Case study of a child with birth defect (cleft lip and cleft palate)

This case study highlights the success achieved in a child with birth defect (cleft lip & cleft palate). It emphasizes the importance of (a) good quality nurturing care that can be provided to a rural middle class family through guidance (b) the value of adoption of a continuum of care approach that is integrated (c) identification of problem through the use of mobile phone, pictures and video clips (d) providing ongoing guidance and support to the family through phone.

The family lives in a village in district Yamuna Nagar that is about 25km from the district headquarter and about 105 Km from Panchkula (SWACH location). The mother is 25 years old. Her husband is a farmer with a monthly income of about INR 10,000 per month. The mother is a graduate while the father has a master’s degree.

This is the second gravida of the mother. She had received good ante natal care. At seventh month of pregnancy USG revealed that the baby had some defect though earlier USGs done in third and fifth month of pregnancy did not reveal any abnormality. The whole family was shocked when they came to know of the problem. Family did not believe this report and went for further consultation in PGIMER, Chandigarh. In PGIMER doctors suspected limb defect and heart disease which further disappointed the family. Someone in the village advised them to visit the gynecologist (who is very popular) in the Sub district hospital (SDH) at Jagadhri in the district Yamunanagar. Mother went to SDH for checkup. After examining the client and the investigation report, the gynecologist at the SDH told the family that the baby had cleft lip and mother is having oligohydramnios. The family felt relieved and this consultation helped to reduce tension and stress in the mother.

The child who is 2nd in birth order was delivered normally at 2:30pm on 11 September, 2015 at SDH after 40 weeks of gestational age. This male child weighed 2500 grams at the time of birth. The baby had a cleft lip and a cleft palate. Mother and the family were very upset at the sight of such a child. They did not know how to feed the child. She stated “Shayad bagwan ki yehi marji hai ki hum esko paalen” (Perhaps this is the wish of the Almighty god that we should bring up this child). Since the baby has a cleft lip and cleft palate, expressed breast milk was planned to be given. But the efforts to give expressed breast milk did not succeed. Therefore, the baby was given top milk. After three days of stay, mother and the baby were discharged from the hospital in a stable condition.

The case was reported to SWACH staff by ASHA as a part of project, “Strengthening of HBPNC by ASHAs using mobile phone technology’ in which ASHAs report all ante natal cases, birth, deaths, birth defects, etc. After knowing about the case, SWACH staff established contact with the family and the first step was to make efforts to relieve numerous concerns and tensions of the mother since it was realized that mother’s stress will compromise the quality of caring and nurturing. In the neonatal period, the SWACH staff focused on (a) adequate feeding, (b) keeping the baby warm (c) multisensory stimulation (d) hygiene. Efforts were made to obtain the photographs of the child. SWACH staff maintained ongoing contact with family and provided guidance and support. With the help of ASHA, weight of the child was recorded and immunization was done as per schedule. The mother was also supported to maintain her own health and remain happy, so that she could take good care of herself and felt strong and energetic.
to look after the child. Mother- Child engagement through play and communication was encouraged (look at your baby, rocking the baby lovingly and gently handling the child, and putting the baby to the chest) to bring the mother out of stress and depression (postpartum depression and a baby with orofacial defect). Moreover, the mother and the family were reassured that these can be corrected by surgery.

The process of continued communication with the family through the phone helped to win the trust of the mother and father. Principle was to focus on one or two issues at a time, reaching an agreement and then following up to solve any problems instead of overloading the mother and the family with too many messages. For example, feeding- Feed the baby with undiluted cow milk using bowl and small spoon (chhota chamach) katori (bowl), feed slowly, so that it does not choke the baby, feed your baby slowly about 10 to 12 times in a day and 2-3 times in night, maintain hygiene (clean bowl, spoon hands); and provide warmth to your baby. Feeding is more important especially in this case because of cleft lip and cleft palate. It is very important not just for survival but to make the baby ready for surgical intervention. ASHA was motivated to continue follow up. It was an advantage that the mother and the baby happened to be the close relative of ASHA. The baby was the offspring of the brother of ASHA’s husband. The Family was also given the telephone number of concerned SWACH supervisor and advised to call SWACH if they faced any problem relating to the mother and the baby. Once feeding was correctly done and found to be adequate, other messages were included e.g. baby massage, singing a Lori (lullaby). Iron syrup was advised to keep the hemoglobin level normal so that it does not hinder his surgery. Time and again mother was advised to play and talk to the baby on a ‘serve and return’ basis. It was explained that this will make the mother happy and help the baby in its survival, growth and transformation.

