



[原著]

A mother and visiting nurses notice and share the suffering of a child with severe motor and intellectual disabilities (SMID)

Tomomi Sato ¹, Naoko Machida ², Kaori Hayama ³

1) Department of Pediatric Nursing, Graduate School of Medicine
Yokohama City University

2) Yokohama Rosai Hospital

3) Nagomi Visiting Nurse Station

Summary

The purposes of this study are to clarify how visiting nurses understand the suffering of a child with severe motor and intellectual disabilities (SMID), to examine how they communicate these matters with child's mother, and to clarify how a mother and home visiting nurses notice and share the suffering of the SMID children in order to provide proper medical treatment at home. Semi-structured interviews were conducted with a mother whose child requires medical homecare, and with two home visiting nurses. Four categories for mother's notices: (1) Mother noticed her child's complaints about suffering from the timing and the size of the reaction; (2) Mother noticed her child's suffering through his unusual appearance; (3) Mother noticed a difference between suffering and anger, when a child got a usual treatment; (4) Mother was not confident in reading her child's emotions. Three categories for the visiting nurses' notices: (1) Visiting nurses noticed suffering from comparing the child's appearance when they visited, with what they had previously visited; (2) Visiting nurses noticed suffering from comparing the child's reactions to the care when they visit last time, with a similar care; (3) Visiting nurses respected the mother's judgment because they were not confident in their judgment of the child's feeling. Three categories of notices, which were shared by visiting nurses and the mother: (1) Mother identified the cause of her child's suffering together with various professionals and pursued better care; (2) Visiting nurses gave priority to the mother's judgment because they couldn't be sure to judge her child's feelings; (3) Visiting nurses shared the child's noticed suffering with his mother, and made use of it to decide what to do in the future. We conclude that it is necessary for visiting nurses to learn a mother's past experience and judgment on her child's suffering and to use them, together with mother, to quickly understand the child's suffering in a situation of visiting care.

Keywords: Home Visiting Nurse, Mother, Severe Motor and Intellectual Disabilities (SMID), Suffering, Share

Corresponding Author: Tomomi Sato
Department of Pediatric Nursing, Graduate School
of Medicine Yokohama City University
E-mail: sato0515@yokohama-cu.ac.jp

2019年 9月 3日受付
2019年 10月 7日受理

I. Introduction

The children with severe motor and intellectual disabilities (SMID) has severe intellectual disability and physical disability (Ministry of Health, Labor and Welfare, Japan, 2011). They have an IQ of 35 or below and are unable to maintain a standing position. It is difficult for them to communicate with people around them. Moreover, they can't express themselves verbally and they tend to cause breathing disorder and suffering due to their skeletal deformation. Therefore, it is important for their parents to grasp and handle their reactions to help them to live comfortably.

Mothers grasp their SMID children's needs from their "facial expressions", "body movement" and "eye movement", "heartbeat monitor sound". In many instances, however, they have to make a guess about their needs (Suzuki, 2013). In addition, even if they understood their emotions, they are also aware that the meaning cannot be confirmed (Suzuki, 2013). Nurses derive the meaning from slight expressions and changes in their emotions (Tanaka, 2015). Ward nurses grasp the alarm sound as the children's intention and they sharpen their own sense to confirm whether the alarm sound is their intention of "suffering" (Hirano, 2005). Therefore, their understanding of SMID's could be through gathering and examining a lot of information from caring the child.

Recently, it was found that children with SMID can live at home with the assistance of medical devices (Kikuchi, 2013; Yoshino et al., 2006). Visiting nurses need to gather, grasp, and judge their suffering as well as care for them during their short visiting periods. Their pain can be objectively assessed by Facial Action Coding System (FACS) and Pediatric Pain Profile (PPP) (Kawata, 2016). However, it is important not only to grasp the presence or absence of pain, but also to grasp the distress and discomfort experienced by them.

Moreover, it is necessary to clarify the process of understanding their suffering in order to ensure care and comfort of them. However, there has been no research on visiting nurses to understand the suffering of SMID. Moreover, there was no study on how they grasped the suffering of infants with SMID during

their short visits and responded to it. Therefore, this study aimed to clarify how they understood the SMID children's suffering and examine how they communicate these matters with children's mothers. We do this by looking at a case of a child with SMID who received visiting nurses.

