

The Relationship between Maternity Support and the Psychological State of Mothers of Babies Prenatally Diagnosed with Fetal Cleft Lip/Palate

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Key words: mothers, maternity support, prenatal diagnosis, cleft lip/palate

Abstract

This study was aimed to clarify the relationship between maternity support provided for mothers of infants with cleft lip/palate at the time of prenatal notification and the psychological state of these mothers. A mail survey was conducted using an original questionnaire. The subjects were 31 mothers. For statistical analysis, data were subjected to the Mann-Whitney U test ($p < 0.05$). The results were as follows: 1) Mothers who had “only received an oral explanation” at the time of prenatal notification showed a significantly lower willingness to adapt themselves soon after delivery. Mothers given “explanations using photos of the current and postoperative conditions” showed a significantly stronger willingness to accept the situation at the time of notification, and adapt themselves soon after delivery; 2) Mothers given an “explanation about surgical treatment” felt significantly weaker senses of shock, denial, and sorrow soon after delivery, and showed a significantly strong willingness to adapt themselves soon after delivery; 3) Mothers receiving an “explanation about public aid (for rehabilitation of disabled children)” showed a significantly stronger willingness to adapt themselves and accept the situation soon after delivery; 4) Mothers given an “explanation on self-help groups (parents’ meetings)” showed a significantly stronger willingness to accept the situation soon after delivery; 5) Mothers “feeling positive about support from nurses” tended ($p = 0.066$) to show a stronger willingness to adapt themselves soon after delivery; 6) Mothers who had “consulted a specialist surgeon before delivery” showed a significantly stronger willingness to adapt themselves and accept the situation soon after delivery.

Introduction

“Prenatal notification” refers to informing the mother and family of a fetal disorder diagnosed before birth [1]. Since the late 1980s, there have been case reports of cleft lip/palate diagnosed before birth [2,3]. With the recent spread of 3-D diagnostic ultrasonography and availability of treatment that can make the scar unnoticeable [4,5], prenatal diagnoses and notifications of cleft lip/palate have become increasingly common.

However, these advances in medicinal technologies are likely to lead physicians to simply inform the

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mother; at the same time, they must avoid unnecessarily confusing the mother and family. As a team of children's dentists and speech therapists practicing at rehabilitation centers for disabled children, Takeda, et al. [6] have developed a system for the early rehabilitation of disabled children in cooperation with obstetricians, and have been performing prenatal counseling since the late 1990s. Recently, it has also been reported that some plastic and oral surgeons visit 'prenatally informed' mothers at maternity clinics and hospitals to actively support them [4,5,7]. From the standpoint of health professionals engaged in plastic surgery-based team care, we have also proposed maternity support measures, including the development of a maternity support table describing the contents of care to be provided in the obstetric area at the time of prenatal notification [8].

The effects of maternity support on mothers' psychological state, however, have not been statistically evaluated.

This study was aimed to clarify the relationship between maternity support provided for mothers of infants with cleft lip/palate at the time of prenatal notification and the psychological state of these mothers.

Methods

1. Subjects

The subjects were 39 women recruited on the condition of being mothers of babies prenatally diagnosed with cleft lip/palate, and having their children treated with cheiloplasty at three institutions providing team care for cleft lip/palate in the Kinki, Chugoku, and Kyushu regions.

2. Methods

Using an original questionnaire, a mail survey was conducted from August 2005 through August 2006.

3. Survey items

- 1) Mothers' characteristics: Age, the time of notification, attendant(s) at the notification, the place of delivery, the timing of consulting a specialist surgeon, and the gender, age, birth order, and cleft type of the child.
- 2) Methods for explaining the condition (notification): The subjects were asked to choose either "used" or "not used" for each of five options (allowed to choose "used" for multiple options).
- 3) Support items provided at the time of prenatal notification: The subjects were asked to choose either "provided" or "not provided" for each of 10 items from the "maternity support table for prenatal notification (for the obstetric area)" developed by Nakanii, et al. They were also asked to evaluate support from nurses on a five-grade scale ranging from "sufficient" to "insufficient".
- 4) Mothers' psychological state: For each of the reactions of "shock," "denial," "sorrow, anger, and anxiety," "adaptation," and "acceptance," which respectively correspond to the first to fifth "stages of emotional reactions of normal parents to the birth of an infant with a congenital malformation" by Droter, D., et al. [9], the subjects were asked about the intensity of their reaction at the time of notification and soon after delivery on a five-grade scale, comprising "never experienced," "experienced a little," "experienced," "rather strongly experienced," and "strongly experienced" (giving 1 to 5 points, respectively). A higher score indicates a stronger reaction.