Family was asked to send photographs and video clips. Initially there was hesitation on
the part of the family because of the apprehension that confidentiality might not be observed. They were reassured that these would help to provide appropriate guidance and support for the betterment of the child and confidentiality would be the utmost priority. ASHA also reinforced it. As a result, photographs and video clips were sent by the family regularly. These were very useful in analyzing the nutritional and development status of the baby and providing guidance and support. The family with the guidance and support from ASHA and SWACH were able to bring the child to such a level that met the requirement of the doctor at Karnal for surgery (lip). The readiness for surgery was a combined effort of family, ASHA and SWACH.

Mother Child Protection Card (MCPC) was also prepared at SWACH by the concerned block supervisor; weight was measured regularly initially on a weekly basis for 2 months followed by monthly basis. Monthly weight was plotted in the MCP card and growth was regularly monitored. Growth was plotted in the Mother Child Protection Card (MCPC) to see the nutritional status and to ensure that feeding was adequate. Immunization was done according to the National Immunization Schedule and was recorded in MCP card. The family was gently reminded for the next immunization whenever it was due. ASHA was told to adopt this child. She worked just like a local agent of SWACH and helped the family to implement the advice by SWACH staff relating to feeding, play, communication, prevention and treatment. Initially the child was followed thrice a week and it reduced to once in 15 days to once a month gradually when the progress with the baby was found to be satisfactory.

The family was very much interested in corrective surgery, so that the child looks normal and cute. Though they were given the option of various health facilities, the advice that appealed to them the most was the advice of a fellow villager to go to a charitable hospital in Karnal, around 70 kms from their village where quality health services are provided free of cost. They went there. Doctors at the
hospital advised them to take care of the baby and let the child grow a little then they would do surgery. The family followed the advice of the doctor and also remained in contact with SWACH.

At the age of seventh month, corrective surgery of the lip was done. On the advice of the doctor the baby was given diet in liquid form. Any semisolid given to the child came out through nose. As a result the growth curve slipped down. It was a challenge for the family and SWACH. Neither party lost hope nor got panicky. Play and communication activities were reinforced along with feeding. Mother talked to the child, played with the child, massage was done 3-4 times a day. The focus was on nurturing care of the child. All these measures made the mother and the child happy and relaxed and helped him to come out of post operative trauma and also improved his hunger. Biscuits/Rusk/ bread mixed with milk were given. Since the child was taking less than required in a feeding, frequency of feeding was increased. Fruit juices were also given. Iron syrup was prescribed by SWACH. Play and communication along with feeding improved the nutritional status of the child. He was ready for the second surgery (surgery for palate).

In the ninth month, second operation (operation of palate) was done in the same hospital. During this period when the child was in hospital, mother was encouraged to engage in play and communication activities with the child, so that child would be able to cope up with post operative trauma and recover early. When the child was discharged from the hospital family was advised to maintain hygiene, follow the medical advice correctly and continue to engage with the child in play and communication.

When surgery of palate was healed, the family was advised to give semisolids to the baby which was already delayed by 3 months because of cleft lip and cleft palate. It was very difficult for the family to feed the child semisolids. Family was encouraged not to give up. The technique of feeding was discussed in detail and the mother slowly got better and the responsiveness of the child stimulated the mother to do more and better. For example, put the food in to the inner side of the mouth not on the tip of the tongue. If you put it on the tip of the tongue there is every possibility that the child would spit.
it out. While feeding the child, you also eat the same food with all enjoyment. ‘Bada maza aa raha hae’ (Yummy....). Express yourself that the food is so tasty. Play and communication with the baby was always encouraged.

Now the child is one and a half years old. He speaks words like mummy, papa, bua (father’s sister). He understands much more about the words spoken and the language. Whenever he wants to go out he indicates towards outside with finger. If he needs anything he indicates that with finger. He is very active and his nutritional status is normal. Family is very happy. They are very thankful to SWACH because of the timely and appropriate guidance and support that they received for their child.

It was a very good learning experience for SWACH. This experience has helped SWACH to help other families with children who have a birth defect. With the permission of the family, the photograph and video clips are used to teach others and encourage them that their child can be alright like this child. This is not a single case. There are many more children in the society with cleft lip, cleft palate or both. Many times the cleft palate remains unnoticed which is a threat to the very survival of the child. Simply putting the finger in to the mouth of the newborn and examining for possible cleft palate at the time of birth can be very useful in early detection of cleft palate. No doubt they require surgical interventions in an appropriate health facility. But an additional and very important requirement is quality home based care by the family through nurturing. This is possible only when mother (caregiver) is healthy strong and free of tension. This was achieved through continued actions which are simple, doable and effective. This is challenge which needs to be addressed.

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