

Experience of Mothers whose Children Undergo Labioplasty and Palatoplasty

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ABSTRACT

The purpose of this study was to elucidate the experience of mothers whose children undergo labioplasty and palatoplasty. A constant comparison method with reference to Grounded Theory was used for analyzing semi-structured interviews with ten mothers. Each mother's experience was categorized into six types: "entering the treatment process", "obtaining family support to maintain medical life with their child", "having a sound relationship with relatives and neighbors", "interpreting cleft lip and palate as unrelated to disease and disability", "responding to difficulties step by step", "expanding their role as mother through caring for the child". These categories showed that there were. These results suggested the need to understand many of approaches and efforts in the mother's experience and to facilitate mother's roles in the treatment process.

I. Introduction

Cleft lip and palate is a congenital anomaly involving cosmetic disturbance such as aberrations in facial morphology and functional disorder. It is one of the most common congenital external malformations which occur in about one out of every 500 children born. It is considered to arise from the interaction between genetic and environmental factors but the causes for its occurrence and concrete preventive measures are not yet understood well^{1),2)}. It is not expected that its occurrence rate will decline in the near future because of the negative effects of pollution on maternal environment³⁾ and relative increase of genetic disease arising from the change of disease structure⁴⁾.

Surgical treatment and speech therapy are the main methods of treatment for cleft lip and palate. They are conducted during the period from three to four months after birth to adulthood. The surgical treatments of cleft lip and of cleft palate are performed in three months after birth and in around sixteen months after birth, respectively. Treatment for cleft lip and palate has been advanced enough to cure it completely if patients receive right treatment in a proper period. Yet, a mother of an infant with cleft lip and palate is likely to experience immeasurable suffering when she knows that her baby's face is malformed⁵⁾. This is because we are more likely to react emotionally to external malformation than to the malformation of the viscera which cannot be seen⁶⁾. In addition, surgical treatment is not enough to cure cleft lip and palate, necessitating additional treatments such as orthodontic treatment and speech therapy. A mother has to shoulder an overly burdensome responsibility to engage in childcare activities and have her child receive treatment for cleft lip and palate for many years.

For these characteristics of this disease the problem of when a doctor should disclose it to a mother of a child with cleft lip and palate has been addressed⁷⁾. It is reported that a mother is likely to feel disturbed and embarrassed when she sees the face of a baby with cleft lip and palate shortly after delivery for the first time. Kerin B. Johansson, who conducted interviews with parents with babies with cleft lip and palate, shows that reactions and support of people around them affect their attitudes on this disease⁸⁾. It is also reported that

mothers' attitudes on it change through the long-term process of treatment^{9),10)}.

These researches are mostly questionnaire surveys which are conducted shortly after delivery or infant's operations, focusing on mother's feelings of distress and anxiety. It is expected that mothers will have a variety of feeling when their infants received surgical treatment when they were 3 or 18 months old. Yet, researchers tend to examine more invasive operations such as heart and transplant operations when they address how mothers feel about their children's surgical operations^{11),12)}. In other words, it has not been clarified how mothers understand and accept surgical treatment of their children with cleft lip and palate. Nakanii also reported that there are few data containing straightforward words uttered by mothers of children with cleft lip and palate, so that researchers must listen to their own words seriously for understanding the feelings of a mother, her family members, and her child patient¹³⁾.

Therefore, in this study we attempt to clarify the experience of mothers of children with cleft lip and palate by focusing on the surgery of cleft lip and palate which is considered to have significant meaning for them. We consider that such an analysis would bring about new perspective for deepening our understanding of them.

II. The Purpose of Research

The purpose of this research is to clarify the experience of mothers whose children undergo labioplasty and palatoplasty for understanding and supporting mothers of children with cleft lip and palate.

III. Definitions of Terminology

In this research we attempt to elucidate the experience of mothers not as passive but as active actors. Based on this research purpose we defined experience as the things in which an independent-minded person learns through a variety of actual events and involvement with others.

IV. Methods of Research

1. Research Design and Theoretical Premises

We conducted a qualitative inductive analysis of the plain experience of mothers of children with cleft lip and palate for clarifying how and what they perceive their children's disease and surgery for repair of cleft lip and palate. In order

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to understand mothers' experience through the interpretative framework which treats them not as passive but as active actors, we adopted the theoretical premises of H. Blumer's Symbolic Interactionism which problematize independent-minded attitudes of human being and attempted to uncover his/her internal aspects from the standpoint of an actor^{14),15)}.

2. Criteria of Selecting Subjects

Labioplasty is usually undertaken when an infant is about eighteen months after birth. In one university hospital palatoplasty is conducted one time while in the other university soft and hard palates were closed in two-stage surgery. Most patients of cleft and palate are treated in university hospitals, therefore, we asked mothers of children who had already undergone labioplasty and palatoplasty in oral surgery wards of two university hospitals.

3. Data Collection Period

Eleven months from February to December 2008

4. Methods of Data Collection

We conducted semi-structured interviews in a following procedure:

- 1) An interviewer explained the purpose of this research to ward managers and ward nurse managers.
- 2) An interviewer explained the purpose of this research and other necessary matters to subjects and obtained their agreement to participate in the research.
- 3) An interviewer conducted two interviews with each subject.

