

# Lifestyle Adjustment Process to Maintain Family Life for Mothers with Children Who Need Home Medical Care

Yuko Nakakita<sup>1</sup>, Yuko Tomari<sup>2</sup>

<sup>1</sup>Faculty of Nursing, Mie Prefectural College of Nursing, Mie, Japan

<sup>2</sup>Faculty of Nursing, Osaka Medical University, Osaka, Japan

Email: [yuko.nakakita@mcn.ac.jp](mailto:yuko.nakakita@mcn.ac.jp)

**How to cite this paper:** Nakakita, Y. and Tomari, Y. (2018) Lifestyle Adjustment Process to Maintain Family Life for Mothers with Children Who Need Home Medical Care. *Health*, 10, 1679-1696.  
<https://doi.org/10.4236/health.2018.1012127>

**Received:** November 6, 2018

**Accepted:** December 10, 2018

**Published:** December 13, 2018

Copyright © 2018 by authors and Scientific Research Publishing Inc.  
This work is licensed under the Creative Commons Attribution International License (CC BY 4.0).

<http://creativecommons.org/licenses/by/4.0/>



Open Access

## Abstract

This aim is to clarify lifestyle adjustment process to maintain family life for mothers with children who need home medical care. We conducted semi-structured interviews with the mothers of children who required home medical care comprising procedures such as suction of sputum and respiratory management over a period of several years since the initiation of home medical care, and analyzed the results using the modified grounded theory approach (M-GTA). We found the process to be composed of nine categories. Immediately after their child who required home medical care began living at home, mothers were concerned about the protection of their unstable child and, therefore, made care of the child a priority. However, they gradually started experiencing the need to engage services for the child in the course of their daily lives and live their lives with assistance. In the course of this new lifestyle, mothers began to regulate their fluctuating feelings and discover a new lifestyle for the family by making the father's role clear and having him take on some responsibilities, such as dealing with people outside the household. As a result, once making home medical care consistent with the family's lifestyle, even if this care was not at the same level as that provided while the child was hospitalized, mothers felt they found a way that allowed them to spend time with their other children. In addition, they began to perceive the necessity of maintaining their health, which is crucial to the child's care. Overall, this facilitated incorporation of prospects for the family's future life because they tended to pay more attention to their health and the health of their other children. Further, this contributed in coordination of the selection of services that would benefit the entire family, thereby maintaining the family's lifestyle.

## Keywords

Home Medical Care, Mother, Lifestyle Adjustment, M-GTA

## 1. Introduction

In Japan, the neonatal mortality rate has demonstrated substantial decline owing to the development in medical technologies associated with perinatal care, such as infusion therapy and artificial respirators. This improvement has contributed to prolonged life among children. Despite the substantial decline in neonatal mortality rate, the number of children with severe motor and intellectual disabilities (SMID; *i.e.*, problems that lead to high-degree dependency on medical care such as problems related to motor development, growth and development, visual and auditory senses, and respiratory system) [1] has been increasing since the latter half of the 1980s [2].

Although medical and welfare support system for home care is still undergoing improvement, the national government is promoting home medical care, resulting in increasing number of children receiving home care [3] [4]. The primary home caregivers for children with SMIDs are their mothers, accounting for 84.3% of all home caregivers [5]. Mothers are not only involved in rearing and caring of children with SMID at home but also in playing their role as a member of their families [6]. Therefore, they are expected to create a household environment responsive to the medical management needs of the child with SMID and the needs of other family members [7]. Compared with mothers of children without SMID, the mothers of children with SMID requiring medical care tend to experience greater responsibilities [8], indicating that mothers playing the roles of caregivers also require improved support [9].

Even in conventional households having nursing infants, busy mothers are expected to follow appropriate time management. Mothers tend to be even busier if they have a child requiring medical care. However, it remains largely unclear how such mothers habituate to their new lifestyle to the extent that their daily life with a child with SMID becomes “ordinary.”

## 2. Purpose

This study was conducted to elucidate the process by which after a child requiring home medical care transitions to a home care setting, how mothers coordinate their daily lives to maintain their family life until the child begins schooling. Elucidation of this process may assist in focusing on the timing of support provided to such mothers and in providing them with support designed to give them prospects on their future life.

## 3. Method

### 3.1. Definition of Terms

Children who need home medical care: Children with SMID who require daily care at home, including suction of sputum, administration of enteral nutrition, urethral catheterization, and similar procedures.

Lifestyle adjustment process: The gradual changes in a mother’s thinking and behavior designed to facilitate maintenance of the lifestyle of a family with a

child requiring home medical care.

### 3.2. Selection Criteria for Research Subjects

We included the mothers of children who required home medical care comprising procedures such as suction of sputum and respiratory management over a period of several years since the initiation of home care. Regarding inclusion of children, they had to be from late infancy to early school-age, *i.e.*, age 3 - 10 years, and had to be living a stable life. We excluded mothers whose child's condition was not stable and whose psychological state was not stable.

