CONGENITAL AND ACQUIRED DISABILITIES
AMONG CHILDREN IN THE HORN OF AFRICA

A special one-day conference
21 September, 2015

Hosted by the Edna Adan University Hospital
Reported by Bedri Hassan Muhumed
Executive Summary

Since 2011, the Edna Adan University Hospital (EAUH) has been hosting surgical camps for infants and children suffering birth defects and acquired disabilities. Patients travel from all corners of the Horn of Africa to receive **free treatment for conditions such as hydrocephalus, spina bifida, hypospadias, clubfoot, cleft lips and palates.**

This one day conference offered approximately 100 attendees an opportunity to reflect on how children suffering physical disabilities in East Africa might best be served by the hospitals, medical schools and practitioners charged with their care. It is hoped that this will assist with the referrals, follow-up and treatment from a health facility in their own region, district or country.

In light of their experience and expertise in the field, the three keynote speakers and other invited experts presented on the opportunities and challenges surrounding surgical treatment of these conditions, what might have been overlooked in the past and what needs to be addressed in the future. Several allied health presenters also discussed community rehabilitation for children following surgery.
Background

Since 2011, the Edna Adan University Hospital has been hosting surgical camps for infants and children suffering birth defects and acquired disabilities. Patients travel from all corners of the Horn of Africa to receive free treatment for conditions such as hydrocephalus, spina bifida, hypospadias, clubfoot, cleft lips and palates.

Over these four years the doctors involved in the surgical campaigns noted that there was a need for education among health professionals, both of the nature of the conditions and of the availability of treatment.

It was decided early in 2015 that a conference would be held on congenital and acquired disability in the horn of Africa. The conference objectives were as follows:

**Objectives**

- Provide education about some congenital and acquired disabilities.
- Discuss treatment availability and management methods in Somaliland.
- Provide opportunity for health professionals to discuss management of children with these conditions.
- Discuss how best to communicate future surgical campaigns, including referral and screening of children prior to referral.
Methods

In the first half of 2015, having decided to hold the conference, invitations were sent to various medical and allied health experts inviting them to submit an abstract for possible inclusion in the program. Abstracts were received and a program assembled with a mix of international and local speakers from medical, surgical, nursing and allied health professions.

In early August, invitations were sent to potential delegates including dignitaries, health administrators, relevant local and international NGOs and health providers in Somaliland, Djibouti, Ethiopia, Puntland, Kenya and Somalia. No honorarium was offered to attendees. More than 100 chose to come, most of them from within Somaliland.

The conference was held at the Mansoor Hotel in Hargeisa, Somaliland. This was an appropriate venue to hold a conference of this nature. The Mansoor hotel is well acquainted with holding international gatherings and capably handled security, catering and all our requirements. We are grateful to them for their contribution.

It was a busy day with an early start and a full program. Some elements were cut short due to time constraints but all presentations were completes and attendees reported the conference as being valuable to them.

Conference Program Report

The conference started at 08:40 with opening Quran Recitation by Mohamed Osman Hussein, President of Edna Adan University. Following this, Edna Adan Ismail, Director and founder of EAUH welcomed all in attendance. The conference was officially opened by the Director General of the Ministry of Health. There were around 100 attendees throughout the day. Thirty organisations were represented. Among them were representatives of both local and international non government organisations, health facilities, educational facilities. Thirteen representatives of the Ministry of Health attended, from all regions of Somaliland.
First Keynote: Dr Richard Bransford, MD FACS (USA)

BURNS: Reconstructive Surgery in Somaliland.
Dr Richard Bransford presented on reconstructive surgery for burns, including about 279 surgical procedures for burns and snake bites and even the etiology of burns. He also spoke about contractures of full thickness burns and infection with conversion to full thickness. Delayed excision, grafting and inadequate splinting and therapy all contribute to disability due to contractures. Strategies to prevent contractures were discussed along with methods for treating contractures if the patient presents an old, already contracted burn.

