

## Understanding the barriers to clubfoot treatment adherence in Uganda: A rapid ethnographic study

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### Abstract

**Purpose.** The Ponseti method has been demonstrated to be an effective, low-technology method of correcting congenital clubfoot. The purpose of this paper is to identify barriers to adherence to the Ponseti method of clubfoot treatment in Uganda. Understanding of barriers underlies successful and culturally appropriate approaches to program implementation.

**Method.** A qualitative study (rapid ethnographic study), using semi-structured interviews, focus groups and observation, was conducted. Interviews were conducted with parents of children with clubfoot (42), adults with clubfoot (2), community leaders (40), traditional healers (39) and practitioners treating clubfoot (38). Some 48 focus groups (24 male, 24 female) were conducted with general community members to ascertain their opinions on the potential barriers. The data was collected by a team of researchers in 8 districts of Uganda over the period of one month. It was then coded manually by the researchers and sorted into themes.

**Results.** The barriers to adherence were classified into 6 themes: (i) problems with programmatic resource availability and regional differences, (ii) distance to treatment site, (iii) poverty, (iv) lack of paternal support, (v) caregiver's other responsibilities, and (vi) challenges of the treatment process. A number of factors that were helpful for encouraging adherence were also identified: (i) outreach and follow-up services, (ii) counselling/caregiver-practitioner partnership, (iii) family harmony and solidarity, and (iv) receiving quality care.

**Conclusions.** Our study highlights the barriers to adherence in the treatment of clubfoot, as well as factors that could be helpful for overcoming these barriers. This information provides health planners with knowledge to assist them in meeting the needs of the population and implementing effective and appropriate awareness and treatment programs for clubfoot in Uganda.

**Keywords:** Club foot, adherence, compliance, barriers, Ponseti method, qualitative research, USCCP

### Introduction

'Approximately 80% of children born with a clubfoot deformity are born in the developing world' [1, p. 153]. In Uganda in 1994, there was an estimated 10,000 children with neglected clubfoot [2]. Untreated clubfoot results in significant physical impairment that limits mobility and has lifelong functional implications in this predominantly agricultural society. Children with clubfeet grow up with painful, deformed feet and as a result may be severely restricted in participation in typical daily life. Contextual factors or environmental barriers in

society may further disable them emotionally, economically and socially. In Uganda, there is currently limited infrastructure to support people with physical disabilities and stigmatization surrounding disability can result in marginalization. Girls with clubfoot can be further disadvantaged as they may be 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 [2].

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, Uganda)

The goal of the Uganda Sustainable Clubfoot Care Project (USCCP) is to reduce the consequences of disability from neglected clubfeet in Uganda. This is to be accomplished by means of institutionalizing the Ponseti method of clubfoot treatment throughout the Ugandan healthcare system and by providing universal Ponseti clubfoot treatment. There are three methodologically foci: (i) enhancing the capacity to detect the deformity, (ii) enhancing the capacity to treat the deformity, and (iii) conducting research (cultural perceptions, incidence surveys and outcome evaluations).

Due to the multiple ethnic groups and cultural diversity within Uganda, the cultural study is an important first step of the research component of USCCP. In order to effectively implement a culturally appropriate and relevant clubfoot treatment program in such a diverse population, it is vitally important to gain an understanding of the population's knowledge, attitudes, beliefs, practices, as well as the context of their lives. The rapid ethnographic study methodology is ideally suited for this purpose as it allows for an in-depth look at a particular health issue in a reasonable amount of time [3].

The purpose of this paper is to discuss the results of one of the objectives of the broader ethnographic study: Identifying the barriers to adherence to the Ponseti treatment regime in the Ugandan setting.

## Background

To begin, we undertook a literature search to determine if there has been previous research undertaken regarding adherence to this type of orthopaedic treatment in an African setting. We found no studies discussing caregivers' perceptions and experiences with adherence to the Ponseti method of clubfoot treatment.

The literature we discovered does however support research into culture and context and recognizes these elements as vital components of successful implementation of healthcare programs. Ethnographic research provides planners with insight into macro-level cultural, social, political, historical and economic factors, all of which have important practical implications for healthcare service delivery [4,5]. For instance, other studies have identified poverty and lack of physical access to facilities as barriers to seeking healthcare in an African setting [6]. Failure to address these barriers can lead to the failure of healthcare programs and blaming of patients. As Farmer notes, when we fail to recognize

these macro-level issues we are at risk of blaming the patients and their families for 'non-compliance': 'All too often, the notion of patient non-compliance is used as a means of explaining away program failure. Patient dependent failure should be a "diagnosis of exclusion"' [4, p. 227]. Therefore, by studying the issues that influence people's ability to adhere, we gain an insight that consequently presents us with an opportunity to address barriers and benefit of the population being served.