II. Method

1. Participants

Two visiting nurses and one mother of a child with SMID (boy), who used the facility of visiting nurses.

2. Study design

For qualitative descriptive research, a method referred to "Case Study Research" (Yin, 2011) was employed. This method was chosen because a typical case can be confirmed if a case study is an excellent case. (Yin, 2011). This case was an excellent case where both mothers and nurses could understand contents of suffering of children.

3. Study period

June, 2016 to October, 2016.

4. Data collection

Data were collected through interviews. The participants were the child, his mother and two visiting nurses who were recommended by the visiting nursing station manager. The interviews were conducted from the perspective of the nurses in order to answer the questions "How did mothers and visiting nurses understand the suffering of their children?" and "How do mothers and visiting nurses communicate about their perceptions of the child's suffering?". Interviews were conducted in accordance with the participants' convenience of time and place. Interviews lasted for 1520 minutes and repeated interviews were conducted two to three times as to contend understanding requirement. The contents of the interview were recorded either in an IC recorder or in handwriting scripts with the permissions of the research participants.

5. Analysis

The interview was created as a verbatim record, read carefully, and then divided into sections. Data were classified in terms of their meanings, summarized and encoded. The code was then typed, categorized and subcategorized. The category is built with the similar theme of complaints. The research process was supervised by a veteran researcher, a

child nursing researcher, and a peer reviewer. In the analysis, member checks were performed to ensure the trustworthiness (Lincoln & Guba, 1985) of the analysis.

6. Ethical considerations

The study was conducted after the participants of the study were informed about the research plan and their consents were obtained. The research participants, visiting nurses and mother, were explained the research purpose, method, freedom of participation and freedom of refusal, confidentiality, and data processing methods. Signatures were obtained after participants consented to be part of the study. This study was carried out after obtaining a Certificate of Approval from the Yokohama City University Ethics Committee (Approval No. 160324045).

III. Results

1. Participants

The participants were a mother of child (boy) with SMID and their home visiting nurses. The average of clinical experiences of the nurses was 16 years, with an average of seven years of visiting nursing experience. The child with SMID was eight years old. He always used a wheelchair on an account of severe brain damage due to hypoxic encephalopathy. He could not make eye contact with people. He received the visiting medical treatment once a week, visiting nursing twice a week, and visiting class three times a week. He received hygiene care, developmental support and home-based nursing care as well as rehabilitation. He had high medical needs and received gastrostomy, pulmonary physiotherapy, noninvasive positive pressure ventilation. The results of this study found that the mother's and visiting nurses' understanding of his suffering consisted of 82 codes, 22 subcategories, and 10 categories. The categories were divided into three themes: 1) The mother's notices, 2) The visiting nurses' notices, 3) The notices shared by the visiting nurses and by the mother (Table1). In the following, each theme is shown with [categories], <subcategories>, and "narratives".

2. Results

Theme 1: The mother's notices

(1) [Mother noticed her child's complaints about suffering from the timing and size

of the reaction]

<Mother noticed what the child wants to say from his strong reaction shown at the timing of painful treatment.>

She noticed that when he underwent painful treatment such as injection, even if she tried to distract him, he disliked the treatment, the timing of it, tried to say something, or simply suffered from pain.

(2) [Mother noticed her child's suffering through his unusual appearance]

<Mother noticed that the child was "annoyed" from his unusual physical tension, appearance and facial expression.>

The reason was that she felt that his kick, handshake, and whole body force was different from his usual reaction.

<Mother noticed the child's "boredom" and "discomfort" from his state of poor response while playing.>

She grasped his "boredom" and "discomfort" when he did not respond or change even when she played a game that he usually enjoyed.

(3) [When the child got the usual treatment but his reaction was different, his mother noticed the difference between suffering and anger]

<Mother noticed the reason for suffering through how he cried changed by switching from soothing him to apologizing to him.>

When he was both annoyed and painful, he had the same reaction i.e. "crying".

She took notice of the cause of crying through the difference in his reaction when she apologized to him, who kept crying even though she was soothing him.