4. Statistical analysis

After simple addition, data were subjected to the Mann-Whitney U test ($p < 0.05$) to assess the relations of methods for explaining the condition ("used" or "not used"), 10 support items ("provided" or "not provided"), mothers' evaluation of support from nurses ("positive" or "negative"), and the timing of consulting a specialist surgeon ("before delivery" or "after delivery") with mothers' psychological state

at the time of notification and soon after delivery. Calculations were performed using SPSS (13.0J) for Windows.

5. Ethical consideration

In the open recruitment of the participants, a poster was specifically designed so as not to disadvantage any group, and displayed at surgical hospitals which had agreed to cooperate with us. The investigators held interviews with mothers who had offered to participate or accepted an offer from us, and obtained their written consent after explaining the study to them. The explanation was given both orally and in writing, regarding issues such as the study purpose, participation on a voluntary basis, the protection of privacy, and the publication of study results. In addition, this study was approved by the ethics committee of the Kawasaki University of Medicine and Welfare (No. 041).

Results

1. Background of mothers and their children (Table 1)

Responses with each mother's psychology-related items fully completed were accepted as valid, and collected from 31 mothers (response rate: 79.5%). The majority of these mothers were in their "30s" (54.8%), while there was also a "teenager" (3.2%). The places of delivery included a "maternity clinic" (48.4%) and a "hospital with a specialist surgeon" (29.0%). The timing of notification was primarily "at 28 to <32 weeks" (32.3%), while some mothers had been told "between the 36th week and the day before delivery" (16.2%) or "at 16 to <22 weeks" (9.6%). Attendant(s) at the notification were mainly "nobody (alone)" (48.4%), while others were accompanied by the "husband" (29.0%) or the "family" (22.6%). The timing of consulting a specialist surgeon was "before delivery" in 38.7% and "after delivery" in 58.4%.

Their children were "male" in 45.2% and "female" in 54.8%, and aged 0 to 3 years, with the majority being "0 years old" (61.3%). Their birth order was the "first child" in 41.9% and the "second child" in 51.6%. The cleft type was "cleft lip/jaw and palate" in the majority (87.1%), "cleft lip alone" in 9.7%, and "cleft palate alone" in 3.2%. No complications were observed in these children.

2. The relationship between methods for explaining the condition and mothers' psychological state

Figure 1 shows the cumulative number of mothers for whom each of five predefined methods for explaining the condition (notification) was used. The most common method was "oral explanation alone" (n=16), followed by "explanation by drawing pictures" (n=10) and "explanation with photos of the current and postoperative conditions" (n=5).

Then, the relationship between these five methods and mothers' psychological state was investigated. A comparison between the "used" (n=16) and "not used" (n=15) groups for the method of "oral explanation alone" (Fig. 2) revealed that mothers who had only received an oral explanation scored significantly lower points in the stage of "adaptation soon after delivery." Another comparison between the "used" (n=5) and "not used" (n=26) groups regarding the method "explanation with photos of the current and postoperative conditions" (Fig. 3) showed that mothers given explanations using photos of the current and postoperative conditions scored significantly higher points in the stages of "acceptance at the time of notification" and "adaptation soon after delivery." No significant difference was noted regarding the other three methods.

3. The relationship between support items provided at the time of prenatal notification and mothers' psychological state

Figure 4 shows the status of providing support items at the time of prenatal notification. More commonly provided items included "information on lactation" (90.3%), "the addresses of specialist surgeons" (83.9%), "timing for consulting a specialist surgeon" (77.4%), "support for the mother not to feel responsible for the condition" (71.0%), "an explanation of surgical treatment" (64.5%), and "an explanation of public

Table 1 Characteristics of mothers and their children

Background		Number	(%)
Mothers			
Age	10-19	1	(3.2)
	20-29	13	(42.0)
	30-39	17	(54.8)
Place of delivery	Maternity clinic	15	(48.4)
	Hospital with specialist surgeon(s)	9	(29.0)
	Hospital without specialist surgeon(s)	7	(22.6)
Time of notification	16 to <22 weeks	3	(9.6)
	22 to <28 weeks	4	(12.9)
	28 to <32 weeks	10	(32.3)
	32 to <36 weeks	6	(19.4)
	36th week - Day before delivery	5	(16.2)
	No answer	3	(9.6)
Attendant(s) at the notification	Nobody (alone)	15	(48.4)
	Husband	9	(29.0)
	Family	7	(22.6)
Timing of consulting a specialist surgeon	Before delivery	12	(38.7)
	After delivery	18	(58.1)
	No answer	1	(3.2)
Children			
Gender	Male	14	(45.2)
	Female	17	(54.8)
Age	0 years old	19	(61.3)
	1 year s old	4	(12.9)
	2 years old	6	(19.3)
	3 years old	2	(6.5)
Birth order	First child	13	(41.9)
	Second child	16	(51.6)
	Third child	2	(6.5)
Cleft type	Cleft lip	3	(9.7)
	Cleft lip and palate	27	(87.1)
	Cleft palate	1	(3.2)

