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Clinical Report

Prenatal Counseling on Prenatal Diagnosis of Cleft Lip and/or Cleft Palate at Tokyo Dental College Ichikawa General Hospital

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Abstract

Remarkable technological advances have been made in the field of medicine in recent years, one result of which is that a prenatal diagnosis of cleft lip and/or cleft palate (CL/P) is now possible. In this situation, it is extremely important to provide the parents with mental care from the moment they are informed. Here, we describe cases of CL/P treated at our hospital and how such a diagnosis and prenatal counseling are handled. A survey was carried out on 4 cases seen at our department between April 2013 and March 2014. Patients are referred to our department from local or our own obstetrics clinics on a prenatal diagnosis of CL/P based on findings from ultrasonography. If the case is a referral from outside, the patient will first be seen at our own obstetrics department. Our department may then be subsequently requested to provide the parents with prenatal counseling. Effort is made to reassure the parents that postnatal support will be provided, right from the start. Next, the multidisciplinary nature of the treatment process is explained. However, only the essential outline is given at first so as to avoid inducing unnecessary anxiety. A response is also given to any questions the parents may have. Our experience of giving such care leads us to believe that improvements are required in the way that explanations and assistance are provided. The number of cases in which prenatal counseling is required is expected to increase in future.

Key words: Cleft lip — Cleft palate — Cleft lip and palate — Prenatal diagnosis — Prenatal counseling

Table 1 Prenatal counseling

Case	Time of prenatal diagnosis	Time of counseling	Period from diagnosis until counseling	Prenatal diagnosis	Cleft type
1	25w1d	33w1d	8w0d	Local obstetric clinic	Comp-UCLP
2	31w	33w1d	2w	Local obstetric clinic	Comp-UCLP
3	29w1d	34w2d	5w1d	Local obstetric clinic	Comp-UCLA
4	29w1d	31w3d	2w2d	Local obstetric clinic	unknown

Comp: Complete, UCLP: Unilateral Cleft Lip and Palate, UCLA: Unilateral Cleft Lip and Alveolus
w=week(s), d=day(s)

Introduction

Cleft lip and/or cleft palate (CL/P) is a congenital anomaly which occurs in approximately 1 in 500 births[10]. Treatment usually requires a multidisciplinary approach involving several different medical departments. The arrival of a baby with this condition can be a very stressful experience for the parents, and even more so if the delivery has been painful. The first doctor the parents are likely to encounter on commencement of treatment is an oral surgeon, who is there initially to create and fit a Hotz plate[5]. As such, they will also usually be in charge of giving the parents an overview of the entire treatment process. In this situation, the doctor will probably concentrate on attempting to reduce any concern or anxiety the parents may have by responding fully to their questions rather than trying to go into minute detail regarding the treatment plan itself.

Ultrasonic examination is one way to screen for CL/P during pregnancy. Significant advances in imaging technology over recent years have enabled easy prenatal diagnosis of CL/P[2,9]. Therefore, providing an explanation at this early stage of how cheilognathopalatoschisis is treated has grown in importance as the condition has become increasingly common[1,13]. Here, we will discuss cases of CL/P encountered at this hospital, the treatment given, and issues that have arisen in reference to the literature.

Cases

A survey was carried out on cases seen at our department between April 2013 and March 2014 in which prenatal counseling was provided. Items included time of prenatal diagnosis, time of counseling, the period from diagnosis to counseling, prenatal diagnosis institution, and cleft type. Prenatal counseling was given in all cases in accordance with the policy of this institute.

Results

Table 1 shows the 4 cases in which prenatal counseling was provided. Time of prenatal diagnosis ranged from 25 weeks 1 day to 31 weeks (average, 28 weeks 4 days). Time of prenatal counseling ranged from 31 weeks 3 days to 34 weeks 2 days (average, 33 weeks 0 days). The period from the diagnosis to prenatal counseling ranged from 2 weeks 2 days to 8 weeks 0 days (average, 4 weeks 3 days). The patient was referred to us by a local obstetrics clinic in all 4 cases; the initial diagnosis was made elsewhere in all cases. There were 2 cases of unilateral complete CL/P, 1 of unilateral complete CL and alveolus, and 1 undetermined.