Speaker 1: Dr Deeqa Cumar, MBBS (Somaliland), Erigavo

Dr Deeqa Cumar presented on hydrocephalus in Somaliland. Hydrocephalus is a condition in which there is a lack of absorption, or the blockage of flow, or overproduction of the cerebral spinal fluid (CSF) that is found inside the ventricles (fluid-filled areas) of the brain. This may result in a build up of fluid that can cause the pressure inside the head to increase and the skull bones to expand to a larger than normal appearance. While historically some traditional healers sought to remedy the problem by utilizing hot metal to burn spots on the head, it was not until 2007 that the first shunt was inserted in Somaliland.
From January 2011 to November 2013, Somaliland doctors, in cooperation with a visiting surgical team, have provided surgical care for these children at the Edna Adan University Hospital.

Community-based rehabilitation teams from the Disability Action Network (established in 2002) visited remote villages seeking to identify disabled children. Local doctors screened the disabled patients and referral was coordinated with the arrival of the visiting surgical team.

Surgical results have been good with very few complications. With availability of surgical treatment for some types of hydrocephalus, some of the longer term disabilities can be prevented.

**Speaker 2: Dr Riikka Valjakka, MD (Finland), Paediatric Surgeon, Amoud University**

Dr Riikka presented on congenital anorectal anomalies. The incidence is 1: 5000 - 1: 3300 live births. 55-70% are in male patients. The etiology is unknown but it is known that 60% have other anomalies. The level of the anomaly must be detected! There is usually no urgency before 24 hours. Definitive surgery is highly specialised but a colostomy can be done in Somaliland as an interim measure. "Colostomy is never wrong."

**Speaker 3: Miss Joy Robinson, MBChB FRCS (UK), General Surgeon, EAUH**

Miss Robinson presented on the pathophysiology of gastroschisis and abdominal wall defects. She also discussed management of these conditions including initial stabilization of infants born with these problems prior to referral for the surgery which is available within Somaliland.
Speaker 4: Professor Richard Bransford, MD FCOS (USA)

Professor Richard Bransford presented on club foot. Club foot is an idiopathic deformity of the foot of unclear etiology and epidemiology. It is the most common birth defect, 1:250 to 1:1000 depending on population, and more common in males. Half of cases are bilateral. If detected early it can be treated in the neo-natal period with casting and no need for surgery. Disability Action Network can provide this service here. In older children and adults who are unable to walk properly due to club foot, surgery is an option. Several techniques can be used. Some of these techniques have been taught to Somaliland doctors at EAUH while more complex surgeries are performed by visiting specialists.

Second Keynote: Dr Shukri Mohamed Dahir, MBBS (Somaliland), EAUH

Dr Shukri presented on spina bifida and myelomeningocele. Due to poor ante-natal care (lack of folate supplementation) and prenatal diagnosis, a neural tube defect is common in East Africa. Without a practicing neurosurgeon in Somaliland, these children used to die from this preventable congenital problem. Many successful surgeries have been performed for treatment of spina bifida and myelomeningocele at EAUH. Results of the surgeries performed here are comparable to those achieved elsewhere. Rehabilitation after surgery is also available within Somaliland. Prevention is always better than cure. All women of reproductive age should be given access to affordable folate supplements. Folate is needed pre-pregnancy.
Speaker 5: Mr Hosea Cheruiyot, Nurse Anaesthetist (Kenya), EAUH

Mr Cheruiyot presented on anaesthesia safety and access in East Africa. East Africa is classified as a low middle income economy (LMI). In the UN Millennium Development Goals Report (2013), striking successes have been noted.

Globally, the maternal mortality ratio declined by 47% over the last two decades, from 400 maternal deaths per 100,000 live births to 210 between 1990 and 2010. The mortality rate for children under five dropped from 87 deaths per 1,000 live births in 1990 to 51 in 2011. Further gains will require access to both surgery and anaesthesia. Access to safe anesthesia should be considered a basic human right in the twenty-first century. However, it is far from being achieved in East Africa where lack of trained providers and poor infrastructure, utilizing a variety of often poorly maintained donated equipment, contributes to unacceptably high morbidity and mortality rates.