<Mother judged the difference between "suffering" and "anger" through the change of the timing of care, the difference in reaction duration and in the reaction after the same treatment.>

The mother took notice of this through his screaming duration, treatment, and time when the reaction stopped, as they got distracted.

(4) [Mother was not confident in reading her child's emotions]

<Mother was not confident in reading of the child's emotions.>

She stated that she could not read his feelings: "Maybe I'm just making a decision.", "His feelings may be different.", "I don't know if his needs are not.", "I can't always read his feelings." and "At first I don't understand his emotions."

Table 1 A mother and visiting nurses notice and share suffering of a child with SMID

Theme	Category	Subcategory
1.The Mother's Notices	1.[Mother noticed her child's complaints about suffering from the timing and size of the reaction]	• Mother noticed what the child wants to say from his strong reaction shown at the timing of painful treatment.
	2.[Mother noticed her child's suffering through his unusual appearance]	• Mother noticed that the child was "annoyed" from his unusual physical tension, appearance and facial expression. • Mother noticed the child's "boredom" and "discomfort" from his state of poor response while playing.
	3.[When the child got the usual treatment but his reaction was different, his mother noticed the difference between suffering and anger]	• Mother noticed the reason for suffering through how he cried changed by switching from soothing him to apologizing to him. • Mother judged the difference between "suffering" and "anger" through the change of the timing of care, the difference in reaction duration and in the reaction after the same treatment.
	4.[Mother was not confident in reading her child's emotions]	• Mother was not confident in reading of the child's emotions.
2.The Visiting Nurses' Notices.	1.[Visiting nurses noticed suffering from comparing the child's appearance they felt when they visited, with what they had felt]	• Visiting nurses noticed "scary feeling", "uncomfortable feeling", and "painful feeling" from how strongly and where hypertonia occurred when touching first at the visit • Visiting nurses noticed suffering by comparing it with the reaction of the child during the last visit.
	2.[Visiting nurses noticed suffering from comparing the child's reactions to the care when they visited, with a similar care]	• Visiting nurses noticed the "suffering" from the change in the reaction after the care in this visit. • Visiting nurses noticed feeling of "disgust" from the appearance different from usual. • Visiting nurses noticed the "suffering" of the child by noticing how strongly and where hypertonia was, through comparing with same care last visit. • When Visiting nurses noticed discomfort from a reaction while care was administered, they stopped care and thought about the cause of the reaction.
	3.[Visiting nurses respected the mother's judgment because they were not confident in their judgment of the child's feeling]	• Visiting nurses were not confident in their judgment of the child's emotion. • Visiting nurses respected the mother's judgment.
3.Notices shared by the visiting nurses and the mother	1.[Mother identified the cause of her child's suffering together with various professionals and pursued better care]	• Mother identified the cause of the child's discomfort from the result of the care she performed to solve his discomfort . • Mother tried to improve the care by adding the advice from professionals to the cause of child's discomfort she specified. • Mother and professionals considered the cause of the discomfort and direction of the care from the reaction after the care they did together.
	2.[Visiting nurses gave priority to the mother's judgment because they couldn't be sure to judge her child's feelings]	• Visiting nurses judged the child's suffering and its cause from his appearance when they were not visiting that told by his mother. • Visiting nurses did the care against the child's suffering together with the mother which she usually did . • Visiting nurses noticed carefully and understood how the mother took notice of the child's suffering , and her childcare policy, through their care.
	3.[Visiting nurses share the child's noticed suffering with his mother, and made use of it to decide what to do in the future]	• Mother and visiting nurses shared and supplement their opinions of the child's suffering and their causes, and did care together. • Visiting nurses cared together with the mother to prevent deformations and suffering that they expected would happen in the future.

Theme 2: The visiting nurses' notices
 (1) [Visiting nurses noticed suffering from comparing the child's appearance they felt when they visit, with what they had felt]
 <Visiting nurses noticed "scary feeling", "uncomfortable feeling", and "painful feeling" from how strongly and where hypertonia occurred when touching first at the visit.>
 They first touched him and grasped his pain and emotion through his muscle tone, muscle hardness, and breathing status.

