



## Experiences of Parents/Caregivers of Children with Congenital Talipes Equinovarus: A Qualitative Study

Naomi Wanjiru\*

Department of Orthopaedics and Rehabilitation, Moi University, Kenya

### Abstract

**Aim:** Disability in childhood remains a challenge globally. Linked to this disability is an apparent increase in the prevalence of infants born with congenital clubfoot. Clubfoot can, however, be effectively managed but this management faces various challenges. This study aims to explore the experiences of parents/caregivers of children with congenital talipes equinovarus in Kenya.

**Methods:** Structured interviews were conducted with 15 parents/caregivers. Interview guide was used for data collection. Informed consent was sought. Field notes were taken and the interviews tape-recorded. The interviews took 45 minutes to 1 hour. They were transcribed verbatim and analyzed by thematic content.

**Results:** The results indicated that the experiences were marred with numerous challenges which included; long travelling distance, cost of treatment and travelling, poverty, stigmatization, lack of family support, and problem with abduction braces among others.

**Conclusion:** The challenges facing parents/caregivers of children with clubfoot start after birth and are enormous. Action to remove these challenges is warranted. Improved support for parents/caregivers, information to community, and provision of treatment more locally is needed. Financial support for parents/caregivers is key to enhancing children's life chances.

**Keywords:** Barriers; Clubfoot; Experience; Disability; Treatment; Perceptions

### Background

Juvenile disability remains a huge threat globally [1]. Linked to this disability is increase in the prevalence of infants born with clubfoot [2]. Clubfoot is one of the most common childhood developmental disabilities seen in the developing world [3]. The incidence of clubfoot in sub-Saharan Africa is 1.2 per 1,000 births [4]. East Africa, Central Africa and Polynesia present the highest prevalence of clubfoot of 8 per 1000 live births [5]. In Malawi, for example, the prevalence of clubfoot is approximated to be 2 to 3 per 1000 live births [6]. while in Uganda the prevalence of clubfoot is estimated to be at 1.2 per 1000 live birth. Clubfoot can be treated, however, if untreated, causes physical impairment and defect, which affects the individual's gait and results in disability [7,2,8]. The impact of clubfoot is profound; it leads to activity limitation, participation restriction, social and educational disadvantages, and strengthens the cycle of poverty and disability [9]. Clubfoot is effectively managed by the use of conservative and less of surgical methods [1,2]. Review of medical records in one of the clinics in Kenya, in 2009 indicated that there was an increase in neglected and complex (inadequately managed) cases. 5/36 patients managed per month had neglected and complex clubfoot. This certainly led to increased rates of related disability. In Africa, the structural deformities are associated with stigma, which has a psychological and social effect on children, parents and caregivers. It is therefore imperative to understand the experiences of parents/caregivers of children with clubfoot.

### Methods

#### Setting

The study took place in the Kenyatta National Hospital, Mbagathi District hospital, and Kijabe Mission Hospital. Kenyatta National Hospital is the biggest referral hospital in Kenya, and has a bed capacity of 2,500. It serves as the referral hospital for East and Central Africa and the eight provinces in Kenya. Mbagathi District is the second largest hospital in Nairobi province with a bed capacity of 360 with an interdisciplinary clubfoot clinic; it provides services to eight districts. Kijabe Mission Hospitals is in Central Province and offers a specialized service in orthopedics and pediatric surgery.

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#### \*Correspondence:

Naomi Wanjiru Kingau, Department of Orthopaedics and Rehabilitation, Moi University, Kenya, Tel: 254706164074; E-mail: nkwanjiru@yahoo.com

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**Table 1:** Social demographic profile.

Participants Code	Age	Occupation	Relation to the child with clubfoot	Area of residence	Type of Management
P1	24	House wife	Parent	Rural	Conservative
P2	32	Clerk	Parent	Urban	Surgical
P3	26	Secretary	Parent	Urban	Conservative
P4	35	House wife	Caregiver	Rural	Conservative
P5	31	House wife	Parent	Rural	Conservative
P6	25	House wife	Parent	Rural	Conservative
P7	30	House wife	Caregiver	Rural	Conservative
P8	32	Teacher	Parent	Urban	Conservative
P9	25	House wife	Parent	Rural	Conservative
P10	34	House wife	Parent	Rural	Conservative
P11	39	House wife	Parent	Rural	Conservative
P12	20	House wife	Caregiver	Rural	Surgical
P13	37	Business Lady	Parent	Urban	Conservative
P14	23	House wife	Parent	Rural	Conservative
P15	18	Student	Parent	Urban	Conservative

**Key:** P-Participant

All parents/caregivers reported at least some difficulty in relation to the treatment that their children received. Difficulties were categorized as financial, transport-related, attitudinal and practical.