Discussion

Prenatal diagnosis of CL/P by ultrasound

was first reported by Christ and Meininger[3]. At that time, such images were still only 2-dimensional (2-D). Now, however, 3- or even 4-D ultrasonography allows much greater diagnostic accuracy. This has meant an increase in the number of CL/P cases diagnosed prenatally, with a concomitant rise in the need for counseling at this early stage. To our knowledge, the first report of prenatal counseling for CL/P in Japan was published by Takeda *et al.* in 2001[15]. This earlier study made some interesting points regarding prenatal diagnosis and notifying of parents. Prenatal notification of CL/P was actually given in 27 out of 38 cases (71.1%). However, parents accepted counseling in only 6 out of 27 cases (22.2%), meaning that the remaining 21 cases (77.8%) only received notification. We believe that receiving notification but no counseling would probably only serve to increase anxiety in such cases. Moreover, the parents chose to have the pregnancy artificially terminated in one case. It is possible that this decision might have been different had counseling also been given in this case, although this occurred some 15 years ago now. According to a report from Taiwan published in 2011[8], an abortion was chosen in 17 out of 74 CL/P cases (23.0%) in which the parents had received counseling. Even allowing for cultural and social environmental differences between Taiwan and Japan, this still represents a very regrettable situation. In the present study, the parents in Case 4 received prenatal counseling at our hospital, but then requested a change of hospitals. They had considered having the pregnancy terminated after receiving counseling at our hospital, but in fact no cleft was observed at the time of delivery after changing hospitals. This indicates the importance of addressing the emotional needs of such parents over the course of the pregnancy, and not just in the run-up to delivery itself.

Prenatal counseling at our hospital was given at a minimum of 2 weeks 2 days and a maximum of 8 weeks 0 days after the prenatal diagnosis. This was due in part to the fact that these patients had all been referred to our obstetrics department from other hospitals. Thus, it took some time before these patients were able to receive a diagnosis from our team. We believe, however, that prompt short-term counseling is needed in such cases, and not just notification. The parents in such cases often attempt to gather information on CL/P by themselves, which can lead to an increase in anxiety as that information is likely to be inaccurate, false, or redundant. Therefore, attempts should be made to provide the parents with accurate and valid information as soon as possible. To do so, doctors need to form a close relationship with the parents, not just provide medical care. While the obstetrician or gynecologist usually provides the prenatal diagnosis, subsequent treatment will vary depending on the decision of each individual obstetrician and gynecologist. In some cases, the parents are directed to the appropriate source for prenatal counseling, but not always. In such cases, the burden of anxiety on the family is even greater[12]. Therefore, early prenatal counseling should be provided as soon as possible after notification of fetal CL/P.

Prenatal counseling was provided in all 4 cases in the present study, and all had received an initial diagnosis at a local obstetrics clinic. There are two routes by which prenatal counseling is provided at our hospital. In one, the mother concerned is already a patient at the obstetrics department of our hospital (Fig. 1A), and the department of oral and maxillofacial surgery will receive a direct request for assistance. In the other, the initial diagnosis of CL/P will have been made at the obstetrics department of another hospital/clinic (Fig. 1B). Here, our obstetrics department will be requested to provide a range of related medical services, including arranging those related to delivery and subsequent treatment for CL/P, which is where the department of oral and maxillofacial surgery will be required to assist. Counseling is then given in line with our policy on prenatal diagnosis of CL/P and postnatal treatment.