The first time: The period in which one hour passed after a child patient entered an operation room and a subject stayed in a waiting room. She would have a variety of feelings about her infant undergoing surgery. This rare experience to be away from her infant would also give her an important opportunity to reflect on herself. We expected, therefore, that a subject will express a variety of feelings in this period. An interviewer asked each subject about whether she would agree to an interview before starting it out of respect for her feelings.

The second time: We conducted an interview with a subject about a week from surgery for reaffirming the content of the first interview and asking about her current feeling.

4) In a semi-structured interview we tried to let a subject talk about her own experience freely.

5) An interview was recorded in an IC recorder with subject's consent. An interviewer wrote down an interview with subject's content when she refused audio recording.

6) After an interview an interviewer recalled its situations and recorded the facial expression and bodily movement of an interviewee and her conversations with other family members in a field note.

5. Main Questionnaire Items

In the first interview an interviewer asked a subject about following: 1) experience from pregnancy to the present; 2) feelings when seeing her baby; 3) feelings and everyday life until cleft lip surgery begins; 4) feelings and everyday life until cleft palate surgery begins; 5) feeling toward her own child. In

the second interview an interviewer reaffirmed the content of the first interview and asked about her current feelings and everyday life.

6. Methods of Data Analysis

This research relied on Grounded Theory Approach with a theoretical background of Symbolic Interactionism. It was proposed by Barney Glaser and Anselm Strauss¹⁶⁾, and Japanese scholars such as Shigeko Saiki, Yasuhito Kinoshita, and Mami Kayama¹⁷⁾⁻¹⁹⁾ also used this approach for their own analysis. This research is based on the constant comparative method in Grounded Theory Approach²⁰⁾. Subjects are mothers of cleft lip and palate children who undertook primary labioplasty and palatoplasty in theoretical sampling, collecting data during the period in which they were undertaking surgery. We extracted data appropriate for our research purpose from one case and coded and categorized them. Then, we examined its relationship with categories of all cases.

1) We transcribed recordings of interviews and read them over and over.

2) We extracted contexts showing subjects' active involvement from the linkage of sentences and coded them in each subject's data.

3) We checked both data and codes for ensuring that each code represents data appropriately. Then, we classified data and codes from the standpoint of their similarities and differences for subcategorizing them.

4) Categories were abstracted from subcategories. We continued to check both data and categories until we were confident that no categories could be created further, and important codes, subcategories, and categories were collectively exhaustive. At the final stage of analysis we specified each category, subcategory, and code.

5) A storyline was formed by using categories and subcategories in order to capture a complete picture of research results. It was represented graphically in order to show the relationship between categories and subcategories clearly.

7. Efforts to Enhance Reliability of Data Collection and Analysis

There are a variety of views on validity and reliability of qualitative research with little consensus. It is considered to be important to spell out the process of analysis for gaining them²¹⁾. Therefore, in addition to Methods of Data Analysis mentioned earlier, we did following things:

1) We asked a subject how long she could have an interview in order to let her speak in a relaxed way. We also tried to have supportive attitudes toward her.

2) During an interview we checked the meaning and intentions of statements a subject uttered carefully in order to eliminate prejudice and dogma researchers tend to have. We also conducted interviews two times and attempted to clarify what were unclear and ambiguous points in the second interview.

3) Our analysis was conducted with a supervision by an expert of qualitative and inductive research. In addition a maternity nursing specialist checked the appropriateness of research process and results.

8. Ethical Considerations

This research was approved by the health and nursing

research ethics board of K University. We explained purposes and methods of this research fully to subjects verbally and in a written form, and obtained their agreement to participate in this research in a written form. We explained that the participation in this research was voluntary and anonymous, and non-participation did not affect medical treatment and nursing of their infants. We also told them that an interview would be conducted in a room where interviewee's privacy could be protected and they could suspend or postpone an interview at any time.

V. Results

1. Outline of Subjects

The outline of subjects is shown in Figure 1. There were 10 subjects whose ages range from 26 to 38 (the average age = 31.3 years old). 5 subjects were housewives and 5 subjects were full-time workers. Infants' ages were from 14 months to 3 years old (the average age = 21 months old) and their sexes were 6 males and 4 females. Their cleft lips were either unilateral (5 infants were on the left side and 2 infants were on the right side) or bilateral (3 infants). They were diagnosed as cleft lip and palate either before birth (3 infants) or after birth (7 infants). Their fathers' ages were 25 to 38 years old (the average age = 34.2 years old). 7 infants had a sibling, one of them having a younger sibling.

2. Summary of Interviews

1) Summary of the First Interview

We conducted interviews in an interview room or a private hospital room. Nine interviews were recorded in an IC recorder with subject's consent. We made a note of one interview because a subject declined to be recorded in a recorder. In one case subject's husband joined an interview, therefore, we used some of his statements representing mother's feelings and situations in the research.

2) Summary of the Second Interview

The second interview was conducted 4 to 7 days after surgery (5.4 days on average). We made an appointment before visiting a subject's home. During our visit a subject's infant was sometimes in a bad temper and sleeping, which made it difficult to conduct an interview, therefore, in such a case we waited for a while to start it.

