



Complex surgical management of patients with Cleft Lip and Palate in Ethiopia

Yekatit 12 Hospital, Addis Ababa, Ethiopia

January 13th to 17th, 2014

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Preamble: In 2013, a team of staff from the Hospital for Sick Children, Toronto was invited by Transforming Faces Worldwide (TFW) to participate in a needs assessment at Yekatit 12 Hospital (below) in Addis Ababa, Ethiopia. Specifically, the team was asked to determine the feasibility of developing an orthognathic surgery program to manage the needs of patients with cleft lip/palate. A site visit was organized by TFW from January 13th to 17th, 2014.



Background: The CLP (Cleft Lip and Palate) project began with the support of the Norwegian government and the establishment of a cleft unit at Yekatit 12 Hospital in 2003. Support from TFW began in 2007 and additional support exists on a case by case basis from Operation Smile. From discussion with staff, the program sees over 500 cleft patients annually and approximately 250 patients are operated on each year. There are many challenges in providing cleft care to the population of Ethiopia that include but are not limited to resource limitation, health care system focus upon infectious diseases like malaria and HIV/AIDS and lack of awareness of the community about the need for holistic care for cleft patients not to mention the huge bureaucratic issues of bringing in resource and surgical supplies to this country.

Project Goal: Our main expectation from this visit was capacity building for orthognathic surgery by assessing the setup (surgical, orthodontics and social work), determining skill sets in patient evaluation and decision-making and assess feasibility for safe and effective surgical treatment options.

Personnel: The team from SickKids consisted of a social worker (Farah Sheikh, MSW, RSW), orthodontist (Bryan Tompson, DDS, D. Ortho, D. Peado, FRCD(C), plastic surgeon (Christopher R. Forrest, MD, MSc, FRCSC, FACS) and a representative from TFW (Laura Lewis-Watts). TFW have been instrumental as a non-profit NGO in supporting cleft care in Ethiopia and other places around the world and have been partners with the group at Yekatit 12 Hospital for almost 7 years. This partnership was essential to the success of this mission. We liaised with the local team that included Mekonen Eshete MD, FCS-ECSA, Consultant Plastic and Reconstructive Surgeon, Shiferaw Degu DDS, M.Phil.Dent, Orthodontist and Hirut

Mengistu, BSc, Social Worker. During the visit, we were able to meet all levels of staff within the hospital which was invaluable in understanding the complex cultural and practice variations associated with the health care system in Ethiopia.



Analysis: The week was busy, well-organized and tremendous hospitality was displayed by the local host team who were generous with their time and expertise. Access to all aspects of the program were available, perhaps with exception of a review of the database. By the end of the week, the SickKids team felt qualified to provide an informed opinion on the possibilities of developing an orthognathic surgical program at Yekatit Hospital. The highlight was a coffee ceremony at the home of one of the former patients of the SickKids craniofacial program who had been supported by TFW and the Herbie Fund.



Strengths: It was a pleasure for us to interact with a dedicated, engaged and focused health care professionals who are enthusiastic and passionate about improving cleft care in Ethiopia. They have a common mission shared by all members of the team and have managed over 5,000 cleft patients with a multi-disciplinary approach. There are dedicated ORs and surgical beds and there are renovations ongoing at the Dental faculty to improve their facilities. The alliance with TFW and other NGO's is crucial to the ongoing success of the hospital as local funding is scarce. Several members of the cleft team have visited sophisticated cleft units around the world, including SickKids and as such realize what potential is available. There is strong and passionate leadership and excellent communication between team members with absence of hierarchical bureaucracy. All members of the team have a voice.



Weaknesses: Resource limitation is a significant barrier and there is little administrative and government buy-in to recognize the importance of cleft care. Importation of equipment and supplies is subject to arbitrary and bureaucratic delays from customs. The facility not equipped for complex surgery (intra-op equipment for complex monitoring, ability for induced hypotension etc.) with lack of surgical equipment and supplies, ICU post-operative monitoring and the x-ray machines non-functional. Ordering blood is a process that can take days. A huge cultural issue relates to the stigmata of having a child with a cleft (guilt, superstition, avoidance of socialization, lack of educational opportunities) which is difficult to overcome. The government is focused upon the relatively “easy wins” such as infectious diseases and nutritional disorders and isn't committed to funding cleft care. This is paradoxically compounded by a heavy reliance on NGOs for support and continued function. Currently, the database is basic and there are no obvious metrics to measure success of program. Finally, geography and patient education continues to impact the provision of cleft care in Ethiopia.



Opportunities: There are many opportunities available that include the creation of important alliances with hospital administration and highlighting a few “wins” in terms of longitudinal cleft care. This would tie in developing patient advocacy groups involving families and connected individuals, a chance for fund-raising and a way of taking cleft care into schools for purposes of education and engagement. Improved data collection and use of a computerized clinic recall system to notify patients and staff is also highlighted. There is a new free-standing hospital that is currently slated for completion in the next two years that has dedicated modern facilities and designated Plastic Surgery wards. Although the mandate of the mission was to try and assess the potential for an orthognathic surgical program, the team felt that it was important to focus upon doing alveolar bone grafts in mixed dentition as a preparatory step to more complex surgeries. We also felt that continued educational opportunities with some of the cleft team members visiting SickKids would be very beneficial. A repeat site visit by the members of the SickKids team coinciding with a local CME event would also help to raise the profile of the Yekatit program.



Threats: Despite the optimism generated by the visit, some harsh realities of providing health care in Ethiopia persist. Staff retention, morale and fatigue is an over-arching problem and there is possible collapse of program if NGO support or senior surgeons/orthodontists is lost. The stigmata of clefts is culturally ingrained and will be a challenge to change.



Summary: The fact that a cleft team exists and remains passionate about providing care to infants, children and adults with cleft lip and/or palate and is interested in partnering with other cleft centers around the world speaks highly for the future of this program. Partnership and continued collaboration is a key to success thereby opening the door to research opportunities and education. It was suggested that the Yekatit unit hold off proceeding with orthognathic surgery until program relocated in the new hospital and focus on alveolar bone grafts as opportunity to demonstrate success. We have asked them to consider a partnership with the SickKids team and plan a return visit in January 2015 in combination with a CME event and invite a multi-disciplinary audience. Improved access to information for the team members such as membership in the ASPS for the Consultant Plastic and Reconstructive Surgeons allowing them to receive the Journal of Plastic and Reconstructive Surgery and other information sources (web-based) was also recommended. Finally, provision of a clinic data-base and booking system that allows for automatic patient recall would be of significant benefit to the team.



A 46 year old who travelled 3 days to receive care for his incomplete cleft lip.