This hospital functions as a core medical

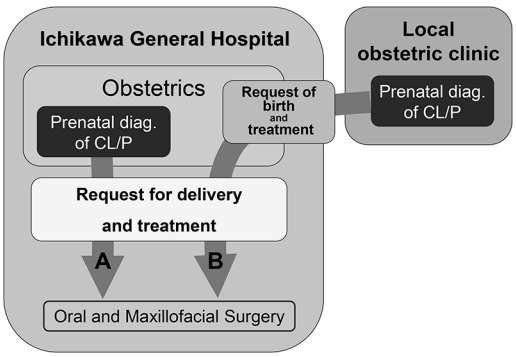

Fig. 1 Flow chart from diagnosis to prenatal counseling
A: CL/P prenatally diagnosed in patient to be delivered at obstetrics department of our hospital
B: CL/P prenatally diagnosed at obstetrics department of local hospital/clinic

Table 2 Our counseling policy

1. Request that parents come to hospital as couple
2. Start counseling session with opening statement such as "Congratulations on your pregnancy!"
3. Explain treatment plan as simply as possible
4. Treatment plan depends on cleft type
5. Information on Internet not always accurate
6. Avoid spending too much time on explanation; take more time to answer questions
7. Direct feeding not so difficult
8. Facial cleft not just caused by genetic factors
9. CL/P means patient will be mentally retarded

institute in this area and strives to improve cooperation with other medical facilities. The fact that all 4 of the present cases were referrals indicates that this system is functioning well.

The goals of prenatal counseling for CL/P are to reduce parent anxiety, while ensuring a smooth transition from a safe delivery to the treatment required. Table 2 shows a breakdown of the main points of our counseling policy.

1. Request that parents come to hospital as couple

Husbands are often busy with work outside the home, which can make it difficult for them to find the time to accompany their spouse to the hospital. Indeed, often only the wife comes to the hospital for a medical checkup. As a rule, therefore, we try to encourage the parents to come in to see us as a couple. This is because there is a danger that a misunderstanding may occur if the husband only hears an explanation of the issues involved in the diagnosis at second hand from the wife. Moreover, if the husband has any questions, he will need to ask a medical professional, which his wife is probably not, and this again will help prevent any incorrect information being shared. There is also the possibility of a difference in diagnostic comprehension between the husband and the wife. For these reasons, we believe that the husband should also come to the hospital

and receive counseling along with his wife. It is also important for the primary doctor to gain an understanding of the domestic environment of the parents as this may have a bearing on post-delivery treatment.

2. Start counseling session with opening statement such as "Congratulations on your pregnancy!"

Parents who come to the hospital/clinic are usually nervous and have various concerns or anxieties regarding the future of their child. Under the circumstances, a counseling session should begin with a positive atmosphere. If the counselor opened the meeting with something like "We are sorry, but your baby has CL/P", it would immediately create an extremely gloomy and negative atmosphere. This would only serve to exacerbate concern regarding the future prospects of the unborn child and postnatal treatment, making it even more unlikely that they would register the doctor's explanation clearly. Therefore, our policy is to create a positive atmosphere at the outset in order to facilitate easy digestion of the diagnosis. It is recommended, therefore, that the conversation be commenced with a warm congratulatory message such as "Congratulations on your pregnancy!" and a little time spent on personal small talk. If the parents can face the diagnosis with a positive attitude, the counseling session will be more fruitful, with greater exchange of opinions and questions.

3. Explain treatment plan as simply as possible

We normally try to explain the treatment plan as simply as possible. When a surgeon conducts a counseling session, there is a tendency for the explanation to focus too much on the details of the procedures involved rather than giving an overall picture of what is to be done. The goals of prenatal counseling are to help the parents face the situation calmly, reduce anxiety as much as possible, and secure preparation for delivery. Explanation of surgical risks should be provided at the time of surgery. Therefore, any surgical explanation included in prenatal counseling should only focus on the general flow of the process such as what kind of treatment or surgery will be performed and when. Further details of procedures and graphic surgical images, for example, should only be provided if the family requests such at that time.