3. Results of Analysis

We showed the results of analysis in Table 2. Sixty five codes and fourteen subcategories were extracted as the experiences of infants of cleft lip and palate who had undergone primary labioplasty and palatoplasty. Their experiences were categorized into six types: <<entering the treatment process>>, <<obtaining family support to take care of their child>>, <<having the social support with relatives and neighbors>>, <<interpreting that cleft lip and palate is not disease>>, <<responding to difficulties step by step>>, and <<expanding their role as mother through caring and nurturing for the child>>. We showed the experiences of mothers of infants with cleft lip and palate undergoing primary labioplasty and palatoplasty as a storyline. Category, subcategory, and code are written in << >>, < >, and [], respectively.

1) Storyline

A child with cleft lip and palate must undergo several treatments on a continuing basis: surgical treatments (primary labioplasty at around 3 months of age and palatoplasty at around 18 months of age), speech therapy, and corrective treatment. <<Entering the treatment process>> is very important for a child with cleft lip and palate to continue to grow healthy with his/her mother's support.

A mother went through the surprise and confusion of the <first meeting with her baby.> This period did not last long but the medical staff's explanation of this disease affected her <understanding of the step-by-step process of treatment> and her perspectives on nurturing life after a baby's birth. At any rate she had to conduct breastfeeding and the plate treatment for a baby with poor suckling ability, compelling them to engage in <nurturing life requiring efforts>. During this process she tended to have <worry about appearance>, affecting her infant's living activities.

<<Entering the treatment process>> implies the continuance of nurturing life for a long period of time during which the burdens imposed on an infant with cleft lip and palate and his/her mother were enormous. They relied on <<obtaining family support to take care of their child>> for easing burdens on them. This <family cooperation and assistance> became an indispensable support, without which mothers would not be able to continue their infants' nurturing life and treatment for years. Furthermore, they met medical staff and other mothers who have infants with cleft lip and palate. This experience of <<having the social support with relatives and neighbors>> was helpful for them to learn childhood disease and handicap.

Table 1. Outline of Subjects

Case No.	Mother	Infant		Time of Diagnosis (before birth or after birth)
	Age	Age	Sex	
A	late 20s	18 months	female	after birth
B	late 20s	17 months	female	after birth
C	late 20s	3 years	female	before birth
D	late 30s	2 years	female	before birth
E	late 20s	15 months	male	before birth
F	early 30s	18 months	male	after birth
G	late 20s	23 months	male	after birth
H	late 30s	27 months	male	after birth
I	late 20s	16 months	male	after birth
J	late 30s	14 months	male	after birth
Average	31.3 years old	21 months		before birth (3), after birth (7)

Table 2. Results of Analysis: The Experience of Mothers whose Children Undergo Labioplasty and Palatoplasty

Category (6)	Subcategory (14)	Code (65)
1. Entering the treatment process	First meeting with her baby	First meeting with her baby
		The time of diagnosis
	Understanding of the step-by-step process of treatment	The period in which a mother gets pregnant
		The period in which a mother gives birth to a baby
		Expectation and preparation on the possibility that a handicapped child is born
Nurturing life requiring efforts	Medical professional's response until treatment starts	
	Surgery and treatment undergone in stages	
Worry about appearance	Palatoplasty undergone in stages	
	Nurturing life with an infant	
Desire toward medical staff members and health-care environment	Tasks on nurturing life with an infant	
	Life bound by a palatal plate	
2. Obtaining family support to take care of their child	Family cooperation and assistance	Hospital stay with an infant whose environment differs from home
		Concern about others
	Maintenance of everyday life through family role playing	Worry about appearance
		Outdoor activities affected by appearance
		Evaluation of postoperative scar after labioplasty
Having the social support with relatives and neighbors	Request to medical staff	
	Request to medical environment	
3. Having the social support with relatives and neighbors	Family cooperation and assistance	Criteria for selecting a hospital
		Family response and assistance
	Maintenance of everyday life through family role playing	Step-by-step response and support by grandparents
		Telling family members about a disease
		Parent's role and responsibility on other children
4. Interpreting that cleft lip and palate is not disease	Understanding of the step-by-step process of treatment	Role and responsibility on family
		Surgery arranged for parents' convenience
	A variety of views on cleft lip and palate	Maintenance of family life
		Changes of family relationship
		Response and assistance of medical professionals
5. Responding to difficulties step by step	Tentative comparison and evaluation	Interaction, relationship, and association with mothers of infants who had similar disease
		Others' response and assistance
	Sustained effort	Telling others about a disease
		Request to others
		Society's response
6. Expanding their role as mother through caring and nurturing for the child	Transition of feelings during treatment process	Understanding the feeling of those who have a disease and a handicap
		The change of understanding a disease and a handicap
	Enlargement of mother's feeling and role	Uncommon disease
		Disease which can be understood in stages
		Disease with a handicap
5. Responding to difficulties step by step	Tentative comparison and evaluation	Disease without a risk of death
		Disease which has to have surgery many times
	Sustained effort	Disease which does not have negative points
		Disease affected by appearance
		Endeavoring to understand cleft lip and palate
6. Expanding their role as mother through caring and nurturing for the child	Transition of feelings during treatment process	Disease which is considered to be someone else's problem
		Disease which is considered to be serious
	Enlargement of mother's feeling and role	Unacceptable disease
		Disease which have positive points
		Disease which becomes child's own problem
5. Responding to difficulties step by step	Tentative comparison and evaluation	Evaluating through comparison
		Looking for information and causes
	Sustained effort	Making use of resources
		Changing one's views
		Overcoming problems in stages
6. Expanding their role as mother through caring and nurturing for the child	Transition of feelings during treatment process	Prepare oneself
		Change of feeling accompanied by the explanation of medical professionals
	Enlargement of mother's feeling and role	Incessant anxiety and worry until labioplasty starts
		Change of feeling after treatment and surgery process ends
		A sense of guilt
5. Responding to difficulties step by step	Tentative comparison and evaluation	Parent's role and responsibility
		Expectation for surgery
	Sustained effort	Understanding child's growth
		Change of how to perceive a child
		Policy on how to raise a child
6. Expanding their role as mother through caring and nurturing for the child	Transition of feelings during treatment process	Parents' hope and expectation
		Growth as a mother