## Clubfoot in Uganda

Uganda is thought to have the same incidence of children born with clubfeet as elsewhere in the world; hence it is estimated that approximately 1 in 1000 infants are born every year with one or two clubfeet. Idiopathic clubfoot (Talipes Equinovarus) is a condition in which the child is born with the hindfoot adducted, flexed and supinated (or inverted) and the forefoot pronated in relation to the hindfoot [7]. There are varying degrees of severity.

In Uganda, the deformity is often not diagnosed, or if diagnosed it is neglected (Figure 1) as the conventional treatment of surgical correction is simply not possible with the resources available. Neglected clubfoot results in significant impairment in body structure and function and may result in activity limitations and participation restrictions.



Figure 1. Neglected clubfoot.

'Globally, neglected clubfoot is the most serious cause of physical disability among congenital musculoskeletal defects' [7, p. 4].

### The Ponseti method of clubfoot correction

The Ponseti method of clubfoot correction is a low-technology approach involving accurate gentle serial manipulation and weekly casting. Most children also undergo a tenotomy of tendo Achilles to complete correction of equinus prior to application of the last cast. To prevent recurrence of the deformity, a corrective Steenbeek foot abduction brace (see Figure 2) is worn full time (23 hours a day) for the first 2 months. After the first 2 months, it is worn at night until the child is two to four years of age.

In Uganda, there is currently no data available on the number of children being partially or fully treated with this method, but the numbers have expanded substantially in the last decade. Part of the research begun this year will look at collecting this data as a component of the outcome study.

In the current literature, there are numerous accounts of the effectiveness of this method of treatment for clubfoot [8–10]. However, research has also shown that though correction can be achieved in over 90% of children below 1 year of age, recurrence rates are high unless a brace is worn as per protocol [10]. Therefore, it is evident that the process requires sustained adherence in order to be effective. With adherence, children can obtain complete long-term correction of the condition and join a typical life trajectory.

Treatment using this method is most effective if it is begun before the age of 9 months. Successful correction can be achieved after this time, but with age there is a greater likelihood that the child will require surgery. Therefore, a key element of successful implementation is ensuring that children with

clubfoot are identified early in life and that treatment is initiated as soon as possible.

Another key element of implementation is ensuring that the method is readily accessible to the population. The Ponseti method is recognized as a low-technology method that can be taught to orthopaedic officers [8] and therapists, making it widely accessible in countries where orthopaedic surgeons are scarce [7].

### The Uganda Sustainable Clubfoot Care Project

This ethnographic study was the first phase of the Uganda Sustainable Clubfoot Care Project (USCCP); a six-year project funded by the Canadian International Development Agency. USCCP partners include: The University of British Columbia, Makerere University, the Ugandan Ministry of Health, the Children's Orthopaedic Rehabilitation Unit (CORU), Uganda, & Christian Blind Mission (CBM). Uganda is a signatory to the many United Nations Resolutions which guide nations regarding their approach to the provision of services for persons with disabilities and the Ministry of Health in Uganda has standards to help districts develop services that meet the needs of persons with disabilities. Considering these guidelines, USCCP's goal is to reduce the consequences of disability from neglected clubfeet in Uganda by building capacity throughout the Ugandan healthcare system to enable it to provide universal Ponseti clubfoot treatment to all Ugandan children born with clubfeet.

### Methods

Qualitative methodology was used to collect data in 8 districts of Uganda; 2 western districts (Mbarara and Ntungamo), 3 central districts (Kampala, Mukono

