Uganda Sustainable Clubfoot Care Project

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Partner Institutions

University of British Columbia

Makerere University

Children's Orthopaedic Rehabilitation Unit (CORU)

Ministry of Health, Government of Uganda

Enable Canada

Partner Institutions

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1) Background information

Uganda is one of the least developed nations and has one of the highest birth rates on Earth (50 per thousand population). Its population is largely rural (90%) and dependent mostly on subsistence farming for their daily needs. In an agrarian society, disability is a major cause of the developmental challenges of ill health & poverty. Affected individuals are socially and economically disadvantaged with reduced educational and employment opportunities. Affected females are further disadvantaged (less likely to marry - more likely to suffer abuse). The burden of care of the disabled child falls on the mother, who has less time for other children, domestic, agricultural and economic activity.

2) The Problem Addressed

An estimated one thousand infants are born every year in Uganda with one or both feet affected with a birth defect known as congenital clubfoot. Usually the deformity is not diagnosed, or if diagnosed it is neglected, as the conventional treatment of surgical correction is simply not possible with the resources available. In 1994, there were an estimated 10,000 children in Uganda with neglected clubfeet (Atria). Congenital deformities (mostly clubfeet) are responsible for 30 % of musculoskeletal ill health & disability in children in Uganda. (Lutwama, 2002).

Children with neglected clubfeet are destined to grow up with deformed & painful feet, leading to physical disability. Untreated, this disability affects an individual's mobility and threatens their potential productivity. The neglected clubfoot deformity results in disability for the individual, a reduced standard of living for the entire family, and a burden to the community.

Professor Ponseti from the University of Iowa has developed a non-invasive method of correcting the clubfoot deformity, with an efficacy rate of 98% in compliant patients (Morcuende – Iowa City). It is appealing where surgical resources are scarce. In 1999, a Canadian led Rotary funded pilot project introduced the Ponseti method of treating the clubfoot into selected areas of Uganda by increasing awareness of the deformity & training suitable health workers in the method. Results of treatment at the Mulago Hospital Clubfoot Clinic were very encouraging.

This project's goal is to reduce the consequences of disability from neglected clubfeet in Uganda by institutionalizing the Ponseti Method of clubfoot treatment throughout the Ugandan healthcare system & provide universal Ponseti clubfoot treatment.

3) The Link Between The Project And The National Priorities

This project's objectives - to institutionalize the method throughout the Ugandan healthcare system & provide universal Ponseti clubfoot treatment - will directly address the Orthopaedic Department's concern re insufficient surgical resources, & help address

Uganda's concerns (& at the same time Canada's ODA priorities) regarding poverty eradication, gender equality & provision of basic human needs.

This project's goal (to reduce the consequences of disability from neglected clubfeet in Uganda) is an issue of relevance to the Ugandan Government & specifically to the Ministry of Health. The *Uganda Poverty Eradication Plan* (3/2002) states that Ill health was the most frequently cited cause & consequence of poverty. Its four pillars of action include "actions which directly improve the quality of life of the poor, & actions which directly increase the ability of the poor to raise their incomes." By preventing this disability, this project's objectives will directly help affected individuals to improve their quality of life and increase their ability to improve their incomes. The Ministry of Health has already expressed the desire to incorporate the principles of clubfoot management espoused by this project within their next five year plan (HSSP2 – Health Sector Strategic Plan 2: 2005-2010)

4) <u>The Relevance And Scope Of The Proposed Project</u>

In 1997, The Ministry of Health in Uganda released an information booklet "Making A Difference For Persons With Disabilities: Learn More About Disability & Rehabilitation" to provide more information on disability and rehabilitation of PWD (persons with disability) in Uganda so that "all Ugandans including the disabled participate in the goal of heath for all." In this booklet, the Ministry points out that Uganda is a signatory to the many United Nations resolutions that have been passed to guide nations re their approach to the provision of services to PWD. One such document is the Standard Rules for Equalization of Opportunities for PWD. The booklet states 3 of 22 rules. One rule on medical care is excerpted below.

