

## The work of an HSP with a child (grade 7) with a blood disorder

—The study of HPS support that encourages children to overcome their challenges—

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### I . Introduction

In our pediatric ward, patients of pediatrics, pediatric surgery and the pediatric cardiovascular department are treated all together. Currently the number of beds in the ward is 32. Six (6) beds out of 32 are private rooms for those who suffer from leukemia, aplastic anemia, or malignant lymphoma.

Since 2010, there have been three HPS working in the wards and they have provided private support for children with blood disorders by rotation.

Because the ages of children vary from 1 to 15 years, the type of play preparation also varies depending on the child's interest. Children can select their favorite play before play preparation.

The contents of play and its schedule are planned based on the treatment status and test schedules of a child. As age goes up, however, it is evident that as well as play, psychological support and counseling may also be required.

As shown below, the work of the HPS was recorded in order to clarify the roles and the tasks of HPS through the interaction with patient K for a month right after he was to the hospital.

### II. Case summary

1. K (12 years and 10 months old)
2. Name of disease : Aplastic anemia, the most severe case

※Aplastic anemia;

Aplastic anemia is a disease in which a type of blood cell (hematopoietic stem cell) residing in the bone marrow decreases for some reason that causes a deficiency of all three blood cell types: red blood cells, white blood cells, and platelets. The diagnosis are determined by the low density of bone marrow cells but at the same time there shall be no sign of symptoms caused by abnormal cells such as leukemia cells.

[...]

A course of treatment and prognosis vary widely depending on the degree of severity of the disease. The degree is determined by the amount of blood cell deficiency. Stage 1 and 2, considered to be the most severe stage, indicate two out of three of the following conditions: less than 500/1 in neutrophil count, less than 2/μl in blood platelet count, and less than 20,000 / μl in reticulocyte count. Stage 3 and stage 4, the moderate and mild stage respectively, show none of those three.

※Major symptoms ;

Anemic conditions including pallor, shortness of breath, palpitations and dizziness, and bleeding tendency including subcutaneous bleeding, gingival bleeding, and nasal bleeding are evident. A patient may develop a fever due to inflammation led by severe neutrophil depletion. There are cases of patients who do not have an apparent symptom even though he/she may be severely anemic if it progresses slowly. In such a case, a patient often unexpectedly finds the disease by a regular health check at a medical clinic.

※Treatment ;

Two major treatments for aplastic anemia are immunosuppressive therapy and allogeneic marrow transplant from HLA (human leukocytic antigen-matched donor).

(Abstracted from <http://health.goo.ne.jp/medical/search/10N10400.html>)

3. Hospitalization : From (month)(day), 2011 to (month)(day), 2011 (for a month)(currently still in hospital)
4. Family: Father, Mother, Older sister (14 y/o)
5. Development: Appropriate for his age
6. Background:

Due to subcutaneous bleeding K was taken to a dermatologist where he was given a referral form to K city-run hospital (hereinafter referred to as K-hospital). Soon after K visited K-hospital, he was transferred to our hospital. The only apparent symptom was subcutaneous bleeding and nothing else. He was playing rubber-ball tennis even on the day when he visited K-hospital and did not show any sign of the disease. Because of no subjective symptom, both his family and himself were stunned by the rapid development of the situation.

1) Previous health status and characteristics

- Seldom had any illness and rarely had an episode of fever
- No history of hospitalization. Had rarely visited hospital.
- The result of a health examination taken in May showed “ no problem”
- Loves sports and enjoyed his school life very much
- Likes talking about his family, school and friends

2) Impression of K for HPS

- Friendly and talkative. Cheerful habit of mind. Shows no hesitation to greet strangers.
- Not shy about asking questions
- Not afraid of expressing what he feels: “I had no idea that there were people who would play with me. I am really lucky to be here”. No fear of accepting strangers.

3) Therapeutic strategy/procedure

- For this case, immunosuppressive therapy, bone marrow transplantation from a HLA (human leukocyte antigen) -matched donor (his older sister, 14 y/o), regular blood testing, bone marrow punctures, MRI examinations are scheduled.

If everything goes well, K may be able to leave hospital in the middle of XX (month), in three months from now.

\* Bone marrow transplantation (BMT); A procedure to replace damaged bone marrow with healthy bone marrow stem cells. It is performed for patients with serious hematological diseases, such as leukemia or aplastic anemia. The recipient's immune system is usually ablated with radiation or chemotherapy before the transplantation, this is called the conditioning regimen. Since the conditioning regimen completely destroys the recipient's hematopoietic function, transplantation must be conducted; otherwise the recipient would die. The hematopoietic stem cells from a donor are injected into the recipient's veins. There is no surgical operation.

