

# **Understanding Clubfoot in Uganda: A rapid ethnographic study**

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## Executive Summary:

### Introduction:

This rapid ethnographic study was designed to study knowledge, attitudes, beliefs, and practices across different regions in Uganda. It is the first phase of the Uganda Sustainable Clubfoot Care Project (USCCP) and will serve to inform the subsequent phases of the project. USCCP endeavors to implement a culturally appropriate and relevant awareness and treatment program for clubfoot, therefore it is vital to have an in-depth understanding of how people view this condition.

### Objectives:

- To define local terminology for this congenital condition.
- To investigate the local explanatory models or theories of causation.
- To outline appropriate methods of knowledge dissemination in the local cultures
- To identify current treatment-seeking behaviour or lack thereof and the factors that influence this behaviour.
- To explore gender differences in treatment-seeking behaviour and underlying reasons for this difference.
- To describe potential barriers to adherence in treatment so that an effective and culturally appropriate approach may be implemented.

### Methods:

This study was conducted in 8 districts of Uganda (Kampala, Masaka, Ntungamo, Mbarara, Mukono, Mbale, Iganga, and Tororo) using qualitative methodology. It was a cross-sectional, descriptive study employing: 48 focus group discussions, 156 interviews and participant observation.

### Key findings and recommendations:

#### I: Defining local terminology for this congenital condition:

- Across all ethnic groups, there is no single local term for what biomedicine describes as clubfoot.
- Multiple terms were discovered which can be categorized under the following themes:
  - Lameness or crippled (i.e. general term for disabled)
  - Congenital condition (i.e. a deformity present at birth)
  - Descriptive Terms (i.e. turned, twisted, spoon-like)
  - Bowlegs
  - Polio
  - Deformed/Abnormal (i.e. derogatory/stigmatizing terms)
- Special names given to children with clubfoot were similar to those given to all children with disabilities. These can be categorized under the following themes:
  - Lame person
  - Associated with twins
  - Nicknames/Proverbial names
  - Abnormal person
  - Traditional gods names (i.e. gods who cause condition). Unlike the others, these were ethnic-specific

### **Recommendations for the project:**

#### Detection:

1. Awareness campaigns and education should rely heavily on visual aids such as models, pictures and hands on practical experience. Language is an unreliable tool if used in isolation.
2. Due to the grouping of people with disabilities into similar categories, it is advisable to promote universal health consultation for children born with impairment of body structure or function. Health professionals can then identify children with correctible impairment such as clubfoot, and arrange for support services for all children with disabilities through the Uganda Society for Disabled children.

#### Adherence:

3. Due to the stigma which is attached to disability, it is advisable to give strong visual messages that children with clubfoot may be returned to full function following treatment.

### II: Investigating the local explanatory models or theories of causation:

- Respondents were often not certain about cause but presented a number of theories they felt were likely or probable.
- Layperson beliefs or theories of causation can be categorized into the following themes:
  - Hereditary
  - Higher Power (God sent, spirits, witchcraft, curses)
  - Physical disruptions-fetus related (i.e. big fetus)
  - Maternal related causes (i.e. small womb, mal-positioning, poor nutrition, accidents, abuse, drug-use)
  - Contraceptive Use; specifically family planning pills.
  - Germ theories (polio, malaria, sexually transmitted infections, etc)
  - Lack of antenatal care
  - Environment, weather conditions and terrain
  - Do not know.
- Practitioners generally were aware that the cause of clubfoot is unknown. However, they presented many postulated theories including many of the theories listed above.

### **Recommendations for the project:**

#### Adherence:

1. Practitioners should be trained to identify and acknowledge caregivers explanatory models in order to increase understanding and trust between the parties. The message given to caregivers should be that whatever their beliefs, they can work with the practitioner to achieve the desired result of correction.

### III: Outlining appropriate methods of knowledge dissemination in the local cultures

- All categories of respondents mentioned the following themes when asked about knowledge dissemination:
  - Media (i.e. radio, TV, newspaper) with radio as the most common response.
  - Posters in public places
  - Use of local leadership to inform community.
  - Informing health practitioners (both biomedical and traditional)
  - Broad sensitization and public address.
  - Using current health systems (i.e. antenatal, immunization, birth registration with LC)
  - Outreach services to the community
  - Services closer to home.

#### **Recommendations for the project:**

##### Detection:

1. Use the media to the advantage of health services to promote health service awareness about clubfoot and its treatment.
2. Use posters which rely heavily on accurate pictures to promote awareness of the condition and place these in public areas including all health facilities.
3. Utilize the currently available and functioning health services to promote both awareness of the condition and treatment availability i.e. immunization, antenatal services and local council birth registration.
4. Use established community structures, such as the local council leaders to promote awareness among their communities.

##### Adherence:

1. Use posters in clubfoot clinics and beyond which show individuals with corrected clubfoot actively participating in daily life (i.e. working, driving cars). This visual image may act as a positive reinforcer for adherence.

### IV: Identifying current treatment-seeking behaviour or lack thereof and the factors that influence this behaviour

- People use both biomedical and traditional care.
- Medical pluralism exists (i.e. concurrent and sequential use of multiple methods of care)
- Self-treatment through drugs and herbs.
- When seeking care for clubfoot, influences on treatment-seeking can be categorized under the following themes:
  - Level of awareness
  - Beliefs
  - Place of birth, access to transport and distance to health facility.
  - Poverty and access to finances
  - Challenges of the process
  - Social influence
  - Responsibilities at home (i.e. other children, harvests, etc.)
  - Positive factors (i.e. social encouragement, avoiding stigma, positive care experiences and good treatment outcomes)

**Recommendations for project:**

## Detection:

1. Midwives, nurses and health practitioners in all health facilities should be trained to identify and refer child with clubfoot to the regional clubfoot clinics.
2. Traditional healers should be trained to identify and refer children with clubfoot.
3. Put up permanent signs in hospitals directing patients to clubfoot clinic so that when they come to clinic for the first time they are able to locate the service with minimal hassle.

## Adherence:

4. For traditional practitioners who are already treating clubfoot, the project should consider closer partnerships with biomedical practitioners.

V: Exploring gender differences in treatment-seeking behaviour and underlying reasons for this difference.

- Gender preference does not appear to significantly impact treatment-seeking for clubfoot.
- Women's lack of access to finances impedes treatment-seeking.
- There is increasing educational attainment for girls but boys may still be prioritized for education by some.
- There are remaining undercurrents of boy preference.
- Men are heirs to family wealth.
- Teenage pregnancy and early marriage as reasons for preferring boys.
- More attention/protection for girls (i.e. due to weakness, preservation of beauty, etc)
- There is an ideological shift towards equality.
- Tensions exist between the genders.
- Gender roles remain fairly distinct.
- Women's roles remain primarily in the domestic realm.
- Men are primarily providers.
- Money is a contentious issue between the genders.
- There is clearly positive change and a way forward (i.e. changing roles for women)
- The results of this study do not explain the 5:1 ratio of males to females being reported in some clubfoot clinics in Uganda.

**Recommendations for the project:**

## Adherence:

1. Consider providing treating practitioners with additional training on counseling so they can better assist males who may be reluctant to support their wives in care-seeking.

VI: Describing potential barriers to adherence in treatment so that an effective and culturally appropriate approach may be implemented

- Poverty of caregivers
- Lack of paternal support for female caregivers
- Caregiver's other responsibilities (i.e. conflicts between childcare, harvest, etc. and treatment-seeking)
- Distance to health facilities, and cost of transport for caregivers
- Caregiver's challenges with the process (i.e. length of treatment, casting, etc)
- Programmatic resource availability and regional imbalances in service delivery.
- Inadequate programmatic resources for follow-up.
  
- Overcoming the barriers to adherence involved:
  - Personal counseling and support from practitioners for caregivers
  - Observing positive results in one's child and having positive interactions with healthcare practitioners.
  - Programmatic outreaches and follow-up services.

**Recommendations for the project:**

Adherence:

1. Based on the findings of this study, we felt that the barriers to adherence were sufficiently critical as to require attention in order to ensure the success of the program. Therefore, we suggest:
  - Practitioners receive additional training on the barriers to adherence and counseling skills to facilitate adherence. This should include: enquiring about caregivers beliefs, addressing their misconceptions, alleviating fears, and joint problem-solving for over-coming barriers.
  - Practitioners should be trained to counsel fathers and involve them in the process of treatment-seeking.
2. In order to further address the issue of adherence, the project planners may want to consider further research examining outcomes when adherence support is provided to caregivers.

**Recommendations for the healthcare system:**

***Many of these issues are systemic issues. We therefore offer the following recommendations to health care planners:***

Adherence:

1. There is need to increase efforts to provide adherence support through outreach services and community follow-up. The community-based rehabilitation services should be reviewed as a model of service delivery which can be expanded. This will require increased spending, but when viewed in terms of long-term cost benefit, will be far less expensive than costly surgeries and impeded life courses for children who relapse or remain neglected.
2. Expanded outreach services should involve conducting follow-up early in the bracing phase in order to improve adherence. Outreach practitioners could carry an 'adherence kit' with them containing various sizes of braces, cotton wool, pressure wound care, etc to deal with issues right away in the field.
3. Improve current service delivery at clubfoot clinics so that patients are treated consistently and with respect. Put monitoring systems in place to ensure that

treatment quality is maintained and corruption minimized.

4. Increase capacity for brace production and/or distribution to prevent running out of stock; and conduct quality control across regions.
5. Consider brace recycling programs to minimize costs and maximize resources.
6. Remove fees for braces or ensure social work involvement to help clients meet the costs. Charging for braces appears to continue to be a problem in most of the regional hospitals and must be addressed to ensure consistency and improve adherence.
7. Ensure resource availability in all hospitals including: plaster of paris, cotton wool, and tools for casting and bracing.
8. Correct regional imbalances in resources availability and strive for consistency. Ensure accountability systems are in place.
9. Increase social work involvement in regional outreach teams to assist with addressing individual client barriers and adherence support. Ensure that they are provided with resources to conduct their jobs effectively; for instance, pool of finances to provide transport support.

Outcomes for all cases treated should be monitored and reasons for failure documented. Results of monitoring should be reviewed regularly so that programs can be adjusted to meet the needs of the population

## Introduction:

In Uganda, approximately 1000 infants are born every year with one or two clubfeet and there is estimated to be 10000 children with neglected clubfoot (Pirani, & Naddumba, 2003). According to the human development report, the Ugandan population is increasing at a rate of approximately 3.5% per year, indicating that we can anticipate an increase in the number of babies born with clubfoot (<http://hdr.undp.org/>).

Typically, in Uganda, the condition is not diagnosed or treated, resulting in significant physical impairment that impedes mobility and has life-long functional implications in this predominantly agricultural society. Children with clubfeet grow up with painful, deformed feet and as a result are severely restricted in their life-courses. Their feet physically impair them, but their environments and society further disable them intellectually, emotionally, economically and socially...

A recent study by Lwanga-Ntale (2002) looking at chronic poverty and disability in Uganda found that 'disabled people are not only among the poorest of the poor in the country, but that they remain poor for very long periods of time, and from generation to generation' (p.1). Neglect, exclusion, discrimination and isolation from their communities are common experiences for people with disabilities (Yeo and Moore, 2003). They often lack access to the educational systems or employment opportunities and have limited opportunity to actively change their situations. Girls with clubfoot may be further disadvantaged as they are considered unmarriageable in this predominantly paternalistic society. Mothers as primary caregivers for the family are often under great stress to care for a child with a disability and may have less time for other children, agriculture, money-generating pursuits and domestic work (Pirani & Naddumba, 2003).

### **The Ugandan Context:**

Uganda is described as one of the gems of Africa and is touted as being both beautiful and friendly. It is a culturally diverse country consisting of a multitude of ethnic groups. In fact, Uganda has over 50 ethnic groups, which fall under four major regional categories namely: the Nilo-hamites, Nilotics, Hamites and the Bantu.

Uganda is located in the east of Africa surrounded by the Sudan, Kenya, Rwanda, Tanzania, and the Democratic Republic of the Congo. According to the human development index (<http://hdr.undp.org/>), in 2002 approximately 87% of the population of Uganda lived in rural areas with the majority of the population engaged in subsistence farming.

Currently, the majority of the population is reported Christian and there are also small numbers of Sikhs, Hindus and followers of Islam. Many people are



*Sipi Falls, Mbale, Uganda*

believed to have a combination of beliefs that enmesh world religions with local beliefs focusing on ancestors and spirits.

In 2002, the adult literacy rate was 68.9% of people age 15 and above (59.2% for women). According to the Human Development Index, from 1990-2001 the percentage of people living below the national poverty line was 44%. In 2000, the population without sustainable access to an improved water source was 48%. The country has a high fertility rate of 7.1 births per woman between 2000 and 2005. Infant mortality in 2002 was 82 per 1000 live births. In 1995-2002, a survey of children under age 5, demonstrated an estimated 23% of children underweight for age and 39% under height for age. The average life expectancy in Uganda at birth from 2000-2005 was 46.2 years. AIDS is a leading cause of death for persons 15-49 years old ([www.UNAIDS.org](http://www.UNAIDS.org)). In the 1980s, HIV/AIDS developed as a serious problem in Uganda and it continues to be so today; although prevalence rates are declining. In 2003, there was a ratio of five physicians per 100,000 persons in the population whereas there was at least one traditional healer per 290 persons (World Bank, 2003). Traditional healers and practitioners are recognized formally in Uganda by official government policy.



*Typical rural mud hut with banana leaf roof, Masaka, Uganda*

**The Uganda Sustainable Clubfoot Care Project (USCCP):** Unlike many disabilities, there is a low-technology treatment available for correcting clubfoot in children: the Ponseti method. USCCP has two broad aims: The first is to increase capacity within Uganda for early detection and treatment of clubfoot using the Ponseti method. The second, is to concurrently conduct extensive research, so that the knowledge base in this area is expanded, making the information available for other developing countries. This project has been funded by the Canadian International Development Agency and Enable Canada for a six-year period. In kind contributions are also being provided by Makerere University, the University of British Columbia and the Children's Orthopaedic Rehabilitation Unit, Uganda.

### What is Clubfoot?



*Baby presenting for clubfoot correction*

Due to the obvious nature of clubfoot, it is recognizable from birth. Idiopathic clubfoot (Talipes Equinovarus) is a condition in which the child is born with the foot demonstrating cavus, midfoot adductus, hindfoot varus, and equinus deformities. In lay language, this means that the foot is turned so that if weight bearing, the child will walk on the outside edge of the foot. The bones of the foot are misaligned and consequently, the joints are also altered. There is excessive pull from some of the muscles of the lower leg, and the ligaments at the back and middle of the ankle become very thick



*Older child with neglected clubfoot*

and tight. This restricts the foot by maintaining it in this deformed position (Ponseti et. al, 2003). The causes of idiopathic clubfoot are uncertain, but appear to be multifactorial (Athearn, 1995).

**Ponseti Method of Correction:** In developing countries, clubfoot may not be recognized due to a lack of awareness, or may not be treated due to a lack of resources. However, the Ponseti technique is especially well suited to developing countries such as Uganda where there is a lack of surgeons (i.e. 12 orthopaedic surgeons for the entire county) (Ponseti et.al, 2003). The technique can be learned by allied health professional such as therapists or orthopaedic health officers, thereby greatly improving the accessibility of treatment.

Treatment using the Ponseti method is most effective if it is begun before independent walking starts. Though it can be treated after this age, there is a greater chance that the foot will require surgical correction. The upper limit for effective correction of the deformity by this method is not known, but cases of good correction to age five have been reported.

Serial manipulation and casting: The ligaments are easily stretched when the child is young and by working within the range of natural stretch present within the infant's ligaments, the joints and bones can be remodeled. The Ponseti method involves using manipulation and serial casting to move the foot gradually into the desired functionally normal position. There is usually a series of 5 manipulations and casts required to correct the foot over a period of 5 weeks, although this can vary depending on a number of factors.

#### *Serial casting using the Ponseti Method*

Tenotomy: The one tendon that does not have a lot of stretch is the tendo Achilles, or the large tendon at the back of the ankle. This tendon may have to be snipped (tenotomy) in order to finish correction of the deformity. This is usually done prior to the last cast. The cast is left on for 3 weeks so that the tendon can heal into the necessary length and position. This is a simple procedure done in the clinic under local anaesthetic.

Bracing: Following the correction, the child must wear a splint continuously for 2 months (23 hour per day) and then a night splint until 4 years of age. This splint maintains the correction by keeping the soft tissues stretched, and in doing so, prevents recurrence. In Uganda, these foot abduction splints are made locally and consist of a boots and bar system. Manufactured locally, the cost is under \$10 per brace. They have to be changed as the child grows.



*Child wearing the boots  
and bar splints to prevent  
relapse.*

**Outcomes and Cost-benefit:** Ponseti conducted a 35 year follow-up study confirming that clubfoot treatment using the Ponseti method resulted in long-term correction in which the feet continued to be strong and flexible. Conversely, surgically corrected feet sometimes became weak, stiff and painful and could become disabling after adolescence (Ponseti, 2003).

Steenbeek (2004) from Kenya has estimated the cost of treatment based on when children presented for treatment: As has been discussed, if children present for treatment in the first year after birth, they will have better results with far less intervention and consequently, treatment costs are much reduced at approximately \$121 USD including casting, tenotomy and foot abduction brace. If children present for treatment after 1 year of age, the results are not as assured, and the cost is more likely to include orthopaedic surgery averaging \$600 per child. If children present at greater than 5 years of age, surgery will be required, feet will not correct to a normal position, and the cost jumps to \$783. It is evident that in terms of cost benefit, it is by far the most efficient and effective if children are identified and brought for treatment within their first year.

However, there is a further consideration when looking at benefits vs. costs and this component is not measurable: the significant improvements in quality of life for the child and their families after correction.

The child is returned to a typical life trajectory and families are spared the costs of caring for a child that may remain dependent for life. The child has typical opportunities for school, work and inclusion in the broader society. There is clearly a far greater benefit than there is cost to providing this method of treatment early in life.



*Children playing in Tororo District, Uganda.*

**Goals and Objectives of this study:**

To effectively implement a culturally appropriate and relevant awareness and treatment program for clubfoot, it is vital to have an in-depth understanding of how people view this condition: their beliefs, knowledge, attitudes, practices and the conditions of their lives. The goal of this research was to conduct a rapid ethnographic study to describe how clubfoot was conceptualized by the diverse population of Uganda. The objectives were as follows:

- To define local terminology for this congenital condition.
- To investigate the local explanatory models or theories of causation.
- To outline appropriate methods of knowledge dissemination in the local cultures
- To identify current treatment-seeking behaviour or lack thereof and the factors that influence this behaviour.
- To explore gender differences in treatment-seeking behaviour and underlying reasons for this difference.
- To describe potential barriers to adherence in treatment so that an effective and culturally appropriate approach may be implemented.

## Research Design and Methods...

### **The setting:**



*Map of Uganda*

This qualitative research was conducted throughout 8 districts of Uganda; 2 west, 3 central, 3 east: Kampala, Masaka, Ntungamo, Mbarara, Mukono, Iganga, Mbale and Tororo. There were two research teams who spent one week in each district. The fieldwork in total was conducted over the period of one month, July 2005.

Due to conflict in the north, we were unable to cover the northern region; however, effort was made to reach ethnic groups from the north who were living in the other regions.

Our team made an extensive effort to reach the rural populations as we were keenly aware that these people often had different issues than the urban populace. We were somewhat restricted by

transportation availability, but on more than one occasion we walked for periods of time deep into the villages, to gain their perspective and the context of their lives. We also covered several of the overpopulated urban poor areas in Kampala and the other urban centers, in order to gain the range of perspectives that come from wealth and poverty.

### **The Sample:**

As Uganda is a very diverse country, we wanted to ensure that we reached a broad range of informants to provide depth and validity to our data. Conscious effort was made to cover a range of ethnicity, age, socioeconomic status, and gender.

In total we interviewed 40 community leaders, 39 traditional healers, 38 practitioners treating clubfoot and 40 case studies (i.e. caregivers of children with clubfoot and adults with clubfoot). Efforts were made to ensure that our case studies encompassed not only those individuals who were in treatment, but cases that were considered 'neglected' i.e. who had not received treatment, or who were significantly delayed in seeking treatment. Additionally, we attempted to capture cases who had been treated, then subsequently experienced relapse due to non-adherence.

In addition, we conducted 48 focus groups with general community members; 24 male groups and 24 female groups. We attempted to ensure that these groups were

conducted in communities in which there were no case studies. We chose our focus groups to represent a range of socioeconomic statuses and variability in terms of proximity to hospital and urban centers. We attempted to travel out into the villages to avoid a bias of only sampling urban areas. We also attempted to vary the ethnicities of our focus groups as we were conscious of the fact that various tribes have differing beliefs and practices. Therefore, our FGDs were held among 16 ethnic groups of Uganda. The table below shows the different ethnic groups that participated in the FGDs.

Table 1: Ethnic groups that participated in the FGDs

<b>Tribe</b>	<b>Region</b>
Acholi	Northern
Langi	
Nubians	
Japadhola	Eastern
Ateso	
Banyole	
Bagwere	
Basoga	
Bagisu	
Baganda	Central
Banyankole	Western & South-western
Bakiga	
Bafumbira	
Banyarwanda	
Banyoro	
Batoro	

**Recruitment Procedures:**

The team brought a letter of introduction from the Institute of Public Health at Makerere University to each of the eight districts. Upon arriving in the district, the team leader of each of the 2 teams (east and west) approached the district health office and requested a letter of introduction to the community. They would also ask for a community guide, or would seek out an individual from the community to act as a guide. The role of this person in their community varied with each of the communities, but they were knowledgeable about their communities and helped us seek out our key informants and organize our focus groups. We requested that they bring us to a variety of community leaders (i.e. government, local leaders, religious leaders, etc). We also requested they recommend a variety of traditional healers (traditional birth attendants, bone setters, spiritualists and herbalists).

After obtaining our letter of introduction, we would also attend the regional referral hospital where all of the Uganda clubfoot clinics are based. We would arrange to interview some of the practitioners at their convenience, and would ask them to refer us to anyone else in the community who was working with this population (i.e. community based rehabilitation teams, Uganda Society for Disabled Children, etc.). We would then choose a range of practitioner informants for interview. The practitioners were also asked to assist us with compiling our lists of case studies. Sometimes we would simply interview caregivers who had come to the clinic for

treatment, but as has been mentioned, we also requested names and villages of children who were neglected or had relapsed in order to get a range of cases.

For focus groups, our team leaders would approach a community with their local guide and would seek out a local council leader. They would set a time for a focus group to be held later that day, and would ask the local council leader to mobilize the groups: one male, one female.

Generally the interviews would be conducted in the mornings and focus group discussions (FGDs) were conducted in the afternoons. Attempts were made to set up appointments in advance to allow respondents time to prepare and organize their schedules

### **Methods:**

This rapid ethnographic research employed a variety of qualitative methods in order to meet the outlined objectives. The purpose of using multiple methods was to verify the data gathered and increase the validity of the study through triangulation (Harris, et.al, 1997). Focus groups, interviews, in-depth case studies and participant observation were the methods used for gathering data. In addition to method triangulation, we also employed data triangulation. Space triangulation was in effect, as we collected data from eight districts in eastern, central western Uganda.

Data collection occurred in the participants' natural environments except in the case of some case studies who were attending clinic when they were interviewed. This allowed the researchers to experience the context of participants' lives and make



*The research team, Mulago Clubfoot Clinic, Kampala*

notes. Attempts were made to make settings private enough to ensure confidentiality, although this was not always possible, especially for focus groups which were often conducted outdoors in a bit of shade.

Selection of research assistants: There were 10 research assistants, who were divided into 2 teams. The teams started data collection in the central region and then moved east or west. The research assistants were selected based on previous research experience and

language competency. These aspects were vital as they required skill in translation as well as research technique. Because we conducted research in many languages, we were unable to translate all the tools, and therefore relied on the language abilities of the research assistants.

Training of research assistants: To ensure reliability, the research assistants underwent an extensive training period to guarantee accuracy and consistency. We gathered in the institute of public health for over a week and went through general principles behind the research, how to probe, how to avoid bias, etc. We also

reviewed each of the interview tools, discussing the purpose of each question and relating them to each of the objectives of the study. The questions were re-worded many times until they accurately reflected the purpose of the question, and were appropriate to the culture and language. The team also practiced translating the questions into Lugandan to ensure that the meaning remained consistent. It was vital for the research assistants to understand the meaning and purpose of each of the questions because they were asked to translate into their local languages, and then write their notes in English.

In addition to training in the research tools and techniques, the research assistants received training from the orthopedic officers who conduct the Ponseti training in Uganda, and attended clubfoot clinic at Mulago hospital, Kampala so that they could witness the treatment procedures.

Pilot testing: Finally, the tools were also pilot tested for 3 days in the field. We conducted interviews and focus group and were able to work out some of the issues before commencing the formal data collection. For instance, we noted that the team could not use the brochures that had pictures of clubfoot because it described treatment procedures and would bias our results. We therefore borrowed models of clubfoot from the clinic and made up some plastic-coated pictures of virgin clubfoot and neglected clubfoot, to use as visual aids when conducting the research. The brochures were saved for conducting awareness and education with our respondents at the end of each interview.

Visual aids: In both focus groups and interviews, by using pictures and models as visual communication aids, we were able to ask respondents to identify the condition without leading them to terminology in the introduction. We were then able to use their own terminology to conduct the rest of the interview, thereby increasing comprehension.

Record keeping: Record keeping was vital for all aspects of this research. One research assistant was present at each focus groups and interview for careful note taking and observation. The research assistants transcribed all notes in English during interviews and groups. In addition, the focus groups were all audio taped and were later transcribed and translated. Because the interviews and focus group notes were written in English, this allowed the researcher to conduct on-going analysis as the research progressed and enabled her to provide suggestions to the assistants, and re-iterate the intention of certain questions where the desired information was not being captured.



*Female focus group discussion*

## **Focus Groups**

The purpose of using focus groups was to gather a broader perspective into the perceptions of people in the various subgroups being studied. It was an excellent method of gaining information, as it allowed people to build on the ideas and responses of the other participants. However, it worked best when combined with other methods to verify and validate the results, as there is greater social influence with focus groups i.e. there is a tendency for people to sometimes change opinions upon hearing the opinions of others. Groups consist of 6 to approximately 15 participants and lasted from 55 minutes to over 2 hours. Semi-structured interviews were the method of interviewing. Simple questions were provided to the moderators as opposed to using general topic guides to ensure that information obtained was consistent between moderators. (See appendix for interview tool).

Focus groups were an excellent method of obtaining cultural information as they elicited the group perception or the cultural norms. Groups were divided by characteristics when deemed necessary i.e. community members of a particular ethnic background, etc. Since we were exploring gender issues, all of our groups were divided by gender so that we could truly explore the issues. Male and female interviewers were also helpful for increasing participant's comfort level and we attempted whenever possible to keep the gender of the interviewer consistent with the group. However, this was not always possible due to the language issues. The purpose of attempting to obtain homogeneity in the groups was to provide safety and maximize the shared experience.

Researchers were trained in group facilitation techniques in order to keep discussions focused, to manage conflicts or power issues that arise within the group and to obtain feedback from all members. The researchers were also reminded of these issues as the work progressed. Multiple researchers were used to run the groups and record data. Assistant moderators sketched out seating arrangements with numbers of respondents for later reference. They also ensured that all relevant background information had been obtained through a brief interview either prior to or immediately following the group i.e. age, ethnic group, gender, socioeconomic status, occupation, educational level, etc.

## **Interviews:**

Interviews were conducted in order to describe the perceptions of individuals who either had experience with clubfoot (i.e. practitioners, caregivers and adults with clubfoot), or had the potential to encounter clubfoot because of their positions in the community (i.e. healers, leaders). Interviews were once again semi-structured in format with



*Interview with caregiver of child with clubfoot, Tororo, Uganda.*

predominantly open-ended questions. This method provided a guide for researchers (important when more than one researcher is involved) and ensured they would obtain the desired information to meet the study objectives, but it also allowed for some flexibility and probing. Flexibility was important for allowing exploration of unexpected themes that emerged. Once again, simple questions were provided to the interviewers to ensure that information obtained was consistent between interviewers. (See appendix for interview tool.)

### **Observation/Participant observation:**

This method was helpful as it allowed the researcher team to observe the real behaviour in the actual context of people's lives. This constant involvement helped give a broader and more comprehensive perspective by including the research team's perceptions, which rounded out the data from the perceptions provided by participants. It also greatly increased the understanding of people's lives. Participant observation occurred in orthopedic clinics, in villages, homes, etc.

### ***The conceptual framework***

Rapid ethnographic study.

### ***Data analysis:***

Data was collected from the transcribed documentation of interviews and focus groups, along with additional notes. Data analysis was on-going throughout the research, and emerging themes or holes in the data were used to inform the gathering of new data and for on-going analysis.