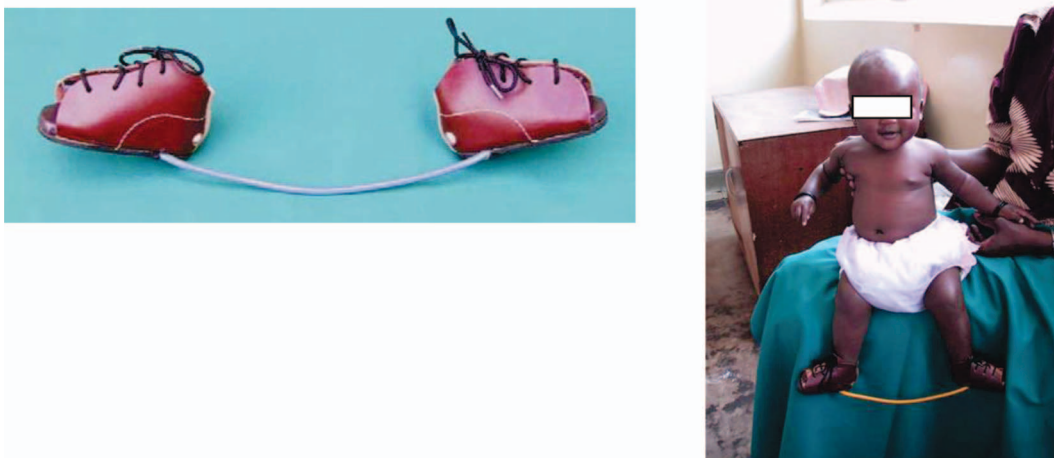


Figure 2. Child wearing a Steenbeek foot abduction brace.

and Masaka) and 3 eastern districts (Iganga, Mbale and Tororo). Effort was made to reach a diverse range of informants (i.e., different gender, socio-economic status, educational level, ethnicity and both urban and rural dwellers) in order to provide depth and validity to the data. The northern region of Uganda was not visited because of logistical and security concerns, although ethnic groups from the north currently residing in other regions were included in the study.

Data collection employed a variety of qualitative methods including interviews, focus group discussions and observation. The purpose of using multiple methods was to verify the data gathered and increase the validity of the study through triangulation [3]. Focus groups (24 male and 24 female) were conducted from amongst general community members and attempts were made to ensure that these discussions occurred in communities where there were no case studies. The interview questions were open-ended and the research assistants were trained in group facilitation techniques. Interviews were conducted with parents of children with clubfoot (42), adults with clubfoot (2), community leaders (40), traditional healers (39) and biomedical practitioners treating clubfoot (38). Effort was made to ensure that the case studies encompassed not only those individuals who were in treatment, but also cases that were neglected, i.e., who had not been treated or were significantly delayed in seeking treatment, as well as those who experienced relapse due to non-adherence. All interviews were composed of open-ended questions and research assistants were trained to probe for further information.

Recruitment for general community members (focus groups), community leaders and traditional healers primarily involved seeking out a local guide who would direct us to the interviewees and organize the focus groups in the region. Practitioners were recruited from the regional referral hospitals where all of the clubfoot clinics are based. Case studies were generally identified through referrals from the community-based rehabilitation teams, the hospitals, or the Uganda Society for Disabled Children.

The research assistants who conducted the focus groups and the majority of the interviews were Ugandan university graduates from a variety of disciplines (not necessarily health related) who were selected based on language competence and previous research experience. These skills were vital as the research was conducted in 12 local languages (Luganda, Lusoga, Lugwere, Lunyole, Gisu, Japhadhola, Ateso, Runyankole, Rukiga, Kinyarwanda, Runyoro/Rutooro and English) and as a result, it was unrealistic to translate all of the interviews into the multiple languages. However, to ensure reliability, the research assistants underwent an extensive

training period to maximize their accuracy and consistency in the various languages. The interview tools were re-worked many times until they accurately reflected the purpose of the research and were appropriate to the culture and language. The tools were also pilot-tested for 3 days in the Kampala district, where many ethnic groups reside, and problems were corrected. The team utilized pictures of untreated and neglected clubfoot, and models as visual communication aids (see Figure 3).

The research assistants conducted the interviews and focus groups predominantly in pairs; one person took notes while the other conducted the interview or focus group. All notes were recorded in English. The research assistant who had conducted the interview was asked to review the notes at the end of the session to ensure validity. In addition, we confirmed the validity of the data by summarizing the notes for the respondents at the end of each focus group/interview to ensure that their responses had been accurately captured [11]. The focus groups were all audio taped and were later transcribed and translated.

The interview notes were reviewed regularly and analysis was ongoing over the month of data collection in the field. Questions not eliciting the desired information were revised and research assistants were coached to probe more deeply into certain areas of interest.



Figure 3. Model of clubfoot used to facilitate understanding and communication.

A random sample of transcripts were re-transcribed and translated by an unbiased third person to ensure consistency and accuracy of the data. All analysis was done manually over a period of two months. Data from the interviews was compiled on a computer and organized by similarities of response within each question; these groupings emerged as our themes. Attention was given to contrasting information such as outliers. Transcribed focus group data was summarized, categorized and coded by two of the research assistants. Coding involved systematically sorting through the data, labelling ideas and phenomenon as they appeared and reappeared [12]. After coding, the data was sorted according to themes; using the objectives of the study as a guide for this process. Finally, using a team approach to ensure thoroughness, conclusions were drawn about the organized data.

