

## Negative Events Experienced by Mothers Raising Children with Cleft Lip and Palate

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(Accepted May 17, 2010)

Key words: children with cleft lip and palate, mother, negative events, genetic counselor posttraumatic stress disorder

### Abstract

This study is aimed at clarifying the negative events experienced by mothers raising children with cleft lip and palate. Semi-structured interviews were held with 18 mothers living in Western Japan. The following factors were extracted from content analysis: birth of an unhealthy child, difficulty in remedial education, anxiety over the child's future, improper treatment in the maternity ward, lack of the family understanding, unavailability of social support, the mother's excessive responses to others, and feelings difficult to overcome. Feelings difficult to overcome, which covers points such as being unable to accept the fact and hesitation in bearing another child, may be considered a posttraumatic stress disorder. To prevent a vicious cycle of negative events, establishing a system that allows mothers to see other specialists early after childbirth is recommended. This will provide mothers with the opportunity to receive advice on the expected remedial education, and to integrate certified genetic counselors into team-based care.

### Introduction

Cleft lip and palate is considered the most common congenital malformation in Japan, with an incidence reported to be 0.18% by Matsuoka, et al. in 2000[1]. In Japan, while the number of children born with cleft lip and palate is decreasing due to in the declining birth rate, the incidence of this malformation has remained unchanged[2]. Globally, it is known that cleft lip and palate occurs more frequently in Mongoloids- which includes Japanese people [2, 3].

It has been noted that although mothers who deliver children with cleft lip and palate are initially shocked when they first see their child, the majority of mothers adopt a constructive attitude in a relatively short period of time [4]. However, it has long been pointed out that their psychological shock and emotional distress are immeasurable given the facial abnormality, dysfunctions such as nursing difficulty and speech disturbance, and the prolonged process of treatment. Most notably, it has been reported that most mothers of cleft lip and palate sufferers did not go out with their children until the completion of corrective surgery because of the conspicuousness of the anomaly [5]. Mothers who delivered children with cleft lip and palate are considered to be sensitive to the behavior of others, and are vulnerable to matters that other people would consider trivial. Although the nursing by mothers during their maternity stay [6,7] and their psychological state [8,9] were previously investigated, most of these studies were based on a questionnaire survey and did not focus on the mothers' feelings in regards to the specific behavior of

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other people.

This study aimed to clarify the negative events experienced by mothers raising children with cleft lip and palate.

## Methods

### 1. Subjects

The subjects were mothers of children receiving outpatient treatment at 3 institutions for cleft lip and palate in Western Japan (Osaka, Okayama and Fukuoka).

### 2. Data collection period

July 2005 - January 2006

### 3. Data collection methods

Following an oral explanation, the subjects were provided with an informed consent form. Those whose written consent for participation in this study was obtained received a semi-structured interview regarding the perceived negative behavior of other people that they had experienced since the time of prenatal notification or immediately after childbirth. In the interview they also detailed their feelings about the behavior and their own attitudes toward child-raising. The interview was held either at the subject's home or in-hospital in a quiet location on a consultation visit or during hospitalization for the child's operation. The time required for an interview was approximately 60 to 90 minutes. On obtaining each subject's permission, the interview was recorded on an IC recorder to prepare a verbatim record.

### 4. Analysis methods

A negative event was defined as "speech or action causing emotions in a mother that prompted her to deny herself or her child, for example: hurt, shocked, sad, pained, or any other negative thought by the mother over the course of raising her child". Based on the verbatim record, each sentence considered to be meaningful as a negative event was labeled as a code. Then, subcategories and categories were generated using methods for content analysis. Questions that arose during the analysis were repeatedly discussed with nurses experienced in the treatment of children with cleft lip and palate, and confirmed with subjects to ensure the reliability of the data.

### 5. Ethical consideration

The subjects received an explanation on the purpose of the study, protection of their privacy, freedom of participation and withdrawal, absence of disadvantages, and a copy of the study results. They then submitted their written consent. This study was approved by the ethics committee of the author's university (No.029).

## Results

### 1. Background of the subjects

The subjects were 18 mothers aged in their 20s - 40s, three of whom had been notified of the malformation before giving childbirth. Their children were aged between 2 -16 years old: 5 under the age of 5, 11 between 5 and 10, and 2 at 10 years or older. The gender of the children in the study was split between 9 males and 9 females and their birth orders were 9 first and 9 second or later children. The disorders were: unilateral cleft lip and jaw in four of the children, unilateral cleft lip and palate in eight

children, and bilateral cleft lip and palate in the remaining six children. Two children had the further complication of hearing loss. In regards to the family structure, 14 belonged to a nuclear family and 4 to a three-generation family.