Anesthesia mortality in East Africa is about 1:133. For this to be improved East Africa needs more well trained anaesthetists with access to appropriate infrastructure, reimbursement, equipment and medications. Nurse anaesthesia training has been happening in Somaliland since 2012. Seventeen have graduated and a similar number are currently training. More still need to be trained. There is also need for supporting infrastructure and professional development to be put in place. Surgical treatment of congenital and acquired disabilities is not possible without good anaesthesia.

Third Keynote: Dr William Rhodes, MD FACS (USA)

Dr William Rhodes presented on the cleft lip and cleft palate. These are second only to club foot deformity as the most frequently occurring congenital deformity. Cleft lip and palate is associated with many problems. Besides the obvious cosmetic deformity, there are issues with speech, hearing, dental, and facial bone growth retardation. Surgical correction is possible. In the case of
cleft palate it is preferable to operate on the children while young to allow normal speech to develop. Even in adults, cleft lip and palate can be fixed. The results are dramatic and allow patients to participate normally in their community.

**Speaker 5: Ali Jama Hassan (Somaliland), Disability Action Network (DAN)**

Mr Ali presented on physical rehabilitation services in Somaliland. Rehabilitation services are internationally recognized as one of the key components of healthcare (WHO, 1995). The aim of rehabilitation is to correct impairment so as to improve function, prevent activity limitations, prevent participation restrictions, prevent social and educational disadvantage, and improve the quality of life of the person (Pal, Chaundhury, Sengupta and Das, 2002). DAN is involved in identification of persons with disability in the community as well as in rehabilitation after surgery. Rehabilitation centres offer a variety of services in both Borama and Hargeisa. In areas where there is no centre, home based services are offered.

**Speaker 6: Miss Julie Propst, Masters in Disability Education (USA), Uganda**

Miss Julie Propst presented *Paul: A case study. A call for inclusive education*. She discussed the case of ‘Paul’ a Ugandan child born in 2002 who received treatment for spina bifida and hydrocephalus in early childhood. She discussed the benefits and challenges of education for Paul at a mainstream school. There were many challenges including mobility, frequent absence due to illness and lack of urine/bowel control. Ways were found to manage these issues allowing Paul to attend school and gain acceptance from the other children. As well as educational outcomes, Paul was also able to care for himself better because he wanted to attend school.
Speaker 7: Dr Susan Murr, PhD Physiotherapy (USA), Uganda

Dr Susan presented on *Physiotherapy in resource-constrained regions. Strategies for effectiveness*. She discussed strategies for providing physiotherapy in low resource settings with the aim of promoting functional mobility and functional social participation. It was emphasized that it is not important for the children’s actions to be ‘normal’ as long as they are ‘functional’ and allow them to achieve the tasks they need to achieve.

Closing Remarks and Presentations

Edna Adan Ismail thanked those in attendance and invited Dr Ahmed Hashi Oday to close the conference and present certificates to those who presented.

A special presentation was made to Drs Shukri Dahir and Deeqa Cumar in recognition of their competence to independently perform some of the procedures they have learned from Dr Bransford over the past four years. They will now be able to perform some operations at any time of the year, referring more complex cases to be operated on when visiting experts are also present.

Discussion / recommendations

This one-day conference offered 100 attendees an opportunity to reflect on how children suffering physical disabilities in East Africa might best be served by the hospitals and other health providers.

The conference highlighted the large number of children within the Horn of Africa with congenital and acquired disabilities. The presenters provided education about the conditions and also about how they can be treated / managed within Somaliland. Some
attendees, despite previous work with the disabled, were unaware of treatments available within Somaliland. The knowledge they received can hopefully be shared with their colleagues and within the communities they serve. With available treatment and management those affected by these disabilities can receive treatment and have improved quality of life.

More time was needed to allow in-depth discussion of the topics presented. Time constraints meant that there was inadequate opportunity for participants to discuss how best to communicate future surgical campaigns, including referral and screening of children prior to referral. We recommend that a conference or forum be held to specifically discuss these things with relevant stakeholders and care providers.

We also advocate, as presented by Dr Shukri Mohamed Dahir, that a way be found for all women of reproductive age to have education about and access to folate supplementation as part of the comprehensive package of health services.

We are grateful to all our speakers and participants for making this conference successful. Their contribution will ultimately lead to improved lives for those with disabilities in Somaliland.