Rule 2- 'Medical Care'
1. States should ensure the provision of effective medical care to PWD
2. States should works towards the provision of programs by multidisciplinary teams of professionals
3. States should ensure that all medical and paramedical personnel related personnel are adequately trained and equipped to give medical care to PWD & they have access to relevant treatment methods & technology.

In 1997, The Ministry of Health in Uganda released a set of standards to help Districts in Uganda develop services that meet the needs of persons with disabilities (Essential Services for Rehabilitative Health Care for Persons with Disabilities in The District). This document elaborates on disability and Rehabilitation health services to be available at the district level according to the National Health Policy's "*Uganda National Minimum Healthcare Package*." Strategies for strengthening these services include decentralization, raising public awareness, capacity building of medical personnel to new approaches, & incorporating rehabilitation in the basic & in-service curricula for health workers.

The Uganda Sustainable Clubfoot Care Project works hand in hand with these standards and strategies by

1. Aiming to raise awareness of the clubfoot deformity throughout Uganda
2. Training local healthcare personnel to provide treatment with a method that is socially acceptable and economically viable for Uganda.

5) Project Methodology

This project has three methodology foci:

a) Enhance the capacity to detect the deformity.

The detection of deformity will ideally occur at or soon after birth. When delivery occurs in a health facility (about 40% of deliveries) the nurse midwife will be trained in detection. For births outside a health facility it is Ministry policy that newborns are to be taken to a health care facility for birth registration at which time a well baby check and immunization will be done & a "Child Health Card" issued. This project will work with the Ministry to supply in-service training & materials to those health professionals (usually a nurse) already in the community first seeing the at risk population (at the time of issuing the Child Health Card) in detection and referral of abnormal screened children. This project will also strengthen the curricula of the Nursing & Midwifery Schools in Uganda with training modules on clubfoot detection.

b) Enhance the capacity to treat the deformity

The **Orthopaedic Officer** is primarily responsible for musculoskeletal abnormality management at the district level. It is this officer who will examine the screened children to confirm the diagnosis of clubfoot and then initiate management. Therefore all orthopaedic officers already in the community need to be sufficiently trained and supervised to be able to carry out Ponseti treatment of clubfoot. This will be done with a series of Ponseti Method Workshops throughout Uganda. This project will also strengthen the curricula of the School of Orthopaedic Officers with training modules on clubfoot treatment by the Ponseti method. Medical Officers, General Surgeons & Orthopaedic Surgeons working at the district & regional level are an integral part of the management of these cases as there is a need for a minor surgical procedure to release the Achilles tendon by severing it and then allowing it to heal with the foot in the functional position. These doctors will be given continuing medical education materials explaining the method and their role in it, through the orthopaedic officers at the time that the intervention is needed. Education and training will be offered during their training. Medical students in the country's medical schools will be given a module on their role in the management of clubfoot deformity in Uganda. Residents in the general surgery program assigned to orthopaedics during their training will be exposed to Ponseti Clubfoot treatment at the Mulago Clubfoot Clinic. Clubfoot exposure for Orthopaedic residents will continue at each weekly clubfoot clinic for a total of four months during the their second year of training.

c) Cultural Perceptions/ Incidence Survey & Evaluation.

i) Cultural perceptions; Although it is well known that having a visible disability results in discrimination, the cultural context of this discrimination is not well documented in Uganda (or elsewhere). The cultural & gender context of the discrimination, particularly in the different tribal groups (5 main tribal groups are present in the country), will be described. As the cultural perception of the disability and gender may affect not only the initial presentation for assessment but also the compliance with the treatment regimen, a survey will be done using focus group methodology to explore in different tribal groups the perceptions of clubfoot, the causes of the deformity and the need for treatment. These groups will also explore the differences in the disability and the responses to it in boys and girls. Directed by a qualified Ugandan social scientist, focus groups will be carried out in each of the main tribal groups. Culturally sensitive educational materials for the treating health professionals and for the public can then be prepared to maximize detection and fully compliant treatment. The reaction of the parent to a malformation in a newborn is within the cultural context of the parent. This project will carry out a socio-anthropological study of clubfoot in the Ugandan context to determine how the context of the disability is associated with the referral and treatment of clubfoot. Differences in the context of girls and boys will also be explored in this study.