aid (for rehabilitation of disabled children)" (51.6%). Relatively uncommon items included "information on genetic counseling" (3.2%), "an offer of an explanation to the grandparents" (25.8%), "information on opportunities to hear experiences of others" (29.0%), and "information on self-help groups (parents' meetings)" (45.2%).

Then, the relationship between the status of these support items and mothers' psychological state was examined.

A comparison between the "provided" (n=20) and "not provided" (n=11) groups for the item "an explanation of surgical treatment" (Fig. 5) demonstrated that mothers given an explanation of surgical treatment scored significantly lower points in the stages of "shock soon after delivery," "denial soon after delivery," and "sorrow soon after delivery," and significantly higher points in the stage of "adaptation soon after delivery."

A second comparison between the "provided" (n=16) and "not provided" (n=15) groups for the item "an explanation of public aid (for rehabilitation of disabled children)" (Fig. 6) revealed that mothers given

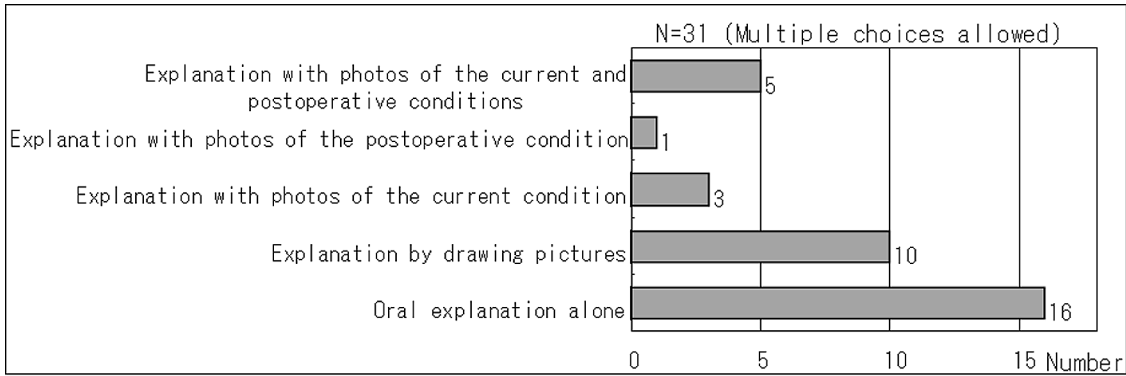


Fig. 1 The cumulative number of mothers for whom each method for explaining the condition was used

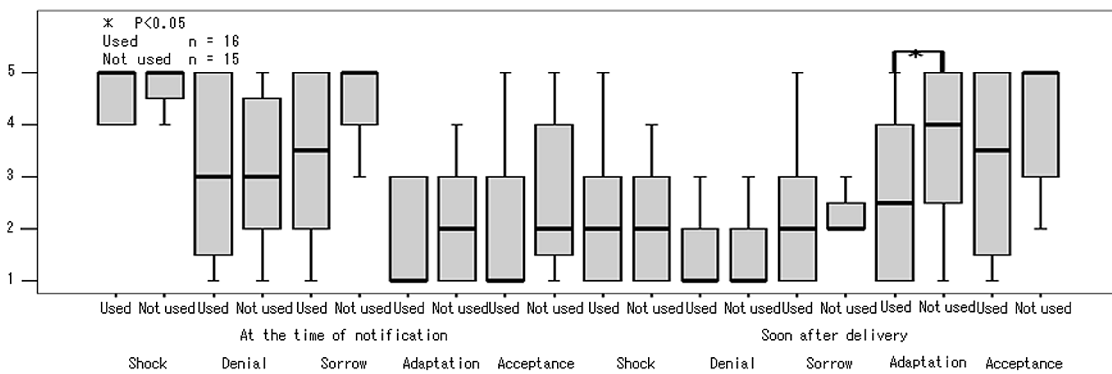


Fig. 2 The cumulative number of mothers for whom each method for explaining the condition was used