The research proposal was passed through multiple ethics committees: Makerere University (Uganda), National Council of Science and Technology (Uganda), University of British Columbia (Canada) and Curtin University of Technology (Australia). Informed consent was obtained by either having the interviewees read and sign the consent form, or in the case of language barriers or literacy issues, the consent was read for the individual in their local language. No names were attached to the data and all data was stored in a secured location.

### Data collection and the setting

Attempts were made to ensure privacy when conducting the research, but this was sometimes difficult due to the cultural gathering practices. Generally in Uganda the communal gathering places are located outdoors in a bit of shade. Consequently most of our interviews and focus groups were conducted sitting on stools under a tree or in the shade of a building. There was often much going on around us such as children playing, traffic passing and animals grazing. Only when we were in the clubfoot clinics were we indoors and then we were typically in a bustling, overcrowded hospital setting.

Our participants were varied and diverse being composed of multiple ethnicities, ages and educational levels. It is difficult to describe a typical respondent as a range of informants were purposefully sought. However, the caregivers and practitioners treating clubfoot are the predominant voices represented in this paper and their demographics were as follows: Our group of caregivers were primarily female. Caregivers spanned the ages of 15 to 60+ years old, with the largest number of caregivers between the ages of 25 and 34; 68% of caregivers were married. 18% of caregiver respondents had no formal education, 11% had

primary 1–3 level, 40% had primary 4–7 level, 18% had Secondary 1–4 and 13% had educational attainment higher than secondary 4. The largest number of caregiver respondents reported earning a living through subsistence farming (34%), 18% reported small businesses, 13% were housewives and the remaining caregivers worked in service industry, sales, teaching, nursing, etc. Housing ranged from banana leaf or grass-roofed mud dwellings with dirt floors, to cemented floors and walls with iron sheeting roofs.

The practitioner respondents were composed of the following professions: 19 orthopaedic officers, 4 physiotherapists, 3 occupational therapists, 3 physiotherapy assistants, 3 orthopaedic surgeons, 2 orthopaedic/rehabilitation technicians. The final 5 respondent were: A faculty member of a paramedical training school, a nursing assistant, a member of the Uganda Society for Disabled Children, and a community-based rehabilitation worker. The educational levels of practitioners were as follows: 71% had diplomas, 13% had certificates, 11% had degrees, one respondent was unknown and the last had Secondary 1–4 education. Practitioners were generally quite experienced working with clubfoot with 39% reporting more than 10 years experience, 18% 6–10 years, 32% 1–5 years and 11% less than 1 year.

### Results and discussion

For the purpose of this paper we will not be discussing the barriers to initiating treatment, but will focus only on those factors that make it difficult to adhere to this lengthy treatment regime once it has been initiated. Therefore, the themes presented are primarily those reported by our caregivers and our practitioners, as they have first-hand experience of barriers and facilitators. However, other participants also contributed to our understanding of these issues in a general manner; for instance, traditional healers were provided with education about this intervention at the end of interviews and were asked: ‘what could make it difficult for parents/caregivers to get this type of treatment for their children?’

It is important to note at the outset that when community members and interviewees were asked whether children with this condition should be treated, we got a resounding yes. Caregivers’ desires to resolve the child’s impairment were expressed almost universally. Inability to continue with treatment that was promising a successful correction of clubfoot was generally reflective of barriers. In fact, only 2 of our caregivers reported that there was nothing that made it hard to seek or sustain treatment.

The process of sorting and separating these barriers influencing adherence proved challenging.

Human behaviour is complex and the many factors that influence behaviour are often intertwined. In our interviews with practitioners, caregivers and other respondents we asked a large variety of questions that elicited barriers. Themes emerged across questions and were repeated in responses to various questions. The results we have noted some percentages of response in regards to particular questions, but have not presented values as a percentage of the total number of respondents. The following themes emerged repeatedly from the data across questions and across categories of respondents:

#### *Problems with resource availability and regional differences*

There are clearly regional differences in resource availability, service delivery, access to treatment and follow-up in Ugandan hospitals. Many of the club-foot clinics report offering treatment free of charge; however this fact is not universally true. Practitioners in only 1 out of the 8 regions studied in our ethnographic survey reported that the caregivers incur no costs. However, caregivers from this one region reported that they had in fact been asked for money for services. Depending on where a family lives, they may be charged for some aspect of treatment (cost sharing, subscription fees, etc.), have to pay for supplies when the hospital stock runs out, or have to purchase their braces either at full or partial cost (if the braces are available).

