

## Clubfoot in Malawi: treatment-seeking behaviour

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**SUMMARY** We explore the treatment-seeking behaviour of guardians of patients undergoing treatment for clubfoot at clinics run by the Malawi National Clubfoot Programme (MNCP). Core data was collected and analysed using qualitative methodologies of critical medical anthropology. Sixty detailed case studies were completed, each based on an extended open-ended interview with patient guardians. Two positive drivers in seeking treatment for clubfoot were identified: a desire to correct the impairment; and a direct instruction to do so, usually from a health-care professional. Four main barriers prevented treatment seeking: lack of knowledge about the condition and its treatment; familial resistance; logistical obstacles; and socio-economic pressures. In delivering effective health care, organizations should seek to minimize barriers and their impact, whilst maximizing drivers that lead to positive action.

### Introduction

Idiopathic clubfoot (congenital talipes equinovarus; CTEV) is a condition in which a child is born with the hindfoot adducted, flexed and inverted and the forefoot abducted and pronated in relation to the hindfoot. Neglected clubfoot results in significant impairment in body structure and function and may result in activity limitations and participation restrictions. Clubfoot can be treated using the Ponseti method of staged manipulation and casting.<sup>1</sup>

In 2009, we undertook the first detailed anthropological study of clubfoot in Malawi, examining perceptions of, and treatment-seeking behaviour for, CTEV. The aim of the research was twofold: first, to determine new empirical data on the perspectives of clubfoot and its treatment in Malawi, amongst patients and their guardians; and, secondly, to make recommendations to develop the services of the Malawi National Clubfoot Programme (MNCP) through the qualitative analysis of patient and guardian perspectives. We report on one component of the wider research project – the treatment-seeking behaviour of guardians of children undergoing treatment at MNCP clinics.

We identified a range of drivers and barriers that significantly influenced the behaviour of guardians seeking treatment for patients with clubfoot at MNCP clinics. The drivers led to positive treatment-seeking behaviour, whilst the barriers were impediments to sustained and effective treatment.

### Methods

Core data collection was carried out in Malawi over five weeks (June–July 2009 with follow-up in March 2010). The research was based at Beit Trust Cure International Hospital in Blantyre, from where the MNCP and its 26 clinics are co-ordinated. Eight other MNCP clinics (Nkhota-Kota, Mzuzu, Lilongwe, Mwanza, Mulanje, Balaka, Dedza and Rumphu) were included in the research and each was visited at least once. These nine clinics were specifically chosen in order to render a substantial body of rich and diverse data. They were located in different areas of the country; employed different clinical set-ups; had been established at various stages of the MNCP's development; and encompassed a range of patient demographics.

A total of 60 case studies were completed which comprised a transcription of the guardian's extended interview, a summary of the patient's medical history and a set of documentary photographs (to confirm the nature and severity of the condition). In all cases, the guardian was a parent or close familial member.

Core data was elicited using informal (or soft) open-ended interview techniques in the vernacular. A broad spectrum of interview questions was designed by the research team. These were reviewed and refined during the research period in light of themes arising during the course of interviews conducted. The direction and content of each interview was determined by the guardians and focused on the issues they self-identified as priorities. Dominant themes were identified in the case studies. This involved the systematic sorting of the data, labelling ideas and phenomena as they appeared and reappeared. The apparent behavioural trends and the drivers and barriers to treatment seeking that emerged were critically analysed.

Permission for the research was granted by the College of Medicine Research and Ethics Committee of the University

of Malawi and signed informed consent was obtained from all guardians participating in the study.

### Results

Of the 60 case studies, three were re-starting treatment after a period of intermission and one was a neglected case starting treatment for the first time. Of the 56 cases already in treatment, 13 reported they had defaulted at least once.

In the course of their interviews, guardians expressed many reasons for seeking treatment and a variety of issues they had had to overcome in order to do so. Dominant drivers and barriers were identified and their common elaborations detailed. Their inter-relationship means that there is necessarily some overlap between the stimuli identified (see Table 1).

### Discussion

We identified two drivers that stimulated guardians to seek treatment at MNCP clinics. The first was a desire to correct their child's clubfoot. Guardians regarded the impairment as a problem that could be solved through treatment and many reported that their motivation to seek treatment had been the wish to give their child a 'normal' life in order to participate fully in the social and economic life of their family and community. For most guardians, ensuring mobility was a priority. Several explained that their child was required to walk long distances to collect firewood, go to market or attend school. Children themselves reported

wanting full mobility to enable them to climb trees, play football and, most frequently, to ride a bicycle. In neglected or defaulted cases, restricted movement or the child's inability to walk was often the catalyst for seeking treatment. In several cases, the impetus to seek treatment had been the guardians' desire that the child could one day get married and have a family of its own. In two cases, guardians reported attending MNCP clinics because other courses of treatment (a traditional doctor and attempted home remedies) had been unsuccessful.