ii) Incidence Survey: Pilot data show a sex ratio of five males for every female infant presenting for treatment at the Clubfoot clinic at Mulago Hospital. A widely quoted figure worldwide for sex incidence in clubfoot is 2.5 males for every female. It is unknown whether the Mulago data represent a different sex incidence of clubfeet in the Ugandan population or a bias within the population to seek treatment by sex. An incidence survey of clubfoot in all live births over one year in Uganda's eight principal hospitals is planned to evaluate this question. This group of infants with clubfeet will then form the cohort that will be followed for final outcome (see below).

iii) There will be two main evaluation activities, a mid-term evaluation done by the study team and an end of project evaluation. The mid-term evaluation will be carried out starting in year three and will be a process evaluation. It will use a stratified random sample as the basis of a survey of villages. The village survey will be done to determine the numbers of children with undetected clubfoot deformity, the number of un-referred children and the number of children that while referred did not come for treatment. Attention will be paid to referral rates by gender to detect gender bias in the treatment of clubfoot. This evaluation will also follow up children who were non-compliant to determine the reasons for not completing treatment, again by gender. Although monitoring the referrals and treatment plans of children will be an ongoing quality assurance and surveillance aspect of the program, a report of these finding will be prepared and circulated by the mid-term evaluation team, The rates of referral will be compared by district to determine if case finding is occurring at the same rates in all districts for boys and girls. If a district is

significantly lower than the mean, the reasons will be determined. The final evaluation will be an outcome-oriented evaluation to determine the effectiveness of the treatment of clubfoot. As the full treatment course takes up to four years, this evaluation will be based on following a stratified random sample of treated children to determine the outcome. This will allow an estimate of the effectiveness of the method to be made. This is crucial to the goal of using this method in other settings and countries.

6) Activities Planned (see Workplan for details)

a) Clubfoot Conferences
b) Awareness Program
c) Module Production
d) Fellowship Support
e) Orthopaedic Officer & Technicians Workshops
f) Rural Support/Supervision
g) District FPD & Nursing Trainers Workshops
h) Outcome Evaluation
i) Incidence Survey
j) Ethno-Cultural Survey
k) Public Engagement Video
l) Mid-Term Evaluation
m) Purchase Capital Equipment & Library
n) Management Committee Meetings
o) Advisory Committee Meetings

7) The Risks & Mitigating Strategies (In Brackets) To The Project

a) Lack of resources within MOH to supply plaster and braces to districts, (advocacy & sensitizing of health care administrators in value of the treatment)
b) Parental compliance with treatment (to be specifically researched, and parental education strategies developed if necessary)
c) Political instability in the country, & insurgency in rural areas
d) Lack of resources within teaching institutions to effectively teach detection and treatment of clubfeet (teaching modules designed to be effective)
e) Long distances between partners (clear & effective communication strategies)

8) Sustainability Strategy

This project's theme is sustainability. As stated above, *"the Uganda Sustainable Clubfoot Care Project works hand in hand with these standards and strategies by*

- *Aiming to raise awareness of the clubfoot deformity throughout Uganda*
- *Training local healthcare personnel to provide treatment with a method that is socially acceptable and economically viable for Uganda."*

The project partners have emphasized this to policy makers within the Ministry of Health and the Ministry has already expressed the desire to incorporate the principles of clubfoot

management espoused by this project within their next five year plan (HSSP2 – Health Sector Strategic Plan 2: 2005-2010)

9) Roles And Responsibilities Of Participating Institutions;