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. Two out of 10 can't pay. They come back later when supplies are available. They also buy the braces, i.e., 15,000 shillings for night splints... (Practitioner treating clubfoot)

The price for the braces is quite expensive. The child now has recurrence due to lack of braces... (Parent of a child with clubfoot)

There are ongoing problems with availability of braces and sometimes the children with clubfoot receive manipulation and casting in one centre, and then must travel to other centres for braces. Travelling, especially longer distances, means money spent on transport. Additionally, there are hidden costs to be incurred at some facilities where caregivers are asked for money by service providers or hospital workers, even though treatment is supposed to be provided free of charge.

Parents may be told to contribute or pay for treatment and may not have the money... (Practitioner treating clubfoot)

There is little predictability to the pattern of resource availability and this factor becomes a general barrier to treatment. The distribution of resources throughout Uganda is inequitable and sometimes erratic. Caregivers are unable to rely on the consistency of the service and when there are changes it can lead to inconvenience and unplanned hardship due to additional costs and travel.

#### *Distance to treatment site*

In 2003 approximately 87.7% of the population of Uganda lived in rural areas with the majority of the population engaged in subsistence farming [13]. Only a very small percentage of Ugandans own vehicles (i.e., cars, motorcycles or even bicycles) for their personal use. Therefore in order to travel to a health facility, they must have the finances to purchase transportation as a service; provided this service is available.

Access to the service is a problem, most come from deep in the villages. Sometimes there is no transport available... (Practitioner treating clubfoot)

Even if the treatment is free, weekly transport costs can become a barrier to adherence. This cost increases with distance to health facilities and when parents must travel long distances, these costs become a heavy burden. If funds cannot be raised, then the caregivers may be forced to walk long distances carrying a child in order to seek treatment. A child wearing bilateral casts is awkward and heavy and the roads in Uganda can be busy and dangerous.

There are some days I have to walk to the health centre to get treatment for my grandson. I have a heart problem and I find it is a problem to walk long distances and carry the baby... (Grandmother of a 2-year-old child, currently in treatment, Tororo, Uganda)

#### *Poverty*

According to UNICEF, between 1992 and 2002, 82% of the Ugandan population lived on less than one dollar a day [14]. With such overwhelming poverty, it is not surprising that we present this theme as the major barrier and a barrier that underlies many of the others presented. The majority of respondents in all categories talked of money as a barrier for seeking or sustaining treatment. As an example, in response to the question 'if fees were charged were they manageable?' 63% of caregiver respondents reported difficulty. Of those who reported that the fees were manageable, 31% said that they were being supported by others, i.e., church, 'muzungu' (i.e., non-Ugandan people), husband.

The majority of practitioners (94%) we spoke to reported that if money is charged, it is difficult for most people to pay. Most caregivers struggle under hardship to meet the costs of treatment and transport. If by will and effort they do borrow, save or raise money for regular transportation and treatment, it can mean that the rest of the family does not get some of their other basic needs met.

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)

The financial constraint on most families often means that they are forced to prioritize. The repercussions of their decisions to seek treatment can be far reaching and ultimately some caregivers, having managed to gather the funds to seek the assistance of practitioners, will then fail to adhere to the treatment because they cannot manage the ongoing expense (even if this expense is only a few dollars for transport). This treatment is a financial commitment, sometimes over a period of years as the method requires braces worn over an extended time to maintain the correction. Children grow rapidly in their first years of life, so multiple braces are needed over time. In cases where hospitals charged for braces, the result was an increase the rate of non-adherence and relapse. For instance, in one region where parents are charged, all practitioners interviewed mentioned caregiver's difficulty managing the cost and half mentioned this as a reason for non-adherence.

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, Uganda)

There is also the issue of resource scarcity which was discussed earlier. When hospitals run out of materials, caregivers are asked to purchase the materials from an external supplier. We must imagine the caregiver's plight: Having sold the few crops you have grown to get sufficient funds for transportation to hospital; you are told that there are no supplies and you will have to come back another day or find additional resources to purchase the materials....

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 treating clubfoot, Uganda)

#### *Lack of paternal support*

Although there are certainly fathers who support their wives in seeking care for their children, financially and otherwise, in Uganda it is primarily women who are responsible for the children's health and care. When you enter any clubfoot clinic in Uganda you will see women seeking treatment for their children. In our sample of caregivers interviewed, there were 32 mothers, 1 aunt, 2 grandmothers and 1 great grandmother; 5 fathers were interviewed alone, and 4 fathers accompanied their wives.