### Sample

The study population included parents/caregiver of children with clubfoot (130) acquire through a survey that preceded data collection. Purposive sample of parents/caregiver was generated from the population. The sample was further conveniently sampled based on the availability of parents/caregivers and were present during the time of data collection; sample included working and non-working parents/caregivers from different backgrounds and from different geographical areas. The sample included 15 parents/caregivers. An interview guide was used for data collection. Parents/caregivers were interviewed on their experiences with clubfoot in the society as well as management. The researcher did interviews. Interviews were carried out in English and Swahili. The interview guide was translated into Swahili and three interviews done in Swahili, later translated into English by a specialist in linguistic services, and transcribed verbatim by a professional transcriber. Only two parents/ caregivers were involved in surgical care at the time of study. This was due to early intervention hence conservative management.

Each interview lasted between 45 minutes and 1 hour, and was audio-recorded. Saturation (point in data collection when no new or relevant information emerges) was reached with the 13th parent/caregiver. However, the 14<sup>th</sup> and 15<sup>th</sup> parents/caregivers were interviewed since a prior appointment had been made and the interviews were included in the study.

### Data analysis

Data were subjected to thematic content analysis, which involved identifying codes and categorizing patterns [10-11]. Following transcription; each interview was initially read for accuracy and then reviewed to identify the emergent themes and potential contradictions [12]. On completion of all the interviews, the entire set of transcripts was read to obtain a sense of the whole and to generate a coding system based on issues identified from the data. The codes were then applied to the data to refine the coding development and to establish potential categories [13]. Thereafter, categories were developed and they served to organize codes into meaningful clusters. Codes and

categories were collapsed to evaluate emerging patterns and themes until the point was reached where no new information pertaining to the study question was generated [13]. Participants' transcripts were then reviewed to determine the proportion of participants whose answers corresponded to the major codes. The credibility and rigor of the analysis was aided by co-analysis of the transcript by the researcher's supervisors and continued re-examination of the emergent data throughout the process. Arbitrary initials were used to distinguish the participants whilst ensuring confidentiality. These initials are used in the paper.

### Results

Social demographic characteristics of participants in the current study are presented in Social demographic characteristics of participants in the current study are presented in (Table 1).

### Financial

Participants explained that Clubfoot Care Kenya (CCK), a Non-Governmental Organization (NGO), did support clubfoot management in most of the clinic in Kenya. However, some of the clinics were not supported. In these clinics, a fee of US\$12 for casting and US\$18 for abduction braces was charged. This, they felt, was not affordable for most and thus definitely negatively affected compliance. 'The clinic I attend is not supported by Clubfoot Care Kenya, so I have to pay for every visit. It is not easy to raise Ksh1000 per week for treatment' (P 3) Nine parents reported to have sort an alternative source of finance; six parents went into debt, two sold family property and one shut down her business to pay for treatment. 'I had to close down my business to cater for treatment cost' (P13)

Likewise, two parents sort financial aid from grandparents, and one received aid from a charity organization. 'Treatment is being catered for by my mother in-law' (P5) Majority of parents/caregivers reported to be unemployed and depended on their spouses or relatives for financial support. They revealed that they had no direct control over the finances that were essential for meeting the expenses. As a result, they dropped out when no funds were available

and only returned for treatment when money was forthcoming. 'Am a house wives and depend on my husband for support.'(P7) Social and attitudinal experiences several parents/caregivers identified a range of situations where stigma and discrimination occurred. Most parents/caregivers (n=10) explained that many people thought that women that gave birth to children with clubfoot had been cursed by witchcraft or were being punished.

'My mother in-law would say that my child's condition is as a result of a curse' (P2) One participant described the myth that if a woman gave birth to a child with clubfoot, all her children are condemned to disability. Most of these women avoided taking their children for treatment as they felt that treatment was a form of displaying their bad genes. 'It took me long before bringing my child to the hospital, i had believed that all my children will be disabled since that's what the villagers say'. (P12) Thirteen parents/caregiver experienced social segregation in relation to their child's impairment. Two mothers hid the child's foot to avoid shame, and fear of rejection from their extended families and the community. 'I would cover my child's feet whenever there were people around me' (P10) Eight mothers reported being accused of wrongdoing during their pregnancies, such as attempted abortion, failure to observe local taboos, and two sustained verbal abuse. One parent was advised to take her child to a traditional healer. As a result, some parents/caregivers reported to keep their children at home and miss treatment appointment to avoid ridicule. 'I would deliberately fail to attend clubfoot clinic for fear of mockery' (P9) additionally, children with clubfoot were also reported to experience "labeling". Some participants said that the children were sometimes called "kiwete" in Swahili, which is a derogatory term meaning disabled. They explained that to use the word in the context of labeling a child was offensive. Such terms used to explain clubfoot were discouraging and affected the psychosocial life of the parents/caregivers negatively. Likewise, stigmatization was reported to contribute in breaking families and reduced support for the mother and the child when a child with clubfoot was born. This in return significantly affected adherence to treatment appointment. Several informants (n=12) explained that when a child was born with clubfoot, fathers always blamed the family of the mothers. "When he saw that the child had clubfoot, he disappeared never to come back" (P6). Five parents/caregivers did not experience negative reactions from their families, mostly because other children in the extended family had been born with clubfoot and received treatment in the past. Nevertheless, 10 mothers were sad, despaired about their situation, and felt rejected and embarrassed. Both rural and urban families reported these problems.