Stage 1: Data reduction: The data from all the interviews was compiled and organized by similarities in response. This process began from the first week of research and allowed for investigation of important patterns of response. There was also attention given to contrasting information such as outliers of response as these offered protection from self-selection bias (Taylor & Bogdan, 1998).

Transcribed responses from the focus groups were summarized, categorized and coded by two of the research assistants using manual approach and the codes were validated. Coding was completed at the end of the fieldwork and only after the researcher had compiled all of the interviews, this helped to ensure that the data was not over-coded. Coding involved systematic sorting through of the data, labeling ideas or phenomenon as they appeared and reappeared (Krueger, 1998). The coding scheme were refined and expanded as the analysis proceeded, and codes were constructed to fit the data, not the other way around (Taylor & Bogdan, 1998). The research assistants were instructed to make rough sheets first to give themselves room for expansion and refining. A team approach was employed in analyzing the data in order to ensure triangulation (i.e. coding occurred separately by the various team members and was then compared). The importance of multiple coding was in the alternative interpretations it yield and the consequent thoroughness of analysis (Barbour, 2001). It also allowed for validation.

Stage 2: Data Organisation: After data was coded, it was sorted according to themes. The objectives of the study were used as a guide for organizing themes in this analysis (Krueger, 1998).

Stage 3: Interpretation: Making decisions and drawing conclusions about the organized data. Once again, this was done through a team approach to ensure thoroughness. We divided the analyses between the researchers by objectives, but verified and confirmed each others work.

### ***Quality criteria addressed***

As has been outlined, measures were taken to ensure that our study was both reliable and valid. We employed a number of forms of triangulation to verify our data. Interviewers and moderators were trained to ensure skill level and consistency and their performance and data were monitored during data collection. Interview questions were reviewed in copious detail with the research assistants to ensure that when translated into the various languages, their meaning would remain consistent. This increased both the validity and reliability of our study.

Observer/researcher bias was overcome by using an international multi-disciplinary research team. There was naturally some selection bias as the respondent selection was often purposive, however great effort was taken to ensure a range of demographics and of circumstances, to ensure that we covered a wide range of respondents. Wherever situations arose where we suspected there could be bias, it was discussed so that the situation could be avoided in the future. For instance on one occasion we had one community leader waiting while another was being interviewed, he may have over-heard the first respondents answers and been influenced.

There was, of course, always the risk of participant bias or participant's intentional efforts to alter their responses and this could have occurred if participants were concerned about revealing sensitive information in interviews. It was even more likely in our focus groups, as respondents were less likely to respond openly in such situations or may have altered their responses to conform to the group. We tried to minimize this bias by ensuring confidentiality, attempting to have privacy in interviews and focus group settings and by careful selection of groups i.e. homogeneity of groups, etc.

We confirmed the validity of our results by feeding the findings back to the participants at the end of each focus group/interview to ensure that we had actually captured their perceptions (Pope & Mays, 1996). By feeding back, we also allowed them to alter or add anything that we had misunderstood or missed. However in addition, as interviews were generally conducted in pairs, we requested that the interviewer review the note-takers work at the end of each session to verify the data as well as add anything that had been missed. Finally, after the focus group tapes were transcribed and translated by the research assistants, we had a random sample transcribed and translated by an unbiased third person (who had not been involved in the study). The two transcripts were then compared to ensure consistency and accuracy, and we found that although styles differed, the content was consistent.

During the analysis phase, data was analyzed by multiple researchers to avoid selective perception and to verify of themes and patterns (Krueger, 1998). In addition, it was recognized that delay affects the quality of analysis, and therefore this process of analysis occurred throughout the data collection phase and immediately following (Krueger, 1998).

### ***Ethical considerations addressed***

The literature was thoroughly searched and it was confirmed that this study did not replicate previous studies. This study was a genuine contribution to the knowledge base in this area.

To the best of our knowledge, this study was completed without causing harm to anyone involved. Risks and benefits to participants were weighed to ensure that there was overall benefit to the Ugandan population through a contribution to local knowledge. This study also has the potential for tremendous benefit for children born with clubfoot and their families.

Results of the study will be shared with all interested parties and will be used to improve accessibility of services for children with clubfoot. We will seek to publish results so that this research becomes available to the broader community, thereby decreasing the possibility of duplication.

Respondents' confidentiality and privacy were protected and their trust respected in this study. Methods were employed to ensure that informed consent was received from all study participants. Information was provided verbally and consent was obtained in the participants' mother tongue to confirm that language barriers did not interfere with this process. Participation was voluntary and consent was not considered final; participants were free to withdraw at any point and one participant chose to do so. The only ethical issue that arose was unfortunately not pointed out to the researcher until after the fieldwork was completed. Reportedly and understandably, some of the participants were uncomfortable signing a consent form that was in English, even though it had been verbally translated to them in their mother tongue. Because this issue was not brought to the attention of the researchers in advance, we were unable to address it, but this should be a recommendation for future studies.

This proposal has passed through multiple ethics committees: Curtin University, Makerere University, University of British Columbia and the National Science Council of Uganda.

## Analysis of Findings:

For the sake of improving readability, we have arranged the findings according to the objectives of the study. The reader will find that each objective begins with an introduction, a literature review and a conclusion.

### **Objective I: Defining local terminology for this congenital condition.**

#### **Introduction:**

We set out to study the local terminologies for clubfoot among various ethnic groups in Uganda. The aim of this objective was to use this information to design an appropriate and socially acceptable nationwide clubfoot awareness program.

#### **Literature Review:**

Often within various African cultures, it has been discovered that multiple causes, taxonomies and descriptive words are recognized to describe what biomedicine may classify under a single term. For instance, in the majority of the local dialects in Uganda, there was found to be no single term for the English word 'disabled' (Lwanga-Ntale, 2002).

Winch et al, (1996) reviewed a number of studies looking at terminology in Africa related to diarrhoeal diseases and malaria and found that the suitable selection of language and terminology were essential to the development of relevant health communications. Without this consideration, there is the risk of 'nominalist fallacy' or the tendency to falsely believe that a single term in a language can be used to capture a disease and its multiple symptoms (Kendall (1990), quoted by Winch et al (1996)).

#### **Review of findings:**



*Using visual aids: model of untreated clubfoot used for effective communication with respondents.*

##### **1.1 Local term used to describe clubfoot**

Respondents were shown a model of clubfoot and then asked what local term is used to describe this condition. A variety of local terms were mentioned and these have been classified under 7 themes.

##### **Lame/crippled**

Lameness (or crippled) was the most commonly mentioned local term that is used to describe clubfoot among the various ethnic groups that were studied. Lameness was mentioned in all FGDs, and most of the interviews. Even the three adults with clubfoot that were interviewed described their condition as lameness. However, we came across a variety of local terminologies that are used to describe lameness among the different ethnic groups that were interviewed and these are described below.

- *Mulema or bulema*, which means lame among the Baganda, Basoga, and Banyole. Similarly, the Banyakole, Bakiga, Batoro, Bafumbira and Banyoro from western Uganda describe clubfoot as *oburema/kalema*, which translates into lame. The Banyakole and Bakiga also use the term *ekimuga or kamuga* to describe lameness, mentioned in 7/9 FGDs.
- The Bagisu call it *buleme* as was mentioned in all the FGDs (6/6) that were conducted in Mbale, home to the Bagisu. Key informants in Mbale confirmed this. *Walemele ekigele or muleme webikele* is another term that is used to describe lameness among the Bagisu. A traditional healer and practitioner in Mbale mentioned it.
- *Shelemala ate shaborokha* was mentioned by 1 practitioner in Mbale. It means 'feet are lame and folded' in Lugishu.
- *'Kiwete*-meaning the feet are lame –reported by a parent to a child with clubfoot-Mbale
- *Angwal or langolo* among the Acholi and Langi refers to a lame person
- *Angwelu or engweilit*, *angwelu* means lameness while *engweilit* stands for a crippled leg among the Ateso
- *Ongoli* which means lame person was mentioned in both FGDs that were conducted among the Japadholas. Another term *jarangolo*, which is synonymous with *ongoli*, was mentioned in one of the FGDs. In this particular FGD, we were informed that a lame foot is specifically described as *tiendemongoli* by the Japadhola.
- *Okugongobala* means crippled among the Baganda. Was mentioned by a practitioner in Masaka.

### **Congenital condition**

Some of the local terms used to describe clubfoot allude to it being a deformity that one is born with i.e. congenital condition. One of the key informants mentioned that the Banyankole describe clubfoot as *oburema bwobuzarwa*; implying that the person was born lame. Other terms mentioned are:

- *Wazalibwa kyalemala kikono* (born with both legs lame) by the Bagisu
- *Waneema or walugono* which mean born lame by the Baganda (2/13FGDs) and Basoga (5/6FGDs) respectively

### **Descriptive terms**

The key informants and FGDs mentioned a variety of words or phrases that describe the uniqueness of clubfoot. These have been categorised under the theme descriptive terms.

Some tribes refer to the condition clubfoot using terms that imply that the feet are twisted or facing each other. The Bagisu use the term: *bikyele byalemala byaburwana*, while the Baganda and Banyakole describe them as *akagere ekefula* and *akagere ekefula* respectively.

*Zamufula*- was mentioned in some of the FGDs that were conducted among the Baganda (2/13FGDs) as a term that describes clubfoot. It means that the legs are twisted or turned with the soles of the feet facing inside out. This was confirmed by practitioners from Masaka (1/5), Mukono (4/5) and Mbale (2/5). The Basoga use a similar term '*damufula*' to describe clubfoot (mentioned by a practitioner in Iganga).

Some Japadholas use the term '*akajene nu ibeloro*' which means legs that are turned. However, only one practitioner from Tororo District mentioned this.

*Ebigere ebyekifuulannenge or kafuulanenge*-which means feet that are turned inside out in Luganda or *kifuranenge*-a term that describes something that is twisted in Luganda were descriptive terms that were mentioned by a practitioner from Masaka District.

*Akenda malamali*- means she walks with legs curved inwards. This was mentioned in Mbale District by a parent to a child with clubfoot.

Some Banyankole refer to clubfoot as *Obugyere bwobugiko or bugiko*, which means spoon-like foot in Runyakole. This was mentioned by practitioners in Mbarara district (4/5). A practitioner from Ntungamo mentioned that clubfoot is also referred to as *akagere kendosho*. This means a foot shaped like a wooden serving spoon in Runyakole.

### **Bowlegs**

Some of ethnic groups also refer to clubfoot as bowlegs. Bowlegs are locally known as

- *Bitege* among the Baganda (6/12FGDs), Basoga (2/6FGDs) and Bagwere (1/1FGD)
- *Ebitegye* among the Banyakole, Bakiga, Banyoro, this was mentioned in 2/12 FGDs or
- *Kamadamali* by the Bagisu (2/6FGDs)

### **Polio**

Some people describe clubfoot as polio. The term polio is derived from the medical condition poliomyelitis, which cripples limbs of affected persons. This term was mentioned in FGDs (10/40) and interviews conducted among the Baganda, Bagisu, Bafumbira, Batoro, Banyakole, Bakiga and Basoga. People tend to confuse clubfoot with polio owing to the shape of the foot. Surprisingly polio was never mentioned in any of the FGDs conducted among the Japadhola, Ateso as well as ethnic groups from the northern region who are mainly Luo speakers.

### **Deformed/abnormal**

It was mentioned in one of the FGDs that such feet are described as *kikule kule* in Luganda, which means something that is abnormal or deformed. This term is usually used to describe children or persons born with congenital deformities such as missing limbs.

A key informant stated that the Basoga at times refer to persons with clubfoot as *omugede*, which means a person who has an abnormality.

Two of the practitioners in Mbale mentioned that sometimes children with clubfoot are called *watoya*- meaning that the child is spoiled or useless. This had also been mentioned in one of the FGDs conducted in this area.

All the above terms that describe clubfoot as a deformity tend to stigmatize the affected persons as echoed in the words of this practitioner from Mbale.

*‘Some people call children with clubfoot watoya. This is abusive in Lugishu, so we health workers discourage the use of this term’.*

### **Twins**

Among the Baganda, such feet are sometimes called *balongo*, which means twins. This was raised in 3 of the 13 FGDs that were conducted among the Baganda. Culturally, twins are believed to possess supernatural powers that are associated with abnormalities. It is alleged that misfortunes will occur in a family (both nuclear and extended family) such as giving birth to children with deformities like clubfoot if

'the spirits for twins' are not appeased. This was especially the case if rituals associated with the birth of twins are not performed.

## 1.2 Special names given to children born with clubfoot

Special names given to children born with clubfoot were investigated. Several names were mentioned and these have been summarized under 6 themes.

### Traditional gods' name:

Information collected from the FGDs and key informant interviews revealed that children who are born with clubfoot are at times named after traditional gods who are believed to cause deformities. However, it is important to note that these names are generalized to the various types of congenital lameness.

- *Kadu wanema*- was mentioned by some key informants and FGDs (3/13FGDs) as a special name given to children with clubfoot in Buganda. On further probing, we released that kadu wanema is a one of the gods in Buganda. One key informant told us that *kadu wanema* is believed to be crippled hence often associated with lameness among the Buganda.
- *Esejja or Isejja* - is a traditional god that is associated with lameness by the Basoga and Banyole. Boys who are born lame including those with clubfoot are named after this god (7/8FGDs). Two practitioners in Iganga confirmed this. Sometimes lame boys are called *lubaale*, which is a general name for traditional gods in Busoga.
- *Lukowe or lukoye* is the special name given to lame girls in Busoga (1/6FGDs). It is the name of the god responsible for lameness among girls. It is believed that children who are born lame, including those with clubfoot are a result of failure to appease this god.

*'Lukowe needs to eat a goat, cock or sheep...'*

- mother of a child with clubfoot, Iganga, Uganda

- *Ojok* (boy) or *Ajok* (girl) – the Acholi give this name to children who are born with congenital abnormalities or deformities such as clubfoot, or those who are breech presentations. It is associated with a traditional god and such people are considered to be special people; this was mentioned in the FGD that was conducted among the Acholi and confirmed by community leaders that were interviewed.
- *Mukama*- this was mentioned in one of the FGDs conducted among the Bagisu in Mbale and confirmed by a community leader. Mukama is a name for gods or spirits in Lugisu.

### Lame person

The majority of the ethnic groups studied had a special name that is given to a lame person. Some of these names are gender specific as described below.

- *Angwalas* (girl) and *engwalas* (boy) are special names that are given to lame children including those born with clubfoot among the Ateso ethnic group. This was mentioned in both FGDs that were conducted among this ethnic group and was also mentioned by 2 practitioners.
- *Walugono* is the name used by the Basoga (4/6FGDs), Banyole (1/1FGD), Bagwere (1/1FGD) and Bagisu (1/5) to uniquely identify a lame person.
- *Kalema*- is the name given to people (both males and females) who are lame among the Banyakole (5/9) and Bakiga (1/1). However, the Banyole (1/1FGD) and Bafumbira (1/1FGD) limit the use of the name *Kalema* for lame boys and use *Nakalema* for lame girls.

- *Langolo*- is the name that is given to a lame person by the Acholi (1 FGD and Community leader in Kampala)
- *Ngwalo* –descriptive name for deformity among the Langi (*Practitioner 1*)
- *Bugyere*- name given to lame people by the Banyakole (2/9FGDs).

### **Associated with Twins**

As earlier mentioned, clubfeet are often associated with twins by some people. It is therefore not surprising that some people use twins' names for children born with clubfoot. This was said to be the case among the Banyakole (1/9FGDs).

In that same FGD it was mentioned that among the Banyakole, children born with clubfoot are at times called *Kizza*-a name given to child that follows twins in birth order or *Kigongo*- a name given to child whose birth precedes that of twins.

### **Nick names**

A variety of nicknames are given to persons with clubfoot depending on their ethnic origin. *Asambira mungaki* by the Bagishu (1/5FGDs), *mulinya wagonda* by the Baganda (1/13FGDs) and *Ngige tiende* by the Japadhola imply that a person walks on dorsal part of the foot, which is tender, so they prefer to walk on soft/smooth surfaces.

‘such children with clubfeet are called *Ngige tiende* which means that she walks on the upperside (dorsal aspect) of the foot...’

- Parent of child with clubfoot, Tororo, Uganda.

*'Kyikoto'* which means skin in Lugisu (1/5FGDs). It implies that the person walks on the dorsal part of the foot.

*Koloba*—nickname for lame persons among the Baganda. This name was mentioned in 5/13FGDs conducted in Busoga and by 2 practitioners. Two parents to children with clubfoot testified to the fact that their children are referred to as *Koloba*. This term was also mentioned in 1 of the Banyakole FGDs.

*Nami kyendo/nami kyeto* -describes a lame person that walks with the aid of crutches in Lugisu (1/5FGDs).

*Akenda malamali*- means she walks with legs curved inwards. This was mentioned in Mbale District by a parent to a child with clubfoot.

*Ob-ui?* Among the Japadhola, this means that the person's feet sweep everything while walking. A community leader in Tororo mentioned this.

### **Proverbial names**

- *Kawandema* – this is a Runyakole saying, which translates to 'I have no choice'
- *Zamufuula*- 'his or her legs were twisted' among the Baganda. 3 practitioners mentioned this.
- *Byakatonda*- this is a saying among the Basoga that translates to 'it is God's'. A community leader in Iganga mentioned this.
- *Kibikyo*-this was mentioned in one of the Basoga FGDs. It means something bad that one possesses in Lusoga.

### **Abnormal person**

Some of the special names given to persons with clubfoot imply that the person is abnormal. Key informants were the main source of this information.

- *Kiwete*- Swahili

- Omugede –Basoga
- Omuntu eya kozimba-Buganda
- Umuleme/watoya-Bagisu

Generally there is no special name that is specific to clubfoot. However, such children are given names that imply that one has a deformity as reflected in the words of a community leader in Tororo:

‘There is no special name, but anybody born with any deformity on the body is called *ongoli* in Japadhola’

*‘ I am happy now because most of the people like me; except for giving me names like umoja and Kaguru Mbaya...’*

- Adult with neglected clubfoot, Mbarara, Uganda..

## Conclusions

There is clearly no single term that uniquely describes clubfoot among all the ethnic groups studied. However, all ethnic groups appear to describe clubfoot as lameness. Therefore the awareness campaign will have to utilize visual aids for effective communication.

Some of the names given to people with clubfoot are stigmatizing. This might be prohibiting parents from seeking for care due to fear of being seen with such children. There is need therefore, for the clubfoot project to address this issue of stigmatization during sensitization campaigns.

## **Objective II: Investigating the local explanatory models or theories of causation.**

### **Introduction:**

The lay perception of the causes of club foot may differ from the biomedical paradigm. Explanatory models and causes of club foot obtained from the caretakers, clients and community members can provide insight into lay beliefs about clubfoot as a condition. As well, through this exploration we come to understand the personal and social meaning of clubfoot, expectations about what will happen as a result of clubfoot, and how and when a healer is expected to intervene. Finally, through this study of theories of causation we are often also able to identify the short- and long-term therapeutic goals.

### **Literature Search:**

Explanatory models: Brown et al (1998) describe explanatory models as 'personal interpretation of the etiology, treatment and outcome of sickness by which a person gives meaning to his or her condition.' (p.15). People of all backgrounds (both biomedical and laypersons) have belief systems around causes of sickness and possible treatment options (Pelto & Pelto, 1997). They interpret the experiences of their bodies and symptoms through their socio cultural beliefs and assumptions, which act like filters (Brown et al., 1998).

The importance of understanding explanatory models: The explanatory models of health practitioners and their patients can conflict, and when this occurs, healthcare is impeded (Kleinman, A, 1978). Knowledge of lay explanatory models obtained through ethnographic studies such as this one, decreases instances of clinical miscommunication, provides solid ground for discussion around health behaviour, and promotes mutually respectful interactions (Nichter, 1989).

When introducing new treatments, knowledge of local explanatory models is also imperative for judging the likelihood of success (McElroy and Townsend, 1996). People will seek out treatment based on what they believe has caused a condition, and based on their knowledge of what is effective for treatment (Nichter, 1989). If an illness was considered untreatable, then people sought only to manage the illness and spending large amounts of money on treatment was felt to be wasteful of scarce resources. Local health practitioners can be valuable partners in determining the cultural appropriateness of interventions, which fit with local explanatory models (McElroy & Townsend, 1996).

Brown et al (1998) note another very important consideration; while knowledge of explanatory models is essential, explanatory models alone are not good indicators of health-seeking behaviour. A number of factors influence treatment-seeking, so there is often a discrepancy between what people say they believe and how they actually behave. So knowledge of causation must be paired with study of treatment-seeking behaviour.

The dynamic nature of belief systems: Numerous studies have shown that belief systems are flexible and dynamic (Ijsselmuiden, & Faden, 1999, Stone, 1992). Therefore, even in areas where traditional beliefs and biomedical beliefs conflict, if treatments are felt to be sound, people find ways of integrating them into their belief systems (Stone, 1992). For instance, people are often able to use medical

pharmaceuticals and other fundamentals of biomedicine, while retaining their traditional beliefs and explanations of illness (Pelto & Pelto, 1997).

The scientific speculations about clubfoot: The cause of clubfoot is not definitively known, however there are a number of possible causes of club foot suggested in the scientific literature. The biomedical model stipulates the genetic mechanism of inheritance and a family history of clubfoot having been reported in 24.4% of families (Lancet, 2004). There are also environmental causes that have been suggested to cause clubfoot. For instance it is thought that intrauterine crowding causes clubfoot. This theory is supported by a significantly higher incidence of clubfoot among twins compared to singleton births (Lancet, 2004). Intrauterine exposure to the drug misoprostol has also been linked with clubfoot.

Researchers in Norway have reported that males who are in the printing trades have significantly more offspring with clubfoot than men in other occupations (Lancet, 1998). Amniocentesis, a prenatal test, has also been associated with orthopedic problems like clubfoot (Kmom, 2004), and the risk of clubfoot is increased ten-fold after early amniocentesis (from 0.1% after second trimester amniocentesis to 1.3% after early amniocentesis). It was also reported that infants of mothers who smoke during pregnancy have a greater chance of being born with clubfoot than offspring of women who do not smoke (Lancet, 1998). Finally, it has been proposed that clubfoot may occur because of arrested development of the limb early in the fetus' life (Athearn et al., 1995)

### **Review of findings:**

Respondents were asked what they think are the causes of clubfoot. The responses were varied ranging from the natural to the supernatural causes. In most cases the respondents were not sure of the cause but would offer theories which were probable to them. This often meant that respondents expressed more than one theory of causation; for instance, a female focus group discussion from Nyenge in Mukono district summed up that:

*'There are three causes; these are spiritual, hereditary and family planning.'*

This objective seeks to provide the reader with a summary of the various causes. We have divided this discussion into two: Firstly we will review the lay person's perceptions of the causes of club foot as described by general community members, parents, traditional healers and community leaders. Secondly, we will discuss the theories of causation as proposed by practitioners working with children with clubfoot:

### **A: The laypersons perspective on the cause of clubfoot:**

#### **Hereditary/Inherited**

Most of the groups and community leaders proposed that clubfoot is hereditary, passed on from one generation to another. If one member of a family had it, there were chances that the offspring would have it. As long as there are grandparents with a similar condition, one of the grandchildren is bound to experience it. That the condition was common in some clans. The condition would have been in either the woman or man's family. A couple of respondents even suggested that a person should avoid marrying someone who had clubfoot in the family, in order to prevent the occurrence of the condition.

*'I know of a neighbor whose family has many lame people, and the lameness descended as back as their grand fathers...'*

- Community leader, Mukono, Uganda

*'Culturally in some clans it is a must to have such a child, most especially if there was a person with a similar condition and in most cases they do not treat them...'*

- Female community member, Mukono, Uganda.

*'Avoid marrying in some families where clubfeet is common...'*

-Community leader, Mbarara, Uganda

However some mothers who had given birth to babies with clubfoot did not believe it was hereditary because it did not run in their family. As reported by these mothers:

*'I cannot rule out heredity but our lineage has no clubfoot...'*

- Mother of a club foot child, Ntungamo, Uganda.

*'It is not hereditary because I have not seen anyone in my family or in the family of my husband...'*

- Mother of a club foot child, Ntungamo, Uganda.

### **God sent**

Just like any other illness, most groups indicated that club foot is GOD sent. One participant compared it to AIDS, which they reported had been sent by God to show his power. A good number of focus group participants think the cause is just God who creates a person with deformity so there is nothing one can do about it, and that they do not mind and accept the situation as it comes. Such a kind of attitude and belief about club foot might affect the health seeking behavior leading to not taking the child early enough for treatment or not seeking treatment at all.

*'Those are deformities from God. He is the one who created people to look like that...'*

-Male community member, Iganga, Uganda.

*'In our culture we do not mind about those feet because we believe they are sent from God...'*

- Male community member, Kampala, Uganda.

*'It is God given since it is only God who knows what is in the womb and you cannot know what God gives, by the time you produce the child is already like that...'*

- Male community member, Mukono, Uganda.

*'It could also be God sent, because for instance, God has sent AIDS to show his power. Professors have tried but failed to get medicine for it. God can decide to send such a condition to a family...'*

- Community leader, Tororo, Uganda.

**Spirits:** Traditionally it was highlighted that club foot is associated with spirits. There are different types of spirits that are thought to cause club foot in the different ethnic groups in Uganda. Some are ancestral spirits that have not been appeased while others are just roaming spirits (*bizimuzimu*) from ancestors. Among the Basoga it is believed the cause is due to *Esejja* spirit from the father's clan/side. Among the Baganda of Masaka it is believed that spirits like *Muwanga* causes that condition because he is not happy with the family members due to being neglected, Similarly if the a family has given birth to twins and has never taken them for cultural rituals performances the spirits can cause them to give birth to children with clubfeet. It is believed that the spirits weaken the bones of the baby, causing that condition.



*Huts built for the spirits by spiritual healer, Masaka, Uganda.*

*'...in our culture we say that at that home there are some sprits (Lubaale) in Lusoga that is why the child is like that, that is what they call Sejji...'*

-Male community member, Iganga, Uganda.

*'Banyole have ancestral spirits in a clan i.e. Walugona and Iseja. These spirits require sacrifice and when there is failure to appease them, they attack the child, a sign of revenge. And when a child with clubfoot dies they do not burry, they put the body in a pot and then abandon it in the forest and any member of the clan is not supposed to fetch firewood from that spot where it was abandoned...'*

- Female community member, Tororo, Uganda

*'Bizimuzimu (sprits) originating from particular clans and are hereditary ...'*

- Female community member, Mukono, Uganda

### **Witchcraft**

Some also thought that witchcraft causes the condition. This happens if one or both parents are bewitched. Bewitching could be the result of disputes within families or communities.

*'For some it is caused by witchcraft ...'*

-Male Community member, Ntungamo, Uganda.

*'Some think it is bewitching by a co-wife, a jealous relative or someone who does not wish you well...'*

- Practitioner speaking of common community beliefs, Tororo, Uganda..

However one mother who gave birth to a baby with club foot reported that in their case witchcraft was ruled out because the child was too young and he would not have done anything wrong to anyone. Others responses confirmed that witchcraft could not be performed on the unborn.

*'With us, we don't believe that an unborn child can be bewitched, witchcraft only affects a person born without the problem, who later becomes disabled later...'*

- Male community member, Mbale, Uganda.

### **Curses**

There were a number of respondents who hypothesized that clubfoot could be the result of a curse. For instance if a pregnant woman laughs at a lame person, it is believed that the mother will be cursed to give birth to a baby with club foot. Alternatively, it can be curses from parents if the mother did not satisfy their requirements or even a curse on the family from dead relatives.

*'They believe that a disabled child is a curse, so such cases are kept indoors. There was a couple who divorced because of a child who had clubfoot, so they sought the traditional healer for help...'*

- Practitioner working with children with clubfoot, Masaka, Uganda.

### **Twin births**

*'In case there are twins in the family, the mother is most likely to give birth to a child with clubfoot...'*

- Traditional Healer, Masaka, Uganda.

Clubfoot can be considered a prediction of twins in the family. Another cause related to twins is when the parents disrespect twin-bearing rituals. When a twin is produced in most ethnic groups, there are certain rituals that have to be performed called '*kwalula*'. If they are not performed there are possibilities of having a baby with club foot.

*'If there are twins in the family, but the cultural rituals were not carried out properly, then such a child can be born. They need to appease the spirits. ...'*

- Male community member, Masaka, Uganda.

Clubfoot can be caused if the father of twins married another wife from the house where the mother produced twins from. This is called *kushobya ahabaana* i.e. mixing of children among the Banyankole.

Some reported that clubfoot was caused by twins in the womb i.e. they will tend to press each other and are fighting for space. At times they sleep on one another. This causes deformity that results in club foot.