### 3.3. Data Collection Method

We provided explanations about this study to visiting nursing stations in the Tokai and Kinki regions of Japan that were involved in visiting children requiring medical care and asked them to refer potential study subjects. We then provided the potential subjects with written descriptions of the details of the study, including objectives and methods, or provided an oral description over a telephonic conversation. A 60-min semi-structured interview was then conducted in accordance with the interview guidelines with each subject who provided consent. The contents of the interviews were as follows: 1) changes in a mother's and her family's lifestyle following the initiation of home care and 2) opinions about and actions taken to maintain the lifestyle of the family despite having a child requiring medical care. Interviews were recorded using a digital voice recorder after obtaining permission. Transcripts of the recording were prepared and used as study data.

### 3.4. Data Collection Period

September 2017-June 2018.

### 3.5. Analytic Method

The Modified Grounded Theory Approach (M-GTA), a form of GTA modified to facilitate easy use in limited fields, was used as the analytical method [10]. We found it appropriate for use in this study, particularly for mothers of children requiring complicated medical care (an area where strict theoretical sampling is difficult), to elucidate the lifestyle coordination process that mothers engage in as they relate to their children under complex and unstable circumstances of living with a child requiring medical care.

About M-GTA:

The details of the analytical method using M-GTA are as follows.

- At first, we decided an analytical focus group and the analytic theme according to research theme in this study.

The analytical focus group was “mothers with children who need medical home care.”

The analytical theme was as follows: “What are the thoughts and actions em-

ployed by mothers to maintain the overall condition of their child requiring medical care and their family's lifestyle?"

- Attention was paid to data related to this theme so as to perform open coding and generate concepts for each piece of semantic content.
- An analytic worksheet was created for each concept and continuous comparative analysis was performed to examine each example while recording the results as theoretical memos. This was done until no more new concepts could be generated.
- After that, categories formed of relationships among several concepts were generated and the analytical results were summarized according to the relationships among categories to create a results diagram.
- The analysis was performed through intermittent discussions among researchers with experience in family nursing, child nursing, and qualitative research. In addition, opinion of an instructor with long-term experience in family nursing education was also collected on the validity of the obtained results. Revisions were done in accordance with the instructor's guidance to ensure validity of results.

### **3.6. Ethical Considerations**

The institutional review board of Osaka Medical College gave their approval for this study to be conducted (approval number: KAN-65 [2172]).

Mothers who were the subjects of this study were provided with explanations regarding the following: study objectives, study summary, participation based on their choice, discontinuation/withdrawal for any reason, how their participation or non-participation in the study would have no effect on care and other types of support they were receiving, how their anonymity would be guaranteed, and the public release of the study as presentations at academic conferences and as a published study report. Mothers who granted consent were individually contacted to coordinate their schedule for interviews and to ensure that only the researchers would be aware of whether they agreed to participate in the study. Private information was stored in a secured locker, and all data were rendered anonymous prior to analysis.

## **4. Results**

### **4.1. Background of the Subjects**

Sixteen participants were interviewed, with an average age of 37.6 years (range: 29 - 46 y).

Average age of children who need home medical care is 4.9 years (range: 3 - 9).

Disease of children who need home medical care is acute encephalopathy, Neurogenic incurable disease, Hypoxic Encephalopathy, Cerebral palsy, Rare refractory gastrointestinal disease, Chromosomal abnormality, Congenital heart disease.

Home medical care required was respiratory management, suction of sputum,

administration of enteral nutrition, urethral catheterization, enema, washing intestine.

The participants are summarized in **Table 1**.

Each subject was interviewed once, for an average of 69 minutes (50 - 90 min).

