

Home Care Support for 3-Year Old Child with SMA Type I and Her Family

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Abstract

In this article, home care support through a play program provided to a 3-year old female with Infantile Spinal Muscular Atrophy (SMA Type I) and her family was reported. Play support was provided considering the level of the patient's development so that the subject was able to participate in playing as actively as possible. Different types of play were designed for the subject to practice her remaining functions and abilities. Consequently, it was revealed that the subject came to select what she wanted to do, play practically by using her sensory ability, fingertips, imagination and understanding. In addition, it was evident that she was able to utilize her remaining physical functions to communicate with others. A number of supporters, including nurses, OT (occupational therapist), helpers and volunteer staffs, involving for her care influenced positively to the subject and to her family. This report indicates an example of how play support shall be provided to individuals with severe disabilities/disorders.

Keyword: SMA Type I Play of 3-year old Communication HPS Home Assistance

I. Introduction (The purpose of the study)

Though medical care for patients who stay home is found important, the importance of play support for such patients tends to be overlooked. In the research report "Support program for self-reliance on long-term home-cared children (長期療養児の在宅自律支援プログラム)", Suzuki and her colleagues reported, that not only the importance of physical health support for home-cared children, but also the development of long-term educational support system should be given attention since such children nowadays were able to survive longer than ever before. This is due to the advancement in therapeutic techniques. In terms of communication for example, few children were able to express their will using existing communication tools including speaking in a way that everyone would understand them. In reality, according to Suzuki, there are few cases where home-cared children receive enough psychological and educational support while their health aspects are well cared for¹⁾.

All children, even with physical/mental challenges, seek fun through playing depending on their own development. No matter how old they are, children feel frustrated if they are given only passive materials such as children's books and TV. All children want to "play actively" and "take initiative" to express themselves. It is considered that the development of children shall be promoted significantly once they find that active playing is really fun and that expressing their own wills to others is really possible. Sato and her colleague also state, that to develop communication skills not only provides a means to express one's will, but also promotes children's other activities. It is, therefore, that communication is one of important segments to support children with severe/multiple disabilities²⁾.

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In this report, active play and effective communication tools considering the development of a female subject who suffered from SMAI with severe motor impairment and speech difficulty were reviewed. (particularly in terms of development)

(Ethical Considerations)

We obtained consent for publication in print from the family after thorough explanation of objectives of the study.

II. Case summary

K-chan (3-year old at the start of play support)

Date of Birth: April 2005 She was born in a private hospital. BW 3020g

Family: Father, Mother and a younger sister (1 year old)

Parents' occupation: Self-employed (managing an acupuncture clinic)

Previous medical history of K-chan

- 3 months old: She couldn't hold up her head. No strength in legs.
- 8 months old: Diagnosed as SMA Type I through genetic screening
- 11 months old: Started tube feeding
- A year and 5 months: Had a tracheotomy and a respirator
- A year and 6 months: Moved to home from hospital
- A year and 11 months: Underwent gastrostomy
- Intellectual development: Her responses and the understanding of language showed that her development is appropriate to her age
- Motor development: Unable to hold her own head, unable to sit up, unable to move limbs on her own
- Remaining motor functions : Eye movement, blinking, faint vocalization and fingertip movement, movement of mouth corner, movement of abdominal part

Note: * Spinal Muscular Atrophy: Due to a genetic defect of spinal motor neurons, muscle wasting and atrophy resulting in mobility impairments including walking difficulty occur. In severe cases, dysphagia and dyspnea are seen during infancy. The disease spectrum is divided into three types: Type I (Most severe form of the disease. Occurs in infancy), Type II (Moderately affected form), Type III (Mildly affected form).

III. Play Support

- 1) Action assignment for HPS regarding the current play situation of the subject
(would the term child be preferable to subject?)