The second driver was the instruction to seek treatment. In the majority of cases (80%) guardians first presented for treatment at an MNCP clinic when their child was less than a year old because they had been instructed to so by a health-care professional, an individual they regarded as a figure of authority. In some cases this led guardians to attend despite their lack of confidence in the proposed treatment. Several guardians reported that the suggestion to seek treatment had come from a friend or family member. In two cases, guardians sought treatment at the instigation of the child themselves. Both had previously defaulted and the patients (aged 6 and 7) had persuaded their guardians to restart treatment primarily because they wanted to be able to ride bicycles and not be teased by their peers.

Guardians of patients already in treatment were also found to be important advocates of positive treatment-seeking behaviour. Several guardians asserted that they were introduced to the MNCP clinics not by a health-care professional but by another guardian. The mutual support and experience-sharing fostered through clinic attendance was often commented on by guardians as being highly beneficial. Seeing other children progress through treatment also encouraged clinic attendance.

In Malawi the stigma of disability is widespread and many guardians reported having experienced socially stigmatizing behaviour due to clubfoot. This ranged from mild teasing to prolonged bullying and, in some cases, severe harassment. Prior to undertaking this research, it had been suggested that the stigma of disability may sometimes prevent guardians seeking treatment. Amongst those attending MNCP clinics, however, the desire to reduce stigma, by correcting the physical presentation of clubfoot, was a powerful force stimulating positive treatment-seeking behaviour.

Four main barriers to treatment were identified. The first was a lack of knowledge about the condition and its treatment. Of the guardians interviewed, 90% claimed no knowledge of clubfoot or its treatment before experiencing it personally and being referred to an MNCP clinic. Many reported that prior to coming for treatment, they had thought that correction was impossible, that treatment did not exist or that the condition would self-correct. This lack of knowledge has been reflected in other studies. In Uganda, for example, Kazibwe and Struthers<sup>2</sup> found that 67% of parents receiving treatment at clinics had not previously known about the condition or its treatment.

In the majority of cases in our sample (72%), clubfoot was correctly diagnosed on the day of birth, yet not all were immediately referred to a clinic and this delayed the onset of treatment. Two guardians reported that they had taken the initiative to present at MNCP clinics having received no guidance or direction from health-care professionals. In one case, the guardian had seen an MNCP clinic poster in the hospital where she had given birth. She presented

**Table 1** Drivers and barriers to seeking treatment for clubfoot

	<i>Stimulus</i>	<i>Elaboration</i>
<b>Drivers</b>	Desire to correct the impairment	Solve the problem – give child 'normal' life. Ensure mobility: walking/riding bicycle /independence. Reduce stigma of disability. Enable marriage and own family. Other treatment attempts had been unsuccessful.
	Instructed to seek treatment	Direct instruction from health-care professional. At suggestion of friend/family. At suggestion of another guardian (guardian advocacy). At instigation of child patient.
<b>Barriers</b>	Lack of knowledge	Belief that condition cannot be corrected. Belief that no treatment exists. Belief that condition would self correct. No direct referral.
	Familial resistance	Lack of paternal support. Family members opposing treatment.
	Logistics of clinic attendance	No/limited/unreliable access to transport. Difficulty in financing transport. Time constraints – livelihood commitments, harvest.
	Socio-economic	Decrease in household income – cost incurred. Reduction in income due to inability to work. Problems due to prioritising one child in family. Problems due to prioritising treatment above other household commitments.

within a week of delivery and treatment commenced. In the other case, however, the guardian was unable to secure effective treatment for four years. He was repeatedly misinformed about treatment options at a number of health centres. In such cases, incorrect or delayed referral exacerbates the lack of public (and the patient's) knowledge of clubfoot and its treatment.

The second barrier identified was familial resistance to treatment. Many guardians reported instances of family members opposing treatment. Resistance ranged from mild deterrence to sustained opposition. Three guardians asserted familial resistance as their primary reason for defaulting treatment or presenting late. In each case, although the guardian had wanted to seek treatment, they had been socially prohibited from doing so. One identified resistance to biomedical intervention as the root of the opposition she had faced from the patient's grandparents. She argued that respect for the older generation and their views prevented her seeking treatment until they granted permission. In other cases, guardians claimed that negotiations between health-care professionals (or pastors trained in counselling) and the resistant family member had successfully alleviated their opposition. A lack of paternal support was the most common elaboration of familial resistance.