<Visiting nurses noticed suffering by comparing it with the reaction of the child during the last visit.>
 Next, in order to judge the current suffering of the child, they recalled his condition during a recent visit as follows:
 "Recently, he seemed to suffer because his breathing was not good." "Recently, his tension was less after he moved." "His tension was strong when he was at home all day." By comparing his previous state with the current one, the degree of suffering was judged.
 (2) [Visiting nurses noticed suffering

from comparing the child's reactions to the care when they visit last time, with a similar care]

<Visiting nurses noticed the "suffering" from the change in the reaction after the care in this visit.>

They knew about his pain from his reaction after taking care. For example, they recalled the following experience: his foot was injured as a shoe did not fit his foot, when a child's muscle tone was strong. Then, when he put on shoes as a trial, the child returned to normal muscle tone, and was judged to have pain in his foot.

<Visiting nurses noticed feeling of "disgust" from the appearance different from usual.>

They took notice of his feeling of "disgust". They compared the two facts. One is that one day he was moving during the care. Another is that he was relaxed and received the same care well another day. They considered, "Today, he doesn't like the care."

<Visiting nurses noticed the "suffering" of the child by noticing how strongly and where hypertonia was, through comparing with the same care last visit> When they read the level of his suffering related to care, they compared the magnitude of his physical movement, response and his muscle tone when performing the same care with prior visits.

<When Visiting nurses noticed discomfort from a reaction while care was administered, they stopped care and thought about the cause of the reaction.> When he clearly demonstrated unusual reactions, such as trembling or an unpleasant expression while they were administering care, they assumed that he disliked the care and hence, ceased to continue providing it. When he seemed to feel at ease after the care stopped, she concluded that "the child actually disliked care" and attempted to clarify the cause.

(3) [Visiting nurses respected the mother's judgment because they were not confident in their judgment of the child's feeling]

<Visiting nurses were not confident in their judgment of the child's emotion.> They said, "Unlike the mother, it is not possible to distinguish between muscle tension caused by the feeling that he

wants to work hard or muscle tension caused by mental tension."

They thought they could not capture his emotions like his mother could.

<Visiting nurses respected the mother's judgment.>

They felt that she best understood him, and wanted to respect her opinion and work without dismissing her thoughts and ideas. They also wanted to give partial advice when her knowledge was biased or when medical knowledge was needed.

Theme 3: Notices shared by the visiting nurses and the mother

(1) [Mother identified the cause of her child's suffering together with various professionals and pursued better care]

<Mother identified the cause of the child's discomfort from the result of the care she performed to solve his discomfort.>

The mother thought that the increase in his pulse during the walk was due to the size of the buggy, the outside temperature, and the posture, and was, therefore, taking measures based on the value of the SaO₂ (arterial oxygen saturation) by pulse oximetry. She settled him down during his walk and took a resting pulse.

The cause of the discomfort was then determined to be the buggy vibration. She then tried to think of ways to reduce the vibration.

<Mother tried to improve the care by adding the advice from professionals on the cause of the child's discomfort she specified.>

The mother consulted the visiting nurse and physical therapist (PT) on the cause of the unpleasant reaction during the care in order to provide better care. This helped identify the cause of the child's discomfort. In addition, she adopted professional's advice that she should use a cushion and this led to better care.

<Mother and professionals considered the cause of the discomfort and the direction of the care from the reaction after the care they did together.>

During the joint care, mother and professionals confirmed that children always screamed after bathing, and the decision that "the wet and cold head causes discomfort". It was concluded from the reaction that the screams calmed down when drying the hair with

a dryer. After sharing, they examined future bathing care.

(2) [Visiting nurses gave priority to the mother's judgment because they couldn't be sure to judge her child's feelings]

<Visiting nurses judged the child's suffering and its cause from his appearance when they were not visiting that told by his mother.>

They tried to understand his condition by listening to what his mother said about his fever and breathing status that occurred when they were not present.

<Visiting nurses did the care against the child's suffering together with the mother which she usually did.>

They said that they practiced what she thought was good for him, and they also did the care for pain the way she usually did. Both of them worked together to understand the change in his suffering.

<Visiting nurses noticed carefully and understood how the mother took notice of the child suffering, and her childcare policy, through their care.>

They gauged the idea of her care, nursing policy, and how to perceive suffering, without touching upon sensitive issues.

