

Original Articles

Multidisciplinary Antenatal Counselling of Fetal Cleft Lip/Palate Deformity in a Single Centre: A Review of 62 Pregnant Women in Hong Kong

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Abstract

Introduction: In the recent years, paediatric surgeon has become increasingly involved in the multidisciplinary management of infant with cleft lip/palate deformity in the antenatal phase. The local epidemiological data on such service was lacking. We reported our centre's experience in providing one-stop multidisciplinary antenatal counselling service to parents of fetus with cleft lip/palate deformity. **Methods:** All pregnant women with the antenatal diagnosis of fetal cleft lip deformity received multidisciplinary antenatal counselling in our centre between January 2011 to December 2014 were reviewed. The maternal age, family history of cleft deformity and the postnatal outcome were analysed. **Results:** 62 pregnant women received multidisciplinary antenatal counselling in our centre. Nine (14.5%) of them chose to terminate the pregnancy after counselling. Two (3.2%) of them defaulted follow up at our center. The pregnant women are three times as likely to choose termination of pregnancy after counselling when the maternal age is ≤ 33 years old ($p > 0.05$) at the time of counselling. **Conclusions:** While multidisciplinary antenatal counselling may have placed substantial strain on resources, the outcome measure of its success is often non-tangible and difficult to evaluate. We reported our centre's experience and provided a baseline local statistical data to facilitate long term planning of resources allocation. Multidisciplinary antenatal counselling may potentially played a more crucial role when the pregnant woman is younger than 33 years old.

Key words Antenatal counselling; Fetal cleft lip deformity

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Introduction

One of the most common antenatally detected surgical anomalies in Hong Kong is fetal cleft lip deformity.¹ The incidence of cleft lip with or without cleft palate among the Asian population was quoted to be about 1.5-2.0 per 1000 births.² However, some literature reported the prevalence of cleft lip and palate is 20 times higher in the analysis of aborted fetuses compared with the prevalence in newborns,³ a study by Li et al conducted in China including livebirths, stillbirths, and pregnancy terminations and found a prevalence of oral clefts to be 3.27 per 1000 fetuses and/or newborns.⁴ The incidence of terminations of pregnancy caused solely by diagnosis of an isolated facial cleft ranges from 0-92%.⁵ The collection of epidemiologic data may also be complicated by the fact that not all clefts may be detected antenatally by ultrasound examinations.

The rate of antenatal detection of cleft ranges from 17.5% to 58% in the presence of cleft lip with or without cleft palate, and 0% to 6.5% for isolated cleft palate.⁶ A recent similar study from Hong Kong quoted 89%⁷ antenatal detection rate for cleft lip/palate.

The active involvement of the multidisciplinary team in the antenatal phase of an infant with a cleft lip/palate deformity has become more popular in the recent few years. The local epidemiological data on such service was lacking. We reported our centre's experience in providing one-stop multidisciplinary antenatal counselling service to parents of fetus with cleft lip/palate deformity in the past four years.

The spectrum of fetal cleft anomalies, maternal age at the antenatal diagnosis, family history of cleft, presence of associated fetal chromosomal or structural disorder and the postnatal outcome were analysed.

Methods

We retrospectively review the clinical data of mothers who received joint multidisciplinary antenatal counselling for fetal cleft lip/palate deformities in our centre. Demographic data including maternal age and gestational age at the antenatal diagnosis, family history of cleft, presence of associated fetal chromosomal or structural disorder and the postnatal outcome were analysed.

Some of the pregnant women were referred to our centre after receiving the antenatal diagnosis of cleft lip deformities from other centres. As not all low-risk pregnant women would be able to receive the antenatal screening ultrasound in our centre due to resources limitation. However, all those that were referred from other centres would receive at least one additional antenatal ultrasound in our centre to confirm the antenatal diagnosis of cleft lip deformity. As the majority of the pregnant women (74%) would eventually choose to have the primary repair of the cleft deformity in our centre, we are able to collect data on the outcome of the newborn postnatally.

For the parents with the affected fetuses, a joint multidisciplinary counselling would be offered within one week from the initial ultrasound to provide further information. The multidisciplinary counselling team included members from different specialties who were directly involved in the postnatal management of patients with cleft deformities. It typically included a paediatrician, a paediatric surgeon, a specialty nurse from our centre's cleft team and when a fetal cleft alveolus/cleft palate is also

detected in the antenatal ultrasound, a nurse or a medical personnel from the oral-maxillo-facial team would also be involved in the joint counselling session. Different members in the counselling team would provide information regarding the management of patients with cleft deformities in their respective specialties. For example, the paediatrician would emphasize on the screening of potential associated anomalies in patients with cleft deformities; the specialty nurse would explain the potential different modes of feeding and the dentist would introduce the concept of early naso-alveolar-molding.

At least one specialist level paediatric surgeon was actively involved in all the counselling sessions, information given included the nature and prognosis of the cleft deformity, the immediate and long term post natal management of the baby, potential complications in the future and our own centre's experience in managing patients with similar conditions in the past. In the recent two years, a standard 15-slides powerpoint presentation with clinical photos and management protocol would be shown to the parents to facilitate understanding and promote communication. Objective, non-directive terms were used, and medical jargons were avoided. Parents were encouraged to ask questions during the counselling session. Any other obstetrics concerns such as the mode of delivery and appropriate length of gestation were also discussed in the same session with the obstetrician.

Statistical analysis was accomplished using the SPSS program for Windows 15.0 (SPSS, Chicago, Illinois, USA). Two proportion Z-test was used to compare the categorical data. A p-value <0.05 was considered statistically significant.