## 2. Negative events

Eight categories and 27 subcategories of negative events were extracted. Under this point, categories, subcategories, and raw data are marked with [ ], < >, and “ ”, respectively.

[Birth of an unhealthy child] consisted of 3 subcategories: <birth of a child with facial malformation>, <remorse of having given birth to a child with cleft lip and palate> and <comparison with healthy children>. Mothers were “shocked” by delivering an unhealthy child with cleft lip and palate and blamed themselves- “I failed to bear you properly” and “Why did this happen to me?”. A mother’s birth mother (the child’s grandmother) who could not help comparing the baby with healthy children, repeatedly said “What a pity!”, this was described as a negative event.

[Improper treatment in the maternity ward] also consisted of 3 subcategories: <keeping a mother away from her child just after birth>, <maternity workers’ lack of knowledge>, and <inconsiderate treatment by maternity workers during hospitalization>. Complaining, “The child was blocked from my view”, a mother expressed a negative feeling regarding the healthcare workers’ infringement of her right to see her child. In complaints such as “healthcare workers only said, ‘I don’t know’” and “To be frank, nurses told me nothing”, mothers indicated feeling negative over the gap between their desired explanation or treatment and those actually provided.

[Difficulty in remedial education] was composed of 4 subcategories: <difficulty in breast-feeding due to the disorder>, <repeated operations and complications>, <the child’s questions about repeated operations>, and <the child’s questions about the scar>. Through statements such as, “My child may not survive because he/she cannot even drink milk”, it was clear to us that mothers had numerous concerns about nursing. Besides “repeated visits to the operating room” and the “complication of hearing loss”, children began directly questioning their situation as they grow up by asking, “Why do I have to undergo operations?” and “Why do I, and not others, have a scar here?” Mothers had negative feelings with confronting such difficulties in remedial education.

[Anxiety over the child’s future] was also composed of 4 subcategories: <questions about the disorder>, <bullying>, <appearance> and <the child’s future marriage and becoming a parent>. By asking, “How should I explain to my child about his/her condition?”, “I’m afraid that my child will be bullied someday”, and “Since my child is a girl, she’ll naturally be concerned about the shape of her lips and nose”, mothers showed their anxiety , without finding any way to proceed, regarding issues expected to arise in their children’s future. They also highlighted , issues that may become problems in the next generation, such as “I cannot help but blame myself for my child’s condition, imagining what the parents of his/her future spouse will say at the time of his/her marriage” and “Will it be inherited when my child bears her own child?”.

[Lack of family understanding] comprised 4 subcategories: <family’s accusation (1): attributing to the mother’s behavior>, <family’s accusation (2): attributing to worries over heredity>, <husband’s indifferent attitude>, and <family’s hiding the child>. A mother’s family attributed it to her behavior during pregnancy, saying “You did something, didn’t you?” The mother described her mental pain due to talk on heredity, confessing, “My birth mother weeps, saying ‘I never expected to have a grandchild like him/her’”. She felt “bitterness” when hearing “her husband say ‘I suspect that it’s attributable to my wife’, despite her expectation of support from him”. “Families tend to prefer to hide children (with the disorder)”, said a mother who wondered if her child should be hidden. She had already developed negative feelings.

[Unavailability of social support] comprised 3 subcategories: <nursery's refusal of acceptance>, <helpless circumstances at the kindergarten/nursery>, and <unintentional words from others>. Some mothers complained, "I experienced a nursery refusing to enroll our child" and "I heard the teacher does not always attend to my child". Mothers expressed negative feelings about dismissive responses from those whom they needed support in raising their child. A mother was hurt by "unintentional words from another mother close to her- 'Since my child is normal...'".

[Mother's excessive responses to others] consisted of 4 subcategories: <mother's hiding the child>, <concern about others' judgment>, <distress due to thoughtless words about appearance (1): from other children>, and <distress due to thoughtless words about appearance (2): from peers>. Mothers "kept (their children) hidden without reporting (the childbirth) even to their friends", and "withdrew into their homes to avoid others' eyes". "Children comment on what they see, saying things like 'He has a split mouth' or 'Her nose is a different shape'", said a mother who responded excessively to others' remarks. She suffered grief and decided to hide her child.