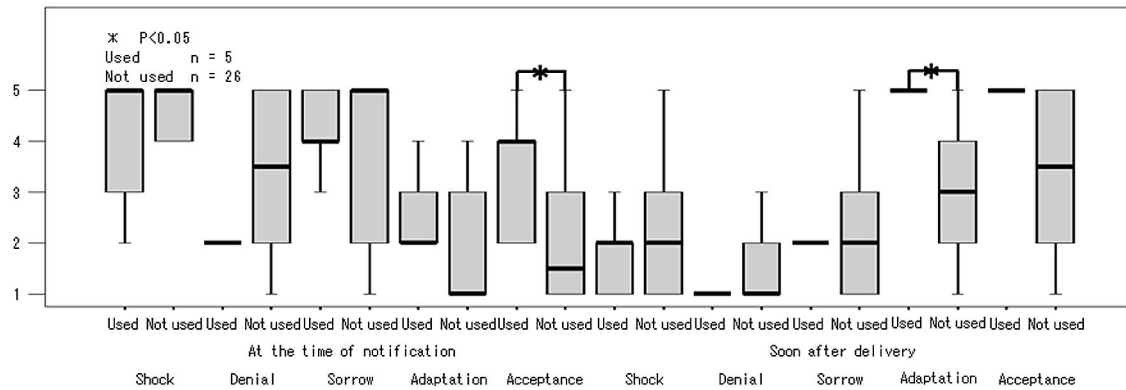


Fig. 3 The relationship between the method using “photos of the current and postoperative conditions” and mothers’ psychological state

an explanation of public aid (for rehabilitation of disabled children) scored significantly higher points in the stages of “adaptation soon after delivery” and “acceptance soon after delivery.”

A third comparison between the “provided” (n=14) and “not provided” (n=17) groups for the item “information on self-help groups (parents’ meetings)” (Fig. 7) showed that mothers receiving an explanation on self-help groups (parents’ meetings) scored significantly higher points in the stage of “acceptance soon after delivery.” No significant difference was observed regarding the other seven items.

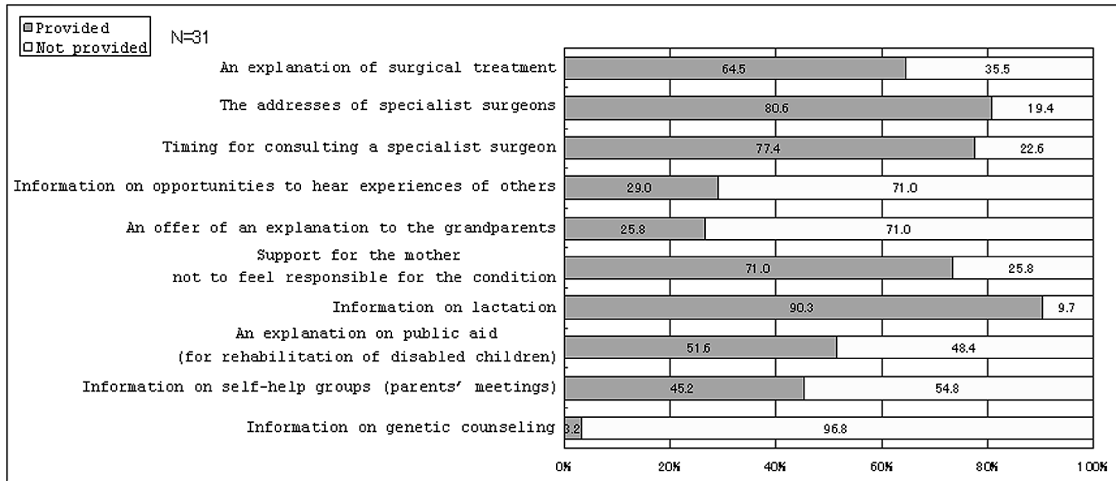


Fig. 4 The status of providing support (explanation) items at the time of prenatal notification