On the other hand, many of them blamed themselves and looked for <a variety of views on cleft lip and palate> because the cause of this disease remains to be identified. Soon, mothers observed that their infants changed their appearance after surgery, focusing less on the <understanding of the step-by-step process of treatment> than on <<interpreting that cleft lip and palate is not disease>>. Through this process mothers made a <sustained effort> by accumulating the experience of <tentative comparison and evaluation> of infants' health conditions. This mother's behaviors were accumulated as the attempts of <<responding to difficulties step by step>>, leading to the resources for conducting nurturing life and the confidence as a mother.

Then, mother's distress and anxiety changed into hope and expectation on their children's healthy growth through <transition of feelings during treatment process> and their consciousness as mothers also transformed into the <<expanding their role as mother through caring and nurturing for the child>>.

2) Explanation of Each Category

Statements of a representative subject were written down in order to show that a category was based on data we collected. A statement of a subject and a subject was represented by " " and Case No. [], respectively. We added another word or changed her statement in () when a statement whose meaning was difficult to understand and revealed subject's identity.

(1) <<entering the treatment process>>

This category shows that mothers of cleft lip and palate infants had to experience a long-term course of treatment. It means that this experience contributes to avoid excessive embarrassment and confusion and leads to understand the disease and prepare for the future. This category was extracted from the following subcategories: <first meeting with her baby>, <understanding of the step-by-step process of treatment>, <nurturing life requiring efforts>, <worry about appearance>, and <desire toward medical staff members and health-care environment.>

① <first meeting with her baby>

This subcategory refers to the first meeting between a mother and her baby with complex feeling. One mother talked to us in tears: "When I saw my baby coming out of my body for the first time...I was perplexed. Why was my baby's lip cleft? This was my first impression." (postnatal diagnosis) [F1-1] **【first meeting with her baby】**

Mothers knew that their baby's lip was cleft either on prenatal diagnosis or on postnatal diagnosis. In each case they showed confusion and puzzlement. In the case where a mother underwent prenatal diagnosis that her baby would have cleft lip she said that she could not expect how severe her baby's case was until he/she was actually born: "This baby was found out to have cleft lip in the sixth month of pregnancy when I got a sonogram. I was told that it must be cleft lip but until the baby is born it is difficult to make a diagnosis..." (prenatal diagnosis) [E1-1] **【the time of diagnosis】**

One mother could not understand the meaning of sudden diagnostic explanation in postnatal diagnosis, telling us the

reason why she could not express her feeling well: "My baby had such a lip. Then I waited in a delivery room for about 3 hours. I did not know what happened. Then, I was moved to another room. Many nursing staff members were there. Doctors also came and I was told that my baby had cleft lip. I could not make out what's going on." (postnatal diagnosis) [I1-1] **【the time of diagnosis】**

② <understanding of the step-by-step process of treatment>

This is to understand the step-by-step process of treatment (e.g., labioplasty → palatoplasty). Mothers could estimate what would happen to their infants through this treatment process.

Ms. H was a mother who delayed to take her baby to a children's hospital where cleft lip and palate treatment was offered due to the lack of knowledge on this disease among medical staff members. She was relieved that she could understand and estimate the process and outcomes of treatment by making her infant undergo medical treatment in a specialized hospital. She noted that: "I'm not nervous because I can know what treatment is waiting for us in each stage of treatment for cleft lip and palate." [H1-91] **【step-by-step process of surgeries and treatment】**

She was realizing that her infant would be cured in stages by seeing her child being cured after cheiloplasty: "My baby's cleft lip was repaired and other parts would be repaired at the next stage. The doctor said this part was also going to be repaired. Finally, a Hotz plate was taken off. Another surgery is necessary but I believe and expect that teeth would be repaired next time and everything would be repaired at the completion of treatment." [J1-33] **【step-by-step process of surgeries and treatment】**

In addition, professional doctors including a doctor of dental surgery needed to explain the process of treatment in order to start medical treatment smoothly and in stages. Ms. F, to whom professional doctors were introduced, told that she could have prospects for her baby's treatment from what a doctor said: "The doctor told me that he would write a referral letter to a university hospital, every cleft lip patient went to that hospital, and it would be surely repaired if your baby was treated there. I did what he said (because he told me that my baby's lip would be repaired)." [F1-3] **【doctor's handling until medical treatment starts】**

On the other hand, in the case where a doctor failed to explain the process of treatment well, a mother was not sure what she had to do in her baby's medical treatment. Ms. D told it to us: "(In prenatal diagnosis) the doctor (in the Department of Obstetrics and Gynecology) did not say anything special. I asked a doctor in the Department of Pediatrics about my baby's medical treatment. But the pediatrician did not talk about the lengthy process of treatment but was just saying to me, "if the baby cannot drink, it was necessary to insert a tube through the mouth and put the baby on a drip..." [D2-38] **【doctor's handling until medical treatment starts】**