When the procedure goes smoothly, the hematopoietic stem cells transplanted into the recipient's body start producing healthy blood in two weeks. Though it can be fatal if a recipient develops severe GVHD \*\*, appropriate immunosuppressive treatment is important since mild GVHD helps to eliminate remaining neoplastic cells and lower the risk for recurrence. When there is no complication after transplantation, a recipient can go home within three months.

(Abstracted from [ja.wikipedia.org/wiki](http://ja.wikipedia.org/wiki))

\*\*GVHD (Graft Versus Host Disease) ; A condition in which lymphocyte cells of a donor attack recipient's organs as foreign. GVHD is less likely to occur when the HLA (human leukocyte antigen) types are matched with a recipient, or the donor is a relative.

### III. Work of HPS

#### 1. Friends who suffer from the same disease

\* Regarding bone-marrow puncture, K was already given preparation by a doctor and nurses. K explained to us what he learnt – the procedure of the test.

The explanation that he was given was, “It is a disease by which cells producing blood decrease. The most important treatment is to regain the energy of the affected cells. The treatments may involve strong medication in order for him not to be infected by any possible germs and viruses including a cold. Some tests may be given to find the best way to make affected cells get better and to see blood status”. K understood that there would be possible side effects including hair loss and vomiting.

K was wondering if there was anyone who had been through the same treatments as he would be undergoing. A person who has been through the same process often feels familiar and can be a great companion.

\* In short, having a friend is very encouraging especially when they are of a similar age. K came to know T who had things in common with K. He told HPS that he would like to know more about him. T (12 y/o) under treatments for leukemia also became curious about K, and eventually HPS worked as a bridge between K and T (See Appendix 1).

#### 2. To become HPS whom children can talk about anything with

\* Emotional change in K had been seen after the first examination along with a restricted life in hospital (clean room, the limited amount of freedom). K seemed to speak out everything on his mind, but still HPS reminded him “You can tell us anything, even when you are having a bad day” so that we hoped he would be able to relax even when he did not feel well.

There are many physical changes while undergoing chemotherapy, and many patients tend to feel anxious by seeing such changes. We, as HPS, try to respond sincerely to their anxieties and fears of patients by visiting them every single day and to develop a relationship based on trust. Eventually patients will gain confidence to overcome their hardships by themselves (See Appendix 1 – K was expressing his feelings to HPS)

#### 3. Planning and practicing of play

Children between grade 5 and grade 12 are likely to enjoy competitive games, especially Othello, tick-tack-toe, and Blokus (See Pic 1). Games in which players try to read other player's strategies and in which players feel accomplished when they win are popular. K liked playing “Blokus”, “Perler Beads” and “Plastic plate creation”.

\* In Blokus, each player chooses a color from blue, yellow, red or green, then has 21 pieces (1~5 piece(s) per piece) as his/her own pieces. Players put their piece(s) on a twenty-twenty-square board starting from its corner and try to reach own piece(s) at the center but not on sides (your pieces may be at a tangent to other player's pieces). The winner is the one who put most pieces on the board.

\* In our hospital, when three HPS staff are available all three visit a patient at the same time and often with doctors and nurses. Children look forward to such a day very much by calling it “a special day”.



Pic 1 (Blokus)



Perler Beads



Plastic plate creation

#### 4. Support before examination, after treatment, and during chemotherapy

\* The more a patient undergoes examinations and treatments, the more he/she occasionally becomes traumatized by his/her physical changes and feels anxious for the next treatments such as “I may get sick after this” “what if I throw up again?” “I may have a fever again” “I may throw up if I eat” ... etc. Please refer to Appendix 1 (a journal) to see the psychological support of HPS.

\* Because HPS staff work the shift, reports like the journal indicating “when/how did a certain thing happen, what did the patient feel” help us to offer support by sharing the patient’s information among HPS staff.

#### 5. Support for parents and a sibling

\* Since everything happened too quickly and unexpectedly for K and his family, it was obvious that the family were greatly upset at the first meeting (See Appendix 1: the underlined part A). Further, they were even facing a bone-marrow transplant (from his sister to him). HPS, therefore, carefully and consistently provided support toward the family until all the family’s questions had been answered regarding the situation.