4. Treatment plan depends on cleft type

It should be remembered that the parents are likely to be completely unfamiliar with what is involved in such a treatment plan, something that is often forgotten by the medical professional. For example, the parents may not understand the differences between the various disorders, such as CL, CP, and CL/P, or they may even consider them all to be the same disorder. However, if the patient only has a CL, cheiloplasty will be all that is required. If the patient has a CP, only palatoplasty will be required. However, if the patient has a CL and a CP, three surgical procedures, namely cheiloplasty, palatoplasty, and alveolar bone grafting, will be required. Therefore, the doctor must be careful to make sure that the parents actually understand the explanations given of each condition and its attendant surgical procedures and methods. This is crucial in avoiding the kind of misunderstandings that may occur if the parents are left to rely on the perhaps erroneous results of their own research. Figure 2 is used to help carefully explain the procedures used, and clearly shows how the type of treatment required will vary according to the type of cleft involved.

5. Information on Internet not always accurate

Much information on CL/P is currently available on the Internet. Unfortunately, this information is not always accurate. For example, although a website may appear to offer a clear explanation of the flow of treatment for CL in a way that is easy for the layman to understand, it may in fact be completely wrong. In some cases, information may even have simply been cut and pasted from other

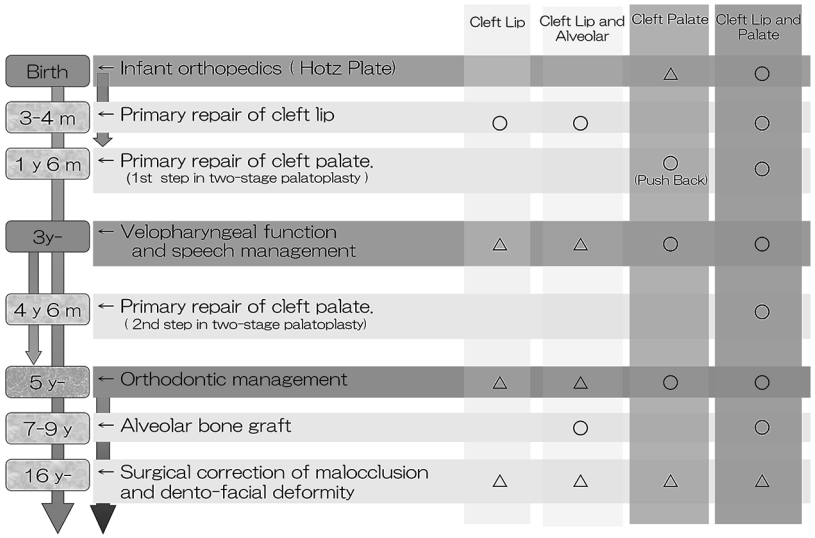

Fig. 2 Our treatment policy
m = month(s), y = year(s)
○: always, △: sometimes

websites. Therefore, it is imperative that the layman exercise extreme caution when consulting unauthorized sites on the Internet. Therefore, we strongly advise parents to only seek such information if the website is hosted by an accredited body such as a university hospital or medical association. Again, many parents visit weblogs written by other parents in a similar situation. Here, the same applies: without a full understanding of the conditions involved in each case, that information may be invalid or simply wrong. Therefore, as previously described, we explain that the treatment plan may change depending on cleft type.

6. Avoid spending too much time on explanation; take more time to answer questions

Care is taken to avoid giving too full an explanation at the initial counseling session, as the parents are often already nervous. Anxiety can hamper a parent's ability to fully take in and accept what is being said, so going into the pathological details of the case and the treatment plan would be inappropriate at this stage. Indeed, the parents may already be overwhelmed or confused at this point if they have consulted the wide variety of information available on the Internet. Moreover, such information, unfortunately, is not always accurate. Therefore, only a pathological summary is given at this stage, with a further more detailed explanation of the symptoms or condition only provided in direct response to a request from the parents. By these means, an attempt is made to reduce any emotional concern or anxiety while correcting any false perceptions during the conversation.