### **Physical disruptions: Fetus related**

Factors related to the fetus/baby that were reported to cause club foot include: poor positioning of the fetus, situations where the placenta ties the baby, premature birth, big babies or prolonged and horrendous birth. Also if the mother bled a lot while pregnant, the fetus can get deformed.

*'May be due to poor positioning of the fetus in the uterus, when the fetus cannot stretch properly...'*

-Male community member, Goma.

*'As a mother I felt that the baby was not properly positioned during pregnancy ...'* - Mother, child with club foot, Iganga, Uganda.

A mother who delivered a baby with club foot indicated that the birth of that particular child was difficult because the child was just pulled out, so it may have caused the deformity, though she was still not sure. A community leader echoed the same sentiments as illustrated by the quote below.

*'It could be due to complication during delivery or mismanagement by the TBA during the delivery process. In the last 3 years, that condition has been very rare in our community. Previously the condition used to be more common especially before women were sensitized about antenatal immunization and visits...'*

-Community leader, Tororo, Uganda.

Finally, some respondents speculated that there are also babies who are born with weak bones so they take long to walk and as the years continue, the legs later fold.

### **Maternal related causes:**

Mother's related causes are varied. Respondents indicated that if a mother has a small womb especially adolescents, this could cause congestion and in the long run, this condition.

*'Girls who get pregnant when still young could have the babies suppressed in the womb and produce such babies...'*

- Community leader, Mukono, Uganda

*'Small uterus. When the uterus is small, the child cannot stretch his/her legs properly...;*

- Traditional healer, Ntungamo, Uganda.

If the mother is fond of sleeping in a bad position it is thought to cause the condition. During child labor it was indicated that the mother can sleep on baby's feet causing this condition especially when labor is prolonged. Similarly overworking (digging, carrying firewood, water and other household chores) while pregnant is thought to cause club foot.

*'In the process of giving birth a mother can sleep on the baby's feet or if it is a prolonged labour it can cause clubfoot...'*

- Male FDG, Ntungamo, Uganda.

*'Other people in the community tell me that that I over worked during pregnancy...'*

- Mother of a child with clubfoot, Masaka, Uganda

The use of gutters by women to tie their stomach is also suspected as a cause of the condition because the baby is not free to move about in the womb. It was alluded to that young girls who want to hide the pregnancy because it is unwanted and they are not married tend to have babies with club food because they 'tie' the stomach. Those who try to abort and fail, also get babies with deformities.

*'Others say that tying the stomach while pregnant like girls when they try to hide the pregnancy... I want to add on what she said, they used to say that don't eat food while tying your stomach you have to leave it free...'*

- Female community members, Mukono, Uganda.

*'The other cause results from girls who use gutters hence restricting free movement of child in uterus. It fractures the child in a bid to avoid being noticed since they are students ...'*

- Female community member, Mukono, Uganda

*'The feet may get deformed when the mother sleeps in a bad position...'*

- Male FGD, Kampala, Uganda

Some thought that if the mother does not space between births the result is club foot.

### ***Physical harm of mother during pregnancy/accident***

Some felt that due to domestic fighting, a fetus could be injured causing clubfoot. Also in situation where a mother had an accident before delivery such as falling down, her body cells may fail to protect the feet of the baby.

*'When the expectant mother is being mistreated e.g. being beaten by the husband...'*

- Female community member, Masaka, Uganda.

### ***Contraceptives (family Planning Pills)***

It is quite surprising that most focus group participants mentioned one of the causes of clubfeet to be the use of contraceptives by women. Generally in Uganda contraceptive use is quite low – about 23% of women 15-49 years currently using contraceptives (UDHS, 2000/01). Among the inhibitors of use is the fear of perceived side effects such as giving birth to deformed babies. This also explains why they attribute club foot to use of contraceptives. However, this belief may also be perpetuated by the local media. One mother of a child with clubfoot gave the researchers a newspaper article in the local language which attributed clubfoot to contraceptive use.

*'Contraceptives used by pregnant women and before birth affects the child and lead to many deformities that have been occurring lately; that is why we feel the condition is due to contraception. It is confusing because even those who have not used them can get this condition, may be they are expired because the level of deformity has increased...'*

- Female community member, Mukono, Uganda

*'Long ago, it was God's plan, but now I hear it is associated with contraceptives....'*

- Community leader, Iganga, Uganda

*'Others believe that it is contraceptives, so they should produce every year, not to get such a child with clubfoot instead of using family planning, which can lead to deformity...'*

- Practitioner treating clubfoot, Mukono, Uganda.

A parent of a child with club foot lamented why she had used family planning pills indicating it was the cause of the condition. She indicated: *'I am worried because I used family planning pills...'*. Another one indicated: *'I think it is family planning because I did not know I was pregnant, so I continued with pills even during early pregnancy...'*

However, at the other range of the spectrum, some community members concluded that clubfoot could not be caused by family planning pills as these were recently introduced, whereas clubfoot had been around for a long time.

*'Family planning pills have just been introduced recently but from time memorial, these bad feet have been existent in some children...'*

- Male community member, Masaka, Uganda.

### **Drugs/bad injections**

The uses of expired drugs, medically indicated drugs or injection when a woman is pregnant were also believed to be causes of club foot. Also drugs that are not supposed to be taken by a pregnant woman were thought to cause club foot.

*'I had a swollen leg during pregnancy and was admitted to the hospital from 6 months gestation until the birth of the child for treatment. I feel it was the pills used for treatment. Then when the baby was born, the clubfoot was on the same leg as mine that was affected, which was further proof...'*

- Mother of child with clubfoot, Kampala, Uganda

### **Drug abuse smoking, drinking**

A few of the groups mentioned overdrinking of the local gin (waragi), causes the weakening of sperms that will produce the deformed child with club foot as illustrated by the quote below.

*'Over drinking of the local gin and when the time coming for having sex, the sperms of the man become very weak and when they fertilize the ovum, the fetus becomes weak and eventually the child with clubfoot is born...'*

- Male community member, Masaka, Uganda.

### **Herbs**

Over use of local herbs is believed to cause club foot as illustrated by a quote from a mother with a child with club foot.

*'On my side I overused local herbs during pregnancy which were given to me by my mother in law because I never new anything concerned with pregnancy. I had dropped from school when I was still young...'*

- Mother of child with clubfoot, Ntungamo, Uganda

Traditional healers give pregnant women herbs when they are consulted. It was alluded to that traditional healers could cause this condition when giving herbs to prevent unwanted pregnancy. It was felt that this could later become a problem resulting in children with clubfoot being produced.

*'When a pregnant mother tries to abort due to unwanted pregnancy, but fails, the (herbs) she took affect the baby, resulting in being lame...'*

- Traditional Healer, Tororo, Uganda

Conversely, some respondents reported that it was a failure to take local drugs during pregnancy, which had resulted in the clubfoot.

*'Mothers should take local herbs because this is what our grandmothers used to take. ...'*

- Community Leader, Iganga, Uganda.

*There are herbs that can be taken to widen the uterus in order to reduce the effect of bones pressing the uterus.*

- Traditional healer, Tororo, Uganda.

### **Poor maternal nutrition**

Also mentioned as a potential cause of clubfoot was poor nutrition of the pregnant mother i.e. eating the wrong things or lacking something such as vitamins in her diet.

*'Biologically I think the mother had problems not the child. i.e. mother lacked some nutrients which were to be passed on to the child during labour....'*

- Male community member, Kampala, Uganda.

*Others say /tell us that eating salt which is not iodized (salt with big particles), which does not have calcium that is why they produce children like that*

- Male community member, Iganga, Uganda

*'In areas like Kanugu, they attribute it to eating grasshoppers when pregnant....'*

- Practitioner treating clubfoot, Mukono, Uganda

### **Diseases/Sexually Transmitted Infections**

There were a number of diseases that were allegedly causing clubfoot. Sometimes it was disease or infection of the child, other times it was suspected to be infection that the mother gets during pregnancy. Most notably mentioned was syphilis (*kabotongo*) and other sexually transmitted infections including AIDS, gonorrhea, etc. In most cultures in Uganda syphilis is known to be prevalent in certain families and is not so much associated with sexual intercourse.

*'I think it is caused by diseases before or during pregnancy like syphilis and gonorrhea...'*

- Female community member, Tororo, Uganda.

*'Mother should have treatment for syphilis. Syphilis interferes with blood circulation because it causes the nerves and blood vessels to shrink. This results in such a condition...'*

- Traditional healer, Mbarara, Uganda

Malaria during pregnancy was sighted by community leaders and some mothers who had a child with club foot. i.e. there is too much heat in the womb when one has malaria and this may result into deformity. One mother lamented that when she was pregnant she got severe malaria at two months and it lasted for three weeks, so she attributes the condition of her child to the malaria.

Other diseases suspected of causing clubfoot included: polio, tetanus, measles, ulcers, epilepsy, kidney failure, ectopic pregnancy, bacterial infections, etc. One practitioner even told us that he had heard from a community member that clubfoot was contagious...

*'I have heard that it is contagious, that mother's don't want to contact a lame person when pregnant....'*

- Practitioner treating clubfoot, Mbale, Uganda.

### **Lack of immunization:**

Related to the previous suspected causes, it was alluded to that if a child is not taken for immunizations i.e. polio, tetanus, measles, etc.; he/she could develop club foot.

*'Maybe it is caused by the failure of the expectant mother to attend or finish immunization...'*

- Community leader, Ntungamo, Uganda

*'Expectant mothers should complete all immunization doses against tetanus..'*

- Community leader, Mbarara, Uganda.

### **Not accessing Antenatal Care**

If the mother does not access antenatal care during pregnancy it is thought that this causes club foot. Community had clearly been sensitized to the benefits of antenatal care, and had extended these benefits to include the prevention of orthopedic conditions such as clubfoot....

*'I was advised that in case I had gone for antenatal, I could have prevented this from happening..'*

- Mother of child with clubfoot, Tororo, Uganda

*If mothers can visit hospitals during pregnancy, practitioners can stop it from occurring.*

- Community Leader, Masaka, Uganda

*Mothers should always contact doctors when pregnant to treat them all diseases they could have to avoid affecting the child in the womb.*

- Community Leader, Mbarara, Uganda.

### **The environment, weather conditions and terrain**

In Mbale which is hilly and sometimes cold, it was thought that the cause of club foot is the hilly terrain and the cold conditions in those areas as illustrated by the quote below.



*Typical Mbale landscape*

*'Weather and hill and landscapes. )In this area that condition is not common, it is more in areas of Bududa, Bufumbo and uphill in Wanale...'*

*'We imagine its due to the cold temperatures, since they are near the forest, because in those areas you find disabled persons after every three houses or may be due to the hilly nature of the landscape in that as you climb the child is affected/gets a shock...'*

- Male community member, Mbale, Uganda

Other respondents attributed clubfoot to other environmental problems such as pollution.

### ***Do not know***

Some of the participants mentioned that they did not know the cause of clubfoot. Alternatively some told us that in general, the cause of clubfoot was unknown.

*'Most people do not know the cause...'*

- Practitioner treating clubfoot, Mukono, Uganda

### **B. Practitioners treating Club foot: what they know as the causes.**

Practitioners who treat club foot were also asked about the causes of the condition. Most of them reported that the cause of the condition is not known, medically, though there are many theories that have been postulated to explain the causes of the condition. Nevertheless, it was indicated that most of these causes are inconclusive. Further an orthopedic officer emphasized that cause of idiopathic clubfoot should be differentiated from clubfoot from other causes such as spina bifida, arthrogypsis. The various inconclusive theories from biomedical practitioners were clustered in the following themes.

#### ***Reduction of the uterine space***

- Narrow/small inter-uterine space
- Abnormal positioning of the baby
- Fat baby
- Intrauterine pressure - pressure to the developing fetus inside e.g. Mothers who have 'tied' to hide their pregnancy increase the pressure in their womb.

#### ***Congenital and hereditary***

- Genetics or hereditary
- Defect in spinal cord
- Polio, arthrogypsis, cerebral palsy
- Unequal formation of foetal structures, especially soft tissues like ligaments

#### ***Use of drugs and Family Planning Pills***

- Family planning methods
- Use of chemicals.
- Drugs taken in early pregnancy

#### ***Misuse of drugs***

- Alcohol
- Cocaine
- Heroine.

#### ***Abnormal bones***

- Abnormality in the bones of the foot which twist and make the feet face upside down, insertion of the tendon can pull the foot in this abnormal way, abnormal components of the muscles and ligaments which have a tendency to develop contracture (collagen fibers).

#### ***X-rays***

- Radiation of the mother when she is expecting e.g. taking an x-ray.

#### ***Hormonal and chromosomal imbalance***

- Hormonal factors during fetal growth
- Chromosomal imbalances cause this condition.

### ***Effects of wars***

- After the liberation war of 1979, Mulago registered high numbers of clubfoot, so there were theories that the bombing had caused this.

### ***Poverty***

- People who have a poor diet, especially with the poor, because most of the children with clubfoot are poor
- Poor nutrition of pregnant mothers

### ***Complications during pregnancy and birth***

- Convulsions during pregnancy.
- Maternal stress
- At birth they may develop deformity if the legs come out first due to the neglect of mothers to come to antenatal care in the last 2 weeks

### ***God sent***

- Will of God

## **Conclusion**

Analysis of the causes of club foot from the lay and biomedical paradigms shows that both share some similar views on the explanations. However biomedical practitioners tend to refer to these as theories of cause as opposed to true cause. Similar views expressed are hereditary, family planning pills, Polio, reduced uterine space, use of drugs, poor nutrition of mother during pregnancy and not going for ANC, However differences are in that the lay community explanations hinge more on the supernatural causes such as witchcraft, spirits, God sent, curses, and twin births. Knowledge of both the community and biomedical beliefs allows for greater understanding between practitioners and patients, and provides clues about the underlying motivation of some treatment-seeking behaviour.

### **Objective III: Exploring appropriate methods of knowledge dissemination in the local cultures**

#### **Introduction:**

Appropriate methods of knowledge dissemination about clubfeet were investigated in focus group discussions in the eight study districts of Uganda, and during interviews with key informants. The key informants represented a range of selected stakeholders.

#### **Literature Review:**

Numerous studies have demonstrated what common sense would tell us: Health interventions will be most successful if local people are involved (Stone, 1992). There is often a lack of knowledge about how to convey health information in a meaningful manner that involves the community and motivates change (McElroy and Townsend, 1996). Written materials are of limited benefit in countries with low rates of literacy. In Uganda, fewer than 60% of women in Uganda were literate as of 2002 (<http://hdr.undp.org/>).

Effective approaches to knowledge dissemination and some of the pitfalls: McElroy and Townsend (1996) have noted effective approaches to education using drama, humor, music, dance, television, radio drama, and accurate visual aids. However, as a cautionary note, the literature reinforces the importance of accuracy when using visual aids. Many interventions have failed in their approach because their visual representations were not accurate: Holmes (1964) found that illustrations of large flies were felt to be irrelevant for the local population in Kenya who noted there were no flies of that size in the country and disregarded warnings (McElroy and Townsend, 1996). Nichter (1989) demonstrated that many mothers felt that nutritional advice provided by professionals was only relevant to the fat and healthy babies depicted in posters and that their thin, malnourished infants were not the target of such nutrition advice.

Disseminating knowledge to traditional healers: Just as biomedical practitioners seek to acquire new knowledge and new practices for the best interests of their patients, so do traditional practitioners. Research has found the majority of traditional practitioners willing to learn new skills to add to their repertoire (Nichter, 1989, Anderson, 1996). As most people are being cared for by traditional health practitioners in Uganda, it would be logical to invest in the training of these practitioners. Werner (1987) suggests that written materials can be used, but should include, line drawings, simple descriptors and illustrative stories. Traditional practitioners have reported demonstration and hands-on learning experiences were most helpful in training (Nichter, 1989).

#### **Review of findings:**

Respondents of various categories were asked about the most appropriate methods of knowledge dissemination. The findings are presented by category of key informants.

### **PRACTITIONERS TREATING CLUBFEET**

The most frequently recommended ways to inform the public included the radio, posters, community leaders, health workers, religious leaders, traditional healers and through public meetings.

### **The radio:**

This was the commonest response. Many of the practitioners recommended special radio programs or short announcements about clubfoot. They explained that most homes in the country have got radios and people listen a lot to the radio. Television was also recommended by some practitioners. Some practitioners, however, even after admitting that the radio would be a popular medium for communication, pointed out some weaknesses of the radio. They said that some homes do not have radios or TVs and in some places there is poor TV reception. This appears to be a caution against relying solely on the radio or TV.

### **Posters**

After the radio, posters were next in frequency of being recommended as a good medium to inform the public about clubfeet. Most practitioners recommended that posters should be placed in trading centres, health centres, public recreation halls and in places of prayer. Typical statements included the following.

*'Use posters with pictures and messages in local languages'*

*'Use posters with before and after treatment pictures'*

Other methods of information dissemination in the media were mentioned by a few practitioners and included: brochures, pamphlets, drama, mobile films and newspapers.

### **Sensitising health workers about clubfeet through workshops**

Many practitioners felt that if health workers are well informed about clubfoot they would be in a position to pass on the information to the general public. Health workers included: community health workers, midwives, nurses and traditional birth attendants.

*'All health workers in the health units should be informed of the condition so that they are able to inform the community when approached. Because even some health workers working here do not have any knowledge about this...'*

- Practitioner treating clubfoot, Mukono, Uganda.

### **Public meetings**

Conducting public meetings as a way of passing on information to the public was recommended by many practitioners across the districts. The common view was that the meetings might be organised as outreach activities from hospitals to the community.

*'Educate the community through outreaches where people can collect in one trading center for this information...'*

- Practitioner treating clubfoot, Iganga, Uganda.

### **Sensitise or train local leaders**

These are the Local Council members (LCs) and traditional leaders. Many practitioners felt that if the LCs were well sensitised about clubfeet they may in turn pass on the information appropriately and help with referring clubfoot cases.

*'Traditional leaders should be used because local communities believe in them so much and what they say to people is taken as the truth e.g. the issue of immunization....'*

- Practitioner treating clubfoot, Masaka Uganda.

### **Other channels**

A few practitioners had additional recommendations including increasing awareness in schools, among church leaders, through politicians and among traditional healers. Additionally some practitioners suggested community birth registration.

### **PARENTS OF CHILDREN WITH CLUBFEET**

The parents of children with clubfeet were informed that there is a new Ministry of Health program to ensure that children born with this condition are treated early because treatment is most effective when started soon after birth. They were then asked to provide advice to help find children with this condition early in life. Most parents provided advice focussing mainly on the radio, posters, LCs, training of midwives, taking services closer to the people and public awareness. Each of these will be presented to capture the parents' views.

### **The radio**

All parents recommended putting clubfoot sensitisation programs on the radio stations. This was the commonest recommendation and it was argued that most people listen to the radio. The radio may be supported by TV programs and newspapers. One parent thought that the whole treatment process could be demonstrated on TV.

### **Training of all midwives**

Most of the parents held the view that all midwives should get special training to enable them to recognise clubfeet and then refer the affected babies to hospital for treatment. This recommendation was frequently mentioned first by most parents of children with clubfoot. Many of them emphasized that the training should embrace all midwives including those in hospitals, health centres, private midwives and those in the villages or traditional birth attendants.

*'Train midwives and TBAs to identify these children early after birth and encourage mothers to take them to hospitals where the condition is treated....'*

- Parent of child with clubfoot, Tororo, Uganda.

### **Attending ante-natal and immunization clinics**

Encouraging all pregnant women to attend ante-natal clinics so that they get sensitised about clubfeet was recommended by many mothers. Most of these parents also felt that affected children could be identified in the immunisation clinics. One parent pointed out as follows:

*'Mothers who deliver outside of hospital should be encouraged to attend both ante-natal services and immunization services so that they get sensitised and their children get examined for clubfeet.'*

### **Taking services closer to the people**

Parents felt that services for the management of clubfeet are not easily accessible especially in the rural areas. Many parents recommended outreach programs to be

organised from hospitals to the community. The outreach programs could include sensitisation and actual treatment. One parent said:

*'Treatment should be brought to the villages so that we can afford to take our children for treatment; and it should be free'.*

### Posters

Posters were also recommended as likely to be useful for increasing public awareness. Posters could be put in public places including hospitals, clinics, schools, churches and markets.

### Community leaders

Training of LCs and religious leaders so that they in turn pass on the knowledge, was recommended for improving public awareness on clubfeet.

### Corruption

A few parents felt that illegal charging of fees at government health facilities may keep some patients away. One parent had this to say.

*'People fear going to Mulago because of the small amounts of money they are always asked for. They say treatment is free, but because of corruption, some people in the hospital ask for money...'*



*Posters used by the Uganda Clubfoot Project.*

### ADULTS WITH CLUBFOOT

Adults with clubfoot were informed that there is a government program to ensure that children that are born with clubfoot receive treatment soon after birth. They were then asked to advise the program on how best to identify children with clubfoot early in life when treatment is most effective.

Responses mainly focussed on improving general awareness about the condition and encouraging parents to use hospital facilities for child birth and immunisations in order to get any afflicted children diagnosed. Specifically this included radio programs and announcements, making use of LCs, and TV advertisements.

### COMMUNITY LEADERS

Community leaders were asked to advise the program on the best way to effectively inform the public about clubfeet.

Continuous sensitisation through various community leaders was a common recommendation. The recognised leaders include LC members and religious leaders. The use of radios and posters was recommended by most leaders in all the districts.

- 'Use posters with pictures of children with the condition'
- 'Most women don't read, so you need to talk to them'
- 'Radio would be a good option but there are some people who do not listen to it or are too busy to listen, or those who fail to buy cells'
- 'Radio is listened to more by men than by women'

## **Public meetings**

These were recommended by many respondents. The meetings may be conducted by health workers, LC members or by church leaders.

## **Improving health services**

Many leaders thought that health services are not easily accessible. Some recommended that more health facilities should be constructed or that outreach programs should be initiated.

*'Open up more health centres and bring them near the local people'*

*'Government should introduce such treatment even at the community level'*

*'Bring health centres nearer to the people'*

## **TRADITIONAL HEALERS**

The commonest recommendations included radio programs, outreach services from hospitals to inform the public and to treat cases, public meetings, posters, community leaders and religious leaders. One traditional healer offered the following advice for gathering the community:

*'It may be hard to mobilize people in communities such as this, where the condition is rare. People may not be excited to participate. But, another alternative is to mobilize people maybe without telling them what you need. Then introduce the topic when they are already gathered'*

Our respondents suggested that we sensitise all TBAs and traditional healers. In order to discover the best way to inform them of this condition and the method of treatment, we asked them: what is the best way for you to learn?

Their responses confirmed what we had found in the literature. They suggested that the best way of learning was practical and hands-on approaches: practice, mentoring, travelling to the clinics and seeing treatment were the most common responses.

*'By practice; you see what is being done and then you master it...'*

-Traditional healer, Kampala, Uganda.

*'I cannot read, but I can learn through practice. Bring the case, and show us how to handle it...'*

- Traditional healer, Masaka, Uganda.

We found traditional healers to be, for the most part, very welcoming of the new ideas we were presenting when conducting this research. There was also an overall impression that they were keen to learn new techniques and increase their repertoire of treatments that would be of benefit to their patients. They were willing to work with biomedical practitioners in a bi-directional knowledge transfer and they were willing to refer to biomedical. However, they also expressed that they too had something to contribute to the health of their population; a contribution which should not be discounted.

*'Yes, it is helpful because we can then treat patients using the two methods. I remove the cause, and then the method can help with the correction. The medical personnel should give us a chance...'*

-Traditional healer, Masaka, Uganda

*'Manipulation of the ligaments and tendons when the child is still young could correct the deformity. We as bone setters also want to deal with such feet with help from you people. If we were trained and given materials such as plaster, we could help in treating the condition at the local level....'*

-Traditional healer, Mbale, Uganda.

*'People have a lot of problems and us as traditional healers cannot help them because we do not work together with the medical side. Traditional healers need training on the medical side, or need to get a way that we can work with medical staff. Medical people sometimes tell people that they will not service them because their situations look grave- yet if they come to a traditional healer, we can help them...'*

-Traditional healer, Masaka, Uganda

*'We have a problem with some patients who really need hospital care and if advised to go to hospital, refuse saying that they know they have been bewitched. There should be training of traditional healers so that they learn how to convince these difficult patients e.g. learn to take blood so it can be brought to the laboratory for testing...'*

- Traditional healer, Masaka, Uganda.

## **Conclusion:**

We asked all categories of respondents about the best methods of knowledge dissemination and found some commonalities and some differences. It appears that in general our respondents suggested: use of the media, use of local leadership, informing health practitioners (both biomedical and traditional), broad sensitization and public address, using current health services such as antenatal care and immunization, conducting outreach and bringing services closer to home.

## **Objective IV: Current treatment-seeking behaviour in Uganda and the factors that influence this behaviour**

### **Introduction:**

In our focus group discussions as well as interviews, we asked a number of questions to ascertain people's pattern of resort and delay when faced with sickness or disability. We wanted to identify their patterns of treatment-seeking behaviour; both in a general sense and specifically in relation to this particular congenital condition. The importance of this objective was to establish our baseline of treatment-seeking behaviour. Additionally, by examining treatment-seeking behaviour we got good indication of the barriers present which were impeding access to care. The understanding gained will allow USCCP and health planners in general to know their populace so that they may move forward together.

### **Literature review**

Medical pluralism: People will often try several forms of treatment either concurrently or sequentially in order to address a health issue: a phenomenon known as medical pluralism (Nichter, 1989, Beckerleg, 1994, Pearce 1993, Pelto & Pelto, 1997, Anderson, 1996). In general, the literature suggests that the African way of thinking is quite open to new approaches (Pearce, 1993). Alternative treatment options are not necessarily felt to conflict or are mutually exclusive and all can hold possibility or strength. For instance, western practitioners may be considered good for surgical procedures and diagnosis, but traditional practitioners better for addressing underlying cause (Pearce, 1993). Another explanation for medical pluralism cited in the anthropological literature suggests that people are often searching for a fast cure rather than a lengthy treatment (Beckerleg, 1994). This can lead them to trial a variety of approaches, searching for the one that rapidly addresses their symptoms.

Seeking traditional care: Anthropologists repeatedly report that lay people often choose and have a high degree of satisfaction with the services of traditional practitioners (Anderson, 1996). In Uganda, 80% of the population depends on traditional practitioners as biomedical professionals are scarce and/or not accepted by communities (World Bank, 2003). These practitioners have 'grass roots legitimacy' or 'professionalization from below', which leads communities to favour them and their approaches. This favoritism stems from local experience, trustworthiness and moral standing in the community (Last, 1996). Layperson's knowledge and understanding of the theory underlying the practitioner's approach is often not considered as relevant as the community's confidence in the approach (Pearce, 1993).

The social influence on treatment-seeking: Social systems are another factor to be considered when looking at treatment-seeking behaviour, as they can have significant sway on healthcare treatment decisions. For instance, Pearce (1993) discusses the finding that in Africa, there continues to be widespread consultation of social networks in determining how to choose health care providers, decide between treatment options, and for obtaining support, funding and logistical assistance. The group involvement in healing is especially important in this culture. However, Ijsselmuiden and Faden (1999) provide another important consideration: The literature describing culture in Africa seems to indicate that there is a single African culture and that it is static phenomenon when in fact there are more than 900

cultures, which are changing. So while it may be true that some cultures in Africa continue to perceive the individual as an extension of the family, this should not be presumed.

Economic influences on treatment-seeking: Economic factors can also have major influence on treatment-seeking behaviour; and in some cases may be the determining factor in pursuing treatment. Considering that the majority of Ugandans live rurally, accessibility and proximity to services can be problematic and transportation costly. Traveling to healthcare involves not only the cost of transportation, but loss of wages, cost of treatment, etc... Between 1992 and 2002, 82% of the population lived on less than \$1 a day ([www.unicef.org](http://www.unicef.org)), so finances and the costs of treatment are major considerations for the majority of Ugandan people. According to UNICEF's State of the World's Children report 2005, only 2% of the Central Ugandan government funding is allocated to health care. With this little governmental support for healthcare, the practice of choosing traditional practitioners is on the rise. It can be anticipated that economic factors will influence treatment-seeking behaviour in Uganda's current climate. However, as Stone (1992) writes, 'where modern curative services are accessible, affordable and effective, they are used' (p. 411)

### **Review of findings:**

Our review will begin with our general findings about treatment-seeking for health issues in Uganda and will conclude with the behaviour specific to this congenital condition.

### **General treatment-seeking behaviour in Uganda:**

We asked both our general community members and our community leaders: where do people in the community go in the case of illness or disability? In general, in each community we found a mix of treatment-seeking with some attending traditional and some attending biomedical care; and sometimes, they did both.

*'It depends on the sick person. There are those who guess that 'when I don't drink any traditional herbs, I can't cure' and there are those like me, I have to go to hospital, and I don't go to traditional...'*

- Female community member, Iganga, Uganda.