## 4.2. Analytical Results

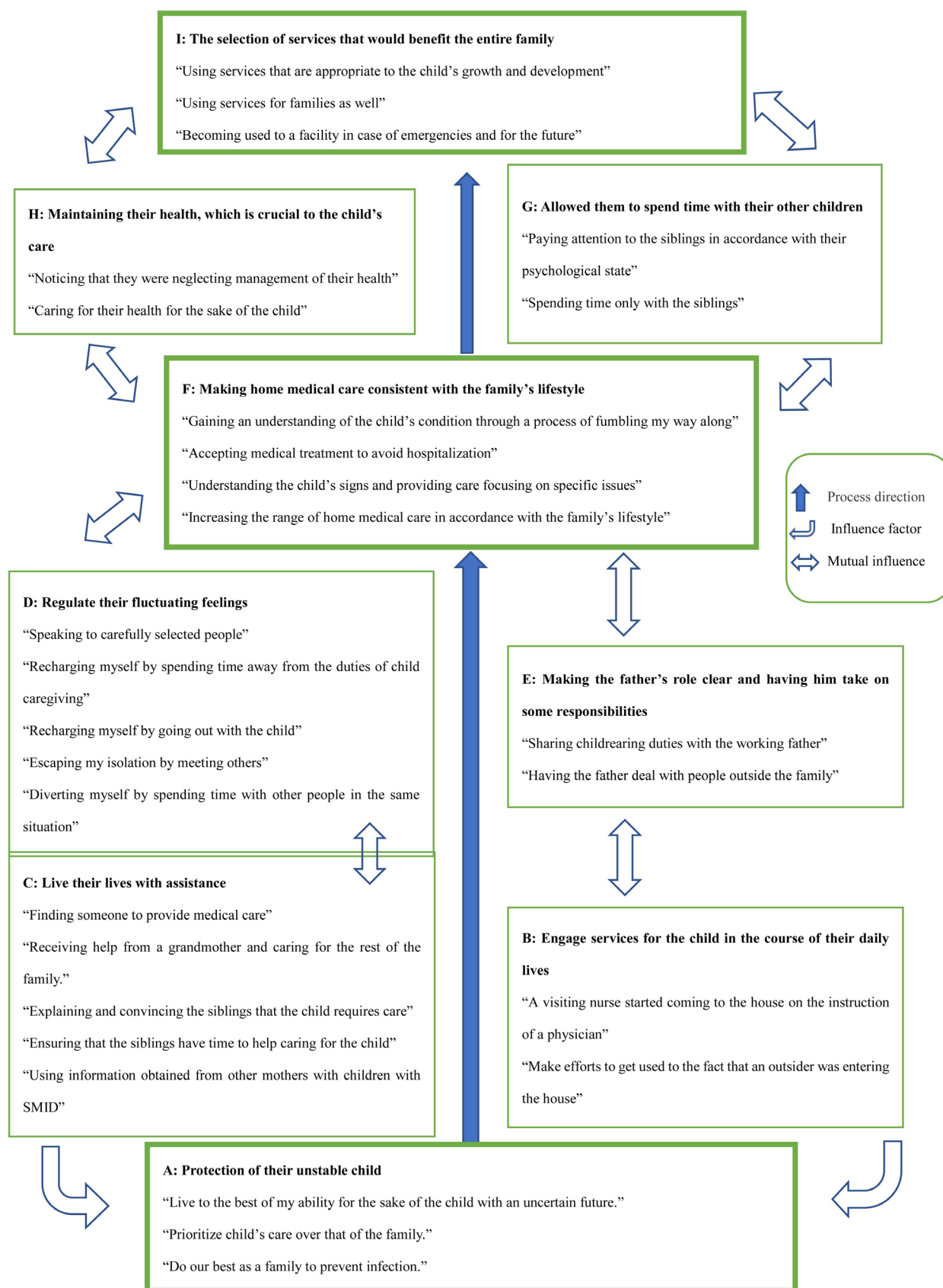
Twenty-eight concepts were identified in the analysis and nine categories (A - I) were identified from similarities and relationships between concepts. The relationships between the categories are presented in **Figure 1**.

### 1) Storyline

The storyline is presented first. This is a comprehensive description of the relationships between categories identified from the data analysis.

**Table 1.** Summary of participants.

No.	Child's age	Disease	Home medical care	Family other than mother
1	3 - 6	Acute encephalopathy	respiratory management, administration of enteral nutrition,	grandparents, a sibling
2	3 - 6	Chromosomal abnormality	suction of sputum, administration of enteral nutrition	father, a sibling
3	3 - 6	Neurogenic incurable disease	respiratory management, administration of enteral nutrition,	father, a sibling
4	3 - 6	Hypoxic Encephalopathy	suction of sputum, administration of enteral nutrition	grandparents, aunt, siblings
5	3 - 6	Acute encephalopathy	respiratory management, administration of enteral nutrition,	father, a sibling
6	3 - 6	Hypoxic Encephalopathy	administration of enteral nutrition, urethral catheterization	father, siblings
7	3 - 6	Chromosomal abnormality, Rare refractory gastrointestinal disease, Congenital heart disease	enema, washing intestine	father, a sibling
8	7 - 9	Hypoxic Encephalopathy	suction of sputum, administration of enteral nutrition, urethral catheterization, enema	father, a sibling
9	7 - 9	Hypoxic Encephalopathy	respiratory management, administration of enteral nutrition, urethral catheterization	father, siblings
10	7 - 9	Acute encephalopathy	suction of sputum, administration of enteral nutrition	father, siblings
11	3 - 6	Cerebral palsy	suction of sputum, administration of enteral nutrition	father, a sibling
12	3 - 6	Neurogenic incurable disease	suction of sputum, administration of enteral nutrition	father, a sibling, grandparents
13	3 - 6	Hypoxic Encephalopathy	suction of sputum, administration of enteral nutrition	father, a sibling
14	3 - 6	Hypoxic Encephalopathy	respiratory management, administration of enteral nutrition,	father, a sibling, great grandmother
15	3 - 6	Hypoxic Encephalopathy	respiratory management, administration of enteral nutrition,	siblings
16	3 - 6	Chromosomal abnormality, Congenital heart disease	respiratory management, administration of enteral nutrition,	grandparents



**Figure 1.** Lifestyle adjustment process to maintain family life for mothers with children who need home medical care.

Immediately after their child who required home medical care began living at home, mothers were concerned about the “A: Protection of their unstable child” and, therefore, made care of the child a priority. However, they gradually started experiencing the need to “B: Engage services for the child in the course of their daily lives” and “C: Live their lives with assistance”. In the course of this new lifestyle, mothers began to “D: Regulate their fluctuating feelings” and discover a new lifestyle for the family by “E: Making the father’s role clear and having him take on some responsibilities”, such as dealing with people outside the household. As a result, once “F: Making home medical care was made consistent with the family’s lifestyle”, even if this care was not at the same level as that provided while the child was hospitalized, mothers felt they found a way that “G: Allowed them to spend time with their other children. In addition, they began to perceive the necessity of “H: Maintaining their health, which is crucial to the child’s care”. Overall, this facilitated incorporation of prospects for the family’s future life because they tended to pay more attention to their health and the health of their other children. Further, this contributed in coordination of “I: The selection of services that would benefit the entire family, thereby maintaining the family’s lifestyle.”