[Feelings difficult to overcome] involved 2 subcategories: <unable to accept the fact> and <hesitation in bearing another child>. The mother of a 4-year-old girl with left cleft lip and jaw was in her early 30s. She was notified of the malformation at 38 weeks of gestation and gave birth to her daughter by cesarean the following week. She stated, "Since my child is disfigured, I'll never be happy regardless of what others say", "I heard my birth mother say to my brother, 'You should not be married, because everybody will be sad (if she delivers a child with cleft lip and palate)'" and "(My husband wants to have a second child, but) I refuse to bear another child".

## Discussion

### 1. Schematization of negative events experienced by mothers of children with cleft lip and palate (Fig. 1)

Negative events experienced by mothers of children with cleft lip and palate comprised of those arising from the disorder itself or the process of remedial education- including [Birth of an unhealthy child], [Difficulty in remedial education] and [Anxiety over the child's future]- as well as the negative attitudes or words of healthcare workers, family members, or other members of society such as those in a nursery or kindergarten- including [Improper treatment in the maternity ward], [Lack of family understanding] and [Unavailability of social support]. Maternity staff keeping a mother away from her child just after birth has been reported. Mothers should be responsible for providing support and this adversely affects the mother in raising her child thereafter [10]. This study supported the presence of the above issue. It also demonstrated the presence of an indifferent attitude by husbands, who should support their wife and child, and the family's accusations against the mother. Furthermore, social support from responsible healthcare workers and nursery/kindergartens remained unavailable to mothers. These circumstances are considered to be secondary threats and possibly induce the [Mother's excessive responses to others].

Continuing this vicious circle seems to have led mothers to develop [Feelings difficult to overcome] (involving being <unable to accept the fact> and <hesitation in bearing another child>). Even when her child was already 4 years old, one mother remained unable to feel secure regarding the child's future and she did not want to have another child despite the fact that a subsequent child would be less likely to develop the same disorder; because of the multifactorial inheritance underlying it [11]. It is not necessarily a goal for her to become willing to have another child, of course, but it is important for her to be able to accept her life with the present child through discussions with her husband. In certain cases, mothers cannot overcome their experience of delivering a child with cleft lip and palate. It is possible to consider this condition as a posttraumatic stress disorder (PTSD) caused by psychological trauma; "an experience