7. Direct feeding not so difficult

The parents often ask if the baby will have a suckling disorder. First, if the parents do not clearly understand the cleft type and pathological condition, it is explained that any suckling disorder will be mild in the case of CL or CP, but that it will be a serious problem if it is CL/P. However, most babies can be fed without using a nasal tube if a Hotz Plate is inserted soon after birth, even with CL/P, unless there are other complications. At our hospital, a feeding bottle is used

for babies with CP (Cleft Palate Teat and Squeeze Bottle: Pigeon Inc., Tokyo). Many mothers are relieved to hear this explanation. Many mothers would like to breast feed their baby. However, it is explained that this may be difficult in CL/P, even with a Hotz Plate, so bottle feeding will probably be required.

8. Facial cleft not just caused by genetic factors

According to Multifactor Threshold theory, facial cleft, including CL/P, is not only due to genetic factors, but also a complex interaction with environmental factors[4,14]. Therefore, it is important to make this clear to avoid the parents mistakenly believing that some genetic mutation of their own is responsible for the baby's condition. It is explained that CL/P may involve both genetic and environmental factors, and only occurs when those factors intricately interact, eventually exceeding a threshold value. As evidence of this, there have been reports of cases where one twin has CL/P but the other does not, even though their genes are identical[11]. Taking this into account, it is important for the doctor to provide the parents with accurate information so as to avoid the danger of them falling out over mutual recrimination or blame.

9. CL/P means patient will be mentally retarded

There is a tendency among some non-medical professionals to erroneously believe that having CL/P means that the baby will necessarily be mentally retarded. However, this is absolutely false. The causes of CL/P and mental retardation are totally different, although syndromic CL/P can occur in conjunction with mental retardation. According to a report by Kohara *et al.*, mental retardation was observed as a complication in 7.6% of patients with CL/P[7]. Therefore, this is explained very carefully to the parents.

When a mother finds out that her fetus has CL/P, she is often shocked, which can lead to a sense of anxiety, struggle, and guilt[14]. Prenatal counseling should aim at alleviating such feelings. In a survey by questionnaire given to 16 family members involved in 12 cases of CL/P, Takeda *et al.* investigated response to prenatal counseling and notification. All family members answered that they should be notified prenatally in the event of a disorder[16]. However, care should be taken to avoid a situation where the parents are left unsupported after notification.

The present findings in association with those of earlier studies carried out at other medical institutions in Japan show that most parents were notified at 22 weeks after onset of pregnancy or later[6,12,16]. However, the Maternal Protection Act in Japan stipulates that any artificial termination of a pregnancy must be carried out within the first 22 weeks, which means that this would have been impossible in most of these cases, even if requested. This does not mean, though, that some parents will not try to have the pregnancy terminated anyway. The objective of providing the parents with a prenatal diagnosis, on the other hand, is to emphasize the possibility of a pro-life choice. Therefore, time must be left for the appropriate treatment measures to be put into effect when notification is given. Thus, great effort has gone into improving postnatal treatment at our hospital, starting with prenatal counseling on presenting a fetal diagnosis. One of our goals is to forge even closer links with local obstetric clinics and thereby offer corrective treatment to still larger numbers of patients with CL/P.

Conclusion

This article describes the current situation and policy on prenatal counseling at our hospital. The aim of prenatal counseling is to reduce parent anxiety and provide safe delivery so that a smooth transition can then be made to subsequent treatment measures through cooperation between the medical staff and the parents. In order to achieve this goal, it is important to gain a picture of the family circumstances so that any problems can

be addressed. Moreover, an attempt should be made to prevent any misunderstanding or misapprehension of what is involved in CL/P by carefully listening to parent concerns and questions. Our mission is to help parents feel they can love and care for their child in the same way as they would for one born completely healthy, and by so doing prevent the decision for a termination being made unnecessarily. This disorder, thus, requires more than surgical care: it is also important to provide mental care, not only for the patient, but also the parents.

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