## 2) Description of Extracted Categories and Concepts

Below, descriptions and variations (Case No.) of concepts organized for each category are written in italics

### **A: Protection of their unstable child**

This category acts as the starting line for the at-home lifestyle and comprises factors indicated by mothers as most important. This category is composed of the following concepts:

- “Live to the best of my ability for the sake of the child with an uncertain future.”

This implies living each day to the fullest and without regrets with a child whose physical condition is unstable and without knowing what the future will bring.

*Only God knows the fate of this child. I do not know what will happen or when, so I will live to the best of my ability and live without regrets (Case 9).*

- “Prioritize child’s care over that of the family.”

The medical care of the child is a priority, and it prevents the mother from assisting the rest of the family members on priority.

*I normally place priority on this child, so I am always asking the other children to wait. The other children tend to feel bad and cry, but what else can I do but place priority on this child? (Case 8).*

- “Do our best as a family to prevent infection.”

Mothers encourage infection prevention behaviors among family members to maintain the physical condition of the child. She separates family members who have acquired an infection to prevent it from infecting the child.

*Infections are the most petrifying, so I have [everyone] wash their hands and perform other infection prevention measures. When the older brother has even*



*the slightest symptom of a cold, I refuse to let him in the child's room (Case 5).*

### **B: Engage services for the child in the course of their daily lives**

Shortly after the start of life at home, mothers tended to express disinterest in engaging a professional service, and they expressed hesitation in introducing a stranger to a situation they yet have not been habituated to. This is composed of the following concepts:

- “A visiting nurse started coming to the house on the instruction of a physician”

The mothers did not choose to receive the support of a visiting nurse but accepted the nurse as a result of a physician's decision.

*Although I had no idea how a visiting nurse would help, I accepted her because the visiting nurse said she came on the instructions of the physician (Case 16).*

- “Make efforts to get used to the fact that an outsider was entering the house”

Although a nurse is a professional, the mere fact that an outsider was visiting one's home acted as a burden on mothers. However, mothers said they made efforts to overcome this feeling.

*Since [the visiting nurse started coming] at a time when I was still not at all used to having the child in the house, I was not in a situation in which I could depend on the nurse to take some of the burden off of me; conversely, the mere fact that the nurse was coming was burdensome to me. However, I felt that this was something that I would have to overcome (Case 8).*

### **C: Live their daily lives with assistance**

Mothers indicated that for the family to live with the child who requires medical care, they had to accept the help of others, following which they were finally able to live their daily lives with this assistance. This category is composed of the following concepts:

- “Finding someone to provide medical care”

After the child was discharged from the hospital, the physician and nurses advised the family (husband or grandparents) to arrange for the child to be cared for by someone other than the mother; this led to their learning on how to provide medical care.

*The father and grandmother are also able to provide all the [required] medical care. Since I wanted someone else to provide medical care when I wanted to go out, I informed the nurses and physician regarding the necessity of someone to provide medical care. Therefore, they taught my family members care giving skills (Case 5).*

- “Receiving help from a grandmother and caring for the rest of the family”

Receiving help from a grandmother allows mothers to take daily care of the child with SMID and his/her siblings. She asked for and received help from a grandmother in taking care of the child's siblings.

*My burden [would be greater] in the absence of a grandma. I did know how I would cope with everyday problems. I have to take care of the child and his/her*



*siblings, Grandma's help is absolutely essential* (Case 9).

- “Explaining and convincing the siblings that the child requires care”

To ensure that the siblings understand and are comfortable with the fact that the child requires substantial care, the mother provides explanation to the siblings as per their age and understanding capacity.

*The child got sick when the older brother was 4 years old. Once the older brother got a little older, I explained in simple words about his younger sibling's illness and condition, which he understood. I told him that once I finish with his younger sibling's care, I will take care of him. I wanted him to wait, to which he agreed* (Case 5).

- “Ensuring that the siblings have time to help caring for the child”

Mothers explained to the siblings how to care for the child; thus, the siblings could watch the child for short periods of time. During these periods, mothers could take care of other household chores.

*I taught the siblings how to perform suction. When I was preparing dinner or doing other things, they took it upon themselves to perform suction without having me to tell them, and they seemed to enjoy it. This helps me as I do not have to stop the tasks at hand and can prepare early dinner for the siblings* (Case 15).

- “Using information obtained from other mothers with children with SMID”

By using information required about the daily life of the child obtained from other mothers with children with SMID, mothers experience easier daily lives.

*I obtain substantial information from other mothers of children with SMID. Ample information is available on how to select among the many available choices, which seems very helpful. I'm grateful because I get this information on a regular basis* (Case 6).

#### **D: Regulate their fluctuating feelings**

Mothers indicated that in their daily lives after the transitioning of their child to home, they could stabilize their fluctuating feelings by conversing with others, spending time away from the child, spending time outside the house, and forming relationships with others. This comprised the following concepts:

- “Speaking to carefully selected people”

Speaking only to carefully selected people among family members and friends can calm their feelings.