(3) [Visiting nurses shared the child's noticed suffering with his mother, and made use of it to decide what to do in the future]

<Mother and visiting nurses shared and supplement their opinions of the child's suffering and their causes, and did care together.>

The visiting nurses checked with the mother how she takes notice of a change in her child and asked her whether she laid the child down when he seemed like he was suffering a little. Then, they shared their points of view. In cases where the cause of the child's suffering captured by the mother was different from the nurses' view, they listened to her thoughts, provided her perspective and knowledge, and supplemented her lack of knowledge. The mother and visiting nurses shared their opinions about suffering and its causes.

<Visiting nurses cared together with the mother to prevent deformations and suffering that they expected would happen in the future.>

The visiting nurses predicted his bone deformation that the mother could not predict, and included back stretches to prevent possible suffering.

IV. Discussion

1. The perception of the suffering of the child with SMID by the mother and the visiting nurses

In this study it was revealed that the mother's perception of the contents of her child's suffering was based on her past experiences of identifying his suffering. Moreover, these perceptions were also interpretations of the differences she observed in him before and after the care that was administered. These included the differences in his state compared to his usual state, the differences in his reactions to the same type of care or treatments, and the differences in the timing and severity of their reactions. Sawaguchi (2013) stated that the mother identified her child's pain based on changes in his complexion and changes in their expressions (based on her senses). This indicated that because she spent large amounts of time with her child on a routine basis, she therefore started to develop the ability to read his emotions and to interpret or understand them from her perspective. Although the mother identifies her child's suffering based on her intuition, in this study it is revealed that she is interpreting the suffering using "how different from usual the child is", "the difference in reaction towards the same treatment", and "the difference in the timing and the severity of the reaction" as her points of reference.

Furthermore, the visiting nurses in this study were identifying the pain of the child by comparing his reaction with his reactions from her past observations. These included the difference in how they felt during a visit observing the recent state of him, and the difference in his reaction to the care, in comparison to past instances of care. Tanaka (2015) referred to this as "comparison with the previous day" as it was used by hospital ward nurses to identify and interpret the emotions of the child with severe disability, clarifying that they give meaning to the children's emotions by comparing them with their past experiences. This study reveals that, for visiting nurses, in order to gauge the child's suffering, they not only compare it with their past experiences but use a specific perspective of interpreting the

suffering by comparing it with the child's state and their reaction toward the care during recent visits.

Based on the above, it is revealed that the commonality between how the mother and the nurses identify the suffering of her child is that they use their experience of gauging his suffering as a reference, with this reference being formulated based on the information they gathered from interacting with him over a long period of time. In order for the visiting nurses to identify and interpret his suffering in the short visitation period, this study suggests that it is important for them to collect the relevant information by understanding that the mother, who has had experience with her child for a long period of time and has a lot of information about his suffering.

2. Sharing information to more accurately understand the suffering of a severely disabled child

This study's results showed that while the mother and the visiting nurses tried to interpret the suffering of the child based on their past experiences, they also felt that they could not feel certain in gauging the child's emotions.

The factor contributing to this is uncertainty characteristic of children with SMID that cause restriction of movement of their entire body, including the facial expression muscles, thus making it difficult to notice a change in their emotions (Sato, 2016). It indicates that approximately half of the parents interpret their child's emotions by making assumptions on how their child probably feels (Suzuki, 2013). He was a child who was the participant of this study, suffered from a severe brain disorder and was bedridden. He also rarely showed clear reactions, such as making eye contact when someone called out for him. For this reason, in this study his mother probably felt uncertain about reading his emotions. In addition, Suzuki (2002) states that background factor contributing to the visiting nurses' uncertainty about their assessment of the child's emotions is attributed to the limited amount of time in which they interact with the target child. Since they interact with the children for a limited period of time, they do not feel certain about their interpretation of the children's emotions.