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, Uganda)

Mothers have a primary duty for care-giving yet they have little or no access to resources or support to seek that care. We found very commonly in all districts, that women, unless working themselves, had minimal or no control over family finances. This was confirmed in both our male and female focus group discussions

I don't make decisions about money because I don't have a job... (Female community member, Iganga, Uganda)

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)

The majority of respondents of all categories told us that women are usually 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. Currently in Uganda women earn approximately 85% less than men [15]. Money is not readily available to them and this impedes their ability to independently obtain medical care for their children. Women are put under further financial strain when they have to come up with money for transport to health facilities either by selling something, borrowing, or by persisting with a resistant husband or family member. The latter sometimes results in significant relationship strain and even separation of spouses.

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 asked for money for transport... (Mother of child with clubfoot who discontinued treatment due to lack of money, Ntungamo, Uganda)

The great effort to gather resources also has implications for adherence; a woman can only struggle for so long without support.

I absconded from treatment since the kid's father provided me no help for 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, Uganda)

Some practitioners felt that this particular barrier was less of an issue in families where there was greater equality between the genders. Equality seemed to be related to higher educational achievement of family members and employment of both partners; perhaps because these scenarios served to empower the women. This particular area requires further study.

There is much more equality and support from the males in more educated or professional couples and both tend to work together and attend clinic... (Practitioner treating clubfoot, Masaka, Uganda)

#### *Caregivers' other responsibilities*

With the majority of Uganda's population living in the rural areas and surviving through subsistence farming, life does not easily allow work to stop for a child requiring weekly treatment. The implications of seeking care away from the home almost always presents adversity and this will influence the ability to adhere to treatment.

Six 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)

When a caregiver is forced to take a day away from work, whether it be cultivation or wage labour, to bring a child to treatment, the implications are felt both at home and in the workplace.

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)

Additionally, women are generally responsible for all household tasks; for instance, we heard from all categories of respondents that women are responsible for cooking.

Girls are for mainly domestic work like: cooking, fetching water, sweeping... (Traditional healer, Uganda)

These domestic roles for women are deeply entrenched, even in urban families where there is greater equality. Men are not often involved in sharing the domestic roles with their wives either because of set cultural values or simply because of their long absences from home as they pursue their roles of family provider.

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)

Our case study respondents reported an average of 7.4 people living in the household with a maximum number of 26 people in one household. Especially in rural areas, one woman is often responsible for large numbers of people and if she seeks treatment for a child with clubfoot, she must leave the other children for whom she is responsible, in addition to her husband and other family members. With all of these pressing responsibilities, taking the time to care for one child can be taxing, and requires a sacrifice. This is yet another example of the complex prioritization process caregivers must work through.

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; doing the childcare, gardening, housework... (Practitioner treating clubfoot, Uganda)

#### *Challenges of the treatment process*

*Long treatment process.* Approximately one quarter of caregivers report the length of treatment challenging. Several practitioners reported that people often come wanting and expecting to be cured the day of visit and are disappointed to hear that the treatment is a process that occurs over time. Sometimes, as we have discussed, the caregivers cannot maintain the costs over time and/or have other responsibilities that they must attend to instead. The length of this treatment method can sometimes lead caregivers to try alternative methods, become frustrated, or even just stop treatment with the hope that the child's feet will remain corrected without retention bracing.

Because of poverty, the caregivers sometimes become comfortable with a slight improvement and stop coming for treatment thinking the child will get better with time. They don't follow through and the child relapses... (Practitioner treating clubfoot, Uganda)

*Uncomfortable/cumbersome treatment.* There were also logistical factors that made parents uncomfortable. When we inquired about challenges faced during treatment 30% of caregivers mentioned difficulty with bathing maintaining hygiene during the casting phase and 24% mentioned logistics such as dressing and carrying the child when they were in the casting phase. Some parents felt that the process (either casts or braces) were uncomfortable for their children or even shameful, and would consequently feel trepidation or even stop treatment. When we asked caregivers to tell us their stories 21% mentioned crying, perceived pain or discomfort.

During the time when the casts are on, it is hard to carry the child. You imagine she will break. There is difficulty cleaning/bathing the child. She cries a lot, so I felt disgusted and nearly gave up treatment; but with the support of my husband, we hang on to treatment... (Mother of a child with clubfoot, Uganda)

*Complicated health system laced with corruption.* Another barrier to adherence mentioned by respondents included: poor handling by health workers, long hospital lines, busy clinics and corruption. This barrier is particularly difficult because it is the very system that is supposed to improve the lives of the children that may disappoint them or even betray a caregivers' trust when they are 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 a clubfoot, and after 3 months we started going for treatment. We got tired of this movement because we could not receive treatment. We would line up and come back without treatment. We did not have the money for transport every day. There was a time when we went to the hospital and only those with money could pass and get treatment. When they asked us for 30,000 shillings (approximately 15 US\$), 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 a child with neglected clubfoot)

#### *The way forward: Overcoming the barriers*

We have presented the barriers to treatment adherence, but it is also important to present the factors that appeared to help caregivers overcome these barriers, because it is these factors that will ensure successful program implementation in the future.