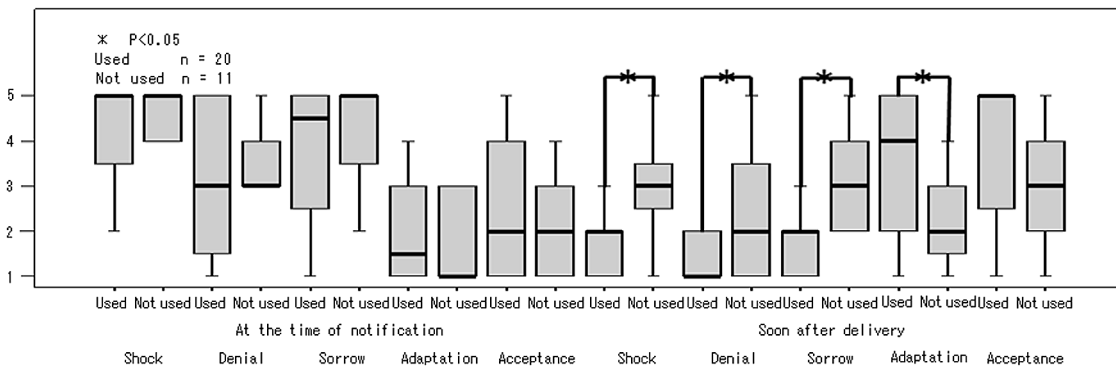


Fig. 5 The relationship between the status of “an explanation of surgical treatment” and mothers’ psychological state

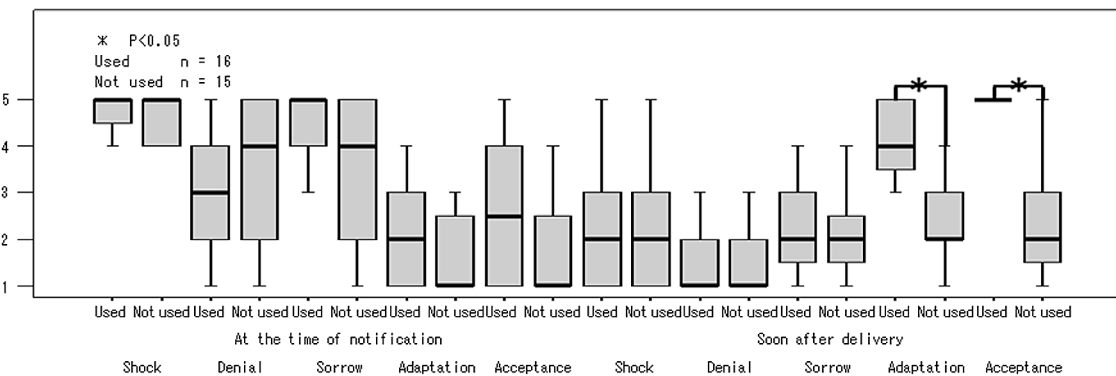


Fig. 6 The relationship between the status of “an explanation of public aid” and mothers’ psychological state

4. The relationship between mothers’ evaluation of nursing support and their psychological state

Figure 8 shows mothers’ evaluation of support from nurses. The “positive” group, including those feeling “sufficient” (19.4%) or “rather sufficient” (16.3%), accounted for 37.4%. Aside from mothers whose evaluation was “neutral” (32.1%), the “negative” group, including those feeling “rather insufficient” (6.5%) or “insufficient” (25.8%), accounted for 32.3%.

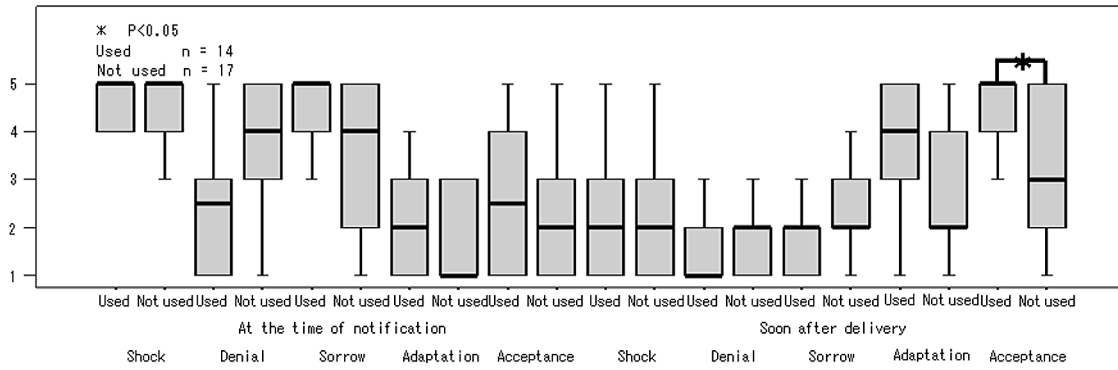


Fig. 7 The relationship between the status of “information on self-help groups (parents' meetings)” and mothers' psychological state