Ms. H, who delayed visiting a special hospital and failed to start treatment process smoothly, showed impatience with such a medical care system: "I was told that it was late...it was too late to come to (a special hospital). Usually we must bring a baby born with cleft lip or palate to a special hospital within a few hours or days after delivery for making a plate, but it took 2 weeks for me to go to a special hospital..." [H1-87] **【doctor's handling until medical treatment starts】**

③ <nurturing life requiring efforts>

This means the life in which a mother puts efforts into taking care of her child with cleft lip and palate by spending most of her time in a home and hospital. She breastfed her baby all day and took care of her breast: "I thought breastfeeding is good for my baby, so I tried to obtain breast milk but it began to dry up. I tried my best to breastfeed my baby. I thought it's good for a baby to drink milk from nipples but I could not... My baby was not good at drinking milk from a bottle." [H1-20] **【Tasks on Nurturing Life with an Infant】**

An infant with cleft lip and palate had to wear a palatal plate for the proper growth of his/her chin and appropriate breastfeeding. But this plate was easy to unfasten and brought a discomfort to an infant, so that a child often tried to detach it by himself/herself when his/her mother was away. A mother told us how difficult it was to keep a plate safe without losing or damaging it: "The plate disappeared. My child unfastened and discarded it, so I had to look for it many times. Sometimes it took several hours to find it in a store. It was a lot of trouble. The plate was so easy to come off. This was the problem." [B1-74] **【Life Bound by a Palatal Plate】**

In such a life a mother tried to find out a good way to breastfeed her infant easily: "I breastfed my child as she wished. If she wanted to drink milk, I gave it to her. If she wanted only a small amount of milk, I adjusted it for her." [B1-17] **【Nurturing Life with an Infant】**

④ <worry about appearance>

This implies that facial deformity of one's child and facial changes after surgery affect living activities such as outdoor activities. Especially child's outdoor activities became an important task: "I could not take my child outside because I got worried about stares from others." [A1-18] **【Outdoor Activities Affected by Appearance】**

However, the change of child's facial appearance after cheiloplasty brought relief and the change of behaviors to mothers: "I was so relieved that my kid could close his mouth properly. The incision also healed well. The doctor told me that surgery on a lip went very well. I was reassured to see my kid's face without a scar." [J2-27] **【Evaluation of Postoperative Scar after Cheilosplasty】**; "My child started to go for a walk with me after her face looked good." [D1-24] **【Outdoor Activities Affected by Appearance】**

⑤ <desire toward medical staff members and health-care environment>

This is a request toward medical staff members and health-care environment during treatment process. Some mothers told that they wanted medical experts to know what cleft lip and palate was: "I want every infant born with cleft lip and palate in Japan to undergo a proper medical procedure as quickly as possible. So I want every doctor know about this disease." [H1-88] **【Request to Medical Staff】**

(2) <<obtaining family support to take care of their child>>

This category was extracted from subcategories of <family cooperation and assistance> and <maintenance of everyday life through family role playing>. It refers to the maintenance of the living conditions of the current family through the support

of a mother and a child patient by all family members.

① <family cooperation and assistance>

This refers to the situations in which a child with cleft lip and palate and his/her mother are warmly treated and cooperated by her family members. The positive response of a father, brothers and sisters to a child patient provided psychological support to a mother: "The baby's brother said just that 'cute!' when he saw the baby for the first time. It has become my mental support." [H1-4] **【Family Response and Assistance】**; "My husband said to me, 'The cleft lip must be repaired. So, it's OK.' I was relieved to hear that." [A2-8] **【Family Response and Assistance】**

② <maintenance of everyday life through family role playing>

This means that each family member plays her/her own role and current lifestyle is maintained in a situation in which a mother has to be devoted to her child's care and nurturing. Her husband and other children tried to maintain it by playing their own roles: "Last year an elder child went to a nursery school. So he stayed in a grandmother's home when my baby was hospitalized. This time my husband told that he would do things around the house." [E1-13] **【Changes of Family Relationship】**; "Many children would miss their mother but my older daughter remained unchanged. It's amazing." [H1-37] **【Parent's Role and Responsibility on Other Children】**

There were also the cases in which a mother and her family members gave priority to their own daily activities: "This was the only period I can go off work for many days at a time. My husband also had to get out of office because he needed to pick up and drop off another child in a kindergarten. The doctor told me to have surgery around April but I asked him to do it in the summer because my husband could take off work in this period. That is, the timing of surgery was determined by parents' convenience." [H1-34] **【Surgery Arranged for Parents' Convenience】**

(3) <<having the social support with relatives and neighbors>>

In this category a mother associates with others by adjusting her relationship with those around her under the situations in which she gets support from medical staff members, other mothers of children born with cleft lip and palate, those who were burdened with cleft lip and palate, friends, and others, deepens the understanding of the disease and people with disabilities, and changes the perspective on them. A subcategory of <associating with other people around them and their infants> was treated as a category.