### Transport difficulties

The influence of distance becomes hard-hitting when considered together with lack of transport and bad roads, which contributed toward indirect cost of visit to health facilities. Most parents/caregivers were reported to cover long distances from home to the health facility in pursuit of their children's treatment. Parents/caregivers that took their children to Kenyatta National Hospital and Kijabe Mission Hospital reported to travel long distances to get to the facility. Six families came from over 100 km away, which meant starting the journey at 04.00 h and catching the last returning bus by 15.00 h, curtailing the possibility of treatment in the afternoon. A further four families travelled more than 300 km due to lack of local treatment; as treatment was weekly they had recurrent costs of overnight stays, which were particularly expensive for them. Costs of transport for some families could surpass the normal costs of

treatment. "Okay coming to this place all the way from Murang'a is not easy, it take time and money" (P5).

Five parents/caregivers lived in the city, however, they all experienced travel challenges. These parents/caregiver travelled by bus, where overcrowding made it difficult to transport a baby wearing splints, thus some parents had to use taxis.

### Practical challenges

All parents had everyday challenges using the abduction splints. All found the splints difficult to wear, and clumsy when travelling. All infants were said to have cried during plastering, some for up to 3 days afterwards. One infant had temporary edema of the foot, and two infants had fever after casting. 'Braces are very cumbersome especially when travelling' (P13) Eleven parents/caregivers were unable to afford disposable diapers: they used small pieces of cloth as diapers, which were insufficient to contain the urine and thus did not keep the plaster of Paris splints dry.

'It's not easy to afford diapers particularly if one is no working' (P12).

## Discussion

The experiences identified in the current study include; financial, travelling, poor social support, stigma as well as every day's challenges. The main challenge for parents/caregivers of children in Kenya is financial burden on families, many of who are very poor. Most families tried to get the finances, yet were often frustrated by the costs of treatment and travelling. When the parents/caregivers were unable to raise the money for treatment as well as transport, the parent/caregiver either looked for an alternative source of the money or fails to attend the clinic. The findings in this study are consistent with those from Latin America [14] Uganda [15] and Malawi [16]. Likewise, the study echo's Pirani et al [1] in a study on understanding clubfoot in Uganda; the author found out that poverty was the major barriers to adherence to Ponseti treatment protocol in Uganda. Similarly, Staheli [17] found that lack of finance to cater for the expense in developing countries could affect compliance with the treatment regime. In the current study, most of the parents/caregivers came from rural areas and were unemployed. The parents/caregivers had to travel to the health facilities by use of motorbike, a cab or walk to the hospital. This means of transport increases the cost of transportation, which is not affordable to many. This is in agreement with Pirani et al. Lack of finance affects most parents/caregivers accessibility to the health facilities. These expenses can be minimized if the services are extended to the communities. Kenyatta National Hospital is an urban-based hospital with patients from rural areas far from the hospital where there are poor road network and transport system. Kijabe hospital on the other hand is a rural specialized hospital with most of the patients coming from all over the country. The distance covered to the health facility is related significantly with compliance to treatment. These results were supported by findings of Beardsley, et al [18] in USA. The authors found that clients who travelled for short distances were likely to adhere and complete treatment as opposed to clients who cover longer distances. In Kenya, transportation expenses depend on the distance covered and the area. Most roads within the capital and urban centre are accessible while those in the suburbs and rural areas are inaccessible especially in the rainy seasons. This increases the costs of transport.

Parents/caregivers experienced stigma, this concurred with the findings of Bedford8in a study on clubfoot in Malawi. The

author found that people used “Kopindika mapazi” which is a derogatory term in Chichewa referring to clubfoot. Clubfoot was often stigmatized by its description as kupunduka, “cripple”. Such generic labels were oppressive and brought associations of permanent disability and abnormality and had the potential to deter treatment seeking behaviors and compliance to the treatment regime. Parents/caregivers faced divorce, reprisals and been ostracized as alluded by Bedford.<sup>8</sup> Stigmatization ripped off the parents/caregivers financial, physical and emotional support that they desperately needed to keep the treatment appointment as prescribed.

### Limitation

Data were collected from parents/caregiver that were attending treatment at the health facilities, the experience of others who were not on treatment could not be evaluated. Likewise, no interviews could be arranged with parents/caregivers who had defaulted. The findings of the current study are based on a purposive and convenience sampling, and thus the study results may not be generalized except to similar settings.

### Conclusion

This study highlights the experience and considerable obstacles, which still exist to parents/caregivers of children with clubfoot. These overwhelmingly relate to the costs of treatment, travel and stigma among others. The results of our work will inform the policymakers to ensure free and facilitated treatment, and public sensitization to reduce stigma

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