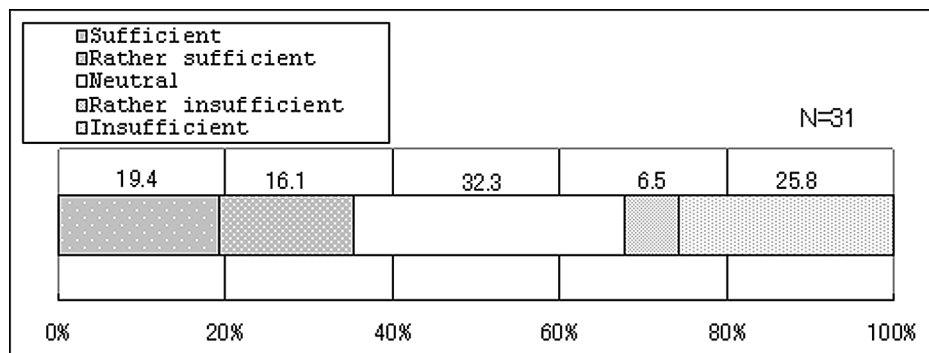


Fig. 8 Mothers' evaluation of support from nurses

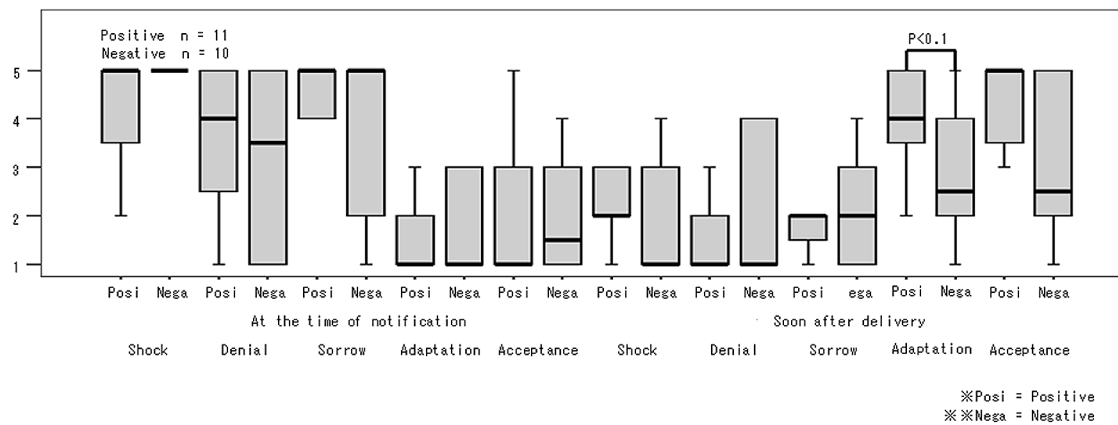


Fig. 9 The relationship between mothers' evaluation of nursing support and their psychological state

To clarify the relationship between mothers' evaluation of nursing support and their psychological state, a comparison was made between the “positive” (n=11) and “negative” (n=10) groups (Fig. 9). The results showed that mothers feeling positive about support from nurses tended to score higher points, non-significantly (p=0.066), in the stage of “adaptation soon after delivery.”

5. The relationship between the timing of consulting a specialist surgeon and mothers' psychological state

To clarify the relationship between the timing of consulting a specialist surgeon and mothers' psychological state, a comparison was made between those who had consulted “before delivery” (n=12) and those

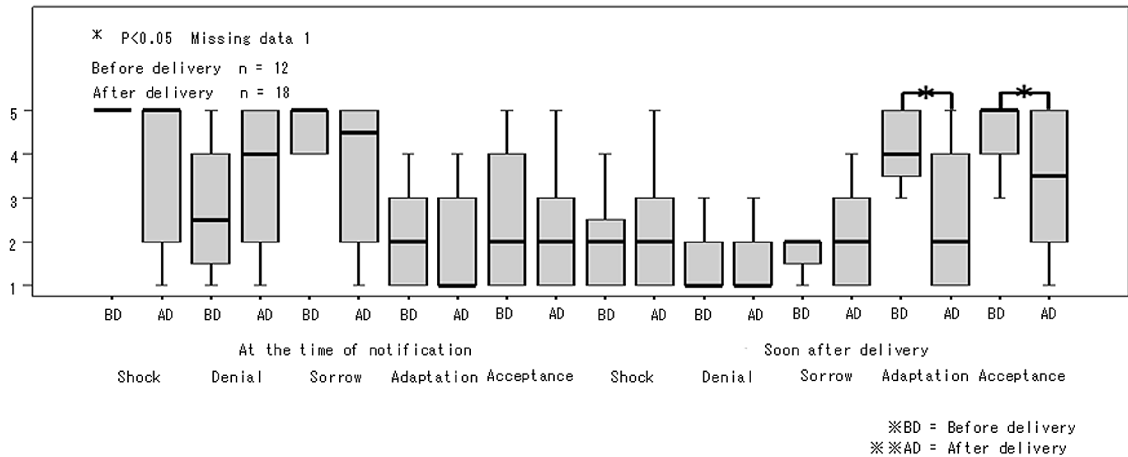


Fig. 10 The relationship between the timing of consulting a specialist surgeon and mothers' psychological state

“after delivery” (n=18) (Fig. 10). The result revealed that mothers who had consulted a specialist surgeon before delivery scored significantly higher points in the stages of “adaptation soon after delivery” and “acceptance soon after delivery.”