The interaction with other mothers of infants born with cleft lip and palate and those who were burdened with it became a good opportunity to exchange useful information about this disease and medical treatment. It was also helpful to have a clear view of treatment process: "In this outpatient care others talked to me about a variety of things. For instance, one woman whose child had similar disease asked me about a course of treatment. Then, she taught us the process of treatment. I was so relieved to talk to her. I could expect the course of treatment after talking to her." [E2-87] **【Interaction, Relationship, and Association with Mothers of Infants Who Had Similar Disease】**

Yet, it sometimes happens that a mother felt frustrated by

what people around her said: "When my acquaintance saw my kid, she said to me, "Oh you poor thing! Is your baby cured?" It was so frustrating. That others saw a tube passed through my baby's nose and gave us a pitying glance was the most irritating thing. Can they say other things such as 'you done good?'" [G2-41] **【Others' Response and Assistance】**

(4) <<interpreting that cleft lip and palate is not disease>>

This category refers to the transformation process in which a mother struggles to understand what cleft lip and palate is. It was extracted from subcategories of <understanding of the step-by-step process of treatment> and <a variety of views on cleft lip and palate>.

① <understanding of the step-by-step process of treatment>

This means that a mother modified her understanding of cleft lip and palate which had been an unknown disease name. At first, cleft lip and palate was recognized as a disease name which was unknown among the public. Ms. C told that: "Nobody around me knew about cleft lip and palate. My friends did not know it. My relatives also did not know it. Nobody knew it." [C1-8] **【Uncommon Disease】**

Yet, mothers started to talk about cleft lip and palate as a disease which did not interrupt the growth and development of children as they underwent treatment process: "This is not a type of disease which we have to worry about the life of a child. My child grows up normally as of this moment." [J1-58] **【Non-life-threatening Disease】**

② <a variety of views on cleft lip and palate>

This refers to the process in which mothers change their views on cleft lip and palate by attaching a variety of meaning to this disease for accepting this situation. They named cleft lip and palate in a variety of ways (e.g. "disease" or "handicap"). They sometimes asked us, "Is this a disease?": "I do not think that cleft lip and palate is a disease. That's because it is not an illness which cannot be cured permanently. I also heard that a patient can speak exactly the same as everyone else. So, I do not think it is a disease." [G2-20] **【Do Not Consider That Cleft Lip and Palate Is a Disease】**

(5) <<responding to difficulties step by step>>

This category is about perception and behavior in which a mother solves or fixes a variety of tasks and problems occurring in the treatment process. This category was extracted from subcategories - <tentative comparison and evaluation> and <sustained effort>.

① <tentative comparison and evaluation>

This subcategory refers to situations in which a mother attempts to obtain positive results by comparing her own child and herself with other children and their mothers. Targets for comparison are a variety of children including a healthy child, a seriously handicapped child, a cleft lip and palate child, and their mothers. She tried to rethink that the severity of her child's malformation was milder than other children by comparing between them: "This may sound rude to you... I saw children who eat through a tube. I was a bit

relieved that my child was better than other children." [B1-26] **【Evaluating Through Comparison】**

② <sustained effort>

This is an effort to solve or fixes a variety of tasks and problems occurring in the treatment process, through which mothers overcome them step by step and modify their views on the disease: "I'm dealing with the problems one by one. This was my tentative goal. I must set a new goal." [D1-71] **【Overcoming Problems Step by Step】**; "It is not still clear why cleft lip and palate infants is born, so I do not think it's a good idea to think about the reason my child was born with cleft lip and palate. I thought that I should not look backward but forward... It seems that I could easily do that." [H1-58] **【Changing One's Views】**

(6) <<expanding their role as mother through caring and nurturing for the child>>

This category refers to the process in which a mother enlarges her role through her involvement with a child patient. It was extracted from subcategories - <transition of feelings during treatment process> and <enlargement of mother's feeling and role>.

① <transition of feelings during treatment process>

This means that mother's complex feelings change into the realization of one's responsibility and enthusiasm toward a child patient. Mothers start to care for their kids much more seriously as treatment process advances: "I bottle-fed my older children while they were lying down. I was also lying down. But in the case of this child, I had her on my hip while I bottle-fed him. I did that even at midnight. [G1-48] **【Transition of Feeling Through the Process of Treatment and Surgery】**

② <enlargement of mother's feeling and role>

This means the change of mother's response to her children by recognizing herself as a responsible mother. After the surgery for cleft palate, a mother who concentrated on raising her child began to think about the hope and expectation for child's self-reliance: "I want my kid to recognize his own handicap... I want him to accept his disease and continue to receive medical treatment for himself. I really want him to think that it is his handicap." [H1-73] **【Parents' Hope and Expectation】**

3) Above categories are shown on Figure 1. This shows that in order to <<entering the treatment process>>, a mother <<obtaining family support to take care of their child>> and <<having the social support with relatives and neighbors>> and has the experience of <<interpreting that cleft lip and palate is not disease>>, <<responding to difficulties step by step>> and <<expanding their role as mother through caring and nurturing for the child>>.