K-chan was brought to outside once a week, including visiting zoos, aquariums, and amusement parks. Common everyday plays were watching DVDs, reading books and practicing Japanese alphabet by listening to actual sound of letters. Her parents took her out (in the future, they would like to take her to Tokyo Disney Land) in order for her to experience as many things as possible. She seemed to have a good environment. There were some concerns regarding appropriate communication tools and her common play materials since she seemed to be just a passive receiver with them.

Accordingly, a play program based on her development was designed and practiced by HPS.

2) Plan and practice of play support

(1) Annual support plan

[Goal] : To design types of play that K-chan is able to play actively so that K-chan feels “I can do it”.

[Practical strategies]

- 1 To obtain appropriate communication tool(s) based on K-chan’s ability and development.
 - A communication tool that everyone can understand easily
 - To have a common sign indicating YES/NO
 - To show consistent attitude toward K-chan
 - Questions to K-chan should be answered by YES/NO
 - To wait until K-chan answers
- 2 To provide a type of play based on the level of her development that K-chan can choose by herself, enjoy the involvement, and be satisfied with
 - From a passive participation to an active involvement
 - To let her play with what she choose (a sense of contentment)
 - Musical play (singing a song together, etc.)
 - Sensory play (sand, play dough, bubbles and actual fruits, etc.)
- 3 To provide play support to maintain her remaining functions and abilities with fun To encourage physical movement while singing [Let’s touch♪] (Appendix 1)

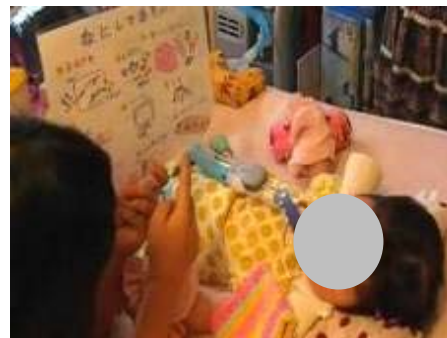
(2) A play list

HPS showed K-chan illustrations indicating types of play (a play list) and pointed one by one. K-chan then chose one type of play that she would like to play.

(Pic.1) (Pic.2)



Picture 1



Picture

(3) Monthly support plan (every two months)

A support plan schedule “Theme and play contents of the month” (see Appendix 2)

Themes were made to provide a sense of the season. Play contents were not changed every time, but new items and contents were added in the previous play contents reflecting the present season and her development.

3) Recording and evaluation of activities

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Recording K-chan's states, evaluations of activities from the perspective of HPS and of her family - General review (see Appendix 3)

K-chan's status the HPS's observations, and that of her family, was recorded every time when the HPS visited. By reviewing the written record, the HPS tried to apply what they had learnt from the previous session to the present session so that HPS was able to provide more practical and efficient play support as time went by.

At the first session, K-chan indicated by her facial expression "I want to play more" while playing with soap bubbles and singing a song (Pic. 3).

During the past 10 sessions, K-chan became used to HPS around by and by. K-chan enjoyed playing and showed her interest. At the same time, she came to understand ways to communicate with people by blinking and making sound from her mouth. Her facial expression showed a sense of satisfaction when she played enough.

Her parents said that it was an eye-opener for them to know that playing would be an important factor for supporting their daughter. They were happy to see that their daughter enjoyed playing and they tried to participate in playing with her despite they had a busy schedule. Her parents requested other helpers (nurses, care-helpers, OT and volunteers) to relate to their daughter in the same manner (Appendix 4).

Further, they even introduced the communication method that HPS did with their daughter into their business (pediatric acupuncture) since they agreed with the concept of HPS's work.



Picture 3 and 4

IV. Discussion

There are few studies on play support for home-cared children with severe handicaps. There are none, especially, for studies on play support for children with SMA type I. To invent types of play and tools for K-chan to involve actively, published books including Nursery Childcare Guidelines, 『Let's have fun with finger plays (みんなで楽しい手遊び)』⁴⁾, 『Ways to play. Let's play with your mum! (ママと一緒に!! あそびの工夫)』⁵⁾, 『A picture book for infant play (乳児のあそび大図鑑)』⁶⁾ and 『I found my favorite play (大好きあそびみつけた)』⁷⁾ were referred for this study. For plays requiring physical activities such as "Here we go round the mulberry bush", we changed our way of thinking and we went round K-chan instead of her moving. How we could involve her in certain types of play, and how we should develop play in a way that K-chan would actively enjoy, were our main focus when we innovated a type of play and eventually we created the play list for K-chan called "Which shall we play?" (Pic. 2).