#### 6. Cooperative work with healthcare professionals in other departments

\*Before the bone marrow transplant, information exchange conferences across healthcare staff that were involved were held. Members of the conference consist of medical practitioners, nurses, dentists, dental hygienists, pharmacists, nutritionists and HPS. Expected future events and support plans were discussed together. There were two conferences: one was with the patient’s mother and another was just with the healthcare team. In the conference with the mother, her emotional change and anxiety level but also what she was looking forward to and how family tried to deal with the situation were also discussed and it provided a good opportunity to know specific requests from the family.

Though the work of HPS has been slowly recognized in our hospital, there are still some tasks to improve in a cooperative system among other healthcare personnel. We have also seen that HPS need to improve their approach toward staff in other medical fields. The future challenge is how to establish a firm position of the HPS in hospital in order to carry out the mission that provides support for patients’ (children’s and their families’) perspectives.

According to the report shown above, the indications of HPS work are as follows:

1) Through the everyday communication with HPS, K came to be able to freely express his feelings including happiness, anxiety and unpleasant emotions. It had also been seen that K received treatments by clearly expressing what he wished.

- 2) As for playing, competitive games were repeatedly played at K's request. To have experienced the joy of winning and the frustration of losing must have encouraged K to fight against his situation.
- 3) Under the situation of limited personal freedom, K felt greatly encouraged to have known a friend having a similar situation as K.
- 4) Even though HPS was trying to provide psychological support for K's parents and to encourage them to express their feelings, it was difficult for parents to talk openly in K's room.

#### IV. Discussion

1. Children around K's age are sensitive to any change in a given situation and how they perceive such change varies depending on their previous experiences and their surroundings (ex. the way that parents see the situation). Whatever the situation or health status that the child was facing, however, the continuous interaction of HPS seemed to have improved K's mental health and to have encouraged him to take treatments in a positive manner.
2. In this case, the longer the hospitalization, the more frustration and stresses toward hospital meals, changes in his physical status, and isolation emerged. Though HPS tried to understand his anxiety and to convey his message to healthcare practitioners in order to make the situation better, it was far from our satisfactory level, indicating that our approach should be improved.
3. In previous cases of children similar to K's age, some children could not really express their true feelings because of the atmosphere of the surroundings, having been too considerate to others, or having lost interests in situations. In such cases, children may even lose their motivation to get better. To avoid it, working with children by considering their personal needs and by providing support from their perspectives are imperative for our work as HPS.

#### V. Conclusion

Fortunately, active information sharing and extensive planning are available in our hospital since three people are regularly engaged with HPS activities.

In this report, the patient's situation was followed up for a month following the child's admission to our hospital. A trust relationship between the child and HPS had established slowly through everyday play and communications. This helped to overcome the challenge of the upcoming bone marrow transplantation including a conditioning regimen. The work of HPS should include the child's mental health and should help the child overcome his hardship, with a good cooperation from healthcare staff in other departments.

#### References

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#### Medical literature

Kimitoshi Murakami (Deputy director of Iwate prefectural Nanko hospital), *Adolescence Mental Health*

Date	Condition/Symptoms	Tests/Treatments	Actions/Approach by HPS	Response to HPS	Others
Monday, ○/○ Day 3	<p>《First Encounter with K》</p> <p>- K was walking down the hospital corridor with a telephone card in his hand. We meet, and he returns our greeting.</p> <p>《Symptoms》</p> <p>- Purpura was seen on hands and legs, but no other symptoms. He looks fine.</p> <p>《In the Bedroom》</p> <p>- He was lying on his bed alone. He tells us how he ended up in the hospital and about his school. We enjoy a good conversation.</p> <p>《K's Mother》</p> <p>- <u>She is surprised by the sudden hospitalization of her son, and seems to have many questions. However, learning that HPS will be of support throughout K's stay at the hospital, she becomes very much relieved.</u></p>	<p>-Bone-marrow puncture test (from 2:00pm)</p> <p>- Explanation of the disease is given by the doctor.</p>	<p>《Listening to K》</p> <p>- We listened to him about his school, family, club activities, and friends.</p> <p>《Answering Questions》</p> <p>- About the Bone-marrow puncture</p> <p>《Planning of Play》</p> <p>- We showed K cards that introduce the types of games and play available in the hospital ward.</p> <p>- We decided on what K wants to do daily and before the bone-marrow puncture.</p> <p>《Play》</p> <p>- 11:00am-11:30am Plastic plate creation</p> <p>- 1:15pm-2:00pm Othello</p> <p>- before anesthesia picture book <i>Mikke</i></p>	<p>- K likes to talk very much, and answers to any questions we ask him.</p> <p>- “What kind of places are there in this ward?” “Where will I have the bone-marrow test?” “How many nurses are there?”</p> <p>-We decided to play Othello and make plastic plates</p> <p>- He was much satisfied with the plastic plate he made. “I want to make one for my sister tomorrow.”</p> <p>- He won Othello after a close game before the anesthesia, and was in a good mood. We stayed until the induction of anesthesia.</p>	<p>《Attending HPS》 : <b>Oya, Hatai</b></p>