Discussion

1. The relationship between methods for explaining the condition and mothers' psychological state

Many mothers had only received an oral explanation from the obstetrician at the time of prenatal notification, whereas those given explanations using photos of the current and postoperative conditions accounted for some 20%. As it was suggested that photo-aided explanation facilitates mothers' understanding [10], we have proposed this method as one of the maternity support measures. However, its usefulness has not been verified in clinical practice, possibly because such visual presentation may have a negative psychological impact on mothers, or because obstetricians, not committed to surgical treatment, may feel embarrassed about showing postoperative photos to mothers.

In fact, our study demonstrated that mothers who had only received an oral explanation were less able to adapt themselves soon after delivery, while those given explanations using photos of the current and postoperative conditions were more strongly willing to accept the situation at the time of notification and adapt themselves after delivery. That is, it was clarified that mothers were supported by explanations using photos, which allowed them to visually understand the current and postoperative conditions, and were adversely affected by explanations using oral expressions alone. Klaus, et al. [11] pointed out, “It is far more shocking to be informed of any congenital abnormality than to actually see the baby.” Oral explanation alone will only increase anxiety in mothers. Visual presentation with photos will help them understand the condition and its potential to be completely cured by surgical treatment, and is more likely to motivate them to “overcome the adversity.”

2. The relationship between the current status of support at the time of prenatal notification and mothers' psychological state

Among the 10 support items, “information on lactation,” the primary concern soon after delivery, was given to more than 90% of mothers. Information about surgical treatment, specifically each of “the addresses of specialist surgeons,” “timing for consulting a specialist surgeon,” and “an explanation of surgical treatment,” was given to about 70% of mothers. These four items are considered to have become

established in practice as support at the time of prenatal notification. Particularly, “an explanation of surgical treatment” was found to have relieved mothers’ shock, denial, and sorrow, and encouraged their adaptation soon after delivery. Earlier literature also reported that mothers given explanations about surgical treatment, or their primary concern, could prepare for their delivery and child-raising with a sense of relief [12], and the results of our study statistically support this observation. However, the fact that more than 30% of mothers answered that they had not received “an explanation of surgical treatment” suggests the necessity of providing treatment information that meets their needs.

While psychological support for mothers was previously reported to be less important [13], our study revealed that more than 70% of mothers had received “support for the mother not to feel responsible for the condition.” It is becoming common for health professionals to protect mothers from discrimination as one purpose of their support. On the other hand, they are still limited regarding providing “information on genetic counseling,” “information on opportunities to hear experiences of others,” “an offer of an explanation to the grandparents,” and “information on self-help groups (parents’ meetings).” Specifically, the fact that approximately 10% of mothers admitted that they had been informed of the deadline for selecting an abortion suggests the necessity of providing “information on genetic counseling” as support for them to realize the birth of their children. The lacking provision of such information is attributable to the limited number of institutions where clinical geneticists and/or genetic counselors are available [14], and to the multifactorial inheritance of this disorder. Given the presence of mothers/families hesitant to conceive or deliver another child for fear of another disorder, however, support in this area must be improved in the future. Regarding inheritance, it is also reported that the grandparents’ verbal expressions, such as “never in our family history,” may increase the mother’s anxiety [10]. To protect mothers from such a situation, obstetricians should directly explain the condition and its possible causes to the grandparents. Evidence-based explanation will help resolve family prejudices, and enable them all to prepare for treatment of the child. Childbirth does not only involve the parents, but is also important to the grandparents. Supposing a disabled infant is born to a family longing for a healthy baby: support from nurses is required to repair family relationships if the family still shows a tendency to try to find fault in the mother [15]. It is very important to give an explanation to the grandparents, or tell the mother that they can receive an explanation if they so desire. Mothers who had been offered an explanation to the grandparents only accounted for a little over 20%. Efforts should be made to establish this option as a support item.