VI. Discussion

Previous studies of mothers of children with cleft lip and palate have clarified that mother's worry and anxiety changed as their children grew up. This research also revealed that their worry and anxiety changed by <<entering the treatment process>>. They <<expanding their role as mother through

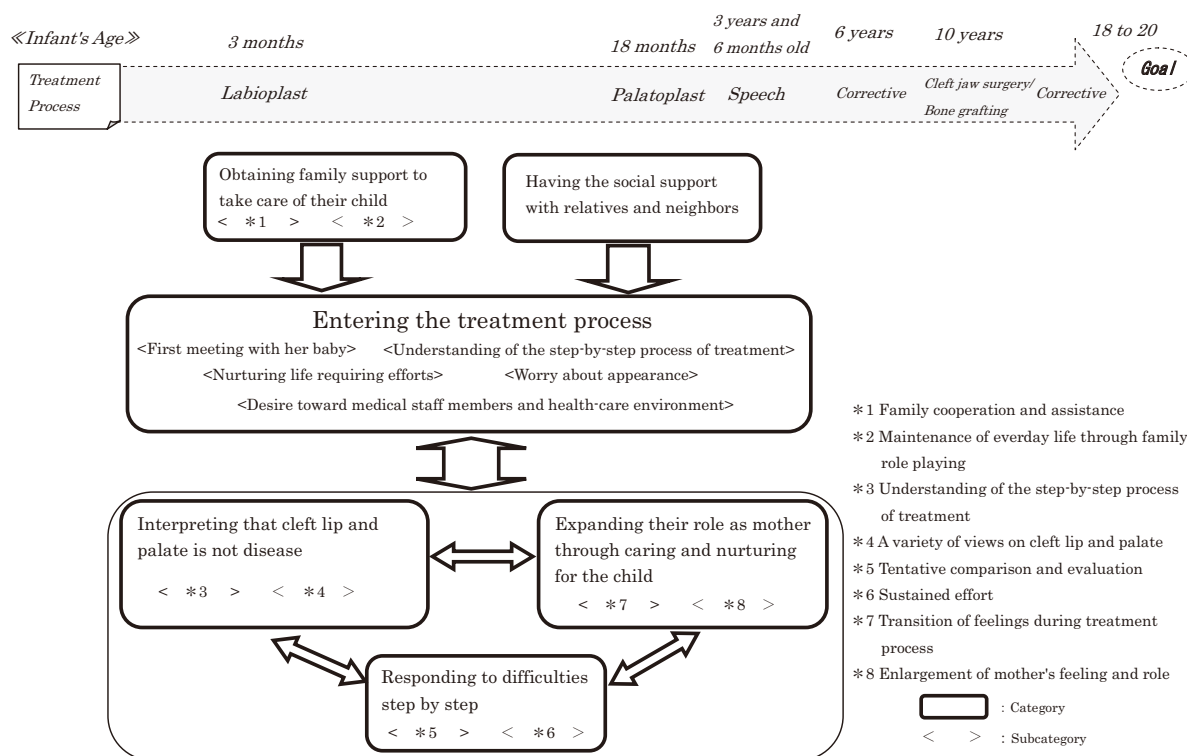


Figure 1. Relations between categories that the Experience of Mothers whose Children Undergo Labioplasty and Palatoplasty

caring and nurturing for the child» by «responding to difficulties step by step» and «interpreting that cleft lip and palate is not disease». Based on these findings we examine the changes and characteristics of the experience of mothers of cleft lip and palate.

1. Mother’s «Entering the treatment process» and The Changes of Her Experience

It is generally considered that there is an appropriate treatment process in most diseases. Those who have cleft lip and palate also has to experience a long-term treatment process until they become adults. The category of «entering the treatment process» revealed that stable treatment process of cleft lip and palate is important for mothers.

There was a task of prenatal diagnosis on an early stage of «entering the treatment process». This is a stage in which an obstetrician and gynecologist found out that a baby in the womb was likely to have cleft lip when a mother got a sonogram. It is expected that more babies are found to have this disease during a mother’s pregnancy as a three-dimensional sonogram has become more commonly used since the latter half of the 1990s²². Taking this situation into consideration, researches on mothers of children with cleft lip and palate have examined a way to tell a mother about prenatal diagnosis and support system after it^{23)~25)}. Yet, it is not still clear whether it is appropriate to tell a mother about the disease of her baby in the womb because it would have a negative psychological effect on a pregnant mother^{26)~28)}.

In our sample 3 mothers and 7 mothers were told about their babies’ disease in prenatal diagnosis and in postnatal diagnosis, respectively. Mothers’ comments on the timing of disclosure were not uniform. A variety of responses are

expected to be given by them, so that it is more important to make a complete explanation of how treatment proceeds than to care about the timing of disclosure in order to realize a smooth treatment process.

It is said that when something is wrong with a child, a mother tends to feel that she fails to fulfill her role, loses her pride, shows a sense of guilt²⁹⁾, keenly feels one’s incompetence, and has a sense of alienation, anger, and despair³⁰⁾. On the other hand, through the hard times of child-rearing a mother experiences her own growth³¹⁾ and plays the role of a mother³²⁾ with an interaction with nursing specialists and other mothers of handicapped children.

A mother of a child with cleft lip and palate tends to have complex feelings when she sees her baby for the first time but through treatment process she is likely to become conscious of mother’s responsibility and enthusiasm for child-rearing, enlarging the role of a mother. This shows that treatment process mothers of children with cleft lip and palate encounter can be regarded as the process of mother’s growth and development as well as the process in which a child recover from cleft lip and palate.

