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Guest Editorial

Cleft lip and palate-will India ever be able to resolve the problem?

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Cleft of the lip and palate (CLP) is one of the most common congenital anomalies in the world¹ with a very high incidence in Asian countries. In India the incidence is 1 in 1000 live births. That means with an estimated 24.5 million births in India per year there are 27,000 to 33,000 babies born with Cleft of the lip, palate or both.² The gravity of the situation can be better grasped when we realise that every hour 3 children with a CLP are born in India.

The most common cause for this occurrence is a lack of awareness and malnutrition among expectant mothers. The frontonasal process and the bilateral maxillary processes that form the head, lips and the palate, develop and fuse together between the 5th to 13th week of intra-uterine life.³ Failure or separation of this fusion is the cause of Oro-facial clefting. Many a times women from socially and economically backward families, are not even aware that they are pregnant during this time. And by the time they realise they are pregnant, the damage is already done. Such non-syndromic clefting is found in 86% of Cleft lips with or without Cleft palate and in 45% of isolated Cleft palates.⁴ So if primary prevention methods were urgently incorporated in the health programs of the government, then a considerable number of Oro-facial clefting would not happen.

In a study conducted on 4657 patients with Clefts in Dehradun, India, it was found that 72% of the parents were illiterate, the family income of 61% of patients was

below Rs 1000 per month, the prevalence of clefting in the minority Muslim population was 2.4 times higher than the Hindu population, microcytic hypochromic anaemia was seen in 83% of patients with eosinophilia in 25.5%.⁵ Hence, it has been established for quite some time now, that the problem of Cleft deformities is directly proportional to the economic and therefore nutritional status of the mother. While more than 300 genes and 150 chromosomal abnormalities have also been associated in clefts, multifactorial environmental factors have a more crucial role to play.

The maternal factors causing clefts are smoking, alcohol abuse, inappropriate use of drugs, lack of multivitamins and anaemia. It was also reported in a study that periconceptional intake of multivitamins with regular doses of folic acid (> 1mg) would not prevent the occurrence of CLP. A high dose of folic acid (6mg and above) given during the crucial phase of primary and secondary palate development was alone found to reduce the incidence of cleft children in expectant mothers.⁶

What happens when a cleft child is born? With intra-uterine diagnosis not made most of the time, the family, on the birth of a cleft child reacts with shock and disbelief. The parents face ridicule, the family is ostracised from the village, and most of the times the mother is held to be at fault. Being illiterate and economically weak, the parents do not know where to go for treatment and what would be the cost incurred in managing a cleft child. Hopeless and frustrated, these children are often left to die.

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And the child has a unique set of problems. It cannot feed at the breast as a cleft lip prevents the generation of sufficient suction pressure required to draw milk. Feeding formula supplements is also difficult, not only is it a costly affair, but improper position of feeding makes the child swallow more air than milk, aspirates into the lungs repeatedly as the palate is open, more prone to respiratory and systemic infection and all these lead to the child becoming progressively malnourished. There is defective speech, loss of hearing and the abnormal face exposes the child to abuse and discrimination.⁷

Is this reason enough to invest in prevention? Is there no effective treatment? Fortunately, the treatment for CLP is fine tuned into a definite protocol all over the world and especially in India. With the help of NGOs like Smile Train etc, the surgical correction of these children is done free at many centres with no compromise of safety and quality. In states like West Bengal, the government itself has signed a MOU with Smile Train so that all primary and peripheral government hospitals can find and refer such children for successful treatment to such dedicated centres.⁸

Even with all this, 1 in 2 patients still do not find the information to reach these centres in time and as such India has around 72000 cases of untreated clefts⁹ with around 27000 new cases adding on each year. With such a huge back log, it is imperative that our health care planners start thinking of ways to prevent CLP rather than attempting to treat it.

While improving the literacy and economic status of the population would need sustained and long-term efforts by the government, a simple and efficient measure that should be employed is to trace women of childbearing age between 18 to 35 years and start them on supplemental iron and high dose folic acid, conduct awareness programs on healthy food, harmful drugs and proper hygiene. While there are so many welfare programs for pregnant women, there is none for young women in general and that is where there is a huge lapse in planning. Since these developmental anomalies occur even before a woman realises that she is pregnant,

it is logical and imperative that preventive measures start well before. If we as a developing nation can install the appropriate health care delivery systems, then this colossal problem of children handicapped with Oro- facial clefting will slowly become an occasional curiosity. India can and should be able to resolve this problem.

Conflict of Interest

None.

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