Team Member/Institution	Responsibilities
Amone/Ministry of Health	• As a Senior Medical Officer with the Integrated Curative Division, Ministry of Health, his role in the Ministry of Health with respect to this project will be regular support supervision to the hospitals to ensure that: • All hospitals budget for and purchase supplies • There is constant availability of Plaster of Paris and braces in the hospitals • Health workers are sensitized on detection and referral of children with clubfoot
Franceschi/CORU	• Supervision of Ponseti Method Workshops • Financial Records/Budgets • Research supervisor
Konde Lule/I PH Mathias/UBC	• Public health/primary care focus of the intervention within the Ugandan health care system, • Research supervisor • The design of the mid-term and final evaluation studies, • Data input, analysis, interpretation and dissemination to the Project Directors, • Quality assurance of the overall evaluation. • Working with the Ministry of health re screening of newborns for clubfoot deformities and their referral for definitive diagnosis at the appropriate health center level focusing on the integration of this requirement into the existing health care system through the well baby visits, immunization programs and other primary health interventions in place in the Ugandan health care system.
McGillivray/UBC	• Member of Steering Committee. • Assistance in capacity building issues related to the region as well as how the program can be expanded in Africa/elsewhere.
Miller/Enable Canada	• Committed ongoing logistical & in country support of training & treatment programs through its extensive network of partners in Uganda.
Naddumba (Program Country Project Director) & Mbonye / Makerere	• Research supervisor, • Curriculum content of Ponseti Method teaching modules for all the training institutions & Ponseti Workshops for orthopaedic officers in the community.
Pirani (Project Director) & Penny /UBC	• Uganda liaison • Research supervisor

	• Curriculum content of Ponseti Method teaching modules for all the medical & paramedical training programs as well as the Ponseti Method Provider & Support Supervision Workshops for orthopaedic officers in the community. • Report Preparation

10) Project Management Structure

a) The Project Director will be Dr Pirani reporting to Ugandan/Canadian Steering Committee, which will meet annually.

Steering Committee Members
i) Dr Ponseti, Professor of Orthopaedic Surgery, University of Iowa, USA
ii) Dr McGilivray, Vice President International, University of British Columbia
iii) Mr. Mossadiq Umedaly, Xantrex Technology Inc. Vancouver, Canada
iv) Dr Tusubira, Makerere University, Uganda
v) TBA, Ministry of Health, Uganda
vi) TBA, World Health Organization.

b) The project will have a Management Team (meeting semi-annually) comprised of:

i) Dr Jackson Amone, Ministry of Health Senior Medical Officer, Integrated Curative Services Division,
ii) Dr Fulvio Franceschi, Paediatric Orthopaedic Surgeon & Head of the Children's Orthopaedic rehabilitation Unit,
iii) Professor Konde Lule, Head of Dept of Epidemiology & Biostatistics, Institute of Public Health, Kampala,
iv) Professor Richard Mathias, Dept of Healthcare & Epidemiology, UBC,
v) MR Ben Mbonye, Orthopaedic Surgeon & Honourary Lecturer, Makerere University Medical School.
vi) Mr. Winston Miller, Enable Canada
vii) MR. Edward Naddumba, (Head of Department of Orthopaedics, Makerere Medical School), & the Project Director.
viii) Dr Norgrove Penny, Orthopaedic Surgeon, Victoria.

Its roles will include (guided by the Narrative Project Description, LFA, Annual Workplan, Annual Budget, Quarterly Report & Forecast):

i) To supervise the project by establishing priorities, setting targets & reviewing progress report
ii) To evaluate & monitor the meeting of targets and performance indicators
iii) To review and approve the budget forecasts for the following quarters
iv) To facilitate liaison with other involved local agencies.

Local (Uganda) project management will be the overall responsibility of the Department of Orthopaedics under the leadership of MR. Naddumba, but day to day activities in the specific areas will be controlled as follows:

- CORP (Orthopaedic Officer Workshops/ Data input /Financial records/Budgets)
- IPH (Surveys/Evaluations/, Data analysis & Processing)
- MOH (Awareness/ Sensitization/ Continuing Health Education/ Quality assurance)
- Dept Orthopaedics (Create/maintain a library of clubfoot reference & educational materials; Undergraduate/Postgraduate education)

Management Team members may be involved in planning, development & monitoring activities of the project, but the intention is that most of the work be carried out by Ugandans with appropriate knowledge and skill sets, thereby promoting the development of capacity of Ugandan personnel to identify, plan, develop and execute solutions for musculoskeletal health problems.