Results

From January 2011 to December 2014, 62 pregnant women at various stages of gestation received joint multidisciplinary antenatal counselling in our centre for ultrasound detected fetal cleft lip/palate deformity.

All antenatal counselling were carried out before 24 weeks gestation, when termination of pregnancy is still legally permitted in Hong Kong.

The mean maternal age at antenatal counselling is 33 year-old, the median maternal age is 33 year-old (range: 22-40 year-old). Nine fetuses were intentionally aborted (14.5%), two pregnant women had defaulted follow up at our centre and one fetus suffered intra-uterine death of

unknown cause at 36 weeks gestation with normal fetal karyotype.

Two fetuses belong to families with familial history of cleft deformity, and one of these pregnant women chose to have termination of pregnancy after the antenatal counselling session. These women were referred to geneticists for work up, unfortunately, the follow up data was missing in their medical records.

The postnatal survival rate of the fetuses born was 100% (50/50). Out of the 50 babies born, 18 (36%) were diagnosed to have cleft lip deformity only and 32 (64%) were diagnosed to have cleft lip and palate deformity. There were no isolated cleft palate deformities that were picked up by the antenatal ultrasound.

One fetus had concurrent sacrococcygeal teratoma and left incomplete cleft lip detected antenatally. The baby girl was born at full term with uneventful sequential elective excision of the tumour and cleft lip repair. Other than that, none of the other babies born suffer from structural anomalies clinically other than the cleft lip/palate deformity. However, due to resource limitation, no formal chromosomal analysis was performed in these patients.

The abortion rate for pregnant women at the mean age of 33 years old or younger is 21% (7 out of 34 women). While the abortion rate for pregnant women above mean age of 33 years old is 7% (2 out of 28 women). Although there is a three folds difference in the abortion rates between the older and the younger groups, it does not reach a statistical significance ($p=0.13$).

Discussions

Our findings have demonstrated a 14.5% abortion rate for fetal cleft lip deformity for women who had received joint multidisciplinary antenatal counselling in our centre.

The results from our review is compatible with the recent literature reported by Liou et al from Taiwan,⁸ in their 11-year study, they reported at 20% termination of pregnancy in the 74 fetuses with antenatally diagnosed cleft deformity. They proposed that their low incidence of termination could be due to easy access to the experienced craniofacial team, well planned delivery and paediatric intensive care.

However, our abortion rate is lower than the data published by Lau et al,⁷ they reported an overall 31% abortion rate in the 38 fetuses with antenatal diagnosed non-syndromic cleft lip deformity. In their study, after analysing

the social characteristics of the pregnant women extensively (including their education level, occupation and religious beliefs), the only identifiable factor in the decision on termination of pregnancy was multidisciplinary antenatal counselling, which has a positive influence in potentially reducing the abortion rate.

Nonetheless, when compared to a retrospective postal survey study conducted by Davalbhakta et al,⁹ only one out of the 30 fetuses was terminated due solely to the antenatal diagnosis of bilateral cleft lip and palate, which gives an extremely low rate of 3% abortion rate. We postulate that this difference is probably due to the cultural difference in different countries and in the methodology in the studies design.

While many factors might come into play when a pregnant woman is considering terminating the pregnancy solely due to the detection of fetal cleft lip deformity, we believe that an accurate and effective multidisciplinary antenatal counselling should be given to all. Our clinical findings of a 14.5% abortion rate for fetuses with cleft lip/palate deformities after multidisciplinary counselling is significant as it can act as a baseline measure for us to monitor the trend in the future. While factors like cultural influences and advances in medical technology may change with time, it is important to establish an objective measure that may facilitate future audit.

With the improving detection rate of fetal cleft anomaly, some may even said that it's our moral obligation to provide timely and informative counselling to the anxious parents. A recent study¹⁰ from our centre has shown an 88% overall antenatal detection rate of facial clefts before 24 weeks gestation in a cohort of 50 infants with cleft lip deformity.

Furthermore, apart from providing the effective antenatal counselling to alleviate parental anxiety, the early interaction with paediatric surgeon might also potentially improve the compliance of the pre-surgical naso-alveolar molding postnatally for infants with complete cleft lip deformity. This is especially true when awareness of the use of the pre-surgical naso-alveolar molding device for infants with complete cleft lip deformity amongst health care personnel is still relatively low in Hong Kong, which might lead to potential delay in the commencement of such device, reducing the duration of the molding, and subsequently affecting the results. Shetty et al¹¹ suggested that the effects of the naso-alveolar molding on naso-alveolar morphology were the most significant when the device was started before one month of age.

From our study, maternal age is the primary indicator that would affect the decision on the termination of pregnancy. As the median age of the women that were being counselled was 33-year-old, we took it as a cut-off point and discovered that women younger than 33-year-old is about three folds as likely to terminate the pregnancy after receiving the diagnosis of fetal cleft lip deformity, and this can be due to many different causes. Although the different abortion rates between the older and younger age group did not reach statistical significant, this finding is somewhat not unexpected as women's fertility decreases with age. Other potential factors that may affect the decision to terminate the pregnancy including social, economic and cultural influences were beyond the discussion of this paper.

While multidisciplinary antenatal counselling may have placed a substantial strain on resources, the outcome measure of its success is often non-tangible and difficult to evaluate. We reported our centre's experience and provided a baseline local statistical data to facilitate long term planning of resources allocation. Multidisciplinary antenatal counselling may potentially played a more crucial role when the pregnant woman is younger than 33 years old.

Declaration of Interest

None.

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