*'In my community people go to traditional healers, others go to health centers. People go to traditional healers because they think the illness is brought by small gods...'*

- Community Leader, Kampala, Uganda

However, respondents also indicated that the type of care sought could be dependent on the type of illness or disability. Biomedical practitioners were considered appropriate for treating certain conditions and traditional healers were more suitable for other types of care.

*'If illness needs hospital care and you go to traditional healer, you will not heal, and if it is traditional and you go to hospital, you will not heal, so when you go to hospital and there is no change, try the traditional...'*

- Male community member, Masaka

*'For those who get complicated diseases which are hard to identify, they go to traditional healers for consultation...'*

- Community leader, Ntungamo, Uganda.

*'There are different reasons that can cause lameness among people. There are some ailments that can be handled by western trained health workers, but there are also cases that can only be handled by traditional healers. But, those who have caused a lot of problems in healing are those western doctors, because they don't believe that an ailment can be caused by traditional problems. They don't know this because it is above their knowledge and understanding, despite the fact that they are bright. They take us the Africans that we are backwards, but, they (the whites) also have lame children. Some of our doctors have been trained and they have completely forgotten their roots. The solution is these doctors coming together and working with traditional healers...'*

- Male Community Member, Masaka, Uganda

**Seeking biomedical care:** As we have reviewed, the World Bank Report (2003) indicated that in Uganda, 80% of the population is dependent on traditional practitioners because biomedical professionals are scarce and/or not accepted by communities. We certainly found that a substantial portion of people seek the care of traditional healers, however, more than double the number of respondents in our study reported that they seek biomedical care if ill. This discrepancy could be for multiple reasons; nonetheless, we will present a few theories which are most probable.

Firstly, it is possible that in the last 3 years there has been a shift towards using more biomedical care as people are being sensitized, and awareness and outreach campaigns have increased.

*'The government sends people to the communities to teach people, like you have come (e.g. HIV/AIDS, family planning, etc). They come to the community, make clubs, do drama, and encourage people, so now people in community know what to do and where to go...'*

- Female community member, Mbarara, Uganda.

*'Around urban areas, they tend to come to hospitals for care- they are more sensitized...'*

- Practitioner treating clubfoot, Mbale, Uganda.

Perhaps our findings are suggestive of an ideological shift occurring over generations.

Some respondents alleged that this move from traditional to biomedical was more of a generational issue: that these days, the young and educated seek biomedical, whereas the older generations choose traditional because of familiarity.

*'The ones who start with traditional care are few; these are mainly elders who grew up with traditional care....'*

-Male community member, Mbale, Uganda.

*'We should put more effort into our traditional values because we have dropped those values. We have these children who are out of hand and this is because the placenta is left in hospitals after birth. So this should be considered...'*

- Male community member, Masaka, Uganda.

Another theory is that these findings may represent bias in the study. This bias could have arisen in a few ways: Firstly we may have seen a greater number of respondents reporting biomedical care use because they assumed we were there to promote biomedical treatment, and consequently told us what they thought we wanted to hear, introducing a reporting bias. Additionally, for the purpose of conducting this study, we selected regions that had a regional hospital with a clubfoot clinic. Therefore, our findings could suggest a selection bias, where our respondents were those who had better access to medical facilities than the general Ugandan population. Finally, some respondents were of the opinion that seeking traditional care was the behaviour of those who were uneducated or impoverished. So perhaps by not going far enough into the villages (due to the limits of transportation), again, we may have introduced sample (selection) bias by capturing more respondents who had access to information due to their proximity to health centers.

*'The possible causes for people resorting to traditional healers could be due to poverty and ignorance. There is also a lack of health education in the communities...'*

- Community Leader, Tororo, Uganda

Regardless of the reasons behind why more people are reporting using biomedical care, there were some important warnings about limitations to accessing care that must be passed on to health planners. We heard numerous stories of hospitals running out of supplies, and of corruption and neglect by health workers. These situations at times led to reluctance to seek biomedical care, or prompted search for alternatives.

*'If you go to the hospital, you will sit and wait for a whole day and come back without a single tablet; your patient may even die while you spend the whole day in hope of getting treatment. So when you see this, you just get your money and go to a private clinic where your patient will be cared for...'*

-Female community member, Mbarara, Uganda.

We also heard of many barriers to seeking biomedical treatment, and these will be outlined in detail in our next section looking specifically at clubfoot.

**Seeking traditional care:** Traditional healing undoubtedly has a strong following in Uganda, and a sizable number of respondents reported seeking the care of traditional practitioners. The contribution to health made by traditional healers is however at times discounted by health practitioners and even some of the general community members who are changing their preferences and advocating new approaches.

There were statements from the traditional healers that implied an underlying mistrust between them and the medical professionals.

*'Mulago officials are not interested in working with the traditional practitioners because they have the mentality that the practitioners cheat their patients'*

- Traditional healer, Kampala, Uganda.



*'Traditional healer in his herbal storage hut.'*

It appears as though in some communities, traditional care is becoming almost taboo and some respondents even reported having to visit traditional healers in secret.

*'People go to health centers because it is what is advocated for nowadays, you see babies being washed with soap instead of 'kyogero' (a local herbal bath) and going to a traditional healer is forbidden, so you just have to sneak as if you are doing something so evil; so we don't go there openly..'*

- Male community member, Masaka, Uganda

*'Very few go to traditional healers and those that do go in secret...'*

- Community Leader, Mbale, Uganda

There are many reasons for choosing to seek traditional care, and our study did not delve deeply into this area. However, as we will hear later in this report, there are certainly emotional, spiritual and cultural benefits to traditional care. Traditional healers live amongst their communities and seem to have a solid understanding of their people; their strengths and challenges. Many healers reported treating patients even though they were not paid, and/or working out systems of manageable installments to ease the burden on their patients. It was clear that for the most part, these traditional healers care deeply about the well-being of their communities and biomedicine likely has much to learn from their social-emotional approach.

**Self treating; drugs and herbs:** A substantial number of respondents reported self-treating as their first line of resort when faced with an illness. Treatment was availed through visiting the local drug shops or making use of traditional knowledge of herbs. We frequently heard that the decision to use drugs or herbs was based on the perceived seriousness of the issue i.e. for illness that was either in early stages, or appeared to be minor in severity. However, this treatment often represented the first stage of a pattern of resort that would escalate as the patient presented with more symptoms, or if their health did not improve.

*'In this community people are 'self-styled' doctors whereby when they fall sick, they seek their own treatment from drug shops. They are taken to hospital when they are seriously sick...'*

-Community leader, Masaka, Uganda.

*'Okay, you will first go and buy tablets from the drug shop, but if the situation worsens, you take him or her there fast (health centers). If the situation is worse and they can't treat him/her, they refer us (to the main hospital)...'*

- Female community member, Iganga, Uganda

*'We have our herbs which are known; and what we know we know even though you are not a traditional healer. But a person knows that if I drink these herbs when I am suffering from this, I can be ok...'*

- Male community member, Iganga, Uganda.

Unfortunately, we also heard of patients choosing to use herbs as a first line of resort because of lack money to seek care. Herbs are readily available and either free or low cost whereas medical care or drugs usually involved cost either in themselves or for the transportation to reach the place where care was available.

*'If they don't have money to treat children, they take herbs or go to traditional...'*

- Male community member, Ntungamo, Uganda

*'If a child fell sick, you would first of all use some herbs for drinking and bathing, but if things fail, that is when you will continue to the health center. Sometimes you may not have money to go to the hospital, so that takes you to: 'let me first try while looking for a plan of getting money to reach the hospital'...'*

- Female community member, Iganga, Uganda

*'Some use herbs, especially those who do not have money or who can not afford buying drugs from the drug shops...'*

- Community Leader, Tororo, Uganda.

**Medical pluralism:** Medical pluralism is indeed a reality in Uganda. People are seeking out both biomedical and traditional care, sometimes sequentially, sometimes concurrently, in order to meet their health needs. Undeniably, our study confirmed that many Ugandan respondents did not consider these treatment options to be mutually exclusive.

*'Some go to both the traditional and the biomedical for treatment...'*

-Community Leader, Iganga, Uganda.

*'The ones who use traditional, use both hospital and traditional at the same time...'*

-Community Leader, Tororo, Uganda.

The behaviour of using different forms of care sequentially sometimes represented an impatience or failure with one method, and a subsequent pattern of resorting to alternatives to solve a health issue.

*'They first go to health facilities and in case they fail, some few resort to traditional healers...'*

- Community Leader, Mbale, Uganda.

*'Some start with Kisoko sub-dispensary, if serious, then to Nagongera and if this fails, then to Tororo town, and if Tororo fails, then to Mbale...'*

- Male community member, Tororo, Uganda.

*'I can go and uproot herbs and I bathe them (patient) and they improve. In case they do not improve, I say to my friend, let me take you to the hospital where there are trained doctors...'*

- Female community member, Iganga, Uganda

Illness is a condition that requires remedy, and people will seek out this remedy in a number of ways. Illness represents a change from a condition of health to one of sickness. However, the same treatment-seeking behaviour does not always apply to disability, and while there are similarities, there are also notable differences. Disability is a condition which may not be perceived with the same urgency and additionally, it has many more meanings and judgments attached. Therefore, we now shift our attention to treatment-seeking behaviour for disability and specifically to the congenital disability of clubfoot....

### **Treatment-seeking behaviour when a child is born with clubfoot and the factors that influence this behaviour:**

We were interested in determining a pattern or resort and delay when a child is born with clubfoot in Uganda. We spoke with caregivers of children with clubfoot, adults with clubfoot and practitioners treating clubfoot to determine what was typically done when a child was born with this condition. We also asked other community members and community leaders what should be done if a child in their family or community was born with such a condition.

The process of sorting and separating the factors which influenced treatment-seeking behaviour proved more difficult than first anticipated. In reality, human behaviour is complex and these factors are inter-twined and many times inextricable from each other. However, for the sake of clarity and presentation we present the following themes representing the factors influencing treatment-seeking behaviour, and we ask the readers to be conscious of the inter-connectedness of the issues.

There appeared to be a number of factors which influenced treatment-seeking behaviour. The major themes or influences which emerged have been categorized as: level of awareness, beliefs, location of birth and access to transportation, access to finances, social influences, challenges with the treatment process, and responsibilities at home. In addition, we discovered positive influencing factors and have outlined these as important approaches for healthcare planners.

**Level of Awareness:** People's treatment-seeking behaviour is influenced by their level of awareness. They must firstly be aware that the condition is problematic i.e. recognition of the condition as atypical. Secondly, in order to pursue treatment they must be aware that correction is an option. Our discussions with parents would suggest that there was rarely an issue with a lack of recognition of the condition. The majority of parents recognized that their child had clubfoot at the time of birth or shortly thereafter. It is a parent's instinct to investigate the health and status of a newborn. Out of our forty case studies; only four did not recognize the condition or have it pointed out to them within the first 3 days of life. With these four who did not recognize initially, they all became aware within the first month of life.

However, even with this recognition, there were times when people did not seek treatment because they were simply not aware that it was available. Their behaviour did not stem from a lack of willingness to treat the child, but merely a lack of awareness about the treatment itself.

*'No, they cannot be treated because me, I have a child like that and they can't do anything...'*

- Female community member, Kampala, Uganda.

*'We were ignorant about the treatment and so we could not do anything. By the time they advised us to go to Katalamwa (rehabilitation centre), there was no money...'*

- Caregiver of a child with neglected clubfoot, Iganga, Uganda

*'They should go after they have been told where to go because if they don't know, they may sit back saying that God gave me this child and I have nothing to do, yet they would have done something...'*

- Female community member, Masaka, Uganda.

There appeared to be some consistent factors which related to the level of awareness of treatment in a region. The first of these was proximity to health facility.

Practitioners told us that people living close to hospital were more likely to be sensitized to treatment availability and seek-out treatment, than those living deep in the villages. Consistent with proximity to hospital, are other related factors; people who had awareness were felt to represent those living in urban areas and those who had more education. The bottom line with these factors is that proximity to health facility also often means proximity to resources and information as health centers are often located in developed areas.

*'Right now people are getting knowledge. They used to think there was nothing that could be done and they still believe this deep in the village. But people closer to the hospital know...'*

- Practitioner treating clubfoot, Mbale, Uganda.

Another probable factor influencing level of awareness was suggested by a community-based rehabilitation practitioner who insightfully noted that rehabilitation care is a relatively new phenomenon in Uganda. Consequently, people had not grown up with this type of care, did not have awareness of its potential until recently, and accordingly did not seek it for disability. Instead, out of a lack of awareness, they sought the care of traditional practitioners, or did nothing. Taking this perspective, we see the origins of behaviour in what previously was a void of care for this population of people with disabilities.

*'If they have a disability they seek traditional care, because in the past rehabilitation health care was not given a priority. People have grown up not knowing about rehab healthcare and what is available...'*

- Practitioner treating clubfoot, Tororo, Uganda.

*'Once it happens in a place where there is someone with information, they are advised to come to the hospital. In case there is no one who knows about this condition, nothing is done to the child with this condition until the Community Based Rehabilitation identifies them. Sometimes, CBR identifies such children and parents refuse to turn up, but the numbers of those who refuse to turn up are small compared to those who turn up'*

- Practitioner treating clubfoot, Tororo, Uganda.

Awareness about rehabilitation is only now spreading as people are being exposed and sensitized. For those living more remotely who have less access to information in general, their link to knowledge about treatment often comes from health workers conducting outreach in remote areas. This method of knowledge transfer seems particularly effective for those living remotely and should be looked at closely by USCCP. We heard many times from both practitioners and caregivers that children were found and informed of treatment only when they were sought out by community based rehabilitation teams and outreach workers. Their lack of awareness was easily remedied by information...

*'Children born outside of the hospital are sometimes found through the outreach teams who are out scouting for patients in the villages. These patients are then advised to go for treatment, or are assisted to go. These children are usually older and may require surgery...'*

-Practitioner treating clubfoot, Masaka, Uganda.

*'We noticed the very day she gave birth at home, but didn't know what to do at that time until after 4 months when one of the Community Based Rehabilitation practitioners from Butiru visited in the neighborhood and I*

*was told of the existence of such a cure. When he came and visited us, he told us what to do and where to go, so we went after one week'*

-Father of a child with neglected clubfoot, Mbale, Uganda.

*'In rural communities, hospital is not the first priority, it is traditional care. Then, mostly it is our staff who has located them in the villages. Most of the children identified and treated have been found by the outreach teams...'*

- Practitioner treating clubfoot, Tororo, Uganda

However, access to information was also influenced by the level of awareness of practitioners present at the time of birth. Regardless of whether the practitioners were traditional birth attendants, midwives or nurses, if they were sensitized to this condition, then the information reached the parents. If they were unaware, then even if the child was born in a facility, they could be missed and sent home.

*'For mothers who deliver from a TBA, these practitioners think that it is not treatable thinking that it's a curse and are not aware of the services...'*

-Practitioner treating clubfoot, Mbarara, Uganda.

*'Even in hospitals sometimes they don't advise patients where to go. They aren't detecting...'*

-Practitioner treating clubfoot, Tororo, Uganda.

*'Give information to midwives and TBAs because some babies are still delivered and sent home. They are the first people to see the baby.'*

-Practitioner treating clubfoot, Mbale, Uganda

There is reason to be hopeful that the level of awareness about clubfoot treatment is increasing. Several practitioners expressed that the level of sensitization was mounting and that they felt there were now more people aware that treatment was available. This theme was confirmed by community leaders and general community members, the majority of who responded positively when asked if treatment was available.

*'Yes, it can be treated. There is a boy in my village that was born like that but was taken to Mulago and corrected. He now puts on his shoes well and is in senior one. The traditional healers had tried to treat the boy, but all in vain until he was taken to Mulago for a surgical operation'*

- Community leader, Tororo, Uganda.

*'We have children in our area who were taken to Mbale Hospital with similar problems, and are now fine...'*

- Female community member, Tororo, Uganda.

*'The feet can be corrected, but it also depends on the responsibility that the mother takes, e.g. If you take the child at 3 months and plaster is put, plus the braces, then the child may heal...'*

- Female community member, Masaka, Uganda.

We should also be encouraged by the level of willingness and positive response from respondents. When we asked community members and interviewees whether children with this condition should be treated, we got a resounding yes. The majority of respondents felt that if parents were aware of treatment, they would want to treat children and should be encouraged to do so.

*'Parents care so much about their children, so if there is any remedy, they would want to use that. If they do not do it, it is because they are not aware of treatment or because they do not trust'*

- Traditional healer, Masaka, Uganda

*'Yes, caregivers should be encouraged to seek treatment because it can be corrected and a child will live a normal life'*

- Community Leader, Mukono, Uganda

While conducting this research, we found people to be very receptive and accepting of the information we provided about clubfoot treatment, even though to some, it was completely new information. They were eager to increase their level of awareness, and in our community discussions, we often heard sentiments of gratitude for bringing information to the village so that it could be put into practice and passed on to others.

*'It has given us hope and strength because I never knew that such people are out there, we can now deliver the information to other people who have not been here...'*

-Community member, Ntungamo, Uganda.

**Beliefs:** People will seek out treatment based on their beliefs. Although belief rarely appeared to be the sole factor involved in treatment-seeking, and although people's behaviour is not always congruent with their beliefs, this theme did emerge consistently enough to be considered very significant.

*'Irrespective of whether they produced in the hospital or village, where they go and when depends on their beliefs...'*

- Practitioner treating clubfoot, Iganga, Uganda

Practitioners reported that those living in the rural villages were more likely to believe in and seek traditional care than those living in urban areas.

*'For disability, it depends on the parent and the location. For the ones born in the village, 80% either do nothing or go to the traditional. 20% go to hospital/health center. But, in town, it is the reverse.'*

- Practitioner treating clubfoot, Tororo, Uganda

With all categories of respondents, some reported the belief that there was a higher power involved in causing clubfoot i.e. spirits, curses, witchcraft, small gods. It would then follow that if a higher power caused the condition, traditional healers, as the experts in such matters, would be sought for treatment. This behaviour was reported consistently among respondents.

*'My child was born with this deformity, I was advised to go to a traditional healer, I went there and I offered sacrifices to the spirits, and they told us that the child will be well. Three to four months passed and surely the child's situation improved and now the child is fine. So if I see a case, I take that person to that healer of mine, he is a good man. He asks for some money...'*

-Father of a child with clubfoot, Masaka, Uganda

Sometimes people believe that the disability is just who the child is; just what God or another higher power has made him or her. In these cases, it may be considered a condition that cannot, or even should not, be altered by man i.e. correction would be a challenge of the spirits. Similarly, some felt it was inherited, or passed down through the clan lineage. Because these people had experience and/or memory of relatives living with neglected clubfoot, they believed it could not or should not be treated.

*'We saw this condition at birth and I thought that the child does not cure with this condition, but I have just realized of late that there is treatment. I asked community people and they told me that they can make the feet get well in the hospital, but I was comfortable with this because there are very many lame children in the village and I wouldn't break what God had made'*

-Parent of 8 year old child with neglected clubfoot, Mbale, Uganda

*'Some rush to health centers and some families hide them. There is one person who refused to take the child for treatment and its now 10 years old. The reason was that the grandparent had such feet, and the child does not cry and is able to walk, so they don't see any reason why they should waste time and money.'*

-Practitioner treating clubfoot, Mbale, Uganda

Sometimes it is merely a lack of awareness that presents as a belief that the condition cannot be treated. However, when this is the case, the belief may be easily altered when information is provided to suggest the contrary.

*'Some are neglected; they are not brought because parents don't have the knowledge about treatment. Many families have never tried to treat because someone is born with it and that is just the way it is, even traditional healers don't try usually'*

-Practitioner treating clubfoot, Mbale, Uganda

*'Based on many persons we have seen, such a leg cannot be corrected. It still remains in that position because most of them do not have the ankle, it has disappeared in flesh and even the ligaments are weak and bent...'*

-Male community member, Mbale, Uganda.

In general, we found belief systems were not rigid determinants of treating seeking and belief systems were often dynamic and open. People were flexible enough to seeking alternatives when one method of treatment failed, or if they perceived that healing was not occurring fast enough. Although generally this pattern of resort seemed to start with traditional care and move to biomedical, the reverse pattern was also noted and at times multiple methods were tried concurrently. It is important to mention that some of our case studies reported high levels of satisfaction with traditional healing after feeling they had been failed by the medical system.

*'Traditionally, people think that there are unappeased spirits causing the problem. Therefore, caretakers usually take their children to traditional healers for correction before they come to hospitals...'*

-Practitioner treating clubfoot, Mbarara, Uganda.

*'In Mukono they believe so much in traditional treatment. We can't tell if a person is using traditional treatment and our treatment, but this is more likely to take place. For instance, sometimes we put on the POP and they remove them and take them to traditional healers claiming that the child removed it...'*

-Practitioner treating clubfoot, Mukono, Uganda

*'80% of treatment is successful. The main reason for failing is defaulting. Defaulting occurs due to cultural beliefs; they may seek traditional healers and waste time. Then they come back. Also, money is definitely problematic in the rural area; they do not have the money for buying the plasters and splints...'*

-Practitioner treating clubfoot, Mbale, Uganda

There were however also parents who did not believe that the clubfoot was problematic and consequently did not feel there was urgency to treat. We have termed this belief: neglect due to acceptance. In reality, clubfoot although debilitating for an older child and adult, is not a life-threatening condition. A baby with clubfoot is not in pain and is able to continue with all of the tasks of daily living that babies do: sleeping, eating....

*'Sometimes the parents didn't look at it as something urgent, they just get concerned when the child reaches walking age and are having difficulty..'*

- Practitioner treating clubfoot, Tororo, Uganda

*'Most people don't take it seriously and some parents are not committed since it is not painful and it does not stop a child from doing what other children could do...'*

- Traditional healer, Mukono, Uganda.

*'I have not experienced anything negative because this condition existed in my family before and since it does not pain, I have never bothered to worry about it...'*

- Parent of a 13 year old child with neglected clubfoot, Uganda

There were other beliefs that were less frequently mentioned by respondents, but which also influenced treatment-seeking. For instance, some parents did not seek treatment because they feared that correction would require surgery. Some neglect to treat due to the belief that treatment must be done when the child is older. We heard beliefs regarding clubfoot as a sign of twins to come in the family. Some practitioners also reported knowing of beliefs that the clubfoot was prestigious, or good:

*'Traditionally, where people take it as an identity and a treasure for the family, it is hard for them to seek treatment'*

-Practitioner, Mbarara, Uganda

*'I think the family should just welcome the blessing. Culturally this is believed to be from the gods...'*

- Male Community member, Kampala, Uganda.

**Location of birth, access to transportation, and distance to health facilities:**

The location of birth was a factor in determining what treatment was sought to treat clubfoot.

*'50% seeks biomedical care and 50% seeks traditional. In town, in urban areas, people go to hospital, but in rural areas far from town, they go to bone setter and traditional healers (10-15% of bone setters may actually be effective)...'*

-Practitioner treating clubfoot, Mbale, Uganda.

Practitioners report that when women gave birth in hospital, they were likely to be identified and treated early. Generally, these women are those living in urban areas or close to health facilities. Those living more remotely were more likely to give birth in the villages. When born at a distance, there was less access to biomedical care, therefore less chance of caregivers being sensitized, being identified and seeking biomedical care. It was more common for those living remotely to either do nothing, seek traditional care, or even try to treat the child themselves at home.

- *'I started moving the leg and using 'perfume' (i.e. Vaseline). I thought of using the perfume myself, nobody told me. I have seen no change, but I am still applying. I cannot manage to get the leg to come straight. I have asked other mothers who have had such a kid. They told me to go to the hospital. Tororo hospital told me to go to Mbale for treatment but we can't manage the transport money. Treatment is free and we could manage the time away.'*  
- Grandmother of a 2 month old child with clubfoot, Tororo, Uganda.

Remote location of birth can mean transportation and travel distance do in themselves become factors determining treatment-seeking. For those living deep in the villages, transportation can be scarce and expensive, perhaps even unattainable. Longer distances mean that the expense increases further, not to mention time away from home responsibilities.



*Remote rural dwellings, Uganda*

*'The health units are very far, so they involve high transport costs....'*

- Traditional healer, Iganga, Uganda.

*'When the child was 5 years old, I took him to Busumbu, the practitioners from Busumbu told me to take him to Kumi, but there was no transport (no money). I got my child from Busumbu and took him home...'*

- Parent of child with neglected clubfoot, Mbale, Uganda

Nevertheless, distance did not universally mean a lack of access to sensitization or assistance. When children with clubfoot lived in the catchment areas of outreach teams or when traditional birth attendants and midwives in the villages had been sensitized, children were being referred to hospital. This illustrates once again that treatment-seeking behaviour is not always solely an issue of the distance, but a reflection that distance from the hospital means less access to resources and information.

*'We see children as early as possible. Children 1-2 days after birth make up about 60% of the patients. Those that come from 5 months to 1 year are about 5%. 35% come late, they are neglected. Why? Because the awareness is not there, they are too far away from health unit, they don't have access to health advice, or transport to the health unit. The neglected ones are found through outreach by health workers or the charitable groups for the disabled that go to the communities.'*

- Practitioner treating clubfoot, Mbale, Uganda.

*'Kids born in villages take long to be brought to hospital due to ignorance, transport costs and hospital fees. These children may come seeking treatment at 3 months old and onwards.'*

- Practitioner treating clubfoot, Masaka, Uganda.

### **Poverty and access to finances:**

Poverty is one of the major factors influencing treatment-seeking behaviour. It is all pervasive and has huge implications for both health and health-seeking behaviour.

*'If treatment is a lot of money, you find that a person would have loved to do something, but due to money, this person withdraws...'*

- Female community member, Mukono, Uganda

The following is an excerpt from the diary of one of the researchers, describing the poverty in a 2 month old case study's home and how it impacted their ability to seek care...



*2 month old child with neglected clubfoot lies on the ground beside a smoking distillery.*

*Money for transport is an insurmountable barrier for them and looking around, it is not hard to see why. They live a 30 minute walk from the nearest road where transport is even an option. They live amongst their crops in a small cluster of mud huts and straw roofs... There are 2 naked toddlers near the distillery. One of them is miserable; he has a big distended belly and*

*white patches on his head; I can't begin to imagine what those are... The child with clubfoot lies motionless under the tree right beside a smoking distillery. You can't actually tell it's a child, it is just a bundle of rags, but when we start talking about the child with clubfoot, the mother points to the bundle and I see it stir. Even later, it squawks and the mother goes over to feed. As the grandmother speaks with us, a small child whimpers and climbs onto her lap to breastfeed. The grandmother looks younger than the mother, but she seems resigned and tired. She tells us about how her only source of money is her small distilling business. With this she pays all of the household expenses, including food. She is the*

*primary caregiver for all of these children (there are 10 plus this new unexpected grandchild with clubfoot). The husband was a mechanic, but he stopped working and now he just goes out to do a bit of 'digging' and sometimes he tends to the animals. In the evenings he goes out to get drunk.... She wants to go to Mbale, and she wants to treat the child, she does not want him to be 'lame'. She says that money is the only thing keeping her from going to treatment...*

-excerpt from the journal of the researcher, case study, Tororo, Uganda

The majority of practitioners, both biomedical and traditional, report that if money is charged, it is difficult for most people to pay. This is of course not universal. Uganda, like all countries has its share of wealthy; but they are few, and stand in sharp contrast to the majority of the populace. For the few with money, private paying clinics are an option.

*'Generally at clinic there is no charge. For private consultations, 5000 shillings then 3000 each visit and 60000-100000 for surgery...'*

- Practitioner treating clubfoot, Mbale, Uganda.

But the majority of caregivers are those who struggle under hardship to meet the costs of treatment and transport. Uganda's per capita income is rising, however, the gains have not been distributed evenly and it is estimated that almost half of the country's populace are living in absolute poverty ([www.unicef.org](http://www.unicef.org)). If by will and effort these people do borrow, save or somehow obtain money for regular transportation and treatment, it can mean that the rest of the family does not get some of their needs met (not that they always get them met even without this additional burden). Sometimes other children cannot attend school because school fees can not be met in addition to treatment costs. The financial constraint of most families leads them to a grim situation where they must prioritize. The repercussions of their decision to seek treatment can be far-reaching and ultimately some just cannot treat the child. The most impoverished, the most disempowered sometimes just don't manage. When there are not sufficient resources to meet the very basic needs for life, treatment for a disability can be an unmanageable extra.

*'People in this area are very poor. If money was charged, most parents would not be able to afford the fees and this would hinder them from bringing their children for treatment'*

- Practitioner treating clubfoot, Ntungamo, Uganda.

