 67% were "Not crying" and had a "Serene look" (Figure 4). None of children answered "the preparation was boring". While 72% answered "I was nervous before the operation", 85% said "I was glad to receive the information through preparation", 76% said "Encouraging", and 75% answered "It was easy to understand" (Figure 5). 67% and 91% of parents at an explanatory session and during play preparation respectively felt positive about their children's behaviours (Figure 6). All parents felt the preparation was necessary. 97% of them said "It was easily comprehensible", 92% indicated "It helped to reduce anxiety", and 69% indicated "it is good the way it is" (Figure 7).



■5点(最大限の抵抗や拒否;帰室時·泣き叫ぶ・思い切り抵抗する)

Figure 4. 行動観察評価(N=36)

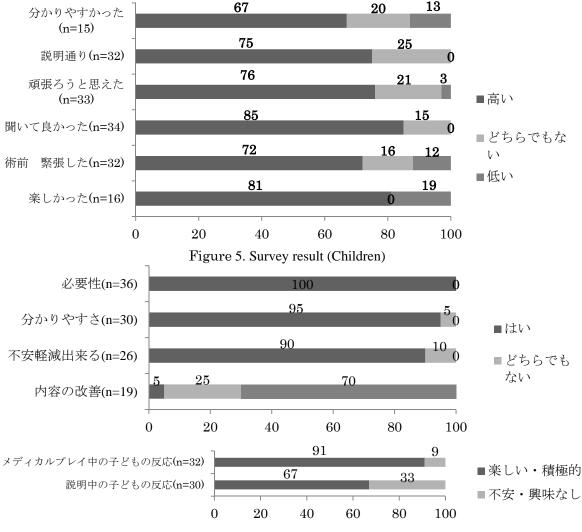


Figure 6. Survey result (Mothers)

V. Discussion

The European Association for Children in Hospital (EACH) set out the 10 principles (EACH Charter¹) for the rights of the children before, during or after stay in hospital. In Article 2 and in Article 4, it states that "Children in hospital shall have the right to have their parents or parent substitute with them at all times", "Children and parents shall have the right to be informed in a manner appropriate to age and understanding, and steps should be taken to mitigate physical and emotional stress" respectively.

Further, preparation shall be practiced to encourage children's coping ability when he/she receives medical care by providing a thorough explanation given from a child's perspective, and to reduce a child's anxiety, fear and confusion as much as possible ²⁾. The effectiveness of preparation seems to vary depending on how much children's individualities are taken into account in the practice, such as one's development age, understanding, previous medical history and one's characteristics.

In our rehabilitation centre, preparation is usually practiced on the second day of hospitalization. We encourage a child's family, the closest entity for the child, to be involved in the planning of preparation. In this way preparation seems to become more fun and encouraging for the child. Since we also encouraged the family to express their anxiety, and discussed with them how they could cope with a child's pain and discomfort after the operation, the anxiety of the family seemed to have been reduced and they could support their child in a relaxed state.

According to the result of the survey in which all children and parents expressed the necessity of preparation and many of them found its importance, we believe that the effectiveness of preparation was well acknowledged. Our method is definitely based on "EACH Charter" mentioned previously in this report and it can be one of the ideal ways to practice it.

Since playing is absolutely imperative for a child's growth and development, Matsudaira ²⁾ states the power of play and its purpose as 1) A child learn through playing, 2) A child heals through playing, and 3) A child gains the sense of individuality through playing.

It is therefore, that our future task is to establish an environment where an "everyday play" based on a child's individuality is more focused on rather than where a play is just a tool of a preparation and/or a distraction. Since the result of the survey indicated that the level of nervousness of a child before the operation was still considerably high, we see that the explanation before the operation merely is not enough and that to establish a system or/and an environment that is/are able to alleviate such emotional distresses through appropriate interaction with a child during and after a treatment is required.

References

1) EACH CHARTER: Hospital Environment for Children & Play Therapy Network NPHC HQ. 2009.

2) Chika Mastudaira (2010). Introductory of Hospital-Play, Kenpakusha Press, 2010.