When we provided play support to K-chan, we always asked her to choose what she would like to do and we tried not to rush for her answer. We consciously introduced to her some sensory plays using water, sand, play dough and soap bubbles to stimulate her five senses. Play using music and songs that required alternating performances (kakeai) were used, so that K-chan did not have to listen to the music passively but enjoyed active involvement with us. K-chan seemed very happy during such music session.

One of K-chan's characteristics was that she never gave up. It was prominent when she played with things that she chose. As Watanabe and colleagues state "When a request of a child is granted, the child comes to understand that he/she can make a change in a given situation through expressing his/her own will⁸⁾", it was evident that K-chan also came to understand that her request would be granted by sending her messages through communication tools understandable to everyone. By this understanding, her everyday life shall be more active than ever before. It was clear that the play support that had been provided to K-chan appeared significantly effective and the result indicated the importance of play for children with disability. It was also indicated that children's development would be promoted when they were stimulated with various types of play.

Our support for K-chan continues. We are working on an integrative support for K-chan in cooperation with her family, nurses, OT, helpers and volunteers by focusing on her remaining physical functions, especially her eye movement, in order to have better communication with her. In addition, we would like to educate society that the importance and the necessity of play support in children with disability and their families.

Acknowledgement

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Evaluation on Play Support Program

Date of Implementation: January 20, 2010

- **Theme: Review of favorite types of play**

- Chose a type of play that K-chan really liked in the previous sessions
- Used eye movement as a communication tool during the play

- **K-chan's status on that day from HPS's view**

During the playtime with K-chan, I was paying extra attention to catch her subtle signs. She was becoming good at moving her eyes to tell us her wills. I was impressed to see that K-chan was really trying to show what she felt, by moving her face, fingers and body. She enjoyed play sessions she chose for a long time and showed her “never-give-up” attitude when she played with the ball race game. We sang a “kakeai (singing alternately)” song together. I'm glad that she had great fun. In the end of the session, she fell asleep while we were playing with our fingers. It showed her satisfaction.

- **K-chan's status from the parents' view**

Today's play started with a type of play chosen by K-chan. K-chan was asked what she wanted to do, by reading one by one on the list, and she gave us a sign (yes/no) by moving her eyes. In the previous session, she learnt to move her eyes from side to side. This time, we added “up and down” movement. With the eye movement, she chose the “tearing-up newspaper” play and enjoyed the sound and feeling of the newspaper with the HPS staff. Later, she played house by cooking the pieces of the newspaper on a toy frying pan, then pretended to eat them. It was good to see that she associated one play with another one.

She also played with a ball rolling down a slide and hit the pins that represented monsters. She struggled to let go of a ball. She looked really adorable when she was working on the ball with great enthusiasm. It also told us that we should place K-chan in an appropriate position so that she could play easily.

She was baking a toy cake while singing with the HPS staff who was disguising as Mickey Mouse. K-chan also enjoyed a magic show where many items appeared from a magic pocket. She was making many sounds from her mouth and expressed her joy by moving her eyes and other parts of her body. In the end, she fell asleep while listening to a song “A song for K-chan's hands”. It showed that she played well and really enjoyed. Her face looked content.


- **Review comment (as HPS)**

K-chan seemed to come to understand how to communicate with people by her eye movement. It was obvious that she tried to move her eyes often. I don't think that it will take much time for her to communicate more effectively. Above all, I was grateful that K-chan seemed to accept the HPS and even fell asleep in peace. Further, her mother also sang together and it showed K-chan and parents really used the HPS's method in their everyday life, even when the HPS were not with them.