*'Money could be a problem, and so they end up leaving children to grow up with that condition and become lame...'*

- Traditional healer, Mbale, Uganda



*Overpopulated area of urban poor, Kampala, Uganda.*

*'The fees were managed under hardship. I had to sell a few goats and the money for school fees had to be used on this case.'*

- Parent of child with clubfoot, Ntungamo, Uganda

**Challenges with the process of treatment:** From all categories of respondents, we heard of people who found the process of treatment challenging, frightening or uncomfortable, and these factors influenced their decisions to seek treatment. For instance, when people in communities hear of corruption or poor treatment by health workers, it can make them reluctant and distrustful of seeking medical care and may lead them to avoid health care facilities, or seek out traditional practitioners.

*‘Some parents have a bias as a result of past negative experience with health workers, so may not want to go to health center. There is corruption among some health workers, so it scares off clients due to charges/costs’.*

- Traditional healer, Mbale, Uganda



*Child with bilateral casts*

There were also some parents whose treatment-seeking behaviour was influenced by their misconceptions and fears about medical care, and/or by the specific techniques involved in Ponseti treatment or surgery. For instance, we heard several reports of feelings that the casts or braces were shameful. People told us of fear that the child’s legs would be broken during treatment. As well, we repeatedly heard of apprehension towards surgery and even fear that the child would die in surgery...

*‘They fear surgery; this is a big fear. Also they fear admission to the hospital because they know they may have to travel and stay for a long period and this is costly. And once there in hospitals, they worry about their husbands, children, harvests. So, sometimes the parents escape and they go back to the village and they leave the child there with a relative or friend’.*

- Practitioner treating clubfoot, Tororo, Uganda

**The social influence on treatment-seeking:** When in a challenging situation, people tend to seek the counsel of their friends, family and community. Treatment-seeking behaviour, like all human behaviour, is easily prejudiced by the social influence. Sometimes the social influences are positive and parents are encouraged to pursue and persist with treatment because of the strength and support they receive from others.

*People in the community were sympathizing with us and encouraging that the condition can be dealt with and will be okay...’*

- Father of child with clubfoot, Mukono, Uganda.

Conversely, there can be negative results from social pressure, where parents are advised not to treat, or to seek out alternative forms of treatment which may not be beneficial to the child. One community leader told us that he would not refer a child in the community for treatment because the treatment had been unsuccessful and the family had been victims of corruption.

*'If a family had this condition, we tell them nothing because it fails if you go for treatment...'*

- Community Leader, Kampala, Uganda

*'Friends encouraged me to go for treatment since the majority are educated. In the village, the majority said I should take the child to a traditional bonesetter, but I did not because I had started Plaster of Paris and had seen improvement. I have been coming around 8 times. I would have gone to a bonesetter too, but since I had been counseled by the doctor and started treatment, I did not go to a traditional healer, but I was so desperate...'*

- Parent of child with clubfoot, Mbarara, Uganda.

*'My parents (Kenyan) wanted to go and treat the child but the father's parents refused due to fear to let us go to Kenya. They blamed the disability on me since I am also lame, even though mine was as a result of polio...'*

- Mother of a child with neglected clubfoot, Mbale, Uganda.

We heard many stories of women who hid their children, because they feared stigma and felt shame. This put great strain on mothers, but sometimes it unintentionally had the positive result of motivating them to pursue and persevere with treatment. However, we also heard repeatedly that women were blamed for the clubfoot and suffered personal shame or rejection because their child had a disability. The experience of having a child with clubfoot could be a very painful one for many women.

*'If the clubfoot is severe, they want the deformity to be cleared due to fear of segregation...'*

- Practitioner treating clubfoot, Mukono, Uganda

*'The child is still young and I am always inside the gate with him, and the few who can see (from community) laugh at me and I used to deceive them that the child got a fracture...'*

- Mother of child with clubfoot, Tororo, Uganda.

*'I have been blamed by my husband's relatives for being the cause of the child's condition. When the condition happened, none of us two parents knew what to do, but later we were told about what to do. But due to poverty, the child was never taken for treatment. Over time, the father of the child died and as the mother of the child I was left alone amidst cruel relatives who did not bother to help...'*

- Mother of child with neglected clubfoot, Mbale, Uganda.

At times, children did not receive treatment because support from relatives was lacking. This lack of support was most often from fathers, but occasionally opposition was received from other family members such as co-wives, mothers-in-law, etc

*'There is no support for mothers from fathers, so no support for a disabled child. The disabled child is considered last since the mother has to care for the rest. Sometimes, they live very far away and they must walk very far because they can't afford transport...'*

- Practitioner treating clubfoot, Mbale, Uganda.

*'My mother in law was against biomedical treatment. Instead she was advising that the leg be massaged with warm water...'*

- Mother of child with clubfoot, Mbale, Uganda.

On occasion there was a lack or delay in treatment-seeking due to the fact that children had been abandoned by parents and left to be cared for by others i.e. grandparents, aunties, etc. In other cases, parents had passed away, once again, leaving children behind.

*'I was just straining to get the money. I would sell until I gathered the money required. The child has no parents...'*

- Grandmother of child with clubfoot, Mukono, Uganda.

*'When my aunty noticed, she took me for an operation at Mulago. I was 10 years old then. I was operated on one time, but I never went back. I went so late because there were no caretakers to take me before this time....'*

- Adult woman with clubfoot, both parents died when she was young, Kampala, Uganda

*'Now that the child was abandoned by the mother, it is now the sole responsibility of me, the father to care for her every need...'*

- Father of a child with neglected clubfoot, Mbale, Uganda.



*Adult with neglected clubfoot standing with a research assistant, Kampala, Uganda*

### **Responsibilities at home:**

The woman is generally responsible for childcare, all household tasks and in the rural areas, also for cultivation. With all of these pressing responsibilities, taking the time to care for one child can be very taxing, and it is always a balance. This is yet another example of the complex prioritization process caregivers must work through. For all caregivers, mothers or otherwise, taking a day away from work to bring the child to treatment has implications both at home and the workplace. When living a subsistence life, some implications are more severe than others, but almost always they present some level of hardship and they will influence treatment-seeking behaviour.

*'In most cases, they enquire about the timing- how long will it take? Because most are housewives and all the housework is done by the same woman. If she stays away from home, it will be difficult for the man to continue running the home i.e. childcare, gardening, housework...'*

- Practitioner treating clubfoot, Tororo, Uganda.



*Busy and curious Ugandan children*

Women are the primary caregivers for children, and in Uganda, there are many children. Fertility rates are generally high with a total fertility rate of 7.1 births per woman (<http://hdr.undp.org>). Our case study respondents reported an average of 7.4 people living in the household with a maximum number of 26 people in one house. These figures indicate that, especially in rural areas, one woman is often responsible for large numbers of people. Not only does she have responsibility

for the child with clubfoot, but she is also responsible for the other children who she must leave behind in the home if she seeks treatment. In addition, the woman is also often considered the primary caregiver for her husband and perhaps other family members as well. This places a tremendous burden of responsibility on a woman, which can certainly influence treatment-seeking behaviour.

*'Sometimes the woman has many children so she cannot leave all the other children. She waits until they (the child with clubfoot and others) are older, and then brings the child and by then the child requires surgery...'*

- Practitioner treating clubfoot, Mbale, Uganda

*'Lack of child spacing leads to more responsibilities so parent's attention is divided and they are not willing to go to the hospital...'*

- Traditional healer, Iganga, Uganda

### **Positive factors influencing treatment-seeking behaviour:**

In outlining the results of this objective, we have been discussing many of the factors which make treatment-seeking challenging. However, it is also essential to review the factors which promote treatment-seeking behaviour, because it is these factors which represent the way forward.

The first theme noted which acts as a positive influence in treatment-seeking behaviour is once again, the social influence, but more specifically, gaining comfort from others. Mothers, who have given birth to children with clubfoot, have many fears about their children's future. In Uganda, the life of a person with a disability, while perhaps getting slightly better in recent years, remains extremely challenging and very limited. They face many barriers in their lives: social, emotional, physical, institutional....



*Rehabilitation center for children with disabilities, Masaka, Uganda.*

*'Most disabled children have been hidden in the houses and not allowed to play with other children or attend school. They are usually dirty, and little care is taken about them. A few educated families can take such a child to school, but many poor families do not unless there is a helper. Recently families are beginning to care for the disabled because of the education or community talks done through outreaches...'*

- Practitioner working with people with disabilities, Masaka, Uganda

*'I have an example of a disabled child who is loved, they do everything for him, and he also goes to school, he does not work because he can't manage. But in other families, the lame are neglected and abandoned and as a result they resort to the streets. They don't go to school because they are lame...'*

- Practitioner treating clubfoot, Mukono, Uganda

*'With disabilities, it is funny...disabled children tend to stay back at home, they are not forced to go to school like normal ones; it is optional. Disabled children's lives are miserable. Their parents don't understand, they are unwilling to help them, they think they are unfortunate and only a few are helped...'*

- Practitioner treating clubfoot, Mukono, Uganda.

These are the words of practitioners who devote themselves to improving the lives of children with disabilities. Although we hear hope in their sentiments, as they know from experience, they cannot paint an image of a positive life experience for a person with a disability. Now imagine the feelings of a mother who gives birth to a child who is 'lame'. Her only experience of people with disabilities may have been seeing them living out on the streets, or hearing rumors of a community member who hid a 'lame' child out of shame. So when a parent gives birth to a child who is 'lame', it conjures many fears. They have visions of their children not being productive in their societies and becoming burdens. They fear their children will not attend school, will not get jobs and that the girls will not be marriable. They fear that their children will be stigmatized and segregated from their society.... However, when they meet a community based outreach worker, or a midwife or a health practitioner who tells them that their child will be healed, they are comforted.

*'After the delivery, the nurse broke the news to us (parents) that the child had clubfoot. The moment was confusing and painful. However, we were strengthened by the midwife when she expressed that there was treatment available. Formal procedures were finalized and we returned home. Then after one week, we went to the clubfoot clinic and accessed treatment...'*

Parent of child with clubfoot, Mukono, Uganda

*'I felt ashamed to have such a child because people in the community would laugh at me and I used to hide the baby. These days, I can even tell people about the treatment, even on the bus when I am going for treatment. I used to be psychologically tortured, but now I am not tortured because practitioners keep on promising that the child will be ok. I used to feel bad and angry, and used to think of abortion before giving birth...'*

- Parent of a child with clubfoot, Tororo, Uganda

*'I felt so bad after noticing the problem. I felt worse looking at other kids that are very normal. I doubted that my child would ever walk properly but then I got consolation from the doctors...'*

- Parent of a child with clubfoot, Kampala, Uganda

Finally, when caregivers are treated well and receive good result, they are likely to spread the word to others. Hearing positive reports encourages caregivers not only to seek out the treatment for a child with clubfoot, but can encourage biomedical care for other health issues.

*'Cases (patients) should be serviced well at the clinic so that they pass the good news onto others....'*

- Practitioner treating clubfoot, Kampala, Uganda.

*'My child is going to be a model for the whole community, and I will always encourage people to bring their children for fixing...'*

- Parent of child with clubfoot, Masaka, Uganda.

This positive effect of spreading the word was already visibly at work in communities. When we conducted our focus groups in communities where there was no child with clubfoot, a significant number of people had heard of treatment, even if they could not remember the exact details. In addition, although the majority of our community leaders cited examples of people they knew with neglected clubfoot, many were now aware that there was treatment.

*'Yes, when these feet are taken to health practitioners in a hospital, they can be treated. There was an example of a family who had a child with the same problems, but was taken to the hospital and manipulations were done, and he got healed...'*

- Community Leader, Masaka, Uganda.

*'That foot can be treated according to the methods studied by doctors today. That foot can be corrected and one becomes ok....'*

- Female Community member, Iganga, Uganda

## **Conclusion:**

The goal of this objective was to outline the current treatment-seeking behaviour in Uganda, as well as the factors that influence. We have seen that people seek out multiple forms of care to deal with health concerns and have outlined both the negative and positive factors involved in the decision to seek care for a clubfoot. Our next section will look at the gender issues in Uganda and how this factor influences treatment decisions....

## **Objective V: Gender issues in Uganda and their impact on treatment-seeking behaviour.**

### **Introduction:**

The purpose of this objective is to outline the gender issues in Uganda and their impact on treatment-seeking. Prior to the start of this study, some clubfoot clinics in Uganda had noted that the ratio of boys to girls being treated was 5:1. This ratio is far higher than what would be expected given incidence rates reported in other parts of the world. Therefore, we were curious to know if there were in fact gender issues at play which led parents to seek treatment for boys rather than girls. Moreover, we were aware that proper understanding of gender issues is imperative for successful implementation of health programs. The status of women in a society greatly impacts health of the population in general, and specifically, the health of children.

### **Literature Review:**

Power differentials and the move to equality: According to UNICEF (2003), Uganda remains a predominantly paternalistic society in which boys are favored. In addition, polygamy continues to be practiced in approximately 30% of families in Uganda. Both of these cultural relational patterns can result in men having significant control and authority over the lives of women; often leading women to be marginalized in their societies. These power differentials between the genders also have direct bearing on children's health and nutritional status. Low status impacts women's ability to make autonomous decisions about their children's health and can limit access to food and money for seeking care (Engle et. al, 1996, Ssengooba, 2003). Lower priority placed on girls can mean they have less access to food, education, and health care treatment.

It has been suggested that inequality is the major inhibitor to health (Gilbert & Walker, 2002). Poor countries that have been successful in keeping their populations healthy tend to have prioritized a strong social sector and a relatively equal populace (Gilbert & Walker, 2002). In Uganda, social development has not been made a priority and yet there have been some noteworthy gains in the movement to gender equality: Women have established more of a presence in politics since the Museveni government came to power and there has been a reported proliferation of women's organizations since 1986 (Tripp, 2004). The country has had a female vice president and significant representation in government at both the parliament and local level politics. Women's organizations have gained a voice and have lobbied for policy and legislation changes around issues such as property rights, inheritance, rape, female circumcision, etc. (Tripp, 2004). These gains have not been forthcoming for the women who are currently fighting for their rights in Uganda. But their struggle puts a voice to the half of the population which is disempowered and often disregarded, and their accomplishments will have major implications both for their health and that of their children.

Maternal education and health: We now have a very good understanding of the positive link between maternal education and health (Caldwell, 1993). Women's education has also been positively correlated with both children's education and children's health (Deininger, K, 2003). In Uganda, like other countries throughout Africa, women have lower rates of educational attainment than men do. In fact,

male-headed households had an average of 83% more schooling than female-headed households (Appleton, 1996).

Nonetheless, in 1997, Uganda began a program of free universal primary education largely as a result of budget support through debt relief. The introduction of this program decreased the gender inequality in primary education, especially in the lower income groups, by increasing girls' access to schooling (Deininger, K, 2003). Encouragingly, the introduction of UPE also involved public campaigns promoting female education and speaking out against early marriage to keep girls in school (Watkins, 2000 in Deininger, 2003). As the authors note, this is a promising development for future generations and yet, challenges remain. The quality of education in the UPE system can be poor and even with no school fees, there remain the costs for books, uniforms etc. which may be prohibitive. Additionally, girls may be required to remain in the home as sources of labour or may be called upon to care for sick family members. Furthermore, education in Uganda is only free until primary seven and as UNICEF (2003) notes, there continues to be high drop out rates for adolescent girls. By the age of 15 to 19 years, approximately 38% of Ugandan girls are married, and by the age of 19 years, 71% of girls have become pregnant (Ssengooba et al, 2003). Even Uganda's Ministry of Health reports teen pregnancy rates as high as 43% of the population ([www.health.go.ug](http://www.health.go.ug)), yet policies do not favour new moms or pregnant girls attending school...

Women, education and productivity: Women in Uganda earn approximately 85% less than men do. Even in non-agricultural wage work, women are equalized at low pay as they are hired equally into low-skill work. Conversely, men are not equalized by wages and have the opportunity to engage in a variety of wage positions (Canagarajah, 2001).

A study by Smith et. al. (2002) revealed that women in Uganda continue to be primarily involved in agriculture-based occupations although there are the beginnings of some expansion into other livelihoods. In Uganda, education has been found to be an important factor for increasing engagement in non-agricultural work and subsequently increasing income. Primary education is estimated to result in a 32 % increase in income and higher education results in approximately 77% increase (Canagarajah, 2001).

An additional boost for women's productivity has come as a result of the increase in women-headed households in Uganda. Culture is flexible and culturally determined roles can change, especially when there is the need for money in order to provide for the family. The country's broader issues: war, AIDS and economic difficulty have been the catalysts for some of this shift in female roles (Appleton, 1996). However, taking up the role of female household head has a positive effect on promoting women's engagement in non-agricultural activity and this is leading to decreases in poverty (Canagarajah, 2001). Women are showing increases in self-employment, which is providing more opportunity for personal economic growth; perhaps reflecting the greater amount of autonomy and variety available to women in this situation (Canagarajah, 2001, Appleton, 1996). Studies have demonstrated that these households when assessed overall by income and consumption are not poorer than male-headed households (Appleton, 1996).

*'...sometimes educated ladies who earn a living plan for their families by paying school fees, buying food for the family, etc...'*  
- Female community leader, Kampala, Uganda

Discrimination and the rights of women: A study by Lwanga-Ntale (2002) demonstrated that in some parts of Uganda if a child is born with a disability, not only does the primary caregiver role fall to the woman, but some in the community may believe that she is to blame for bringing a curse to the family. This can be used as a reason for men to leave their wives, or for general rejection of the women. As we have discussed, a woman's livelihood in a patriarchal society is frequently linked with her spouse. When a woman is abandoned, abused or rejected, it can have devastating effects. Human Rights Watch (2003) reports that domestic violence laws have not been enacted in Uganda and spousal rape has not been deemed a crime ([www.hrw.org](http://www.hrw.org)). Women continue to face marriage and property laws that are discriminatory and that keep them in abusive relationships because they have no alternatives ([www.hrw.org](http://www.hrw.org)). Laws and policies continue to allow women to be victimized with no recourse.

Girls with disabilities: Girls with disabilities in Uganda were often over-protected and disempowered due to societal views, which saw them as 'unfortunate' (Lwanga-Ntale, 2002). Furthermore, when girls had a disability, they were felt to be unable to fulfill their marital roles of child bearing, care giving, cultivating, etc and were consequently not *marriageable*. As marriage is linked closely to livelihood for women in Uganda, a disability often led to a lack of access to resources and a devaluing of girls with disability...

*'Women seem to place more emphasis on their girls because of beauty. A woman who is disabled may not be able to marry, whereas a man can marry as long as he has money...'*  
- Traditional healer, Masaka, Uganda

## **Review of findings:**

As we may surmise from all of these issues, it is important to develop an understanding of gender roles when looking at program implementation. There are numerous studies that have demonstrated that failure to do so, results in failure of programs (Stone, 1992). Therefore, we will begin this review of findings by exploring general gender issues in Uganda as discovered in this study, and will conclude with a discussion of how they impact treatment-seeking behaviour when a child has clubfoot. It is important for the reader to keep in mind when reviewing this objective, that there is generally always a range of responses within each theme discussed. We have sought to present a balanced picture, but also to emphasize themes that emerged more commonly or which were especially poignant.

## **The meaning of gender in Uganda**

The ideological shift towards equality: The descriptions of Uganda as predominantly patriarchal with the role of women primarily defined as mother or homemaker continue to be evident and accurate in Uganda. Nevertheless, Uganda appears to be in the midst of an ideological shift towards greater equality.

When we asked our respondents if boys and girls are treated differently and why, at least a third of respondents report that yes, they are treated differently in terms of roles, expectations, etc., and some said that it depended on the family and the age of the child. Furthermore, some who initially reported that all children were treated the same, when probed, reported different roles, etc. But encouragingly, majority of respondents reported that they were treated the same.

*'We treat them equally in this home. Every child must be brought up equally; for instance, boys should do housework, not only waiting for the girl. We are now moving in the modern society, not in the traditional way of life where differences between boys and girls used to occur. I want them to have equal opportunity...'*

- Mother of child with clubfoot, Mukono, Uganda

We see some factors which may be contributing to this shift in ideology towards greater equality. Firstly, there are now more female headed households in Uganda. When women are in charge of the household, there may be a greater tendency to raise their children equally and have higher expectations for girl children.

*'Since I am a widow, I have to look after these grandchildren so that they are useful in the future, to themselves and the nation too. All go to school; all fetch water, and do housework together with reading at night...'*

- Traditional healer, Masaka, Uganda.

Secondly, we hear clearly from their responses that parents are being sensitized and educated towards gender equality. Some have integrated it as their truth, and some have not. But very clearly they are starting to hear and incorporate the message that girls and boys should be treated equally.

*'Both boys and girls are treated equally because of gender balance and people have to get the knowledge that all children are equal...'*

- Community Leader, Iganga, Uganda

*'Discrimination among sexes is old fashioned, but we who have been educated; we know that both a boy and girl child are the same. There was a difference between a boy and girl at home, a boy always was sent to look after cattle, but now the number of cattle is low and non-existent...'*

- Male community member, Mbale, Uganda

Thirdly, girls now have greater access to education with the introduction of universal free primary education...

#### Increasing educational attainment of girls:



*Children leaving school at the end of the day.*

Sensitization efforts are underway to promote equal opportunity for education, and the majority of respondents reported that both boys and girls should be educated. As this pattern of greater female educational attainment begins to emerge, the population is further encouraged as the benefits become apparent. Education is providing opportunities for women to have a source of income and achievement beyond marriage. There are now more women in

local councils and other positions of power and leadership. There are more women being employed outside of the home and contributing to the family

decision making. Parents are beginning to see that a girl child can also be valuable in the future...

*'People are now aware that a girl can do what a boy can do. Everywhere, even in the villages, it is changing at very high speeds. They see women in positions of power so they are encouraged to send children to school, all children....'*

- Practitioner treating clubfoot, Mbale, Uganda

*'Either boy or girl can turn out to be important/useful. We have seen this already. Practically, you can see a homestead being run by a girl because she has been educated, and for the boys, they are only drunkards. In others, you will find it is the boy who is the model for others. This is just chance...'*

- Male community member, Mbale, Uganda.

*'Nowadays, they have changed because when you educate a girl, she is of more use than a boy. When you educate a boy, when he marries, he helps his wife's family and forgets his own. Both girls and boys are capable of doing the same tasks, e.g. decision-making, plan-making, and it is easier to deal with girls since they are more compassionate. When you educate a girl, her worth and value double. When you educate a girl, you educate the whole nation that is because women are good planners and behind every successful man, there's a woman...'*

- Traditional healer, Mbale, Uganda

The remaining undercurrents of boy preference: Despite the gains which have clearly been made towards equality, belief systems generally do not change rapidly. As was mentioned, a significant proportion of respondents felt that children should be treated differently based on gender. We still see much evidence of a society with a considerable boy preference.

*'If a woman produces girls only, a man can marry another wife for him to get boys...'*

- Community leader, Masaka, Uganda.

*'Traditionally, men have remained superior...'*

- Male community member, Ntungamo, Uganda.

*'They only mind on boys because boys are considered important people not only in homes but in the community. Girls normally get spoiled when they get older and become a waste of that home, which is not the case with boys. Therefore, caring for them (girls) becomes a second priority...'*

- Community Leader, Ntungamo, Uganda.



*Young boy in rural Uganda*

The general impression that emerged as the data was analyzed was that boy preference was expressed mostly by the male respondents. Several ladies told us

that the men prefer and favour their boys, whereas we conversely heard from some, that women prefer their girls, or at least give more attention to their girls. Boy preference was at times seemingly a belief that had been passed on through generations; it represented culture and tradition. But at times, boy preference appeared to stem from a sense of insecurity, or an attempt to retain roles that were felt to be changing. Men seemed more inclined to promote the education, freedom, income generation of their boys so as to maintain not only their lineage, but the place of men in society.

*'Men are changing slowly, but they have not accepted that women should make more money than them. Men have not accepted women working in their hearts, so if a woman works, there is much stress....'*

- Female community leader, Kampala, Uganda

Men as heirs: Girl children have not yet gained the right to culturally inherit property of the family, which likely contributes to favoritism and boy-preference. We heard very commonly that parents view boys as the heir, the keeper of the lineage, whereas women are 'marriage-material'. Consequently, investment in a girl is not as worthwhile, for whatever is invested will go to the husband's family. In addition, the children of a girl are viewed as belonging to the husband's family line...

*'Parents will have hope in a boy as they grow older, they hope that it is this boy who will cater for them as the girl will go into marriage leaving her parents at home...'*

- Male community member, Masaka, Uganda.

*'Most men here would prefer boy children because of inheritance – it belongs to boys. Men take much more concern over boy children. Girls are a bride price. Boys are very valuable, they inherit from their father, they make up the clan and they stay together. Girls leave and go to join their husband's family, so men may think that they are wasting their time with girls. Girls and women are expected to do more work at home...'*

- Community leader, Kampala, Uganda.

*'The advantage of boys is that they are the nuts and bolts of a family. This is the biggest advantage, it is a family's resurrection; once you produce a baby boy, you have got a heir who will name after you and the family will not perish or disappear...'*

- Men community member, Tororo, Uganda.

Prioritizing boys for education: For these reasons among others, even with the gains made in education of females, it is not always a guarantee and parents may still see boys as a priority, especially if funds are limited. Boys may also be prioritized for continuing education beyond P7 when education is no longer free.

*'Boys and girls are treated differently because of culture and tradition. For example, boys are given more opportunity to go to school and girls are denied that chance...'*

- Community Leader, Mukono, Uganda.

*'In the communities especially villages, boys inherit more things. They are treated differently. Boys are considered to be more important than girls. Boys are considered first when considering schooling and they are sent to better schools...'*

- Traditional healer, Masaka, Uganda.

*'Men care so much that the boys should continue with their education while girls do the household jobs, especially when it comes to shortage of funds...'*

- Female community member, Ntungamo, Uganda.

Girls are at times considered less of a priority for education because of the roles they typically play in society (i.e. wife, mother, and home-maker) in which education is not always deemed necessary.

*'Boys may be groomed to be providers and defenders so sent to school where privilege is ok, girls are to offer services so no school because they have to depend on men...'*

- Traditional healer, Kampala, Uganda.

Teen pregnancy and early marriage: Some respondents indicated that another justification for boy preference is the tendency of girls to become pregnant or enter relationships with men at a young age. These issues, while very common, can reduce the worth of females in the eyes of family and community, and lead to lowered expectations and less investment. Sadly, both of these problems are pervasive in Uganda and even though they are clearly symptoms of the larger issue of female disempowerment, the blame for pregnancy appears to remain with the female. Little responsibility is given to the male, although very clearly, he must have played a role...

*'Girls are not reliable in my view. Being near the army/military barracks, girls get married very fast and go for free without even paying a coin to the parents, so parents get demoralized in contributing a lot to their well-being...'*

- Community Leader, Mbarara, Uganda.

*'Boys and girls are treated differently because of cultural attitudes and beliefs. Boys are looked at as the superior sex. Boys are taken as heirs and future leaders whereas girls are married away, and because of early pregnancies, they drop out of school...'*

- Community leader, Mukono, Uganda.

*'They all go to school, but they get to P7 before they discriminate. They prefer boys to go on to school. Girls grow stubborn, they think they are grown up, they get married. If there is a lack of school fees, they send boys rather than girls because girls get married anyways and leave the home. Parents expect boys will be of help in the future because boys don't forget their families, even if they go overseas, girls forget...'*

- Community leader, Tororo, Uganda

More attention for girls: We also heard from some respondents that girl children were given more attention or protection than boy children. This practice cannot be described as a preference, because of the manner in which it was justified i.e. it was not due to their intrinsic value as females, nor their superiority, nor privilege in society. We heard that girls were given more attention because they were more likely to be faced with problems in the future or because of their value as dowry price. We were informed that girls were weak, and consequently in need of more care and protection. Finally, we heard that girls were given more care because of the indiscretions and wrong-doings of boys and men, which made girls more favorable in the eyes of caregivers.

*'Majority of attention should go to girls because they are affected by most problems like dropping out of school because of pregnancy, yet the boys can survive any situation...'*

- Female community member, Kampala, Uganda.

*'A girl child is given more care and attention because they know she will give them dowry. Also they are given more attention because it is believed that they are the weaker sex....'*

- Practitioner treating clubfoot, Iganga, Uganda.

*'Yes, girls are treated differently. Girls are given less work because they are generally weak....'*

- Traditional healer, Mbarara, Uganda

*'Girls are restricted from moving freely or visiting relatives, so they are kept at close range where they can be monitored, to prevent defilement. Boys are sensitized against defilement....'*

- Community Leader, Tororo, Uganda

*'I treat all the children the same. Other people tend to give more attention to girls because boys have become stubborn. Boys spend most of their time outside home playing cards and have become bad mannered...'*

- Mother of child with clubfoot, Mbarara, Uganda



*Girl child caring for a younger infant.*

However, we also heard the opposite opinions about girls: that they are stronger than boys, that they are obedient and that they are expected to work harder. Of course, as we have already discussed, we also heard the perception that girls were less valuable than boys and were judged by different standards when it came to appropriate behaviour.