*At first, I could only talk about my hardships to my family. In fact, I was open to my parents. Although it was tough, I found it difficult to talk to my friends. Then, at a particular instance, I told a friend (who is a nurse by profession) about my child, after which she visited us. She was very kind and gentle with my child. My other friends not involved in the field of medicine also visited me after I spoke to them. Everyone treated my child completely normally, which proved to be a big help* (Case 12).

- “Recharging myself by spending time away from the duties of child caregiving”

Even short periods of time spent away from the child allow mothers to refresh their feelings.

*I spend time outside the house at my pace. At first, this made me really nervous, but just one visit to places such as to the hairdresser seemed fun and cheering* (Case 5).

- “Recharging myself by going out with the child”

Mothers could refresh their feelings by going out not just by themselves or with the other family members but with the child after the child’s condition stabilized.

*Recently, my child’s condition stabilized, and I have been able to take him outside. Hence, I do not feel stressed anymore* (Case 1).

- “Escaping my isolation by meeting others”

Once mothers eventually start meeting other people with whom they share mutual understanding and a connection because they have children who require medical care, they tend to experience an escape from their sense of isolation, and they experience the lifting of some burden. This gives them the courage to do their best as they move forward.

After attending rehabilitation programs, *I learned that I had been feeling quite isolated at home. I believe that all mothers living with a child with disabilities felt “why did this happen to my child?” for a very long time. Once I started going for rehabilitation with my child, I saw many other mothers in the same situation and with the same hardships as mine* (Case 6).

- “Diverting myself by spending time with other people in the same situation”

Mothers experience stress and a sense of guilt in the course of their daily lives with their child, but talking to other mothers in the same situation relieves them from such feelings.

*I attend family association meetings for a break [from my daily routine] and recharge myself. Once I started talking to other mothers, I realized that everyone was in a similar situation. I am relieved just to know that there are people who can sympathize with me. I felt a sense of guilt toward my child, but once I heard that other mothers felt the same way, I did not feel as guilty* (Case 8).

### **E: Making the father’s role clear and having him take on some responsibilities**

Mothers indicated that they asked fathers to take on some responsibilities of caring for the child and siblings in accordance with the mothers’ needs. This comprised the following concepts:

- “Sharing childrearing duties with the working father”

It is difficult for mothers to simultaneously care for the siblings and child, whose range of activity differs from that of the siblings. Therefore, the mother has the father take on some of these responsibilities on his days off and at night to the extent that his schedule permits.

*On days off, we would take turns watching the child or one of us would take the siblings out. Because it is really difficult to simultaneously take the child out*

*and watch the siblings, we all go out together only at certain times and when the weather is good. Since their father is quite busy at work, he tends to be tired sometimes. At such times, I have him stay at home with the child and take the siblings out (Case 9).*

- “Having the father deal with people outside the family”

For issues with outsiders that cannot be handled or negotiated by mothers, fathers take on this role.

*My husband very vigorously appealed to the city hall officials regarding a system we wanted to use, to which they agreed (Case 2).*

#### **F: Making home medical care consistent with the family’s lifestyle**

Soon after the transition to home, mothers simply implemented the learned medical care. However, they indicated that there was a process through which they could handle their child’s condition. This was composed of the following concepts:

- “Gaining an understanding of the child’s condition through a process of fumbling my way along”

After hospital discharge, the mother attempts to understand the child’s condition but fails. Thus, she has to fumble along and do her best daily.

*One or two years after the transition to home, I had no knowledge or idea about caring or raising my child. I found it difficult to understand and know what to do. Shortly after discharge, I was anxious because I did not know how much I could do alone. I felt like I was just performing tasks [“going through the emotions”] (Case 1).*

- “Accepting medical treatment to avoid hospitalization”

Mothers accepted the introduction of an increasing number of medical procedures to prevent their child’s condition from worsening, possibly leading to repeated hospitalization and discharge.

*My child was repeatedly hospitalized and discharged due to aspiration pneumonia. Finally, when the doctor recommended tracheotomy, I argued with the doctor over avoiding the procedure if possible. However, in case aspiration pneumonia continued, my child would be rehospitalized and would require an earlier tracheotomy, so the doctor recommended considering gastric fistula as a prophylactic step against aspiration pneumonia. As I prioritize my child’s ability to stay at home in a relatively good condition over repeated hospitalizations due to aspiration pneumonia, we decided to perform gastric fistula surgery (Case 6).*

- “Understanding the child’s signs and providing care focusing on specific issues”

Mothers understood the signs indicating their child’s condition based on their daily experience of providing specific types of care; as a result, they could provide focused management of their child’s condition.

*Recently, I began to understand the aspects of my child’s care that I need to pay particular attention. First, saturation can fluctuate and whether there is a lot*

of urine or none at all (Case 10).

- “Increasing the range of home medical care in accordance with the family’s lifestyle”

Mothers feel that they have to precisely perform the medical care procedures, but their thinking changes as they realize that they can provide the required care even if their methods are not perfect.