#### *Programmatic outreach and follow-up services*

Many practitioners are facility-based and there are extremely limited resources to conduct outreach and follow-up. Therefore, responsibility for adherence is left almost exclusively to the caregivers. While caregiver responsibility is, of course, absolutely essential, caregivers do not have the vast experience of practitioners when it comes to comprehending the risk of recurrence. The bracing phase can be especially challenging because it requires daily diligence. So when faced with barriers, caregivers may err on the side of discontinuing treatment, thinking the child is cured, or deciding that a bit of time off the regime will not make a difference. Without proper follow-up, these diversions from treatment go un-noticed and the problem then becomes much more difficult to rectify. Some regions, however, are assisting local families to overcome the barriers they face by conducting outreach to meet needs. Community-based rehabilitation teams and the Uganda Society for Disabled Children are reaching out to some communities, travelling to children with disabilities, advising, supporting and even providing some resources on a small scale, for instance, money for transport. This model shows tremendous promise for increasing adherence and it should be looked at closely by healthcare planners:

... 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)

#### *Counselling/caregiver-practitioner partnership*

Counselling by practitioners was yet another positive way to encourage parents to stay with the treatment regime. This was in fact beneficial for all parties, because it also gave practitioners a greater understanding of their patient's needs, fears and beliefs. With this knowledge, practitioners were in a better position to help parents overcome barriers and adhere to treatment.

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 a child with Clubfoot, 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, Uganda)

This last quote represents another positive contributor to adherence: Partnership with caregivers. As the experts, practitioners are in a position of knowledge and power, and through counselling and support, can help caregivers face their barriers. As a partner, the practitioner shares responsibility for achieving the mutual goal.

Those who follow through with treatment are the easiest, but it is your advice as a practitioner that helps them to follow-through. You help them to understand what it is and why they must follow through... (Practitioner treating clubfoot, Uganda)

#### *Family harmony and solidarity*

In terms of the caregiver factors that seem to be positively related to adherence, we noted increased adherence in families where there was cooperation between the spouses. Again, this scenario represents a partnership of people working towards a similar goal. Practitioners, as persons in position of authority, could sometimes foster this cooperation through counselling. In some of the clinics, practitioners were urging fathers to come to the clinic, at least for the initial visit. This allowed practitioners to explain the treatment procedure and get the commitment of both parents.

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., to 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 mutual commitment. It is the officer's role to convince both parents well, if he fails, they will not come back... (Practitioner treating clubfoot, Uganda)

Parents were anxious to believe that their children would recover and some gained solace and motivation from coming to the clinic and seeing other children who were progressing well through different stages of treatment. Having the opportunity to talk to other caregivers who sympathized and related to their experience gave them further reassurance through the knowledge that they were not alone.

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, Uganda)

#### *Receiving quality care*

Finally, when caregivers were treated well and receive good result, they were more likely to adhere and spread the word to others. Hearing positive

reports encourages caregivers not only to seek out the treatment for a child with clubfoot, but can also encourage biomedical care for other health issues. When focus groups were conducted in communities where there was no child with clubfoot, a substantial number of people had heard of the treatment, even if they could not remember the exact details:

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, 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... (Grandmother of a child with clubfoot currently in treatment, Uganda)

### **Conclusion**

The USCCP research has now moved into the next phase which involves an incidence study and commencing the outcome study. The information learned from all findings of USCCP will be used to establish and enforce the objectives in training modules for practitioners studying the Ponseti method of correction. They will also assist with general program implementation. Specifically in relation to adherence, recommendations from this ethnographic study were provided to the program and healthcare system for review.