2. overcoming problems step by step

It is reported that mothers of handicapped children deal with their surroundings in a variety of ways^{33)~35)}. These include: to acquire information on disease and disability, to adapt to situations flexibly, to deal with daily affairs; to be ready for the worst, and to motivate herself. Some mothers of children with disease and disabilities tend to blame themselves by comparing their own child with healthy children or refuse to admit their children’s malformation³⁶⁾. It is also reported that some mothers tried to feel relieved by

comparing oneself with mothers of children who had more serious cleft lip and palate ("My baby is much better because his cleft lip and palate is more likely to be repaired"³⁷). This is a coping technique relying on <tentative comparison and evaluation>.

This mothers' behavior to "compare" is an attempt to examine the difference between more than two things³⁸), whose findings depend on the judgment of those who evaluate it. It may sometimes lead to negative evaluation. It may bring about positive results which raise the hope of more favorable conditions. Cleft lip and palate surgery and treatment can significantly improve the form and function of nose and mouth, therefore, an act of "comparison" does not necessarily distort the judgment of current situations. Rather, it can be a good opportunity to find out better aspects of treatment. For this reason, we consider that an act of "comparison" mothers of children with cleft lip and palate make is a means to come to terms with the disease and to justify a variety of events happening during treatment process.

Cleft lip and palate is a disease in which a patient must continue to undergo appropriate treatment and rehabilitation in each growth stage from birth to adulthood. Mothers have to deal with not only the treatment of their children's morphological and functional damage³⁹). They also must consider their children's social adaptation and the appropriate timing of notice to children. These problems arise in the course of treatment, implying that mothers have to prepare for a complex and variety of tasks now and in the future. Yet, many of them are expected to be solved or cured through treatment process, that is, each task does not necessarily remain to be solved forever. The growth of her child or the improvement of facial appearance after surgery can be a good opportunity to complete tasks one by one, bringing a sense of accomplishment to a mother. It is considered that this sense of accomplishment supports mother's effort, encouraging her attempt to dealing with problems one by one.

3. The Significance to Change How the Disease Name of Cleft Lip and Palate Are Perceived by Mothers

Doctors specify particular disease situations by diagnostic names but disease conditions of cleft lip and palate can be cured by treatment and surgery. The name of diagnosis does not necessarily have a significance to a mother and her infant over a long period of time. Most mothers feel the curing process in a positive way as their children grow up. Mother's recognition of <<interpreting that cleft lip and palate is not disease>> can be understood as the expression of an uncomfortable feeling and doubt. That cleft lip and palate is a disease with no known cause and causes facial malformations puts a shame and stigma to the name of this disease. In order to dispel such negative feelings mothers have to possess cognitive framework to interpret and explain their children's disease from a standpoint of mothers, which differ conceptually from cleft lip and palate understood by medical professionals. <<interpreting that cleft lip and palate is not disease>> can be considered to derive from such a mother's initiative.

It is also said that attitudes on child-rearing⁴⁰), prejudice against handicap, and a sense of guilt toward one's child which a mother possesses bring about child's feelings of low self-concept and inferiority⁴¹). Paying extremely close attention to children⁴²) is also considered to have an adverse effect on the shaping of their characters. Sumida and others, taking up the

issue of how a mother sees and thinks about her own child, reported that it was affected by social and cultural values and affected attitudes and behaviors toward children⁴³). <<interpreting that cleft lip and palate is not disease>> is a perspective in which how a mother thinks about her child's disease. It can lead to the transformation of her views on children, affecting her attitudes and behaviors on children.

Therefore, it is considered that mother's <<interpreting that cleft lip and palate is not disease>> is not an attempt to understand the cause of cleft lip and palate but to have a new view and attitude toward her own child.

VII. Conclusion

Previous studies of mothers of children with cleft lip and palate tended to focus on the state and change of their anxiety and distress. This study, however, clarified the characteristics and the changes of mothers' experience by extracting the following six categories: <<entering the treatment process>>, <<obtaining family support to take care of their child>>, <<having the social support with relatives and neighbors>>, <<interpreting that cleft lip and palate is not disease>>, <<responding to difficulties step by step>>, and <<expanding their role as mother through caring and nurturing for the child>>. <<Entering the treatment process>> is important for mothers of children with cleft lip and palate to make their children continue treatment for a long period of time. Our study suggests that this process is also a process in which they grow up as mothers. They also engaged in <<responding to difficulties step by step>>. Such an engagement can bring a sense of accomplishment. Their recognition of <<interpreting that cleft lip and palate is not disease>> also affects their attitudes and behaviors toward children.

VIII. Suggestions to Nursing Practice

We need to understand that the experience of mothers of children with cleft lip and palate during treatment process can be a process in which they grow up as mothers. There are three implications for nursing practice.

1) Medical professionals must understand treatment process of cleft lip and palate and strengthen coordination to various medical experts.

2) We should not react negatively to mother's proactive efforts but understand their own reasons and explanations for doing them.

3) We need to focus on the process of mother's changes, bearing in mind that treatment process can lead to mother's role enlargement.

IX. The Limits of This Study and Remaining Tasks

Mothers of children with cleft lip and palate in this study were the ones who agreed to participate in the interviews, which might not necessarily represent the whole population of mothers of children with cleft lip and palate in Japan. It is expected that mothers who did not agree to participate in the interviews would have peculiar characteristics such as extreme negative sentiment or regional characteristics of family relations. Therefore, we need to clarify a variety of aspects of mothers' experiences in the future study.

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