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			<p>① 《About T (another patient in the ward)》</p> <p>- We learned by coincidence that T has a similar background as K including age, gender, family members, club activities, and sister's club activity. We talked about him.</p>	<p>- K learns about the existence of T, who by chance had many things in common. K seems excited. He says, "I wish we could play together." He cheers up.</p>	
<p>Tuesday, ○/○ Day 4</p>	<p>《Blood Collection》</p> <p>- K walks to the blood collection room.</p> <p>《In the Bedroom》</p> <p>- After the blood collection, he has stomach pain, nausea, and dizziness. He shows some tears.</p>	<p>- K is in the clean room starting today.</p> <p>- Conference with K's parents and doctors</p>	<p>《Psychological Support》</p> <p>- 11:00am We stay by his side, talk to him, and share his feelings.</p>	<p>- After vomiting he says "I feel better now." His expression brightens.</p> <p>- He says "I want to make plastic plates again", and falls asleep.</p>	<p>《From HPS (Oya and Hatai)》</p> <p>- K says "I didn't feel well last night and could not sleep." K's mother guesses that he may have become anxious after learning the name of his disease.</p>
<p>Wednesday, ○/○ Day 5</p>	<p>《Symptoms》</p> <p>- morning temperature : 37.8 C</p> <p>《In the Bedroom》</p> <p>- K says. "I want to do Othello." His mother is surprised. "What? You looked so weary just a while ago."</p>	<p>- blood collection</p>	<p>《Play》</p> <p>- 2:00pm-3:00pm</p> <p>Othello, playing cards</p> <p>- plays cards including K's mother</p>	<p>- K enjoys playing Othello, saying "I feel better than yesterday."</p>	<p>《Attending HPS》 : Oya, Hatai</p>

**Appendix 2**

K.Y. Pre-Transplant Expanded Conference

Date: Tuesday,  
o/o/ 2011 3:00 pm-**《Conference with the Healthcare Team》**

Schedule towards the transplant:

Conditioning regimen: from o/o/ 2011

Transplant Day: o/o/ 2011

**Comments**

<b>From the doctor</b>	<ul style="list-style-type: none"><li>- The donor is K's biological elder sister (14 yrs.) Leukocyte blood type (HLA) is completely compatible. From this, we believe the transplant will be performed under good condition. We have informed K and his parents of the treatment plan, outlook, side effects of the medications, and possible risks which may result from the transplant.</li><li>- K has fever at present, but if it can be controlled to a certain level, the transplant will be performed as scheduled.</li><li>- As a preparative regimen is necessary, the sister's health condition must be ensured and close attention needs to be paid to before the transplant.</li></ul>
<b>From the nurse</b>	<ul style="list-style-type: none"><li>- We expect a very difficult time during the conditioning regimen. We plan to ask for support to stay by his side.</li><li>- He has not eaten well for the past few days. Is there any good idea to help change the situation?</li></ul>
<b>From the pharmacist</b>	- Explanation on the medicines which will be used, and their side effects
<b>From the dentist</b>	<ul style="list-style-type: none"><li>- On oral care: As the room is dry, lips tend to become dry. K has a clean mouth with no cavities. I would like to ask for continued care to maintain this.</li></ul>
	<b>From the nutritionist</b> <ul style="list-style-type: none"><li>- On Clean food: There are foods which patients can eat besides hospital meals. I would like to ask K's preferences and give suggestions.</li></ul>
<b>From HPS</b>	- On play until today, during the conditioning regimen, and after the transplant: K is much concerned about his fever and the changes of his body. We would like to be whom he feels comfortable to talk to, including sharing fun through play.



**Conference Including K's Mother** 3:40 pm-

<b>From the mother</b>	<p>The doctors have explained to us about the conditioning and the transplant, so we fully understand. We are just worried if the sterile condition can be maintained.</p> <p>- K's sister (donor) is not nervous at present, and I am told she is acting as usual at school. She seems to be thinking "Let's get it over with soon."</p> <p>I work, but I can adjust my schedule, so I hope to take time off and be with K as much as possible during the transplant treatment.</p> <p>- My child looks forward to meeting and playing with HPS every day. Can you be with him during the transplant treatment even under sterile condition?</p>
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