*'Some families favour boys and make girls over-work because over-working them would make them hard working women/housewives in the future...'*

- Community leader, Iganga, Uganda.

*'Men can misbehave, but girls should not misbehave, she can even be disqualified from a village...'*

- Male community member, Ntungamo, Uganda.

**Tensions between the genders:** In Uganda, it feels as though the ideological shift to gender equality is causing tension between the genders: there is a movement to revolutionize beliefs and there is resistance to this change.

**Distinct gender roles:** In general, there are established roles for boys and girls and descriptions of these roles were elicited quite consistently across our respondents. Often even respondents who reported believing in equality, continued to view gender roles as being fairly distinct.

*'Boys and girls are treated differently every day. For everyone God put on earth, there are some activities he wanted divided. A girl was given for what the mother does, like cooking, washing dishes at home, and now the boy, he has to take the goats to eat, grazing animals and taking care of the compound to be clean...'*

- Male community member, Iganga, Uganda.

*'All children are treated equally although they do different jobs. When boys are fetching water and looking after cows, girls are doing the cooking....'*

- Traditional healer, Mbarara, Uganda.

This was not universally true, of course, and some respondents told us that both boys and girls can do all activities. Particularly in urban settings, there was seemingly more blurring of gender roles; perhaps reflective of the greater opportunities for employment and greater access to information and education. However, for rural populations living a subsistence life, there tended to be more consistency in gender roles both within and across generations.



*Boys and girls playing together, Tororo, Uganda.*

*'In urban areas such as Kampala there is more access to information, and women are seen in positions of power, but in villages, women stay closer to home, do the housework, and boys leave the home in search of work.. So there is more equality in urban settings...'*

- Practitioner treating clubfoot, Kampala, Uganda.

*'The differences are there of course i.e. certain work is for girls and certain work is for boys. In the past, girl's education was not given such a priority because of marriage, so they tended to focus on the boys, but this is changing. There are some families where there is only one sex, and they will want the other, most want a combination. Most people I deal with are people in rural areas. Sometimes they give priority to the boys. But it is different with the urban and educated. For the educated families, they have equal opportunities...'*

- Traditional healer, Tororo, Uganda.

Yet even in urban settings some of the roles were distinct and remained with particular genders. Domestic roles for women in particular seem fairly entrenched even in families who are otherwise 'progressive'.

*'Work is equally divided although some work is specifically for the women like cooking...'*

- Mother of child with clubfoot, Masaka, Uganda

*'Even if women do paid work, when they get home the man will sit and wait for the women to do the housework and look after the children...'*

- Community Leader, Kampala, Uganda.

The roles and lifestyle of women in Uganda: We asked our respondents about the roles, activities, expectations, etc. of girls and women both at home and in the community. We wanted to understand from their perspectives what it meant to be a female in Uganda...

When girls are growing up, behaviour is both expressly taught and passively modeled for them by other women.

*'A girl follows in her mother's path and works with the mother, while the boy follows in his father's path and works with the father...'*

- Male community member, Masaka, Uganda.

*'The major activity of women in the community is to take care of children, training children whereby girls are taught feminine duties and boys masculine duties...'*

- Male community member, Tororo, Uganda

Usually the 'path' of a woman in Uganda involved grooming in predominantly two main areas: care-taking and domestic work. Firstly, a major expectation for girls in Ugandan society is that they will marry and produce children for whom they will become primary caretaker. Secondly, girls are to learn the roles in the domestic realm; including all tasks related to caring for home.

*'The girls are the mothers of tomorrow and even no one could marry a girl who doesn't know how to cook food, fetch water and wash clothes...'*

- Traditional healer, Mbarara, Uganda.

The domestic roles tend to encompass most of the housework, i.e. washing plates, cleaning house, washing clothes, etc. We also heard almost universally that the woman is to cook the food in the family. This can include all of the steps involved in locating, preparing and serving the food; for instance, raising hens and other small animals, growing, harvesting, grinding, peeling...

*'In the bringing up; that is how she learns that cooking is important, because no matter where she will go, even though she studied and excellent stuff, she will still know how to cook...'*

- Male community member, Tororo, Uganda.

*'Girls are for mainly domestic work like: cooking, fetching water, sweeping...'*

- Traditional healer, Ntungamo Uganda



*Women cooking on an outdoor cooking fire.*

*'Men never do cooking because it is taken to be women's work...'*

- Community leader, Mbarara, Uganda.

*I do most of the household jobs. Men are not supposed to do such jobs like cooking, peeling and washing. He only assists only when he feels he wants to...'*

- Mother of child with clubfoot, Mbarara, Uganda.

The caregiver role encompasses meeting all the needs of children: general care, washing, feeding, supervising, training, ensuring education, seeking health treatment, etc.

*'The woman has to know which child is sick, how the children have eaten and slept. For decisions about treatment-seeking, it depends on the amount of money the husband has given me, if he gives me money for private clinics, then I go to private clinics, and if he gives me little money, I go to government clinics or hospitals/centers. But, if the husband is not around, I can decide to take the child for treatment and inform the husband later. If I had no money, I could borrow because I could not leave the child to die...'*

- Community leader, Mbale, Uganda.

*'When the woman needs to pay, she will tell you she needs to go to the hospital, but has no money. If it is free treatment, the woman goes without even telling you...'*

- Male community member, Tororo, Uganda.

The role of caring for the sick child fell almost predominantly to the women; however, the role of paying for healthcare often fell to the man. Women, as we will discuss later, rarely had money at their disposal, and as a result were often dependent on the man for seeking care for a child. This placed women in quite a quandary: primary responsibility for caring, with little or no access to money.

*'Now, about paying for treatment...there is no way a woman is involved apart from when she has her own money; it is one in ten who can pay for the child in the hospital. So, it is you the man who decides...'*

- Male community member, Iganga, Uganda.

*Women have the responsibility not the authority. This is because she cannot force you. Women have the responsibility to take the child to the hospital, but the man still makes the decision because he is the true treasurer to the home finances. He can refuse.*

- Male community member, Masaka, Uganda

The caregiver role for women did not solely encompass childcare, but could also mean caring for other adult family members including the husband. Some respondents told us that the women's role involves: preparing food for the husband, washing his clothes, preparing his bath water, etc. Finally, the women's care-giving role also appears to extend to visitors; whom she is to appropriately greet and welcome.

*'The wife's main duty is to look after their home, and their child and also cooking food for the husband...'*

- Mother of child with clubfoot, Ntungamo, Uganda.

*'They cater for men by giving them food, bathing water, washing things at home...'*

- Community leader, Tororo, Uganda

As part of the role of women in the home, some respondents indicated that they are to report to the man about what occurs in the home, what is missing and what is needed. They organize, plan for, and do most of the domestic duties, usually with the financial support of the man. However, a substantial number of women are also involved in cultivation for subsistence and sometimes as a money-making endeavor as well.



*Women selling at a roadside food market*

When we asked about major activities of women outside of the home, in the broader community, we heard mostly of cultivation, followed by small businesses. A substantial number of respondents told us about women's involvement in micro credit financing and loan schemes for group work and income generation. The types of work women were engaging in to earn income included: selling harvests, rearing livestock, handicrafts, making local brews, selling clothes, charcoal, etc. In terms of wage labour, the most common response was women working or running hair salons, but we also heard of employment in bars and restaurants. We heard that employment can be attributed to education, with the educated women seeking work outside of the home, and the uneducated women working within the home.

In addition, there are now more women-headed households or households where the man is unavailable or unwilling to provide support to this family. In these situations women are taking the necessary steps to earn income to support their families and provide the necessities. In addition, sometimes women are working to supplement the family income or to even increase their independence.

*'Women are now finding jobs for their own survival; they work now so that they don't have to depend on the men. Men might have multiple wives, so women don't want to have to beg for every little thing, so they work for survival...'*

- Community leader, Kampala, Uganda

A substantial number of respondents told us that women are increasingly becoming more involved in politics and are even competing for leadership positions with men. There are now substantial numbers of women on the local councils, usually in charge of women's and children's affairs, but also in other positions.

*'Women are becoming more involved in politics...'*

- Community leader, Kampala, Uganda.

*'Because of their bigger numbers, women play a greater role in determining who is to lead us politically...'*

- Male community member, Ntungamo, Uganda.

*'Politics... the way they do it is that one-third of the executives must be women, so there is no way you can really eliminate women...'*

- Male community member, Mbale, Uganda

When we enquired about women's community and leisure roles we heard about women's clubs, groups and associations. Women have formed groups to engage both in activities for recreation (i.e. crafts, drama) and to socially support each other and people in their communities who are in need.

*'Women get involved in associations called 'Muno-mukabi' meaning a friend in need is a friend indeed...'*

- Community leader, Masaka, Uganda

*'They have associations which bring them together if a member loses a kid or a relative. They make burial arrangements together...'*

- Community leader, Mbarara, Uganda

Additionally, women of some ethnic groups are culturally involved in weddings, introduction ceremonies, funerals and female circumcision practices. Finally, many respondents told us that women tend to be more involved with religion and worship activities than men.

*'Most women go to church for prayers...'*

- Community leader, Tororo, Uganda

The roles and lifestyles of men in Uganda: We asked our respondents to tell us about the roles played by men both at home and in the community. We heard that men still carry much of the burden for financially maintaining the family and locating all resources to meet the needs of themselves, their wives and their families. The lack of gender equality in Uganda does not only negatively impact women, but can also place great stress on men by making them almost primarily responsible for providing for the family in situations of scarcity and poverty. This can not only place a great deal of pressure on men, but may also promote tension between the genders.

*'These days when you have a man, all responsibility falls upon him; for example, when you are ill, he is the one to seek treatment, if you are in hardship, such as the famine that hit us recently, it was him to look for food. Some do casual work to support the family; so that is his role...'*

- Female community member, Tororo, Uganda.

*'Since it's the man who marries, it is his duty to meet all household demands such as shelter, food, health, security/protection, education, etc...'*

- Male community member, Mbale, Uganda.

*'He has to plan to look for the resources to look after his family, regardless of whether he is broke, that is his responsibility...'*

- Male community member, Tororo, Uganda.

The main responsibility of men at home was the role of provision of essentials i.e. food, school fees, clothes, money for healthcare. Beyond this, the domestic activities were often limited. Taken to its extreme, some respondents told us that men do nothing in the home.

*'Girls carry the baby, cook food, clean the home and wash dishes. Generally, boys don't want to do household work because they will marry and get wives to help them with household work, while girls have to be trained because they are the mothers of tomorrow...'*

- Mother of child with clubfoot, Tororo Uganda



*Ugandan men using bicycles to transport water.*

However, the majority of people told us that men are primarily responsible for the heavy domestic work i.e. activities such as building, grazing and tending to large animals such as cattle and goats. The role of cultivation at home is generally shared between the genders as is fetching water and collecting firewood, unless it involves bicycles and very heavy loads; then it is the man's role. Other domestic duties could include: slashing, clearing and cleaning the compound, building and brick making.

When it came to children, the role of caregiver was reported almost universally to belong to the woman, although there were some notable exceptions. Some men were clearly more involved in the lives of their children; taking them to school and for treatment and involved in their education. Some also reported that they could help with more of the daily childcare and domestic roles if for instance; the woman was ill or away from the home. This pattern of shared responsibility for children seemed to exist more in urban areas or when both parents were working for income.

*'We share the roles together and work together, even with cooking, when my wife is not around, I can cook...'*

- Father of child with clubfoot, Iganga, Uganda

*'Men may help to wash clothes, only when the women are sick...'*

- Community leader, Mbarara, Uganda.

However, the role of males in regards to children often revolved only around providing for them. This could mean that they were not around to raise the children on a daily basis, because they were generally away from the home, trying to earn money to support them.

*'Every child you produce, you should be able to provide for them in terms of food, shelter, education, medical care, regardless of whether the child is a boy, a girl, lame, blind or normal...'*

- Male community member, Tororo, Uganda.

There were some respondents who felt that men did not care for their families adequately and had gotten into destructive patterns of alcoholism and leisure at the expense of their families.

*'You may find that the majority of men do not care for the children and it is the mother who is responsible...'*

- Female community member, Kampala, Uganda

*'It all depends on the understanding and love between the woman and man at home. If he is understanding and loving, he cooperates in doing housework. If he is not, he does not help, even financially...'*

- Community leader, Masaka, Uganda.

- 'They spend a lot of time drinking. Most of their money goes to drinking...'*  
- Community leader, Tororo, Uganda.

Despite the fact that men did very little in the home compared to their wives, when asked to give the most important person in the house, the answer was most often the husband. The role of provider is very highly valued by both genders and is essential to the well-being of many families. Within this role, men were often also seen as the head of the household, the decision-maker, the advisor. Some respondents told us that the man's presence in the home even contributes to the respect of the family.

- 'The husband is the most important because he is the head of the family and cares about us. The rest come in last, but are also important....'*  
- Mother of child with clubfoot, Mbarara, Uganda

- 'The husband is the most important because he is the one who brings money to help us run the family...'*  
- Mother of child with clubfoot, Iganga, Uganda

- 'They make that family respectable, because if the family has a respectable man, that family must be respected....'*  
- Male community member, Ntungamo, Uganda.

In both the home and the community, men often played a role of disciplinarian, protector, provider of security. They were expected to maintain the peace and justice in their communities. Unfortunately at times this role was taken too far and we heard of situations of mob justice: burning people who commit incest, beating women, etc.

- 'Men settle disputes and ensure there is good understanding among family members...'*  
- Community leader, Iganga, Uganda.

- 'When a man is not in the community, you can find indiscipline among the young people. When a man speaks, they fear. They tend to listen to a man more than woman. When a woman speaks, there are those who tend to despise her...'*  
- Male community member, Ntungamo, Uganda.

In terms of economic roles played by men in the community, by far the majority of respondents reported engaging in farming, some commercially, but mainly for subsistence.



*Taxi park, Kampala, Uganda.*

After this, this most commonly reported productive roles included: business and trade, activities related to animals such as grazing, rearing and animal husbandry, building, brick-making, brick-laying, drivers (taxis and boda-boda) and mechanics. We also heard of men employed in the civil service, as soldiers, teachers, fishermen, traditional healers, casual laborers, workers in factories, quarries and

plantations, cooks, hunters, etc. We clearly see a greater range of income-generating pursuits in the male population, as they are the ones with the major responsibility for money generation.

With regard to politics, many reported involvement, especially at campaign times, and yet a sizable number of respondents also commented that there are less men involved in politics these days.

Culturally, men in some communities are involved in funeral rites, burials, introduction ceremonies and marriage. As well, among the Bagishu, men were reported to be involved in circumcision practices.

Men also appear to play significant roles in developing and sustaining the infrastructure of their communities; for instance, they were noted to be involved with the maintenance and construction of bore holes, roads, wells, hygiene, sanitation facilities and schools.



*Men filling water jugs at the local well.*

Although seemingly to a lesser extent than women, in some communities men have also formed groups and associations to do communal labour or tackle development projects. It was especially common to hear of communal agriculture or communal grazing but also they had formed groups and held village meetings to discuss the development of the community. Community development by men could additionally involve conducting mobilization and sensitization activities and promotion of government programs. It is important to note that these roles were by no means universal, and villages all had varying levels of community involvement by its members.

Some respondents told us that the major activities of men in the community largely revolved around leisure pursuits: playing sports such as football, gambling, drinking, playing cards, looking for girls, being idle, etc.

*'I have to be realistic, developmental-wise; men in this area do not care. They are idlers. They spend most of their time drinking and leave women going for digging. We have got problems with them, and because women are the only ones left to produce food for the home, we usually experience food shortages. Even though you sensitize the youth to form groups like brick-making, they do not mind. However, when it is community programmes like building a health center, men are mobilized by force to participate...'*

- Community leader, Tororo, Uganda.

Men, Women and money: We asked all of our respondents: what decisions can women make about money? The responses to this question clearly brought out the division between the genders and unmistakably demonstrated the tension between men and women that was discussed earlier.

The most cooperation was seen in families where both parties were gainfully employed. This led to more of a partnership and sharing of roles. This situation tended to arise predominantly in educated families, although not always. Some rural families had businesses together, worked cultivating together, and shared the financial planning, budgeting, etc. Our respondents often told us that these scenarios represented households where there was good or proper 'understanding' or 'cooperation' between men and women.

*'Depends on the cooperation in the home, if there is agreement, both woman and man sits and decides on how to use the money...'*

- Community leader, Mbarara, Uganda.

*'Women have decisions on money because together with the husband, they cultivate rice, cotton and sell for money. Therefore, they can decide on what to buy in the home....'*

- Community leader, Iganga, Uganda

Sometimes when the woman was not earning, she would still be left in charge of the family's financial resources. There were varying degrees to this arrangement: on occasion there was complete sharing of money. Sometimes, the woman was in charge of saving money and planning for its use, and often we heard the woman was just given a bit of money to either use or keep for basics and emergencies. Again, the arrangement made seemed to be dependent on the understanding between spouses; sometimes it was a partnership and sometimes a dictatorship.

*'I am the one who decides about money and I give my wife to buy what is missing. In case we sell beans, my wife remains with the money. Whatever is cultivated, the money is given to my wife to buy what is missing. I am a boda-boda cyclist and when I get money, I can give her some. Only I decide when it is from boda-boda and my wife decides in case this money is from cultivation because it is her responsibility to cater for the health, feeding of children because I come back late sometimes...'*

- Father of child with clubfoot, Mbale, Uganda.

*'It depends on the understanding between the wife and husband i.e. some women are given money and allowed to plan, while others can never touch any coin from their husbands....'*

- Community leader, Masaka, Uganda

*'Women are supposed to keep some money for an emergency in the family since men are good at spending any money they have...'*

- Community leader, Iganga, Uganda

*'Even when the woman is not working, she has to share part of your money. You live with that woman at your house, and she makes good food, looks after the children, gives good children who are not lame, are healthy and good looking, you have cause to have happiness in your life. You have to give her money and buy her clothes because she deserves it...'*

- Male community member, Ntungamo, Uganda.

Sometimes the woman was not given direct control over the finances, but acted as an advisor, informing the man about what is missing, what is needed, and planning for the development of the family i.e. school fees, purchasing property, etc. Again, this type of financial understanding between spouses had levels; sometimes women's roles as advisors was appreciated and sought, sometimes it was an arrangement of necessity.

*'One of the responsibilities of a woman is to tell me the requirements that are missing; because a woman does not have any income at all that she can make a budget for...'*

- Male community member, Iganga, Uganda.

*'Some families house women who are good planners and they can influence decisions on money matters even if it is the man who earns the income...'*

- Male community member, Ntungamo, Uganda.

*'In one type of family you will find 2 informed family heads, and the woman can easily give you (man) constructive ideas on how to spend the money...'*

- Male community member, Ntungamo, Uganda.

There were financial arrangements between spouses where the woman had decision-making power about finances solely in the absence of the man. This was often the understanding when it came to seeking healthcare treatment for an acute illness. The woman was often allowed to seek care for the child, but would then account to the man about funds spent.

*'My husband decides about money, but if he is not around, I am the one who decides and when he comes back, I explain how I spent the money....'*

- Mother of child with clubfoot, Tororo, Uganda.

*'When you the husband are not at home, the woman can even sell a cow because she is your vice (i.e. assistant)...'*

- Male community member, Mbarara, Uganda.

However, we found very commonly in all districts that women, unless working themselves, had very little access to the family's money. A substantial number of respondents told us that men make the decisions about money and women do not. A few respondents even told us that if a woman works, she was to give her money to the man who would then make the decisions about all money. Some of

the justifications provided for not allowing women to make decisions included: the women are under the man, women are dependent, they did not earn the money, women have no understanding when it comes to money, they are luxurious, women are thieves, that women have the power to bewitch a man when it comes to money and even simply that women were not allowed to use money and that men did not respect women's decisions in regards to money.

*'Since most of the women are primary drop-outs, there is no way men can allow women to make decisions about money. Only a few women can do so...'*

- Community leader, Kampala, Uganda

*'In fact, women don't make any decisions about money because they don't have any...'*

- Male community member, Kampala, Uganda.

*'Some men have got traditional behaviour as far as their women's finances are concerned. You will find them not ready to discuss a developmental matter with the wife. If anything, he goes and calls a brother and exchanges ideas with him about money issues, rather than doing it with his wife. Most families are still behaving like this...'*

- Male community member, Ntungamo, Uganda.

There is also the issue of ownership of money. It was often felt that if money had been earned by a man, then it belonged to him; not to his wife, not to his children. If he chose to provide money to the family, then that was his decision, but his contribution should not be assumed or taken for granted. The women respondents often echoed this belief and said that they had no power to make decisions about money because they had not earned that money. Conversely, if a woman had earned money herself, she may also assume ownership over that money.

*'There is no decision they can make on the family expenditure, unless they have their own money...'*

- Community leader, Mukono, Uganda

*'She only has authority over her own money or that which we have earned together, but what I have earned personally, no way...'*

- Male community member, Mbale, Uganda.

*'They have decisions only on money made when they make their local brews. But on money got from the sell of agricultural products or harvest of animals, women have no say. It is the man who decides on what should be done with the money. Any decisions made by the woman without the husband's knowledge could easily bring fights in the home...'*

- Community leader, Tororo, Uganda.

*'A woman cannot decide about money. Maybe when she worked for that money, but not my money...'*

- Male community member, Mukono, Uganda.

*'The husband makes the decisions for the home, because he is the one who looks for money....'*

- Mother of child with clubfoot, Ntungamo

*'I don't have decisions about money because I don't have a job...'*

- Female community member, Iganga, Uganda.

Sometimes the issue of ownership also went to the extreme of distrust between spouses, and subsequent practices of concealing money or not disclosing what had been earned. Non-disclosure and hiding was most often reported about men's behaviour, but we also heard of the reverse scenario where women were concealing their money as well.

*'Most men don't show their money to their women so the women don't show their money to the men. Most men are in positions of power and they make the decisions. Most African men are still stubborn and they cannot let the women make decisions. Men are easily threatened by women- they don't like to take women's ideas...'*

- Community leader, Kampala Uganda.

*'He has got the money; he may not tell you about that money i.e. that I got this money...now, you get surprised that he got money and he spent it....'*

- Female community member, Iganga

*'Women don't know what men earn...'*

- Female community member, Ntungamo.

*'The same applies for women; they also don't want us to know about their money...'*

- Male community member, Mbale, Uganda

Sometimes the distrust between couples had arisen because of past negative experiences where one partner disliked how the other had spent the money. Alternatively, one partner may have felt that the other was being untruthful about how they were spending the money.

*'You could be with a woman at home, and maybe she has some children that she produced aside from these ones that are here at home. She decides not to help these and instead helps those ones aside; and you the man, you are there thinking that you are together with your wife, but yet, she has another way; she is not straight with you...'*

- Male community member, Tororo, Uganda

*'Some women are luxurious, so a man tends not to expose his money to the wife with the feeling she will put that money to waste...'*

- Male community member, Ntungamo, Uganda

*'Some women are too dependent on the man, you may find that the woman has about 20 relatives and all these relatives are relying on the man to feed and clothe them. When the man sees this, he will definitely withdraw the money...'*

- Male community member, Ntungamo, Uganda

When women do not have ready access to money, they are left disempowered. To meet the basic needs of themselves and their families including food, clothing and healthcare they are in the position of having to ask, and the man has the ultimate authority and can say no. This situation becomes especially difficult for women when it comes to healthcare treatment-seeking. The majority of

respondents told us that women are responsible for seeking care for their children, but it is the male who generally pays for treatment. In the case of mothers who were seeking money for treating their child with clubfoot, we heard on multiple occasions that the men were not providing the financial support and this contributed to non-adherence. In addition, because women in many families continue to have minimal control over family finances and decision-making, they may have little say when it comes to promoting equality for their children.

*'Traditionally, a woman has no say about money and she has to request and wait...'*

- Male community member, Kampala, Uganda.

*'For us women, we also want our girls to school, but are not able...'*

- Female community member, Ntungamo, Uganda

*'Boys are educated and girls are left out due to lack of money...'*

- Male community member, Kampala, Uganda.

Money was such a contentious issue that in some families, it was even being used as justification for domestic disputes and spousal violence....

*'In the rural areas, women may not know the amount that their husbands get. Even though the husband sells a cow, the woman may not have any say regarding the whole transaction. And if she gets so much involved, she risks being beaten. This is because women in rural areas are not educated.'*

- Community leader, Tororo, Uganda

*'Women have no decisions about money, because they do not work, and if she asks she can be beaten...'*

- Community leader, Kampala, Uganda.

*'Some men do not want the women to tamper with the money, you know, some men are womanizers. They keep their women's money in the house; they will even slap the woman at home if she should tamper with that money....'*

- Male community member, Ntungamo

When women were in genuine partnerships with their men, they were empowered and equal. However for some women, partnership was not an option either because the spouse was unreliable or was no longer present. Regardless, in these situations women took control of the family's finances in order to provide for themselves and their families, and they had full decision-making power.

*'The man manages his own funds and renders no help to us. He is a drunkard too. I try so hard to survive on my own. I dig and sell a little from my harvest like matooke and beans....'*

- Mother of child with clubfoot, Ntungamo, Uganda.

*'Both of us work, but the father is not paid well, and yet he drinks all the money. So, I make most decisions at home, because I use my money...'*

- Mother of child with clubfoot, Masaka, Uganda.

*'Women buy domestic animals for home development that they keep as emergency money for food, urgent issues like sickness and school fees...'*

- Male community member, Kampala, Uganda

*'I am the one who decides about money (grandmother). I make the money through distilling. My husband drinks, goes away. I make the decisions, I am the one. I have to feed the family and provide the money...'*

- Grandmother of child with clubfoot, Tororo, Uganda.

Positive change and the way forward: We heard much about the roles of Ugandan women that was discouraging. However, we also heard much that gave us reason to believe that the roles of women were changing for the better. This pattern of development is extremely important for the health of Ugandans and for development in general. We would like to end this discussion on this positive note....

*'Women now have more opportunity for employment. We now have lady LCs and parish chiefs, etc... .'*

- Traditional healer, Tororo, Uganda.

*'Women are big people now; they are vices (vice chairpersons)....'*

- Male community member, Ntungamo, Uganda.

*'Regarding education they are treated equally. The expectations are the same when all are educated, but when not educated, the girls are expected to get married and boys to start families...'*

- Community Leader, Mbale, Uganda

*'When both the husband and wife are educated, the responsibilities are shared...'*

- Traditional healer, Mbale, Uganda.

*'Women have mobilized themselves into groups where they base to do different activities, for example, craft-making, give each other gifts, loan schemes, counseling, welcome visitors, attend meetings, farming, etc...'*

- Female community member, Mukono, Uganda.

*'People are now aware that a girl can do what a boy can do. Everywhere, even in the villages, it is changing at very high speed. They see women in positions of power so they are encouraged to send children to school, all children...'*

- Practitioner treating clubfoot, Mbale, Uganda

*'In this community there are quite business oriented, there is not the same division between genders, but it would be different farther east. This equality is in town, but the changes are also moving into the villages as well due to increased awareness. The same schooling, the same expectations. I see no difference...'*

- Practitioner treating clubfoot, Tororo, Uganda

### **Gender and Clubfoot treatment:**

We asked respondents: in the case of illness or disability, do families give more importance to seeking healthcare treatment for boys or girls and why? We heard overwhelmingly that all children should be cared for regardless of sex. Respondents told us that all children are humans, that they are all children and need care. They told us that illness does not discriminate by gender, and neither can they when it comes to treatment. They told us that they were sensitized to gender equality, and

that it has influenced their behaviour so they now care for all children equally. They note that a parent cannot know which of their children will be helpful and useful in the future, so all should be treated. And finally, they told us that they do not want any of their children to be in pain, want them all to be well...

*'Ok...the treatment of a person....as long as one is produced as a person, then they are a person, so when he/she gets a disability, you have to treat him/her to become ok....not go saying that I treat the boy and leave out the girl...'*

- Male community member, Iganga, Uganda.

*'If it is a boy who is sick, you treat him. If it is a girl, you also treat her too. If both at the same time, you treat both because they are all your children and you love them equally...'*

- Male community member, Mukono, Uganda.

But of course, like all of our themes presented thus far, there is a range of responses and we heard arguments for treating girls over boys and vice versa...

For girl children, the reasoning for prioritizing was related to the characteristics previously mentioned i.e. they are weak, they need to remain beautiful for marriage, etc. Occasionally we heard that the girl child was favoured by the mother as a justification.

*'Maybe a difference I see is that if a girl has fallen sick or maybe she has a wound on her feet, you have to get treatment because that girl child does not look nice when she grows up. It would have the effect spoiling her beauty...'*

- Male community member, Tororo, Uganda.

*'Girls are treated easily than boys. Girls need to be maintained in terms of beauty, if she is to marry a handsome husband. No man can easily accept a woman with clubfeet. Therefore parents take trouble to care for girls, then boys. For boys, they can get married at any time and to any woman so long as they are rich. Women don't see those clubfeet when the man is rich...'*

- Practitioner treating clubfoot, Mbarara, Uganda.