The third and most frequently identified barrier to effective and sustainable treatment seeking concerned the logistics of clinic attendance. Focusing on practical problems, transport emerged as the main impediment. Guardians reported difficulties in both finding and financing reliable transport, especially in rural areas. Echoing the results of studies in Uganda, the mode of transport, length of journey (time to treatment site) and the cost involved were dominant logistical obstacles in Malawi.<sup>2-5</sup> The majority of guardians used a combination of public transport (mini-bus, truck, hired bicycle) or walked to the clinics. Journey time ranged from under an hour to over 10 hours and normally cost between 50 and 1500 Kwacha (1 US\$ = 140–150 MKW), although a small number of guardians paid over 1500 Kwacha, whilst others paid nothing because they walked or received a free lift. (The World Bank data states that in Malawi in 2009 the Gross National Income [GNI] *per capita* [Atlas Method] was 290 US\$ and GNI *per capita* based on Purchasing Power Parities [PPP] was 780 International Dollars, [www.data.worldbank.org/country/malawi](http://www.data.worldbank.org/country/malawi).)

Another logistical concern raised was the ability of guardians to attend clinics during specific times of year, such as during harvest times. In Uganda, Konde-Lule<sup>3</sup> found that rates of attendance lapsed around this time. The seasonality of treatment seeking in Malawi requires further research.

The fourth barrier identified was socio-economic. Seeking treatment can result in an overall decrease in household income. In addition to the logistical costs incurred, a guardian was often unable to work on the days that they attended a clubfoot clinic. The resulting reduction in income was particularly problematic and when attendance by guardians who were engaged in piecemeal work frequently led guardians into debt.

Although treatment is free at all MNCP clinics, it was clear that attending involved a heavy expenditure in terms of time, money, energy and social capital and could strain already scarce resources. The socio-economic impact of seeking treatment should not be underestimated. For many guardians, seeking treatment for clubfoot required them to prioritize one

child over other family members and to prioritize treatment over other household commitments. Guardians frequently reported that such prioritization significantly encumbered their households, preventing children from attending school and other family members from receiving adequate health care. Money previously allotted to amenities, food and clothing was frequently reassigned in order to meet the hidden costs of clinic attendance. In such situations, a child with clubfoot was at risk of being regarded as a burden on the family. In one case of familial resistance, resentment that the child's condition had been prioritized to the perceived detriment of the household led to fierce opposition to treatment from other family members.

Prior to this research it was hypothesized by MNCP staff and the research team that barriers to treatment seeking might include local theories of causation and the perception that the child would be in pain throughout the treatment. Although guardians vocalized their concerns about causing the child pain (especially during the casting stage), there was no case in which this was stated as a reason to avoid treatment. Neither were local theories of causation found to preclude treatment.<sup>6</sup> In Uganda it was found that, for some guardians, a belief that it was God's will that the child be born with clubfoot, prevented them seeking treatment.<sup>3</sup> In such cases, it was considered that the physical disability could not, or should not, be altered. Whilst the causative belief in the will of God is also dominant in Malawi, it was not found to be a barrier to treatment seeking. Indeed many guardians interpreted the existence of treatment to be a provision by God to solve the problem of physical impairment.

## Conclusion

Studies of treatment-seeking behaviour for physical impairments such as clubfoot have largely focused on barriers to service uptake. We contend that this is only one aspect of a complex equation and that the drivers that lead to positive action require more attention.

While service providers such as the MNCP cannot solve macro-level constraints, such as poverty or lack of infrastructure alone, they should understand the existence of such potential barriers and create contextualized policy around them. Indeed, the MNCP has been proactive in devising ways to maximize the opportunities for guardians to seek treatment whilst minimizing the impact of barriers and the risk of default.<sup>7</sup>

The MNCP is devising strategic education campaigns to increase public knowledge about clubfoot and its treatment and to empower guardians to make more informed choices about seeking treatment. In parallel, the programme is working with other national authorities, including the Ministry of Health, to improve clinical knowledge of clubfoot and to ensure the correct and timely referral of patients in order to reduce delayed presentation. The MNCP also supports research into modifying treatment provision such as the accelerated Ponseti method which may be more appropriate in Malawi and would help reduce logistical and socio-economic barriers associated with a lengthy treatment regime.<sup>8</sup>

In addition to improving knowledge, the MNCP is developing sensitization campaigns. Most treatment is sought by women (only four of the 60 case studies completed involved a male guardian) and the general lack of paternal engagement

coupled with a woman's financial insecurity has a negative impact on their ability to seek treatment. In response to this, the MNCP is seeking ways to better involve male guardians through advocacy and education. The programme is capitalizing on guardian advocacy as a positive driver by creating communication opportunities and by establishing annual Family Days that raise awareness and foster support between guardians already involved in the treatment process and the wider community.

Treatment-seeking behaviour is a complex phenomenon. We identified two dominant drivers and four barriers influencing the treatment-seeking behaviour of guardians of patients undergoing treatment for clubfoot at MNCP clinics. Our research highlighted the high levels of pragmatism and resourcefulness that guardians often displayed to overcome what appeared to be insurmountable obstacles. In providing an effective and sustainable service, the MNCP must continue to find ways to minimize the negative impact of barriers encountered by guardians while maximizing the drivers that stimulate their positive treatment-seeking behaviour.

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