Mothers who had been given “information on self-help groups (parents’ meetings),” although they comprised a small number, showed a strong willingness to accept the situation soon after delivery. This suggests the marked effect of knowing someone in a similar situation on the psychology of mothers, who often get trapped in a victim-based mentality. In this regard, “information on opportunities to hear experiences of others” is also important. Health professionals in the obstetric field should prepare to provide information on these support measures.

Our study involved many young mothers, including a teenager. Those who had received “an explanation of public aid” showed a strong willingness to adapt themselves or accept the situation soon after delivery. This suggests that providing economic information serves as a support for young mothers.

Thus, it was clarified that mothers showed stronger reactions (adaptation, acceptance, etc.) soon after delivery depending on the contents of support provided at the time of prenatal notification. This finding seems to support, to a certain extent, the effectiveness of our “maternity support table for prenatal notification (for the obstetric area)” as a maternity support measure.

Concerning mothers’ psychological state at the time of prenatal notification, however, its relationship with the contents of support was only identified with the “use of photos during explanation of the condition.” We realized anew that, for mothers looking forward to seeing their babies, it was an enormous shock

to be informed of a fetal disorder, and it led to profound reactions that could not be forgotten no matter what words of comfort were offered, nor how many years had passed. There have been many reports on the psychological state of mothers told of the name of this disorder or first seeing the infant. In the late 1980s, when prenatal notification has not yet come into practice, Fujii, et al. announced that 80% of those mothers could not sleep at night due to anxiety over their infants' birth defect [16], and Natsume, et al. reported that 30% of them had actually thought about killing themselves [17]. In contrast to their previous expectations of healthy fetal growth, mothers faced with the fact of the fetal disorder must cope with the delivery while controlling their emotions such as shock, sorrow, and anxiety. It was suggested that mothers' emotions at the time of notification could not be fully covered with the existing support contents.

This is attributable to the lack of certain support items and insufficient support from nurses. Given that mothers who had received sufficient support from nurses tended to show a strong willingness to accept the situation soon after delivery, it is important for nurses to be sympathetic to mothers' feelings at the time of notification. Nurses in the obstetric area will be further expected to strengthen and maintain relationships with mothers in view of the growth of their children while reassuring mothers of the improvement of their children's condition in cooperation with nurses in surgical departments.

3. The meaning of consulting a specialist before delivery

Nearly 40% of mothers answered that they had consulted a specialist surgeon before delivery. Under a situation where cooperation between the obstetric and surgical areas has not been systematically achieved, this percentage indicates mothers' positive attitudes toward prenatal consultation according to their clinics' policies or based on their own free will. Naturally, mothers who had visited a specialist surgeon before delivery were more strongly willing to adapt themselves or accept the situation soon after delivery. Together with the fact that mothers given an explanation about the condition using photos or about surgical treatment showed positive reactions soon after delivery, this suggests that detailed information on treatment can be a great help to mothers. Accordingly, an appropriate explanation from a specialist surgeon, rather than information from an obstetrician not committed to surgical treatment, is considered to be preferable. Consulting a specialist before delivery is not equal to merely receiving an explanation of treatment. It involves encountering a surgeon skilled in the particular treatment as well as nurses and speech therapists skilled in the rehabilitation of disabled children, obtaining information on rehabilitation starting soon after delivery, becoming motivated to overcome the adversity, and proceeding smoothly to the next step of treatment.

All health professionals should recognize the necessity of promoting cooperation between the obstetric and surgical areas to provide better support for mothers. Health professionals in the obstetric area should also understand the importance of explaining to mothers about the benefit of consulting a specialist surgeon soon after prenatal notification, while improving support provided in the obstetric area.

Conclusion

- 1) Mothers who had "only received an oral explanation" at the time of prenatal notification scored significantly lower points in the stage of adaptation soon after delivery. Mothers given "explanations using photos of the current and postoperative conditions" scored significantly higher points in the stages of acceptance at the time of notification and adaptation soon after delivery.
- 2) Mothers given an "explanation about surgical treatment" scored significantly lower points in the stages of shock, denial, and sorrow soon after delivery, and significantly higher points in the stage of adaptation soon after delivery.
- 3) Mothers given an "explanation on public aid (for rehabilitation of disabled children)" scored signifi-

cantly higher points in the stages of adaptation and acceptance soon after delivery.

- 4) Mothers receiving an “explanation on self-help groups (parents’ meetings)” scored significantly higher points in the stage of acceptance soon after delivery.
5. Mothers “feeling positive about support from nurses” in the obstetric area tended ($p=0.066$) to score higher points in the stage of adaptation soon after delivery.
6. Mothers who had “consulted a specialist surgeon before delivery” scored significantly higher points in the stages of adaptation and acceptance soon after delivery.

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