*'Girls first because they are sensitive and need more attention...;*

- Female community member, Tororo, Uganda.

For the boys, the justifications for prioritizing were once again related to their intrinsic value in being a superior or favoured male or because of his ability to carry the clan line. We also heard that fathers sometimes favour their boys.

*'For me, if my children fall sick, I first treat the heir (son)...'*

- Male community member, Ntungamo, Uganda.

*'Traditionally, boys are more important than girls, so when your boy falls sick, you try very hard not to lose that important person...'*

- Male community member, Ntungamo, Uganda

*'Mothers have a general attachment to their children, both boys and girls. But fathers are more attached to the boys and would prefer treating them to the girls...'*

- Practitioner treating clubfoot, Masaka, Uganda

We heard from some respondents that men are not bothered about treating children regardless of gender. The burden was the mothers to bear whether the child was male or female. We will discuss this theme further in the next objective...

*'Men are not bothered when it comes to treatment whether it's a boy or a girl. It is you the mother who will suffer...'*

- Female community member, Ntungamo, Uganda.

Finally, we came to understand from a few of our respondents that children with disabilities, regardless of sex were sometimes treated differently than typical children. This could work both ways. Sometimes they were given more care because they were perceived as being weak or fragile. Other times families gave them less priority because they were not viewed as being useful, or worthwhile.

*'Some think that if a child is lame, he/she may in future not be useful...'*

- Male community member, Ntungamo, Uganda.

*'I would think they give more tender care to girls than to boys. But, I do not know the cause. But generally the disabled, including those with clubfoot are always neglected in many aspects. For instance, when we go for outreaches and ask for those who are sick, they don't bring the lame. However the lame are treated in a tender way. They are not usually allowed to be involved in many of the household activities. Though boys are usually left just to wander and most of them end up as street children...'*

- Practitioner treating clubfoot, Iganga, Uganda.

## **Conclusion:**

We have examined some of the gender issues in Uganda and conclude, based on our findings, that there continues to be much inequality between the genders. The gender discrepancies certainly affect treatment-seeking behaviour, among other issues of general well-being. However, we did not feel that this was the primary factor influencing the number of boy children being treated with clubfoot. Despite all of the gender issues we have reviewed, it appears as though when a child is ill or has a disability, the gender of the child is most often not a factor in treatment-seeking. The results of this study certainly do not explain the 5:1 ratio of boys to girls being treated for clubfoot. Perhaps the next phase of the Uganda Sustainable Clubfoot Care Project, looking at incidence, will shed further light on this issue.

However, our review of gender did highlight a number of serious issues related to health seeking and empowerment. Health planners must recognize these barriers posed by gender and work to facilitate women's ability to care for their children. When we address women, we address their children, and when we empower women, we promote health, human rights and development.

## **Objective VI: Barriers to adherence**

### **Introduction:**

This chapter will review the barriers to treatment adherence as outlined by our respondents. It is important to note that under this objective, we will not be discussing barriers to initiating treatment, as these have been covered in the treatment-seeking behaviours, objective 4.4. The purpose of this objective is to discuss only those factors that would make it difficult to adhere to the treatment. In order for the Ponseti method, a lengthy treatment regime, to be feasible for the population, we must be very sensitive to meeting the needs of children with clubfoot and their families. The barriers to treatment need to be identified so that they may be addressed in the most culturally sensitive, holistic, and feasible manner. Failure to address the broader contexts of people's lives (the macro-level forces) can make it next to impossible to access healthcare.

### **Literature review:**

Non-compliance: The term 'non compliance' has, whether intended or not, a blaming connotation in the medical profession. It is a term that implies choice: a choice in whether or not to follow through with a treatment (Farmer, 1999). It also suggests, as is discussed by Sumartogo, that the patient is subservient to the medical provider who has decided what is best (Farmer, 1999).

'Compliance' is not as simple as a choice to abide or not abide by a treatment regime. This is especially true in countries such as Uganda where most of the rural populace live in poverty. All societies want to care for their children and have them grow to be productive adults. As Rachels (1995) points out, this is a fundamentally true statement. If it was not true, and children were not cared for through the lengthy period of dependency, then society would cease to exist.

A parent's will to treat: People with disabilities are marginalized and stigmatized in their societies and in countries such as Uganda there is currently limited infrastructure to support people with physical disabilities. A study looking at poverty and disability in Uganda found that 'dependency, social isolation, rejection, vulnerability and powerlessness characterize the experience of disabled children. Many disabled children, especially adolescents, are exploited (including sexual abuse) and are discriminated, denied access to social economic activities' (Lwanga-Ntale, 2002, p. 16). Given the degree of difficulty experienced by children with disabilities, it would follow that a lack of parental compliance with a treatment that could correct the disability (i.e. the clubfoot treatment) is not a matter of parent's choosing to not follow through on a procedure that is beneficial to their children but is a reflection of barriers to adherence. From the perspective of healthcare providers and planners, a lack of compliance should be viewed as an indicator that there was a failure to meet the needs of the population being served. As is written by Farmer (1999), 'All too often, the notion of patient noncompliance is used as a means of explaining away program failure. Patient dependent failure should be a 'diagnosis of exclusion' (p.227).

Understanding the barriers: Accurately understanding the cultural, social, political, historical and economic factors has important practical implications for health care service delivery (Farmer, 1999, Gausset, 2001). Uganda has been criticized for

pursuing an aggressive free market policy at the expense of the social welfare of its people (Okuonzi, 2004). Economic policy in Uganda is focused around export and private sector investment, which is meant to lead to greater household incomes in the long term. However, as Okuonzi (2004) notes, in order to create the macroeconomic milieu for investment, public expenditures on social development are being very restricted. The economy has grown, but the investment and growth has come largely from external aid and has focused on the country's manufacturing, trade and economic infrastructure, not on social development (Okuonzi, 2004, Ssenooba et al, 2003). In Uganda, the central government expenditure allocated to health is only 2%, education is 15% and defense is 26% ([www.unicef.org](http://www.unicef.org)). The health sector has been largely handed over to donor aid and Uganda is one of the most donor-dependent health services in the world (McPake, 1999). Health worker wages have not been given priority in economic strategy and consequently there is low motivation and poor accountability within health services that are available (McPake, 1999). Several of Uganda's major health indicators such as maternal mortality, infant mortality and malaria are deteriorating according to the most recent UNDP Human Development Report 2005. Accessibility of quality healthcare and education are poor; unless one can afford to pay privately. Student to teacher ratios in primary school are some of the highest in the world, and the costs of secondary schooling are prohibitive to many.

This is just a very surface overview of some of the macro and intermediate level forces influencing the lives of typical Ugandans. Pearce (1993) notes that when faced with health issues, people are influenced by these macro level forces (i.e. poverty, gender inequality, a lack of education). As well, they are influenced by intermediate forces (i.e. health sector services that are inaccessible or not culturally appropriate) and their own micro-level forces (i.e. the physical symptoms and psychological issues such as a lack of self-efficacy). The barriers to compliance are numerous and could occur at any of these levels and it is not difficult to imagine how any or all of these issues could potentially be barriers for people in Uganda.

### **Review of findings:**

Barriers are the cause, and adherence behaviours are the outcome. Based on the information provided by our respondents, we conclude that poverty, lack of awareness, lack of paternal support, caregiver responsibilities, resource availability and regional imbalances in service delivery, and inadequate resources for follow-up are our major barriers to adherence. We hope that this objective will represent an overview of the issues to help the reader understand that 'non-compliance' is most often not an issue of will, but a signal that there are substantial barriers in play. We will seek to summarize the primary barriers as captured in this study, and present them here as a challenge to healthcare planners; for it is only when planners meet the needs of their population, that their programs will succeed. Finally, we will conclude this objective by reviewing methods that have worked to overcome barriers, leaving the reader with a direction for the future.

## Poverty:



*Toddler standing in the doorway of her rural mud house, Mbale, Uganda*

*'POVERTY is the big barrier throughout Africa. People are so poor and it affects everything...'*

- Practitioner treating clubfoot, Mbale, Uganda.

There is over-whelming poverty in the rural villages of Uganda; it is all pervasive and so restrictive

in people's lives. As we have discussed, the desire to treat children was almost universally present, yet we repeatedly heard that the costs involved in treatment were major barriers to adhering to treatment. Despite adversity, many parents do somehow manage the money to seek the assistance of a practitioner; yet, having got this far, some will then fail because of the costs involved with prolonged treatment. Ponseti method is an appropriate non-invasive, low-technology treatment, but treatment takes time and multiple visits. When hospitals run out of casting material and patients are asked to buy, some of them do not come back to hospital or have to seek help elsewhere. Imagine scraping together the money to come to hospital through selling the few vegetables you have grown, only to be told that there are no supplies, and you will have to come another day...

*'Every other month we run out of plaster of paris (POP) and then parents are asked to buy. They have not increased our budget for POP even though we have an increased population. Many parents get discouraged because they spend what they have on transport, so they give up because of resources, and the child is neglected...'*

-Practitioner, Mbale, Uganda.

This treatment method also requires braces worn over an extended period to maintain correction. Children grow, sometimes rapidly, so multiple braces are needed over time. When hospitals charged for braces, it seemed to drastically increase the rate of relapse and non-compliance.

*'80% of cases cannot afford this because the shoes/splints have to be changed as the child grows. At times parents come and pay deposit for the splints, but then fail to come back because of the balance to be paid, or because of the transport costs. People are so poor...'*

-Practitioner treating clubfoot, Masaka, Uganda.

In general, when patients were charged fees, even if they managed the money to adhere to treatment, it was usually done under hardship. This treatment is a financial commitment over a period of years and some caregivers find they simply cannot continue with the care once treatment is in progress. If we look at the financial implications of absconding from treatment due to inability to pay, it is an incredible waste of time and money; one which none can afford. Emotionally, this situation is extremely disappointing for all involved, both practitioners and patients. For

caregivers, it is a cruel fate to get a glimpse of hope for a cure only to have the child recur because of lack of money...

*'I was happy in the beginning because the treatment was progressing, but when I failed to continue with the treatment I was hurt, sad and depressed because my child's feet had relapsed...'*

- Mother of child with clubfoot who discontinued treatment due to money and maternal illness, Tororo, Uganda

*'Ever since giving birth to this child, my life has changed because I spent all the money I had. I would quarrel with my husband every time I demanded for transport. Generally, I have been so miserable, yet the child did not heal...'*

- Mother of child with clubfoot who discontinued treatment due to lack of funds, Ntungamo, Uganda

*'Ever since the condition was identified, the distance to the hospital was so far- so transport was hard, we reached the extent of even riding, since we had no time for the garden. We were stricken by poverty, could not meet other demands in the home and family problems began that led to our separation (husband and wife) since there was no peace in the home. Slowly I am trying to resettle myself, slowly, but I am in a dilemma of what her future will be, I want to seek treatment again but I am still helpless, yet I would like to see her go to school in order to have a brighter future...'*

- Mother of a 3 year old child with recurrent clubfoot, Mbale, Uganda.

#### **Lack of paternal support:**

When you enter the clubfoot clinic of any region in Uganda, you will see women, always women seeking treatment for their children....

*'Some women don't have the support of their husbands. At least 90% of children come with their mothers; it is rare to see fathers...'*

- Practitioner treating clubfoot, Tororo, Uganda

*'Fathers sometimes reject the child 'that is not my child' and sometimes the father has no interest or time. In the last 3 months, only 1 person has said that the father gave money and the father came. Otherwise, the mothers are on their own...'*

- Practitioner treating clubfoot, Tororo, Uganda.



*Mothers waiting patiently at the clubfoot clinic, Mulago, Uganda*

Women are the primary caregivers of children and are consequently principally responsible for the health of their children. But the quandary of mothers is this: they have primary responsibility for seeking care and little or no access to money. Although there are certainly some fathers who are supporting their wives and children, financially and otherwise, many are not. This leaves women in a position where they have to scrape together the funds for

transport either by selling something, borrowing or by persisting with a resistant husband. The later sometimes resulting in significant relationship strain, and even separation. It also has implications for adherence; one woman can only struggle so long on her own without support.

*'I absconded from treatment since the kid's father rendered no help in terms of transport. I tried so hard through selling bananas to save some transport money. I managed for some time, but when I was referred to Mbarara for shoes, I stopped treatment because I had no money left...'*

- Mother of a child with recurrent clubfoot, Ntungamo, Uganda.

*'I have noted that husbands tend not to come to the clinic with their wives, or offer support to their wives in obtaining clubfoot treatment. Most women are struggling alone to pay for transporting their child for treatment. Only 10% of the women seen at clinic have the support of the man, while 90% are struggling on their own. This may be because many people have not been sensitized about clubfoot management; therefore, the men feel that as long as the child is not in pain, does not have a fever and can feed, then the man does not have to produce money for treatment....'*

- Practitioner treating clubfoot, Masaka, Uganda

As we discussed previously, women are also sometimes blamed for the child's condition by their husbands. A clubfoot can somehow become the fault of the woman, in addition to being her full responsibility for correction.

*'The blame for disability is placed on the woman, so she will be desperate to sort the child out. So the moment she knows about treatment, she will come....'*

- Practitioner treating clubfoot, Tororo, Uganda.

*'Mothers are concerned with the reactions of their husbands i.e. giving them necessary money for transport, saying the problem was from the side of their wives...'*

- Practitioner treating clubfoot, Mbarara, Uganda

Some practitioners felt that this particular barrier was less of an issue in families where there was more equality between the genders and, as we have discussed, this equality often arose because of higher educational achievement and because both partners were working. So perhaps there is hope for the future as the gender roles in Uganda continue to progress...

*'There is much more equality and support from the males in more educated, professional couples and both tend to work together and attend clinic....'*

- Practitioner treating clubfoot, Masaka, Uganda

### **Caregiver's other responsibilities:**

We have already discussed how responsibilities at home can present a barrier to seeking treatment. This issue similarly presents a challenge for parents once they have commenced the treatment regime, and can act as a barrier to adherence. In order to seek treatment for a child with clubfoot, the mother must prioritize the needs of this child with that of the others for the duration of treatment.



*Children living in an urban slum area, Kampala, Uganda*

*'I paid 1000 for registration and I meet transport costs on my own. At times I can walk. Whenever I go for review, the other children are left helpless since their father stays away...'*

Mother of child with clubfoot, Mbale, Uganda.

In addition to child care and cultivation, women often have responsibility for their husband's care in Ugandan society. Men may

feel dependent on women who cook, clean and manage the household. Consequently, husbands may resent having a wife who must leave the home regularly or for prolonged periods of time. Women are aware of this responsibility and it too may impact their ability to adhere.

*'Mothers worry: if I stay in the hospital for 2-3 weeks, my husband may get another woman. The women want to go home early. But when they go home, they may not come back. They may not have the money for transport back, or some forget the dates...'*

- Practitioner treating clubfoot, Mbale, Uganda

*'Mothers face the problem of fathers who lose trust in them for their weekly turn-up to hospital...'*

- Practitioner treating clubfoot, Mbarara, Uganda

According to the human development index (<http://hdr.undp.org>), in 2002 approximately 87% of the population of Uganda lived in rural areas with the majority of the population engaged in subsistence farming. These people work daily for their survival, for their food, their fuel, their water supply. This life does not allow work to stop for a child requiring weekly treatment: the animals must be cared for, the harvests yielded.

*'6 out of 10 are corrected completely. We are hindered because manipulation takes time. When the parents are yielding the harvest, they don't come. They don't come until the harvest is done, and by then the child has relapsed and they have to go for surgery...'*

- Practitioner treating clubfoot, Uganda.



*Man taking matooke to market using his bicycle.*

Even for parents living in urban areas or those who engage in wage paying occupations, there is sacrifice to be made in order to seek care. They must seek time off work on a weekly basis while the child undergoes casting. There are often lines at hospital which means that parents cannot just quickly nip out for treatment. These responsibilities at work present yet another barrier to adherence and even if the barriers of responsibility are overcome, it is not without adversity...

*'Leaving work every Tuesday to bring the child to hospital does not please my bosses, so I have to explain to them every time I leave...'*  
- Mother of a child with clubfoot, Mbarara, Uganda.

*'I used to have a retail shop for vegetables, but I gave it up because I have to attend to the child all the time and every week go for treatment. It has cost money on transport. Sometimes I fail to take the child for treatment. The distance is long from Busia to Tororo and it takes a long period to cure...'*  
- Mother of a child with clubfoot, Tororo, Uganda.

### **Distance to health facilities, and costs of transportation**

This barrier to treatment requires little explanation. Only a tiny percentage of Ugandans own vehicles (i.e. cars, motorcycles or bicycles) for their personal use. Yet, the majority of the population lives rurally and must travel to health centers. This situation dictates that they require money to purchase transportation as a service. However, in some areas they are so remote that even this service is not readily available and parents may have to walk to a main road where transport can be accessed. If money is not available for transport, then even if treatment is free, weekly transport costs become the barrier to adherence. When parents must travel long distances, these costs can be a heavy burden, not to mention the extensive time that is sometimes spent in transit. If raising the money for transport is not an option, then parents may be forced to walk long distances carrying a child in order to seek treatment. A child with bilateral casts is awkward and heavy and the roads in Uganda are chaotic and dangerous...



*Rural dwellings and typical footpaths deep in the village.*

*'Sometimes I fail to get transport to this place, and I reach the center at 2:00 pm because I get money late. There are some days I have to walk to the center to get treatment for my grandson. I have a heart problem and I find a problem in walking long distances and carrying the baby...'*  
- Grandmother of 2 year old currently in treatment, Tororo, Uganda.

*'Transport costs to be incurred every week are a problem. Most patients are from far away and transport costs to reach hospital can be expensive....'*  
- Practitioner treating clubfoot, Masaka, Uganda

*'Access to the service is a problem, most come from deep in the villages. Sometimes there is no transport available...'*  
- Practitioner treating clubfoot, Tororo, Uganda

### Challenges of treatment process

Some find the length of treatment challenging. Several practitioners told us of how people often come wanting to be cured that day and are disappointed to hear that treatment is a process that occurs over time. Sometimes, as has been discussed, they cannot maintain the costs over time and/or have other responsibilities. The length of treatment can at times, lead parents to try alternative methods, or to become frustrated or even just stop treatment with the hope that the child will remain corrected without retention bracing.

*'We treat 50 children in a year and 20 are successful with treatment, where others get relaxed and don't come back. Because of poverty, they sometimes become comfortable with a slight change and stop coming thinking the child will get better with time. They don't follow through and the child relapses. The 20 are successful because of proper following of instructions...'*

- Practitioner treating clubfoot, Mbale, Uganda.

*'What could make it difficult to get treatment? This cannot be treated once or twice, it is time-taking treatment and it is expensive...'*

- Traditional healer, Kampala, Uganda

*'The treatment was free, but this treatment consumed my time, and mainly the mother's time was consumed because she could spend half a day waiting for treatment and this would affect her work schedule...'*

- Father of a child with clubfoot, Mukono, Uganda.

There were also logistical factors which made parents uncomfortable such as difficulty bathing, maintaining hygiene, dressing and carrying the child when they were in the casting phase. Several practitioners told us of caregivers concerns that the casts would become infested with lice. In addition, some parents felt that the process (either casts or braces) were uncomfortable for their children and would consequently feel trepidation or even stop the treatment.

*'During the time when casts are on, it is hard to carry the child. You imagine she will break. There is difficulty cleaning/bathing child. She cries a lot, so I felt disgusted and nearly gave up treatment but with support of my husband we hang on to treatment...'*

- Parent of child with clubfoot, Iganga, Uganda.

*'The treatment was not successful. The plasters/bandage was not put up to the thigh; it was wrapped around the leg and was eating away the flesh. My parents were scared and stopped treatment...'*

- Adult male with neglected clubfoot, Mbarara, Uganda.



*Orthopedic officers learning casting at Mulago Hospital, Kampala.*

*'The shoes are also a bit uncomfortable for children. Mothers sometimes just keep them, and then come later to hospital when the child has*

*outgrown them, so they don't fit the child. This is because they feel their children are uncomfortable and are always crying. When a child cries, the mother removes the braces...'*

- Practitioner treating clubfoot, Mukono, Uganda.

Another barrier to adherence is poor treatment by health workers, long hospital lines and corruption. All of the stories we heard regarding barriers and hardship were sad, but these ones were particularly heartbreaking because it was the very system that was supposed to improve the lives of their children that betrayed their trust when they were most vulnerable...

*'I would advise parents to go to the hospital, but it is not easy to get treatment however much they say it is free. We realized after birth that this child had clubfoot and after 3 months we started moving for treatment and got tired of this movement because we could not receive treatment. We would line up at Mulago, and come back without treatment. We did not have the money for transport every day. There is a time we went to Mulago and only those with money could just pass and get treatment. When they asked for 30000, we gave up. The child was not treated at all because we would line up, and it was costly for us, so we gave up'*

- Parent of child with neglected clubfoot, Iganga, Uganda.

*'Sometimes they come and are waiting and can't get treatment because the therapist is not around or is busy, so they leave with a negative attitude...'*

- Practitioner treating clubfoot, Tororo, Uganda

### **Resource availability and regional imbalances**

Because clubfoot training occurs centrally, when we set out to conduct this research, we expected to see a similar model of delivering clubfoot throughout the various regions of Uganda. However, it was surprising to discover that there are clearly regional imbalances in resource availability and service delivery. These imbalances not only put up barriers to adherence but sometimes they are unjust. Depending on the region a family resides, they could have completely free treatment or have to pay a fee for each treatment, or have to pay for braces, or have to pay for plasters when the hospital runs out.... Sometimes they are treated in one region and then have to travel to another for bracing because braces are not available.



*Caregivers going about their daily lives while living at the hospital, Masaka Hospital, Uganda.*

*'Parents may be told to contribute or pay for treatment and may not have the money...'*

- Practitioner treating clubfoot, Tororo, Uganda.

*'Treatment is free, but sometimes we run out of supplies i.e. cumulatively maybe 1 month out of a year. Then parents are asked to buy supplies. 2 out of 10 can't pay. They come back later when supplies are available. They also buy the braces i.e. 15000 shillings (approximately USD 8) for the night splints....'*

- Practitioner treating clubfoot, Mbale Uganda.

*'As a project we don't charge. But of recent we have initiated a program to charge 1000 as they come to change their casts and 2000 as a subscription fee for services and on a quarterly basis. This means at the end of each quarter, a client pays 2000. Most of them have not started paying the 2000, but others have started to pay the 1000... .'*

- Practitioner treating clubfoot, Tororo, Uganda.

*'Treatment is free, but when it comes to appliances we will share the bill if they are really poor. We do an economic assessment to see what they are able to pay...'*

- Practitioner treating clubfoot, Masaka, Uganda.

Although we have not examined this issue quantitatively, it subjectively appears as though some regions have higher success rates than others and these outcomes appear to be related at least partially to resource availability.

#### **Inadequate resources for follow-up:**

Because of all of the barriers presented, people may have difficulty adhering to treatment. The bracing phase can be especially challenging because it requires daily diligence. If parents are not counseled to the proper bracing process or the risk of recurrence, it is easy to see how they may see the child as cured and relax on their bracing regime, especially when faced with so many on-going responsibilities in the home. This scenario was especially frustrating to practitioners... They have conducted months of treatment, seen the child progress to the point of correction, only to see the condition reverse....



*Looking for the child with clubfoot: A research assistant travels to a rural village in search of a child with neglected clubfoot.*

*'Sometimes there is recurrence, mothers relax and leave the feet free i.e. don't follow instructions. Then the whole process has to be repeated which is a problem for practitioners and parents...'*

- Practitioner treating clubfoot, Kampala Uganda.

*'Some mothers change the brace, thinking their children are over-exaggerated and this deformity recurs...'*

- Practitioner treating clubfoot, Iganga, Uganda.

*'When the shoes are not given out regularly, these children stop putting them on, when enables the condition to recur...'*

- Practitioner treating clubfoot, Mukono, Uganda.

Most practitioners treating clubfoot are facility based, and there are extremely limited resources to conduct follow-up. Responsibility for adherence is left almost exclusively to the parents. While parental responsibility is absolutely essential, as we have outlined, there are also barriers that make adherence very challenging. Parents do not have the vast experience that practitioners have

when it comes to knowing the risks of recurrence. So, when faced with barriers, may err on the side of discontinuing treatment, thinking the child is cured, or believing that a bit of time off the regime won't make a difference...Without proper follow-up, these diversions from treatment go un-noticed and the problem becomes much more difficult to rectify.

*'More follow-up is needed for children after surgery. Relapse always happens when parents don't use the appliance and don't keep appointments. If the child is not followed up, 10% will relapse for these reasons. ...'*  
- Practitioner treating clubfoot, Tororo, Uganda.

### **Over-coming the barriers to adherence; the positive factors:**

Sometimes seeing other children who have been corrected, or speaking with a mother who knows exactly how you feel and tells you of how her child used to have such feet can offer great hope and incentive to adhere...Parents are very anxious to believe that their children will recover, and they can gain solace and motivation from coming to clinic and seeing other children who are at various stages of treatment and are progressing. Having the opportunity to talk to other mothers in waiting rooms, gives them further reassurance in knowing that they are not alone. These factors can be very encouraging in influencing positive adherence behaviour.

*'It was traumatizing, but when we came to the clinic we were comforted by the many cases we found and were sure that they could get the clubfoot corrected....'*  
- Parent of child with clubfoot, Kampala, Uganda.

*'I have stuck to the doctors treatment only because I know the foot will get healed as long as I do what the doctor says; and during the course of the child's treatment I have seen some healed cases...'*  
- Parent of child with clubfoot, Mbarara, Uganda.

*'Parents, while in fear and doubt should go to hospital and get advice and see similar cases, by the time they come back, they are strengthened...'*  
- Parent of child with clubfoot, Iganga, Uganda

*'I would advise other parents to take the child to the hospital to make sure that they finish the treatment in order to avoid any relapse like I have had to go through....'*  
- Parent of child with clubfoot, giving her advice to other parents, Tororo, Uganda

Like every theme discussed, there are however always exceptions to the rule, and we did hear of some parents becoming discouraged in seeing that their child was more severe than others at clinic. But... this was fortunately the exception.

Another factor which tended to encourage positive adherence behaviour was seeing progress in ones own child as the treatment progressed.

*'After first week I was disappointed to see no improvement, but agreed to have a second cast. Next time of removal, I gained strength when I saw improvement and thought the ordeal was over, but another cast was recommended....'*  
Parent of child with clubfoot, Iganga, Uganda

*'Yes, I am happy because the foot is getting corrected and the health of the child is good, though I walk some days from Kisoko up to the center...'*

Parent of child with clubfoot, Tororo, Uganda

Counseling by practitioners is yet another positive way to encourage parents to stay with this lengthy treatment regime. But more than just encouraging adherence, taking the time to talk to parents also gives practitioners greater understanding of their patient needs, fears, beliefs. With this knowledge, practitioners are in a better position to help parents adhere to this lengthy treatment regime.

*'I was on the verge of absconding due to lack of funds but I was advised to finish the treatment. If not, there would be a recurrence and the child would remain lame the rest of his life. I would also have wasted the time and the money I have so far used for the seven visits...'*

- Parent of child with clubfoot, Mbarara, Uganda.

*'You talk to the patients and advise them that it can be fixed. It is important to listen to the patient's beliefs, and to discuss your beliefs, then reach a compromise that will allow them to adhere to a treatment. If you respect them and their beliefs, they will come back...'*

- Practitioner treating clubfoot, Kampala, Uganda.

*'Moral support is lacking i.e. fathers neglect such cases, so mothers have to suffer on their own. Fathers too have to be sensitized i.e. come with the mother to clinic to take responsibility and learn how to care. It is important that there is a consensus between parents with a mutual commitment. It is the officer's role to convince both parents well, if he fails, they will not come back...'*

- Practitioner treating clubfoot, Kampala, Uganda

Adherence should be viewed as a partnership with the parents. As the experts, practitioners are in a position of knowledge and power, and through counseling and support, can help caregivers face their barriers and adhere. The following practitioner beautifully illustrates the responsibility of the health professional in his/her relationship with the parent.

*'Those who follow through with treatment are easiest, but it is your advice as a practitioner that helps them follow through. You help them to understand what it is and why they must follow-through...'*

- Practitioner treating clubfoot, Mbale, Uganda.

And finally, some regions are assisting their families to overcome their barriers by conducting outreaches and meeting needs. Community based rehabilitation teams and Uganda Society for Disabled Children are out in some communities, traveling to children with disabilities, advising supporting and even providing some assistance with transport. This is a model which should be looked at closely by healthcare planners for those living remotely.

*'Transport to hospital can be difficult; we need to bring treatment closer to the community. It needs to be more convenient...'*

- Practitioner treating clubfoot, Mbale, Uganda.