Looking at the financial implications of non-adherence it is evident that non-adherence represents an incredible waste of time and money, something which no one can afford in a country where money, time and health resources are scarce. Emotionally, non-adherence is extremely disappointing for all involved; practitioners, caregivers and the children themselves as they go through life with a functional impairment. For practitioners it is frustrating to have conducted months of treatment and to have seen the child progress to the point of correction only to see the correction reverse. For caregivers, it is a cruel fate to get a glimpse of hope for a cure only to have the child recur because of barriers:

Ever since the condition was identified, the distance to the hospital was so far and transport was hard... we had no time for the garden. We were stricken by poverty, could not meet other demands in the home. Family problems began that led to the separation with my husband since there was no peace in the home. Slowly I am trying to resettle myself, slowly... but I am in a dilemma... what will her future be? I want to seek treatment again, but I am still helpless... (Mother of a 3-year-old child with recurrent clubfoot, Mbale, Uganda)

The Ponseti method is an effective and locally appropriate technology for the correction of clubfoot.

The introduction of this method in Uganda has greatly increased the accessibility of treatment to the general population of children with clubfoot in a country where orthopaedic surgeons are scarce. The positive outcomes of the method have been proven repeatedly [7–10]. However, this method requires adherence by caregivers and it is therefore vital that practitioners understand the barriers to adherence. This paper has attempted to outline these barriers in an African setting and it doing so has once again illustrated the importance of viewing non-compliance as a ‘diagnosis of exclusion’[4]. When practitioners and planners adopt this view, they are in a better position to work towards implementing effective health service programs that meet needs and address barriers. Our respondents have demonstrated some factors which encouraged adherence: offering follow-up services, providing counselling services, quality care, and forming partnerships. Some of these factors of encouragement are immediately possible and others will require planning, resources and infrastructure. We would suggest that a valuable area for future study would be a comparative study to examine outcomes when such adherence support is provided to caregivers. The benefits of adherence and cost savings associated with such support are likely to far outweigh the costs of providing such a service.

### Contributors

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### Acknowledgements

We gratefully acknowledge all of the respondents for their time and the valuable information contributed to this study.

### References

1. Penny N. The neglected clubfoot. *Technologies Orthopaed* 2005;20:153–166.
2. Pirani S, Naddumba E. Uganda Sustainable Clubfoot Care project [grant application]. Vancouver (BC): University of British Columbia; 2003.
3. Harris K, Jerome N, Fawcett S. Rapid assessment procedure: A review and critique. *Human Organisation* 1997;56:375–378.
4. Farmer P. On suffering and structural violence: a view from below. In: Kleinman Das V, Lock M, editors. *Social suffering*. Berkeley: University of California Press; 1997. pp 261–283.
5. Lane S, Rubinstein R. International health: Problems and programs in anthropological perspective. In: Sargent C, Johnson T, editors. *Medical anthropology: Contemporary theory and method*. Westport Connecticut: Praeger; 1996. pp 396–423.
6. Smith E, Murray SF, Yousafzai, AK, Kasonka, L. Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia. *Disabil Rehabil* 2004;26:121–127.
7. Ponseti I, Pirani S, Dietz F, Morcuende J, Mosca V, Herzenberg J, Weinstein S, Penny N, Steenbeek M. Clubfoot: Ponseti management. In: Staheli L, editor. *Global-HELP Organization*; 2003. Available from: [www.global-help.org](http://www.global-help.org)
8. Tindall AJ, Steinlechner CW, Lavy CB, Mannion S, Mkandawire N. Results of manipulation of idiopathic clubfoot deformity in Malawi by orthopaedic clinical officers using the Ponseti method: A realistic alternative for the developing world? *J Pediatric Orthopaed* 2005;25:627–629.
9. Segev E, Keret D, Lokiec F, Yavor A, Wientroub S, Ezra E, Hayek S. Early experience with the Ponseti method for the treatment of congenital idiopathic clubfoot. *Israeli Med Assoc J* 2005;7:307–310.
10. Morcuende JA, Dolan LA, Dietz FR, Ponseti IV. Radical reduction in the rate of extensive corrective surgery for clubfoot using the Ponseti method. *Pediatrics* 2004;113:376–380.
11. Pope C, Mays N, editors. *Qualitative research in health care*. London: BMJ Publishing Group; 1996.
12. Krueger R. *Analyzing & Reporting Focus Group Results*. London New Delhi: Sage Publications; 1998.
13. The human development reports [internet]. United Nations Development Programme. 2005. Accessed 6 October 2005 from: <http://hdr.undp.org/statistics/data/countries.cfm?c=UGA>
14. Uganda Statistics [internet]. United Nations Children’s Fund. Accessed 2 May 2005 from: [www.unicef.org/infobycountry/uganda\\_statistics.html](http://www.unicef.org/infobycountry/uganda_statistics.html)
15. Smith D, Gordon A, Meadows K, Zwick K. Livelihood diversification in Uganda: Patterns and determinants of change across two rural districts. *Food Policy* 2001;26:421–435.