*The nurse told me to change nutrition every 4 h during the night and to wash the bag to maintain cleanliness. Immediately after discharge, I performed procedures accordingly. My child was repeatedly hospitalized and discharged, so I always carefully washed my hands and disinfected the apparatus. However, continuation of conducting these duties precisely would leave no time for sleep. I normally would set my alarm to go off during the night, so that I could take care of the important things. However, I slept through my alarm once, but when I woke up, I felt very refreshed. Although I did not perform the required care during the night, my child did not suffer from diarrhea, leading me to think that everything would be fine. I began to think that it was fine to not always provide timely care (Case 8).*

#### **G: Allowed them to spend time with their other children**

Mothers indicated that they noticed changes among the siblings of the child and that they attempted to deal with these changes. This was composed of the following concepts:

- “Paying attention to the siblings in accordance with their psychological state”

Mothers identified the problems the siblings experienced and started caring for them.

*My older child was very helpful with housework but was underperforming at school, which worried me. I realized this could not continue any longer and required intervention (Case 10).*

- “Spending time only with the siblings”

Mothers said that they intentionally coordinated their time such that it allowed them to spend time with the siblings.

*Once the child’s condition became more stabilized, even if it was only during the feeding time after the child got a gastric fistula, I spent more time with my older child outside. We would go shopping and discuss about recent instances. Increased conversation with my older child led to me to identify the loneliness my child was experiencing (Case 6).*

#### **H: Maintaining their health, which is crucial to the child’s care**

Mothers indicated that to maintain their child’s care and family’s lifestyle while still placing priority on their child’s care, their health (which is crucial for the entire daily life of the family) required care. Thus, they began to understand the need of maintaining and improving their health. This was composed of the following concepts:

- “Noticing that they were neglecting management of their health”

When mothers recalled their experiences, they realized that by placing priority

on providing care to their child, they were unable to take care of themselves during sickness, and this gradually worsened their condition.

*I had a feeling that I was not doing well, but I had to take care of my child. In addition, I was so tired that I could not visit a doctor. I acquired a strep infection, and the doctor wanted to hospitalize me, but I said that hospitalization would be impossible because I had to care for my child. I just went home and rested. Following this, I had a CRP level of 16 mg/dl, and I just stayed in bed for a while. However, I have to take better care of myself (Case 9).*

- “Caring for their health for the sake of the child”

Because having a health problem would prevent them from caring for their child, mothers felt that they had to be more careful about managing their health.

*My husband's company's [insurance policy] includes an annual health checkup, which I unforgettably attend each year. During my sickness, the entire household comes to a standstill, so I have to be careful of my health for the sake of my child (Case 12).*

### **I: Selection of services that would benefit the entire family**

Daily living with their child made mothers realize that they were the primary caregivers. However, they indicated that their feelings and actions tended to shift toward selecting a service that would benefit the entire family. This category is composed of the following concepts:

- “Using services that are appropriate to the child’s growth and development”

Mothers began to understand the need of relying on a visiting nursing service or visiting bathing service to take care of some care activities in accordance with their child’s growth and development.

*At first, I had a visiting nurse for bathing my child without having any particular expectations. But now that I can bathe my child, I have the nurse play with my child in ways that match the child's growth. In the future, I will have the nurse take over the bathing duties as the child grows up and when I am no longer able to do it (Case 3).*

- “Using services for families as well”

Mothers use services to ensure that they have time for the siblings and to stabilize their feelings.

*Now that I have a visiting nurse coming, I have someone to discuss my apprehensions. I think this helps me overcome the related complicated tasks. Further, I can participate in activities with the siblings when the nurse is caring for the child (Case 6).*

- “Becoming used to a facility in case of emergencies and for the future”

At first, mothers were hesitant about having someone about whose caregiving abilities they were unaware. However, because they wanted someone who could take care of the child in case of emergencies, they are prepared to have the child get used to a facility.

*I use the facility about once every 2 months. If we do not use it regularly, the staff and my child would not be familiar with each other. I think it would be dif-*

*ficult for the child if I were to have someone else watch [the child] while I was at an event with the siblings or a ceremony. I am afraid it makes my child feel lonely, but my child is dealing with it. I decided for long that I would not have my child go to a facility. However, because of the other children at home, I realized this decision would not work, so my opinion on this issue has changed* (Case 12).

### 3) Relationship among the categories

On analyzing the relationships among the categories, it was clear that the mother's process of coordinating daily life to preserve the family's lifestyle, despite the presence of a child who requires home medical care, presented three phases: a) a shift from protecting the child's life by themselves to asking for help, b) relaxing and leading a life that was more attuned to the family, and c) could coordinate daily life in consideration of the entire family.

## 5. Discussion

The process by which mothers coordinated daily life to preserve the family's lifestyle despite having a child requiring home medical care could be divided into three phases. We then considered the thoughts and actions of mothers in each phase designed to coordinate daily life.