While this study indicated that the mother and visiting nurses felt uncertain about their interpretation of the feelings of children with SMID, it was realized that, by working with professionals, the mother may be able to identify the causes of her child's suffering and to seek better care, as shown in this study. In addition, the visiting nurses believed that the mother understood him best and improved the care they provided by listening to what she said about his suffering, and assessing and gauging his suffering as the visiting nurses and mother worked together to provide much better care. Wang et al. (2012) revealed that visiting nurses provided information on nursing care to mothers at the time of their visits. Before providing the nursing care they had planned, the visiting nurses in this study first checked the suffering of the child together with the mother and discussed together with her the care and its role in alleviating suffering. Only after listening to her perspective, did the visiting nurses go ahead to administer the care. They first checked about the suffering or discomfort of the child with her, as a cross checking mechanism in order to ensure they were more certain about the emotions they both identified and to provide better care and reduce the suffering. Furthermore, it was revealed that visiting nurses could provide care by predicting the suffering of a child with SMID might feel in the future. Children/persons with SMID experience premature aging, together with deteriorations of various mental and physical functions, manifested in young ages (Ogawa, 2012). It is believed that visiting nurses provide her support by sharing information about future suffering that she doesn't understand and will be caused because of the disability.

V. Conclusion

In this study an interview was conducted with the purpose of clarifying how mothers and visiting nurses identified and shared their understanding and interpretation of the suffering of children with SMID, using a case study of a mother, her child with SMID and two primary visiting nurses.

From the present study, the following conclusions were drawn, by conducting

interviews with a mother who has been providing care for her child with SMID along with the primary visiting nurses: 1. The mother gauged the contents of her child's suffering during treatment by comparing the differences in his reactions. 2. The visiting nurses gauged the presence of the child's suffering by comparing differences in his reactions. At the same time, they believed that the mother understood his emotions best and interacted with him by respecting her opinions. 3. The mother and the visiting nurses provided better care for the child by combining the opinions of her, who understood him best, with the opinions of them, who had the medical knowledge.

VI. The limitations of this study and tasks for the future

In this study, an interview was conducted with a mother and the visiting nurses involved a single case study. In the future, more examinations need to be conducted by increasing the number of case examples and expanding the target facilities.

Acknowledgements

We would like to extend our gratitude to the family and to the employees at the visiting nursing care station who have cooperated in this study.

This study was funded by the Grant-in-Aid for Scientific Research by the Ministry of Education, Culture, Sports, Science and Technology, Japan, Basic Research (C) (15K11714). This study was presented in part at the 3rd International Society of Caring and Peace Conference.

There are no entities or relationships, presenting a potential conflict of interest requiring disclosure in relation to this paper.

VII. References

- Arimoto, Azusa, Yokoyama, Yumi, Nishigaki, Kaori, et al.: Points that visiting nurses think are important when supporting mothers of children with severe motor and intellectual disabilities being cared for at home. *Japan Academy of Community Health Nursing*, 2012, 14(2), 43-52.
- Fjii, Miyoko and Kusaba, Hifumi: Recognition on disagreement between the mother and nurses in the care of children and persons with severe disability. *The South Kyusyu Journal of Nursing*, 2010, 8(1), 13-21.
- Hirano, Miyuki: Nurses' interaction with children who wear artificial respirator and have no awareness nor reaction due to brain disorder: Distinguishing children's voices. *Journal of Japan Academy of Nursing Science*, 2005, 25(4), p.13-21.
- Kamata, Ayumi: Expression of pain shown by children with cerebral palsy who have difficulty communicating verbally. *Journal of Severe Motor and Intellectual Disabilities*, 2016, 41(2), 236.
- Kikuchi, Norihiko: Current state and issues of community living support for children (persons) with severe motor and intellectual disabilities and their families. *The Japanese Journal of Special Education*, 2013, 50 (5), 473-482.
- Matsuda, Nao: Re-examining communication of heavily-disabled children. How to read intentions expressed by heavily-disabled children and interaction measures. *The Japanese Journal of Communication Disorders*, 2012, 29(1), 48-54.
- Matsuoka, Mari: Cooperation between children/family and the medical team and the roles of the nurse. *The Japanese Journal of Child Nursing*, 2014, 37(8), 935-945.
- Tanaka, Mio, Odera, Saki, and Sumiyoshi, Tomoko: Nurse's perspectives for capturing emotions of children with severe motor and intellectual disabilities. *Collected Papers of the Japan Society of Nursing: Psychiatric Nursing*, 2015, 45, 175-178.
- Ogawa, Katsuhiko.: The premature aging phenomenon of persons with severe motor and intellectual disabilities. *Nursing for Profound Developmental Disabilities*, 2012, 7(2), 137-144.
- Suzuki, Machiko.: Parent's perception of communication ability of mechanically-ventilated children with severe disabilities. *The Journal of Child Health*, 2013, 72(5), 713-720.
- Suzuki, Manami, Miyata, Saori, Chikamura, Saeko, et al.: Structure and characteristics of nursing practice terminologies in visiting care. *Journal of Japan Academy of Nursing Science*,

2002, 22(2), 1-22.