*'...They come here and we go to them. If we did not go out, the parents may not come for new appliances. Our success rate is so high because we follow-up with patients...'*

- Practitioner treating clubfoot, Tororo, Uganda.

### **Conclusion:**

It is our hope that this objective has served to outline the many barriers faced by caregivers of parents of a child with clubfoot. It is important that health care providers truly do see non-compliance as a diagnosis of exclusion (Farmer, 1999) and do not get into a situation of blaming. There will be parents who are 'non-compliant' in the true sense of the phrase; but these are very few. We must believe that parents want to do what is best for the health and well-being of their children; and if they are not able to do so, it is reflective of barriers and negative influences. We as health providers are in a position to help meet these barriers and over-come the negative influences to treatment-seeking to the benefit of all involved.

## Discussion of Emerging Themes:

In order to help us understand how people conceptualize clubfoot in Uganda, this rapid ethnographic study was designed to study knowledge, attitudes, beliefs, practices and the context of people's lives.

Our first objective was to outline the local terminology for this congenital condition. It was hoped that this knowledge would be useful for informing healthcare planners about appropriate language for education and effective communication. What we discovered was that there were many, many words used to talk about this condition. Uganda is a very diverse country; there are many languages, many beliefs, and many cultures. Therefore, in Uganda there was no single term that universally captured the congenital condition of clubfoot. There were however some common themes within which all terms could be categorized i.e. general terms for lame or crippled; descriptive terms (folded, bent, spoon-like, etc.); terms which took the names of small gods; and finally, stigmatizing or derogatory terms. In summary, we see that in Uganda, there are many ways of describing what biomedicine has termed clubfoot. Therefore, in order for awareness and education campaigns to be effective, they must rely heavily on visual aids i.e. pictures, models and case examples. Language alone will prove an unreliable communication strategy and should be used primarily as a supporting tool.

Our second objective of this study was to review local explanatory models and theories of causation. The importance of this objective focused on increasing understanding between health providers and their clients as well as providing clues as to motivations behind health-seeking behaviour. Most of our layperson respondents were not certain about causation; however, they offered a number of theories that seemed probable or likely. These theories can be grouped under the following themes: Firstly, it was believed that this condition was hereditary; this theme was reported largely by individuals who had some history of the condition in their lineage, or who knew of families with multiple persons with clubfoot. We also heard numerous theories around a higher power or the supernatural involved in causation; this theme encompasses God-sent, spirits, curses, witchcraft, small family gods, etc. Next we heard of the biomedical germ theories; for instance, polio, tetanus, measles, etc., and in keeping with this theme, it was felt that lack of immunization could potentially cause clubfoot. Sometimes respondents reported causes related to the mothers lifestyle; for instance, over-working, poor nutrition, substance abuse, the use of family planning pills, spousal abuse, accidents, falling, tying the stomach, sleeping in the wrong position, etc. Finally, we heard of maternal-fetus factors such as crowding in the womb due to small womb, twins, or large infant, or poor-positioning of the child in the womb. Most of our medical professionals working with clubfoot reported that the cause of the condition is not known or inconclusive. However, they too offered theories that they had heard of or read about including many of the theories mentioned by our lay persons. In summary, there are a multitude of beliefs which impact treatment-seeking behaviour and treatment delivery. With knowledge of these beliefs, practitioners can be more informed and strive towards reciprocal understanding and mutually acceptable methods of education and treatment delivery.

The third objective of our ethnographic study was to explore appropriate methods of knowledge dissemination for the local context. Our population covers a wide range of

people including those of different socioeconomic status and educational levels. Therefore, it was important to discover what the various categories of respondents felt were appropriate methods of sharing health information. Our respondents suggested many diverse, creative and appropriate methods of knowledge transfer, however, some of the more prominent themes included: use of the media especially radios, use of local leadership, informing health practitioners (both biomedical and traditional), broad sensitization and public address, using current health services such as antenatal care and immunization, conducting outreach and bringing services closer to home. In summary, there are many methods of sharing information about the identification and treatment of clubfoot in Uganda. It would be advisable for awareness campaigns to focus on multiple methods in order to reach the greatest number of people in the population.

The fourth objective of the study was to examine current health seeking behaviour when a child was born with clubfoot; and the factors that influence this behaviour. The importance of this objective was to establish our baseline of treatment-seeking behaviour. However, in addition, in examining treatment-seeking behaviour we were able to gain insight into the barriers present in Uganda, which were impeding access to care. In Uganda, people are using the services of both biomedical and traditional healers. Medical pluralism is often at play, where people seek out a variety of different forms of healthcare either concurrently or sequentially in order to address their health concerns. As well, at times, people are self-treating with drugs or herbs. When it came to clubfoot treatment-seeking, there were a number of factors influencing this behaviour: level of awareness, belief systems, location of birth, access to transportation and distance to health facilities, poverty, challenges with the process, social influences, and other responsibilities. However, there were also positive factors influencing treatment-seeking behaviour including: positive social support, seeing encouraging results in others, being counseled by supportive health professionals, and having positive experiences with the healthcare system. The results of this objective present a number of challenges to healthcare planners. However, only through understanding these influences, can practitioners and their patients move into a partnership with each other where they strive to minimize the negative influences and maximize the positive.

Our fifth objective was to explore gender issues in Uganda in an attempt to determine if they were influencing treatment-seeking behaviour. The results of our study suggest that Uganda remains predominantly patriarchal but with increasing movement towards equality. However, at the present, gender roles remain fairly distinct with mothers primarily responsible for childcare. A major issue for health-seeking behaviour appears to be related to mother's primary responsibility for healthcare, with limited access to finances. Yet, although this gender issue among others affects health seeking, gender issues in general do not appear to be responsible for the significantly greater numbers of boys being treated for clubfoot. In Uganda, the majority of parents reported believing that all children should be treated, regardless of gender. In summary, there remains significant gender inequality in Uganda which impacts the health and well being of the population however, these issues do not appear to be directly responsible for the ratio of boys to girls presenting for clubfoot treatment.

Our sixth and final objective was to identify the barriers to adherence to clubfoot treatment in Uganda. The importance of this objective was to help healthcare planners identify the needs of the population when it came to adhering to this lengthy treatment regime. Our study confirmed that there were indeed a number of significant barriers to adherence to treatment, and very few of these related to non-compliance due to a lack of will. Poverty, distance to health facilities, lack of support

from fathers, caregivers other responsibilities, challenges of the process, scarce resources and regional imbalances, and a lack of follow up services were felt to be the major themes presented by respondents. In summary, in order for the Ponseti method to be feasible for the population, healthcare planners must be sensitive to meeting the needs of children with clubfoot and their families. The barriers to treatment as identified in this study need to be addressed in the most culturally sensitive, holistic, and feasible manner in order for the program to be successful.

***Possible Outcomes from this study:***

The Ponseti treatment has tremendous international potential for decreasing the prevalence of this debilitating but treatable congenital deformity. Improving access to this method of treatment has direct implications for functionally and qualitatively improving the lives of the 1 to 3 in 1000 children in developing countries who are born with clubfoot.

*‘Community members laugh at me saying that the child is only handsome in the face, but lame. I used to hide my child, and my mother told me not to do so, that I should leave them to laugh because he is going to get healed...’*  
- Mother of a child with clubfoot, Tororo, Uganda, 2005

Through conducting this research, we have promoted awareness about treatment in 8 districts of Uganda and have engaged the local population in dialogue, which in itself was empowering and educational (Pope & Mays, 1996).

This area has not previously been studied and it is therefore a genuine contribution to the knowledge base of this field. We will seek to publish results so that the information becomes available in the literature and can be applied to other developing countries.

Finally and most importantly, this rapid ethnographic study provides valuable insights into important contextual considerations. It informs healthcare providers and planners of the local perceptions and thereby increases the potential for greater understanding, improved communication and mutually respectful interactions. Understanding, as gained in this study, gives health care planners the opportunity to face known barriers and meet the needs of their population. Through finding creative and cost-effective means of meeting the needs of the population, Uganda can become an international model of exemplary care.

## **Recommendations:**

We offer the following recommendations firstly to the Uganda Sustainable Clubfoot Care Project and secondly to the country's health care planners. These recommendations are meant to represent the voices of our respondents who have guided us as to what must be done in order to meet their needs. It also represents the successes we have both seen and heard about; for these are the accomplishments on which to build a winning health program. We have divided the recommendation into those made for improving detection, and those mean to address adherence:

### **Recommendations for the project:**

#### Detection:

1. Awareness campaigns and education should rely heavily on visual aids such as models, pictures and hands on practical experience. Language is an unreliable tool if used in isolation.
2. Due to the grouping of people with disabilities into similar categories, it is advisable to promote universal health consultation for children born with impairment of body structure or function. Health professionals can then identify children with correctible impairment such as clubfoot, and arrange for support services for all children with disabilities through the Uganda Society for Disabled children.
3. Use the media to the advantage of health services to promote health service awareness about clubfoot and its treatment.
4. Use posters which rely heavily on accurate pictures to promote awareness of the condition and place these in public areas including all health facilities.
5. Utilize the currently available and functioning health services to promote both awareness of the condition and treatment availability i.e. immunization, antenatal services and local council birth registration.
6. Use established community structures, such as the local council leaders to promote awareness among their communities.
7. Midwives, nurses and health practitioners in all health facilities should be trained to identify and refer child with clubfoot to the regional clubfoot clinics.
8. Traditional healers should be trained to identify and refer children with clubfoot.
9. Put up permanent signs in hospitals directing patients to clubfoot clinic so that when they come to clinic for the first time they are able to locate the service with minimal hassle.

Adherence:

1. Due to the stigma which is attached to disability, it is advisable to give strong visual messages that children with clubfoot may be returned to full function following treatment. Use posters in clubfoot clinics and beyond which show individuals with corrected clubfoot actively participating in daily life (i.e. working, driving cars). This visual image may act as a positive reinforcer for adherence.
2. Practitioners should be trained to identify and acknowledge caregivers explanatory models in order to increase understanding and trust between the parties. The message given to caregivers should be that whatever their beliefs, they can work with the practitioner to achieve the desired result of correction.
3. For traditional practitioners who are already treating clubfoot, the project should consider closer partnerships with biomedical practitioners.
4. Consider providing treating practitioners with additional training on counseling so they can better assist males who may be reluctant to support their wives in care-seeking.
5. Based on the findings of this study, we felt that the barriers to adherence were sufficiently critical as to require attention in order to ensure the success of the program. Therefore, we suggest: Practitioners receive additional training on the barriers to adherence and counseling skills to facilitate adherence. This should include: enquiring about caregivers beliefs, addressing their misconceptions, alleviating fears, and joint problem-solving for over-coming barriers.
6. In order to further address the issue of adherence, the project planners may want to consider further research examining outcomes when adherence support is provided to caregivers.

**Recommendations for the healthcare system:**

***Many of these issues are systemic issues. We therefore offer the following recommendations to health care planners:***

Adherence:

1. There is need to increase efforts to provide adherence support through outreach services and community follow-up. The community-based rehabilitation services should be reviewed as a model of service delivery which can be expanded. This will require increased spending, but when viewed in terms of long-term cost benefit, will be far less expensive than costly surgeries and impeded life courses for children who relapse or remain neglected.
2. Expanded outreach services should involve conducting follow-up early in the bracing phase in order to improve adherence. Outreach practitioners could carry an 'adherence kit' with them containing various sizes of braces, cotton wool, pressure wound care, etc to deal with issues right away in the field.

3. Improve current service delivery at clubfoot clinics so that patients are treated consistently and with respect. Put monitoring systems in place to ensure that treatment quality is maintained and corruption minimized.
4. Increase capacity for brace production and/or distribution to prevent running out of stock; and conduct quality control across regions.
5. Consider brace recycling programs to minimize costs and maximize resources.
6. Remove fees for braces or ensure social work involvement to help clients meet the costs. Charging for braces appears to continue to be a problem in most of the regional hospitals and must be addressed to ensure consistency and improve adherence.
7. Ensure resource availability in all hospitals including: plaster of paris, cotton wool, and tools for casting and bracing.
8. Correct regional imbalances in resources availability and strive for consistency. Ensure accountability systems are in place.
9. Increase social work involvement in regional outreach teams to assist with addressing individual client barriers and adherence support. Ensure that they are provided with resources to conduct their jobs effectively; for instance, pool of finances to provide transport support.
10. Outcomes for all cases treated should be monitored and reasons for failure documented. Results of monitoring should be reviewed regularly so that programs can be adjusted to meet the needs of the population.

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## Appendix:

**MAKERERE**  
P.O. Box 7072 Kampala Uganda  
Website: <http://www.iph.ac.ug>



**UNIVERSITY**  
Tel: 256-41-532207/543872/545002  
Fax: 256-41-531807

INSTITUTE OF PUBLIC HEALTH

### *Informed Consent Form:*

#### **‘Understanding Clubfoot in Uganda’**

**I am a research assistant working with Makerere University in Kampala. I am doing research on people born with these feet (show model of clubfoot) which happens to many children in Uganda.**

#### **Purpose of the research:**

When children are born with these feet (show picture) it can be hard to walk, join in with friends, go to school, and work. Children who have these feet can have their feet fixed so that their feet work the same as everyone else’s, but they have to be brought to a healer soon after they are born. In order to find ways of helping children get their feet fixed, we need to understand what people in this community know about these feet (show picture). For example, we want to know what words you use to talk about these feet, what you think causes it, how to fix it, how it is different for boys and girls, how we can find babies when they are born with these feet so they can be fixed early, and who you think is the best person in your community to fix these feet. We also want to understand your community better so we will ask you some questions about daily life and people’s roles.

To find answers to some of these questions, we invite you to take part in this research project. If you accept, you will participate in an interview with the researcher which will be audiotape recorded so you’re your answers can be reviewed later. It is important that you understand the following information about the study:

- Your participation is entirely voluntary. You may refuse to take part in the discussion. If you decide to take part, you may stop at any time if you do not want to continue. You also have the right not to answer any particular question or questions.
- The conversation will be audio-taped so as not to miss out any details. However, no names will be used on any tape labels. The audio tapes will be kept under lock and key.
- All information collected for this study will be kept strictly confidential. Individual responses to our questions will never be associated with your name or the names of others who participate in the discussion. The findings collected will be used only for research purposes and program development.

- The conversation will be written down on paper later for further study, but names will not be present on any written record of the discussion.

Benefits:

There will be no direct benefit to you, but your participation is likely to give us information that will help us find babies with these feet (show picture) earlier so that they can be fixed and have their feet work the same as everyone else's. This will help them to walk, and participate the same as other children.

Who to contact:

If you have any questions, you may ask now or later. If you wish to ask questions later, you may contact:

Dr. Stella Neema, Department of Sociology, Makerere University 077457576 or Dr. Joseph Konde Lule at

By signing or writing your initials here, you agree that you will participate in the study and that your consent is given voluntarily.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

If a person is unwilling to initial or sign or unable to read or sign:

I (the interviewer) will sign here indicating that the information above was read to you, that you agree to participate in the study and that your consent is given voluntarily.

\_\_\_\_\_  
Interviewer

\_\_\_\_\_  
Date

the Institute of Public Health 256-41-532207/543872/545002

***Interview with traditional healers:***

**Brief background Information**

District \_\_\_\_\_

Sub county \_\_\_\_\_

Parish \_\_\_\_\_

Village \_\_\_\_\_

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**Socio-economic Status**

Type of Housing:

Roofing \_\_\_\_\_

Walls \_\_\_\_\_

Floor \_\_\_\_\_

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Date of Interview \_\_\_\_\_

Name of interviewer \_\_\_\_\_

Type of Practitioner: \_\_\_\_\_

Age of Practitioner: \_\_\_\_\_

Ethnicity of Practitioner: \_\_\_\_\_

Highest level of Education of Practitioner: \_\_\_\_\_

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*It is important to be flexible in the use of these questions. Follow the interviewee's lead and probe on issues that they bring up.*

1. How long have you been healing/treating people in your community?
2. Show picture/ model. What is this condition?
3. What is the local term people use to describe this condition?
4. What special names are given to children born with such a condition?
5. What causes this? (*probe: witchcraft, God sent, curse, hereditary, chance/random*)?
6. Could mothers do anything before or during pregnancy to help stop this?
7. Have you ever treated this condition?
8. If yes, can you give a case example of a child you treated?
9. If no, how would you treat this?
10. Are there ethnic groups where this condition is more common? Why?

11. Who are the most affected by this condition, boys or girls? Why?
12. Are boys and girls treated differently in your community? If yes, why? (*probe the roles, expectations, activities of boys and girls in the community*)
13. In the case of illness or disability, do families give more importance to seeking healthcare treatment for boys or girls? Why?
14. What sorts of patients do you enjoy treating?
15. What sorts of patients would you rather not treat?
16. What do you normally charge for treatment?
17. How much would you charge to treat this condition?
18. Is it hard for most people to pay?
19. Show picture of clubfoot after treatment (give brochure and explain what was done). Ask, would this treatment be helpful in your region?
20. What could make it difficult for parents/caregivers to get this type of treatment for their children? (*Probe barriers to adherence*)
21. Would you be willing to advise and assist people to obtain this method of treatment?
22. What is the best way for you to learn? (*Probe books, pictures, practice, mentoring, etc.*)
23. There is a new Ministry of Health government program to ensure that children born with this condition are identified and treated early. This is important because treatment is most effective when started soon after birth. What advice do you have to help us find children with this condition early in life?
24. This is not a common condition; however, if it is not treated early in life, it results in a life-long disability. What is the best way to inform the community about this condition? (*Probe methods of increasing community awareness*)

**At the end of the interview, please provide a 3-minute summary the respondent's key messages as you have understood them. Then allow the participant to verify the information or add anything they feel you may have missed (Krueger, 1998)**

***Interview with practitioners treating clubfoot:***

**Brief background information**

District \_\_\_\_\_

Sub county \_\_\_\_\_

Parish \_\_\_\_\_

Village \_\_\_\_\_

Date of Interview \_\_\_\_\_

Name of interviewer \_\_\_\_\_

Name of Practitioner: \_\_\_\_\_

Type of Practitioner: \_\_\_\_\_

Age of Practitioner: \_\_\_\_\_

Ethnicity of Practitioner: \_\_\_\_\_

Education of Practitioner: \_\_\_\_\_

*It is important to be flexible in the use of these questions. Follow the interviewees lead and probe on issues that they bring up.*

1. Show model/picture. What do you call this?
2. What is the local term people use to describe it?
3. What special names are given to children born with such a condition?
4. What causes this? (*Probe witchcraft, God sent, curse, hereditary, chance/random*)?
5. Could mothers do anything before or during pregnancy to help stop this?
6. When a child is found to have this condition, what is usually done? (*Probe for pattern of resort and delays*)
7. What care do they normally receive? (*Probe: traditional care, biomedical care*)
8. How long have you been treating this?
9. What training did you get to learn how to treat this?
10. Can you give a case example of a child that you treated recently?
11. How many children do you treat in a year?
12. Is your treatment successful?
13. How do you know your treatment is successful?

14. How early do most caregivers bring their children to your attention?
15. What are caregiver's usual concerns/fears/feelings?
16. What are the common community beliefs about the cause?
17. Are there ethnic groups where this condition is most common? Why?
18. Do you treat more boys or more girls? *(If practitioner says one or the other, probe...why do you think this is so?)*
19. In general, are boys and girls treated differently in this community? If yes, why? *(probe the roles, expectations, activities of boys and girls in the community)*
20. In the case of illness or disability, do families give more importance to seeking healthcare treatment for boys or girls? Why?
21. What fees do you charge for treatment?
22. If money is charged, is it hard for most people to pay?
23. What sorts of patients do you enjoy treating?
24. What sorts of patients would you rather not treat?
25. There is a new Ministry of Health government program to ensure that children born with this condition are identified and treated early. This is important because treatment is most effective when started soon after birth. What advice do you have to help us find children with this condition early in life?
26. This is not a common condition; however, if it is not treated early in life, it results in a life-long disability. What is the best way to inform the community about this condition? *(probe methods of increasing community awareness)*

**At the end of the interview, please provide a 3-minute summary the respondent's key messages as you have understood them. Then allow the participant to verify the information or add anything they feel you may have missed (Krueger, 1998)**

***Interview with parents of children with clubfoot:***

**Brief background Information**

District \_\_\_\_\_

Sub county \_\_\_\_\_

Parish \_\_\_\_\_

Village \_\_\_\_\_

**Socio-economic Status (of the main house i.e. the one where they sleep)**

Type of Housing:

Roofing \_\_\_\_\_

Walls \_\_\_\_\_

Floor \_\_\_\_\_

Date of Interview \_\_\_\_\_

Name of interviewer \_\_\_\_\_

Relationship of the Respondents to the child \_\_\_\_\_

Age of caretaker \_\_\_\_\_

Ethnicity of caretaker \_\_\_\_\_

Education of the caretaker \_\_\_\_\_

Marital Status \_\_\_\_\_

What do you usually do for a living \_\_\_\_\_

Education of the mother \_\_\_\_\_

Education of the father \_\_\_\_\_

Ethnicity of the mother \_\_\_\_\_

Ethnicity of the father \_\_\_\_\_

Ethnicity of the Child \_\_\_\_\_

Age of the child \_\_\_\_\_

Sex of the child \_\_\_\_\_

Family history of condition (*do not name, show model/picture*)  
\_\_\_\_\_

Number of children with this condition born to these parents  
\_\_\_\_\_

*It is important to be flexible in the use of these questions. Follow the interviewees lead and probe on issues that they bring up.*

1. What do you call this condition of your child's feet?  
(*From this point forward, use the term for the condition provided by the caregiver.....*)
2. When did you notice that he/she had this condition?
3. What is the local term that people use to describe it?

4. What special names are given to children born with such a condition?
5. What caused this? (*Probe: witchcraft, God sent, curse, hereditary, chance/random*)?
6. Do you feel there is anything you (the mother) could have done to prevent this?
7. When you noticed the condition, whom did you first go to for advice or help?
8. What did your relatives think/say?
9. What did the community think/say?
10. What have you tried to treat this condition?
11. Did you seek help from a practitioner to treat this condition?
12. Was there anything that made it hard to seek treatment for this condition?
13. Was the treatment successful?
14. How do you know it was successful?
15. Were you happy with the treatment you received?
16. What did it cost to get treatment? (*probe bidden costs: time, money, travel, work time lost, childcare expenses, etc*)
17. Were the fees manageable?
18. What advice would you give to other parents/caregivers who had a child with clubfoot?
19. How many people live in your house, and who are they? (*Probe household composition*)
20. Who makes the decisions about money in your house?
21. Who makes decisions about getting treatment for health problems in your house?
22. How are household jobs/roles divided up?
23. Who is the most important person in the house? Why?
24. Are boys and girls treated differently in your home? Why?
25. How is your child with clubfoot treated by other members of the family? In the community?
26. Tell me the story of what you have gone through having a child with this condition. (*Probe feelings*)

27. What problems/challenges did you face/have you faced as a caregiver in looking after the child? (*Probe functional challenges, social challenges, mobility, access, etc.*)

28. There is a new Ministry of Health government program to ensure that children born with this condition are treated early. This is important because treatment is most effective when started soon after birth. What advice do you have to help us find children with this condition early in life?

**At the end of the interview, please provide a 3-minute summary the respondent's key messages as you have understood them. Then allow the participant to verify the information or add anything they feel you may have missed (Krueger, 1998)**

***Interview with community leaders:***

**Brief background Information**

District \_\_\_\_\_

Sub county \_\_\_\_\_

Parish \_\_\_\_\_

Village \_\_\_\_\_

**Socio-economic Status *(of the main house i.e. the one where they sleep)***

Type of Housing:

Roofing \_\_\_\_\_

Walls \_\_\_\_\_

Floor \_\_\_\_\_

Date of Interview \_\_\_\_\_

Name of interviewer \_\_\_\_\_

Title/designation of Community Leader: \_\_\_\_\_

Age of leader \_\_\_\_\_

Gender of leader: \_\_\_\_\_

Ethnicity of Leader \_\_\_\_\_

Education of the Leader \_\_\_\_\_

What do you usually do for a living \_\_\_\_\_

*It is important to be flexible in the use of these questions. Follow the interviewee's lead and probe on issues that they bring up.*

1. Show picture/model. What is this condition called?
2. What is the local term that people use to describe it?
3. What special names are given to children born with such a condition?
4. Do you know of anyone who has this condition? If yes, tell me about them...
5. What do you think causes this condition? (*Probe witchcraft, Godsend, hereditary, curse, chance/random*)
6. Could mothers do anything before or during pregnancy to help prevent this condition?
7. Do you think it can be treated?
8. What would you tell a family to do if they had a child with this condition?

9. In your community, where do people go if they have a health related problem? (*Probe traditional or biomedical and pattern of resort*)
10. Who are the most affected by this condition (show model/picture) boys or girls? Why?
11. Are boys and girls treated differently in your community? If yes, why? (*Probe the roles, expectations, activities of boys and girls in the community*)
12. In the case of illness or disability, do families give more importance to seeking healthcare treatment for boys or girls? Why?
13. What are the major activities of men in your community? (*Probe: societal, economic, political, cultural roles*)
14. What are the major activities of women in your community? (*Probe: societal, economic, political, cultural roles*)
15. What are the most important things that men do in the family/home?
16. What are the most important things that women do in the family/home?
17. What decisions can women make about money in the home?
18. What decisions can women make about getting health treatment for children? (*Probe household decision-making process i.e. when to get treatment, where to seek treatment, logistics of seeking treatment*)
19. In your community, if a child is born with this condition should caregivers be encouraged to seek treatment (*show model and probe willingness to treat*)?
20. How do we motivate people in your community to seek treatment for their children's feet?
21. There is an effective method of treatment available and orthopaedic officers around Uganda have been trained in this method (show brochure and explain treatment). In your community, who should be trained to advise and assist people to get this treatment for children with this condition?
22. What would be the best way to train these people to advise and assist caregivers? (*Probe: books, courses, mentoring, etc*)
23. There is a new Ministry of Health government program to ensure that children born with this condition are treated early. This is important because treatment is most effective when started soon after birth. What advice do you have to help us find children with this condition early in life?
24. This is not a common condition; however, if it is not treated early in life, it results in a life-long disability. What is the best way to inform the community about this condition? (*probe methods of increasing community awareness*)

**At the end of the interview, please provide a 3-minute summary the respondent's key messages as you have understood them. Then allow the participant to verify the information or add anything they feel you may have missed (Krueger, 1998)**

### ***Focus Group with Community Members:***

**Brief background information:** *Please complete background information sheet and make a diagram of the seating arrangement).*

*Please try to avoid giving examples as this can lead the respondents towards an answer. If the discussion gets off topic, or too focused by one person, repeat the question.*

1. Show picture/model of clubfoot. What is the local term that people use to describe this condition?
2. What special names are given to children born with such a condition?
3. What causes this condition? *(if no answer is given, probe: witchcraft, God sent, Curse, hereditary, chance/random)*
4. Could the mother have done anything before or during pregnancy to stop this from happening?
5. If a family in your community had a baby with this condition, what would you tell them to do?
6. Do you think it can be treated?
7. Whom should they go to for treatment?
8. In your community, where do people usually go if they have a health related problem? *(probe: traditional care or biomedical care and pattern of resort)*
9. Are there ethnic groups where this condition is most common?
10. Who are the most affected by this condition boys or girls? Why?
11. Are boys and girls treated differently in your community? If yes, why? *(probe the roles, expectations, activities of boys and girls in the community)*
12. In the case of illness or disability, do families give more importance to seeking healthcare treatment for boys or girls? Why?
13. What are the major activities of men in your community? *(probe: societal, economic, political, cultural roles)*
14. What are the major activities of women in your community? *(probe: societal, economic, political, cultural roles)*
15. What are the most important things that men do in the family/home?
16. What are the most important things that women do in the family/home?
17. What decisions can women make about money in the home?

18. What decisions can women make about getting health treatment for children? (*probe household decision-making process i.e. when to get treatment, where to seek treatment, logistics of seeking treatment*)

19. Should people in your community be encouraged to seek treatment for their children's feet if born with this condition (*show model and probe willingness to treat*)?

20. How do we motivate people in your community to seek treatment for their children's feet?

21. There is an effective method of treatment available and orthopaedic officers around Uganda have been trained in this method. In your community, who should be trained to advise and assist people to get treatment for children with this condition?

22. There is a new Ministry of Health government program to ensure that children born with this condition are treated early. This is important because treatment is most effective when started soon after birth. What advice do you have to help us find children with this condition early in life?

23. This is not a common condition; however, if it is not treated early in life, it results in a life-long disability. What is the best way to inform the community about this condition? (*Probe methods of increasing community awareness*)

24. What did you like or dislike about this discussion? Do you have any suggestions for future discussions?

**At the end of the focus group, please provide a 3-minute summary the respondent's key messages as you have understood them. Then allow the participant to verify the information or add anything they feel you may have missed (Krueger, 1998)**