### 1) A shift from protecting the child's life by themselves to asking for help

This study elucidated the fact that soon after the child began living at home, mothers tended to invest their energy into the protection of their unstable child. The burden on mothers was severe because the participating children required the use of medical devices and the mothers were unable to perform medical care at home with the similar high standard as provided at a medical facility. However, soon after being informed of the child's disability, families are unable to accept the idea of using a professional service [11]. The participants of the present study also started using a visiting nurse service not out of choice but on the instructions of their physicians. Japanese tend to dislike the presence of outsiders at home; thus, to engage services for the child in the course of their daily lives, they had to make efforts to habituate having someone in their houses. Based on this experience, mothers began to realize that they had to live their daily lives with assistance because they were unable to support their family's lifestyle alone. This suggests that mothers developed an ability to coordinate that allowed them to determine the competency of others despite being busy themselves and consequently obtain the best help from the best available individuals. We believe this is the first step in the process of gaining the ability to coordinate the daily life of the family. Even if there are younger siblings of the child, mothers perform tasks that they are capable of performing as a member of the family and eventually understand that everyone in the family is living each day together. The siblings imitate their mother in performing medical care, although it is more of simple contact among the siblings (including the child with the disability) than it is the actual performance of medical care. We believe that the reason

they reach the point at which they can involve the siblings in this way is that the mothers could regulate their fluctuating feelings. In addition, by making the father's role clear and having him take on some responsibilities such as dealing with people outside the household, mothers could discover their family's lifestyle. This led to the mothers' ability to coordinate their lives to ensure that they had time for themselves. We believe that the ability of the entire family (including of the siblings) to find various ways of providing care to the child while maintaining their lifestyle is an important point in the coordination of the family's lifestyle.

## **2) They began to relax and lead a life that was more attuned to the family**

It is difficult for mothers to identify the characteristics of their child's condition; thus, we assume that they use a trial and error process while attempting to understand unfamiliar medical procedures as they move ahead in conjunction with their child's progress. As they are living with the entire family during this process and not only the child with the disability, they develop their individual care methods and employ these instead of the medical care procedures learned to be performed precisely prior to the child's hospital discharge. Through this process, the making home medical care consistent with the family's lifestyle; therefore, and they believed that they could raise their child at home.

In their study of the relationship between siblings and their mothers, Komiyama *et al.* [12] reported that mothers of children with SMID are aware that the situation has an effect on the behavior and psychology of the siblings, which is consistent with the findings of the present study. In the case of siblings of a child requiring constant medical care, it is even more difficult for mothers to pay a sufficient amount of attention to the siblings. Mothers experience problems such as siblings having trouble with their relations with others as they grow up. We believe that one method by which mothers manage their households to allow siblings to live their lives without restrictions is coordination that allowed them to spend time with their other children.

Hamanabe *et al.* [13] reported that mothers whose children underwent gastric fistula surgery or tracheotomy not only habituated to medical care but also could deal with various problems and that after they achieved these abilities, their daily lives stabilized further. The development of the perception that maintaining their health, which is crucial to the child's care, is vital, which was one of the results of the present study, appeared gradually as the mothers went through the repeated experiences of learning to identify their child's condition and learning new care procedures; this eventually allowed them to pay more attention to their health. This seems to be consistent with the time period identified by Hamanabe *et al.* [13] as the period when the family lifestyle becomes more stable. In addition, Ichihara *et al.* [14] reported that mothers experience excessive burden when, over the course of managing a family including a child with an extremely severe mental and intellectual disability, the child's condition worsens. To care for a child in an unstable condition and maintain the family's lifestyle, mothers



should maintain their health; thus, we believe this issue is a key to their ability to coordinate their daily lives.

Therefore, at this stage, mothers can relax, begin caregiving for the child in accordance with the circumstances of the family (the major methodology), and place increasing importance on spending time with the siblings and her conditions, resulting in a more stabilized family life. In other words, mothers tend to coordinate the daily life of their family.

### **3) They could coordinate daily life in consideration of the entire family**

There are services that can be utilized to protect the life of a child who requires medical care as soon as the child comes home. This study identified the fact that mothers shift their attitude more toward the selection of services that would benefit the entire family; as their life at home with their child develops, they begin to coordinate the selection of such services. This is completely new data that has been identified for the first time in this study.

During this stage, mothers begin to notice the types of service useful in ensuring that the child and family can lead complete lives, and they begin to act on this. Such service is one type of support, and each family should use services that matches well their household circumstances. Respite is a way for a child with SMID to receive stimulation from others in an environment in which he/she can learn to socialize through various experiences [8]. It also improves mothers' competency in dealing with stress, good for family relations, and improves social participation by the child [15]. In addition, repeated use of a facility by the child increases the number of the child's friends and an expanded support circle. The merits of these types of services are not only limited to the child but also to the family. This has resulted from the understanding that the life of a family with a child who requires medical care develops through the appropriate use of a carefully selected service.

## **6. Conclusions**

We obtained the following conclusion from this study.

1) During the stage when there is a shift from the mother investing all her energy in protecting the life of her child to being able to use assistance, mothers are concerned about the protection of their unstable child and, therefore, place priority on the care of their child. However, they gradually engage services for the child in the course of their daily lives and sense a feeling of being able to live their daily lives with assistance. Under these circumstances, mothers could regulate their fluctuating feelings, making the father's role clear, and having him take on some responsibilities, such as dealing with people outside the family. Through this process, they discover their family's lifestyle.

2) Mothers relax and begin to have a lifestyle attuned to the family, making home medical care consistent with the family's lifestyle because they realized that it was fine that they were unable to provide the same level of care that the child received in the hospital. In addition, they learned to adjust their lifestyle in

ways that allowed them to spend time with the child's siblings. In addition, they began perceiving the necessity of maintaining their health, which is crucial to the child's care, and they started to coordinate their activities in ways that allowed the family's lifestyle to become more stable.

