

ELECTIVE REPORT Operation Smile Comprehensive Cleft Care Centre MMC Hospital, Guwahati, Assam, INDIA

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Describe the pattern of disease/illness of interest in the population with which you worked and discuss this in the context of global health.

Cleft lip and/or palate are variations of a type congenital deformity caused by abnormal facial development during gestation. The birth rate of cleft deformities in India is 1 in every 700 patients. This adds to the backlog of children and adults of all ages left untreated due to lack of resources.

There is over an estimated 20,000 untreated cleft patients in the rural state of Assam in India alone. The Operation Smile Comprehensive Cleft Care Centre in Guwahati, Assam was the first permanent Centre set up by Operation Smile to provide free year-round reconstructive treatment for children and adults with cleft lip, palate and other deformities. Apart from causing difficulties in breathing, eating and speaking, the greatest discomfort these children face is often cruel ridicule for their appearance and at times rejection from society. In a country like India where a large portion of the rural population still believes in superstitions, people consider children with cleft lip deformity to be bad luck and some even consider them cursed. The stigma attached to their deformity causes affected children, who are otherwise completely healthy, to lead incomplete, fractured lives. They are often forbidden from attending school, playing with other children, being seen at social gatherings and some are even barred from leaving their homes.

Describe the pattern of health provision in relation to the country in which you worked in contrast with other countries or the UK.

During my time at the Centre, I noticed the patient turnover was much higher than I have ever witnessed during placements in hospitals in the UK. This was enabled by a large supportive team who all completed tasks as they arose without the need for much direction. Resident nurses and volunteer nurses from all over the world worked side-by-side assuming roles as they saw necessary. Some volunteers would stay for a week whilst others would stay for over a year, and with this continual movement of staff their system appeared to work seamlessly.

There was also an exceptional support network between doctors that is rarely seen in other practices. With specialist surgeons, anesthetists and dentists attending from all over the world bringing various skills and experiences to the table, there was opportunity for consultation and advice between them. The lists were discussed and divided between the surgeons based on their specific fortes.

One of the things that has struck me the most in terms of difference in practice in Eastern medicine with what I have been taught in the UK is the the doctor-patient relationship. I have previously completed placements in other parts of India and Sri Lanka and have noticed that doctors tend to have the final say with regards to decisions about treatment without much consultation or checking patient understanding. This is vastly different to the medicine that I have been taught where working in partnership with the patient, gaining consent and ensuring patient understanding at every step is particularly stressed. I was

surprised to see that this was not the case at the Operation Smile Centre, perhaps due to its international influences. Though the surgeons were not always able to spend much time with the patients due to the high patient load, there were other members of the team that ensured patients and their families were fully informed and comfortable with the surgery and treatment.

I met one child and her mother that had previously undergone cleft surgery but had a remaining palatal fistula for which she was at the centre to fix during my time there. The child was noted to have had a difficult time recovering from her first operation and was very anxious during her second encounter. A nurse spoke to the child's mother in her dialect, which was only found in a remote area of Assam, to explain the procedure using pictures as an aid. The child was provided with extra care where therapists and myself played with her, using bubbles with the equipment and masks that she would encounter during her management in an attempt to make her more comfortable with them.

To assess and screen patients cleft lip and palate deformities and develop skills to be able to determine suitability for surgery and management of ongoing patient care.

During my time at the Centre I was able to follow patients through from assessment and pre-operative preparation right through to post-operative care. I also saw many other patients during their follow-up appointments. Some had travelled long distances and at a cost to the family that they could not afford in terms of loss of income and cost of travel, therefore patients had to be dealt with quickly and efficiently.

Assessment clinics at the Centre saw more patients than I thought were possible in one day, never mind in one afternoon. This enabled me to see many patients and get invaluable practice in routine examination. There were many conditions that I encountered that I would not see in the UK as well as untreated facial deformities, such as advanced burn contractures, various tumors and growths. However, the large number and variety of patients of all ages meant I also saw many signs and conditions such as heart murmurs and respiratory disease that I will also inevitably encounter during my practice in the UK. These experiences have made me more confident in detecting and diagnosing clinical signs and I hope to take these lessons forward as I begin my career in August.

To appreciate the multi-disciplinary care of cleft patients including speech and quality of life outcomes following late primary palate repair.

Due to the language barrier, it was difficult for me to communicate with adults that had undergone late primary cleft repair to discuss the effect on their lives. From the few that I spoke to with a translator, I found that young adults described a more positive and hopeful outlook toward the future. Older patients seemed more indifferent, perhaps because they had learnt to survive most of their lives with the deformity.

Operation Smile is known for providing reconstructive surgery for patients in remote areas during their two week missions to various countries. However the permanent Cleft Care Centre in Guwahati enables more long-term and holistic management of patients. Though there are difficulties due to non-adherence to treatments or lack of consistency with follow-up in some patients, it has been possible to implement schemes to deal with other problems associated with cleft lip and palate patients including speech and nutrition.

I was able to get involved and learn about the new Nutrition Program that the Centre has implemented. It recruits malnourished children who are underweight for surgery and provides education and guidance to correct their nutritional statuses. I helped a student

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nurse, who was also from the UK on elective, with her project which studied the patient demographics as well as previous feeding practices. We found that many babies were being fed wrongly or not frequently enough per day to receive all the nutrients that they needed. A frequent problem with formula-fed babies was that their illiterate families were unable to read the instructions that advised how much powder to mix in solution and were therefore drinking formula that was far too watered down. Correction of relatively simple problems such as this with education saw many children in the Program achieve a more reasonable weight as evidenced in follow-up.

Conclusion

Overall I had an enjoyable and most interesting placement at the Operation Smile Cleft Care Centre in Guwahati. The invaluable experiences I have gathered will be taken forward in the hope of making myself a better clinician in the future. I hope to retain the friends and contacts I have made from all around the world in the hope that some of our paths cross again. From my experience in India this year, I know for sure that I will most definitely want to become an active member of Operation Smile and their projects in the future.

January Market Committee Committee