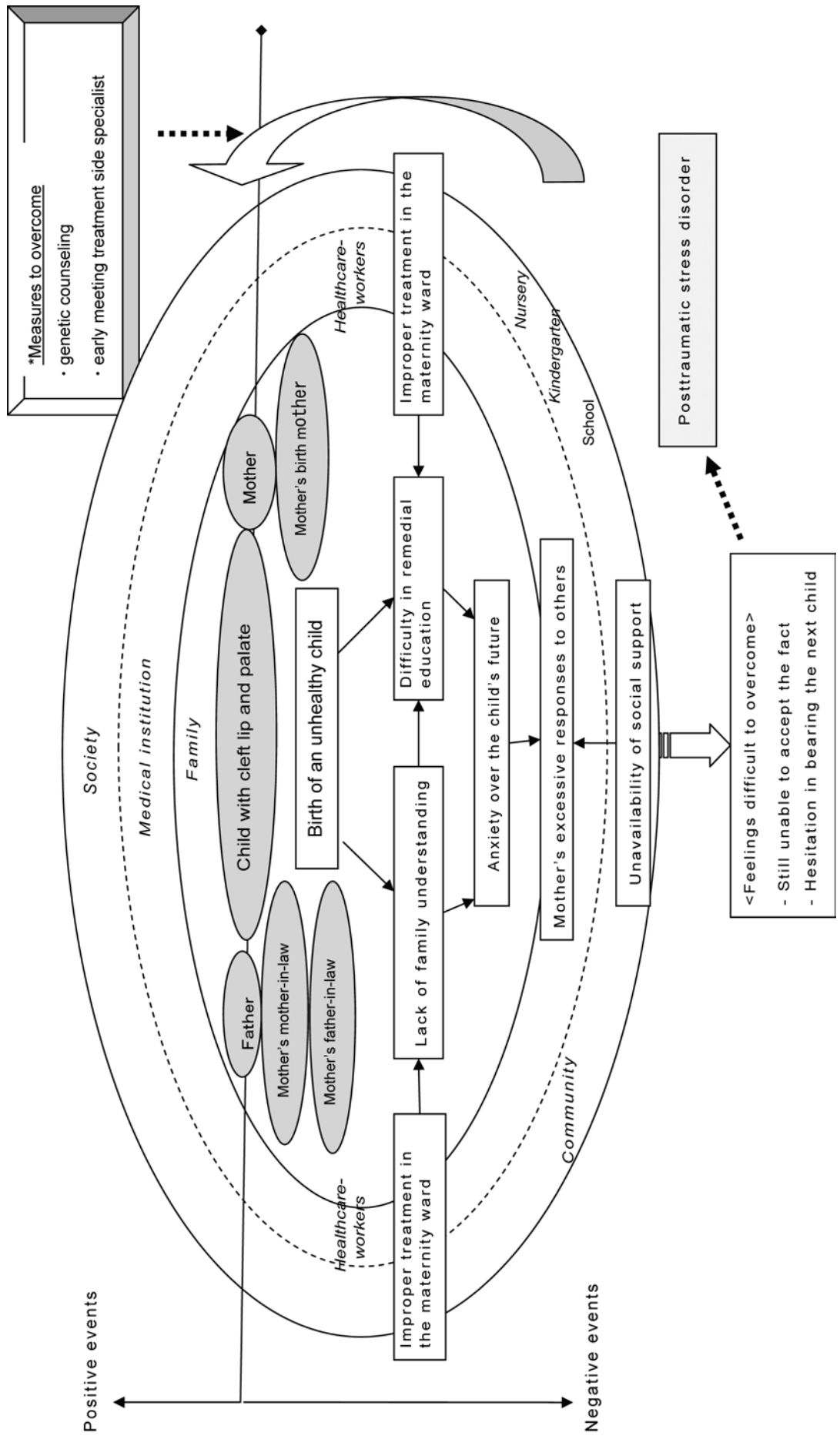


Fig.1 The process of negative events perceived by mothers of children with cleft lip and palate

potentially inducing permanent, irreversible changes to the mind". Figure 1 presents a schematic representation of these extracted negative events. There are also many positive events surrounding the negative ones. It is necessary to identify and present ways to overcome the negative circumstances.

## 2. Future challenges to feelings hard to overcome

Only one of the 18 mothers delivered a narrative significant enough to suggest PTSD. However, even though comprising the only case, the presence of a mother raising her child with [Feelings difficult to overcome] is a factor possibly preventing the sound growth of the child. Healthcare professionals must prevent such a possibility.

A mother gave birth to her child soon after receiving an unexpected prenatal notification. Although mothers notified before childbirth are reported to "adapt" earlier to the situation than those not prenatally notified [12], this mother is considered to be a case that demonstrates the confusion that can be caused by an improper notification. Her narrative suggested that she had experienced inconsiderate treatment by maternity workers and perceived the workers' lack of knowledge during hospitalization. The difficulty in accumulating experience in maternity clinics has long been pointed out [13], and, more recently, cases of team-based care involving cooperation between obstetric and other specialists have been reported [14,15]. For mothers, it is crucial for their success in child-raising to receive quality care immediately after delivery. To achieve this, it is necessary to establish a system that allows other specialists to meet mothers early after childbirth to advise them about all facets of the expected remedial education.

Nevertheless, the most significant impact on the above mother was her birth mother's belief in heredity. In Japan, the mother-child relationship has been profound and strong since ancient times- described by Imai as "linked by the umbilical cord" [16]. In the case of this mother, for example, the grandmother of the child took on her daughter's problem as her own. In such a case, family support, particularly genetic counseling, is essential. Numbers of genetic specialists are gradually increasing in Japan; with 72 genetic counselors certified as of 2009 [17]. One of the future challenges is to position these specialists into, or in the vicinity of, team-based care for cleft lip and palate to prepare healthcare systems that enable them to provide appropriate support regarding genetic issues.

## Conclusion

1. Negative events experienced by mothers raising children with cleft lip and palate, [Birth of an unhealthy child], [Difficulty in remedial education], [Anxiety over the child's future], [Improper treatment in the maternity ward], [Lack of family understanding], [Unavailability of social support], [Mother's excessive responses to others] and [Feelings difficult to overcome] were extracted.
2. The presence of a mother raising her child with [Feelings difficult to overcome] (involving being < unable to accept the fact> and <hesitation in bearing another child>) is a factor possibly preventing the child's sound growth. Healthcare professionals must prevent such a possibility.
3. To prevent the vicious cycle of negative events, it is desirable to establish a system that allows mothers to see other specialists early after giving childbirth, so that they can receive advice on the expected remedial education and to integrate certified genetic counselors into team-based care.

This study is only one part of research which received an extension of a Grant-in-Aid subsidy for Scientific Research (base C, 17592282) in 2005 – 2006.

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