3) When mothers could coordinate their daily lives in consideration of the entire family, they could coordinate the selection of services that would benefit the entire family, facilitating them to maintain the lifestyle of the family.

4) The lifestyle coordination by mothers raising a child requiring home medical care includes division of responsibilities among family members who take on roles that are appropriate to them, a way of organizing the family members into a single coordinated unit. This becomes possible as the mother can include the entire family in her attention.

## Acknowledgements

We would like to express our deep appreciation to all of the mothers with children who need home medical care who agreed to be interviewed for their cooperation. Also I am grateful to the visiting nursing station that recruited my mother who participated

## Conflicts of Interest

We have no conflicts of interest to disclose.

## References

- [1] Kanazawa, T., Yasuda, J. and Kitamura, M. (2007) Mental Developmental Prognosis and Evaluation of Ultra Low Birth Weight Infants. *Journal of Perinatal Medical*, **37**, 485-487. (In Japanese)
- [2] Kumazaki, K., Yoshioka, T., Tamasaki, A. and Maegaki, Y. (2015) A Study of the Utilization of Welfare Systems by Patients with Severe Motor and Intellectual Disabilities and Their Families. *Journal of the Yonago Medical Association*, **66**, 81-89. (In Japanese)
- [3] Taka, M. (2016) Current State of Home Life and Home Care Support for Children Dependent on Mechanical Ventilation with Severe Motor and Intellectual Disabilities and for Their Families. *Journal of Japanese Society Child Health Nursing*, **1**, 15-21. (In Japanese)
- [4] Mizuochi, Y. and Masumori, K. (2016) Current Circumstances of Families Raising Children with Severe Mental and Physical Disabilities. Who Require Tracheostomy Management: Care Guidance Provided by Nurses and Its Issues. *Journal of Japanese Society of Child Health Nursing*, **25**, 45-52. (In Japanese)
- [5] Tanaka, C. and Sajima, T. (2016) Social Support for Adults with Profound Intellectual and Multiple Disabilities and Their Family Caregivers: The Need for Information and Cooperation. *Japan Academy for Comprehensive Rehabilitation*, **17**, 54-60. (In Japanese)
- [6] Yamada, A., Irie, Y., Bessho, F., Kamimoto, S. and Tomiwa, K. (2011) A Novel Trial of Family Respite Care, the Todaiji Method: The Benefit Both for Children with Severe Motor and Intellectual Disabilities and Their Parents. *Bulletin of Department of Nursing, Faculty of Medicine, Nara Prefectural University of Medicine*,

7, 82-87. (In Japanese)

- [7] Shimono, J. and Ichihara, M. (2017) Perception and Relationship of Parents about the Siblings of Children Who Have Profound Multiple Disabilities and Are Medically Dependent at Home. *Bulletin of Chiba Science University*, **10**, 91-99. (In Japanese)
- [8] Yamamoto, T. (2014) A Thought on the Respite Care of Mothers Who Care for Severe Physical and Mental Handicapped Children at Home. *Journal of Seirei Society of Nursing Science*, **4**, 1-6. (In Japanese)
- [9] Komagane, Y. (2016) Necessity of Reducing the Burden of Care in the Mother of Children with Severe Physical and Mental Disabilities. Akita University of Nursing and Welfare. *The Journal of the Institute of Research*, **11**, 35-46. (In Japanese)
- [10] Kinoshita, Y. (2003) Modified Grounded Theory Approach. The Practice of the Grounded Theory Approach. Kobundo, Tokyo. (In Japanese)
- [11] Wakimizu, R., Kuroki, H. and Igarashi, M. (2009) The Process of Mothers' Change of Recognition of "Rearing Severely-Retarded Children"—Focused on the Regional Healthcare System Surrounding the Families Rearing the Disabled Children at Home—". *The Journal of Child Health*, **68**, 366-373. (In Japanese)
- [12] Komiyama, H., Miyatani, M., Koide, F., Irie, S., Suzuki, E. and Matumoto, K. (2008) Mothers' Perception of Difficulties and their Ways of Coping with the Siblings of Children with Severe Motor and Intellectual Disabilities in Home Care. *Journal of Japanese Society of Child Health Nursing*, **17**, 45-52. (In Japanese)
- [13] Hamanabe, F., Sato, T., Ogura, K. and Hayama, K. (2008) Storytelling of Mothers of SMID Persons: Effect of Gastrostomy, Tracheotomy and/or Mechanical Ventilation on Daily Lives. *Journal of Japanese Society on Severe Motor and Intellectual Disabilities*, **33**, 347-357. (In Japanese)
- [14] Ichihara, M., Shimono, J. and Sekido, Y. (2016) Family Management of a Family Living with a Child Who Has Profound Multiple Disabilities and Is Medically Dependent at Home Coping Behaviors Dealing with Family Difficulties Faced in Daily Life. *Bulletin of Chiba Science University*, **9**, 99-107. (In Japanese)
- [15] Hase, M. (2008) Analysis of the Literature on Respite Care for Mothers of Patients with Severe Motor and Intellectual Disabilities in Japan. *Journal of Japanese Society on Severe Motor and Intellectual Disabilities*, **33**, 339-345. (In Japanese)