We were grateful to her parents for talking to us openly, and for letting us learn their struggles that only families of children like K-chan would go through. We have seen that their positive manners toward K-chan seemed to have provided good influences on K-chan.

Let's Touch

| | |
|----------------------------------|-------------|
| Let's touch | (touch) |
| Let's touch | (touch) |
| Let's touch with K-chan | (touch) |
| Let's do "poco-poco" | (poco-poco) |
| Let's do "poco-poco" | (poco-poco) |
| Let's do "poco-poco" with K-chan | (poco-poco) |
| Let's move your eyes | (move eyes) |
| Let's move your eyes | (move eyes) |
| Let's move your eyes with K-chan | (move eyes) |
| Let's talk together | (Ah-) |
| Let's talk together | (Ah-) |
| Let's talk together with K-chan | (Ah-) |
| Let's smile together | (smile) |
| Let's smile together | (smile) |
| Let's smile together with K-chan | (smile) |
| Let's say good-bye | (bye-bye) |
| Let's say good-bye | (bye-bye) |
| Let's say good-bye with K-chan | (bye-bye) |

| | |
|--|--|
|  <p>Which play do you like doing today?</p> | |
| June & July 2010 | Theme: Let's play with water and sand!! |
| Objective | To make K-chan take initiative and enjoy actively |
| | Note for supporters Please ask "Yes/No" questions |
| How about following plays? | |
| Musical Play | Let's sing songs including "Let's clap your hands" "aye-aye" "piggy-raccoon-fox-cat" "panda-koara-rabit" "The field of animal village" Finger play: "Ton-Ton-Ton-Ton a old beard man, Tickle-tickle-one straight bridge, A song for Melonpan, Which color do you like?" |
| Sensory Play | Play dough, soap bubbles, sand, treasure hunting 1), treasure hunting 2). To touch and smell actual materials such as fruits. Handicraft with play dough. Play with water, sand and mud. |
| Play using hands | Play rolling balls, play with PC (with touch sensor). Play house, rain, tearing up papers, drawing pictures with water paint, play dough, colorful arts |
| Play using imaginations | Handy-dandy, children's books, puppet, picture-story show: "MOMIMOMI Doctor" "Alice in Wonderland" "Three Little Pigs" "Let's play together" |
| Play for communication (YES/NO) | Quiz, games such as "Which color do you like?" |
| Physical Play | To move body while singing "Let's touch", Here we go round the mulberry bush", Boiling hot boiling a pot". Communication exercise: "K'chan's hands" Helping-out exercise: Fluffy board |
| Note | <ul style="list-style-type: none"> ● Please make a day schedule with K-chan. Set simple rules with her (ex. TV time, bed time, etc.) ● Please create something that K-chan can help out for you. |

For those who support K-chan

Children grow up through playing.
Children learn through playing.
But those are just by-products of playing.
Playing is fun. Playing brings a joy.
We forget time while playing.
That is the power of playing.

Like everyone else, K-chan wants to play.
She wants to experience fun, thrill and excitement, as much as possible.
Through such experiences, she will be growing up.
Furthermore, she will be seeing her future dreams through playing.

Please make as many play opportunities as possible for K-chan.
Because of her disease, her play opportunities will decrease without your creativity, imagination and innovation.
With you, however, she can play plentifully.
She can play limitlessly.

Please do not forget one thing when you offer a play to K-chan.
When she can “choose” what to do,
Please let her choose.
Please give her opportunities to choose things herself.

Which book do you want to read? Which colour do you want to use? Which song do you want to sing?

Please give her as many chances to choose as possible.

Because she will feel that she is cared for through choosing things herself. She will start recognizing her own “feelings” by choosing. Her personal quality becomes more and more obvious and you can feel it by and by. As she becomes mature, she will learn to take responsibilities of her choices. That is a step to become a mature adult. Unfortunately, experiences of both “playing” and “choosing” of many children in a care environment are lacking.

Children live in the present.
They watch with their glittering eyes the world around them.
Now, let's begin play support!