Sato, Tomomi.: Growth and development of children with disabilities, the fundamentals of care for nursing for children with severe motor and intellectual disabilities. Herusu Shuppan, 2016, pp48-59

Sawaguchi, Megumi: Structuring mother's judgment related to the physical condition of children with severe motor and intellectual disabilities living at home. Journal of Severe Motor and Intellectual Disabilities, 2013, 8(3), 507-514.

The Ministry of Health, Welfare, and Labour.: The Child Welfare Act, Article 7(2), 2005. <http://www.mhlw.go.jp/bunya/kodomo/pdf/tuuchi-01.pdf>. 2016.11.25)

Yin, Robert K.: Case Study Research 2nd ed. (K. Kondo, translator): Chikura Syobo, Tokyo, 2011.

Yoshino, Hiroyuki, Yoshino, Mayumi, Tanaka, Yujiro, et al.: The issues of pediatric at-home medical care and expectations of the nurse. The Japanese Journal of Home Care Nursing, 2006, 1(2), 112-118.

重症心身障害のある子どもの苦痛に関する母親と訪問看護師の理解と共有

佐藤朝美¹⁾ 町田奈緒子²⁾ 葉山香里³⁾

1) 横浜市立大学大学院医学研究科看護学専攻 2) 横浜労災病院 3) なごみ訪問看護ステーション

要旨

【目的】母親と訪問看護師が、重症心身障害のある子どもの苦痛をどのように捉え、共有しているかを明らかにする。

【方法】ケーススタディ法を用いた。研究参加者は1ケースの子どもの母親と担当訪問看護師2名であり、子どもの苦痛をどのように捉えているか、捉えた苦痛を母親と看護師がどのように共有しているかについて、半構造化面接を行った。

【結果】子どもの苦痛に対する理解について、母親のインタビューから「母親は、反応のタイミングと大きさから子どもの苦痛の主張を把握する」「母親は、子どものいつもと違う様子から苦痛を把握する」「母親は、同一処置のケアに対する子どもの反応の違いから、痛みと怒りの差を把握する」「子どもの感情の読み取りに確証がもてない」が明らかになった。

訪問看護師の子どもの苦痛に対する理解については、「訪問看護師は訪問時に触れた感覚と最近の様子を比較して苦痛を把握する」「訪問看護師は訪問時のケアと過去のケアに対する子どもの反応の相違から苦痛を把握する」「訪問看護師は子どもの感情の判断に確証が持てないため、母親の判断を尊重する」が示された。

また、母親と訪問看護師のインタビューから、それぞれが捉えた子どもの苦痛に関して共有し理解を進める場面があることが示された。その共有場面とは、「母親は、専門職と一緒に子どもの苦痛の原因を特定し、よりよいケアを追求する」「訪問看護師は、子どもの感情を確実に判断できないため、母親の判断を優先する」「訪問看護師は、把握した子どもの苦痛を母親と共有しながらケアにつなげる」であった。

【考察】訪問看護師が短時間の訪問の中で子どもの苦痛を捉えるためには、普段から子どもの様子を良く知っている母親が捉えた「子どもの苦痛に関する情報」を知ることの必要性が示された。また、母親と看護師双方に「子どもの感情の判断に確証が持てない」との結果から、訪問看護では母親と「一緒に苦痛に関する判断を確かめること」が重要であると考えられた。

本調査は平成 27-30 年度文部科学省科学研究費助成金(C)を受けて実施した。また、本研究の一部を第3回国際ケアリング学会で発表した。

キーワード：重症心身障害児、訪問看護師、母親、苦痛、共有