

Research Article

# The Burden of Ponseti Management on Financial, Social and Coping Mechanism of Parents and Caregivers of Children at Moi Teaching and Referral Hospital

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**Abstract: Background:** Disability is a worldwide concern which can be caused by clubfoot. If effectively managed, it can prevent disability though it has its challenges. The parents or caretakers of the children should take care of the children with clubfoot and ensure they attend the clinic as they have been booked to ensure timely and effective services and adhere to given instructions for best outcomes. Despite the clubfoot Ponseti management being sponsored by CURE international at no cost, the parents are expected to travel from their homes and get to the clinic at their own cost; they are also expected to fit into the society which has different view on the clubfoot and its causes. There are also other coping mechanisms they need to adapt to in order to deal with the clubfoot and ensure they support their families and affected children. The objectives of the study were to determine the social, financial and coping factors of parents who have children with club foot. **Methodology:** Quantitative non explorative research design was applied to give a description so as to answer the research questions. Hence it was descriptive cross sectional study design. The study population was parents and caretakers who are attending the clubfoot clinic and have undergone Ponseti management. Convenience sampling was applied to carry out the study in the institution that the researcher has identified the gap. The sample size was 95 participants: 52 females and 43 males. This applied the Impact on Family Scale (IOFS) research tool, Multidimensional Scale of Perceived Social Support (MSPSS) tool, and Brief COPE tool. **Result:** Half of the patients (50.6%) had bilateral clubfoot while the other half only one foot was affected. In this study it was noted that the boys (54.7%; n=52) were more affected than the females (45.3%; n=43) to a ratio of 1.2: 1. Financial burden was most sited impact of childhood illness on family with a mean score of 77.5%. **Conclusion:** In this study majority of parent/guardian of children with clubfoot perceived the social support to be from significant other followed by family. The most used coping strategy is that of religion followed by acceptance and positive reframing which are categorized as being in the approach coping. It showed that the parents were facing financial challenges and also clubfoot condition impacted on their family and social activities in the society. **Recommendations:** Further strategies should be developed to provide services near the resident places of the children. Community devolvment of the CURE services will ensure that the parents do not spend a lot of money on transport and meeting other needs of the children while on the way.

**Keywords:** Ponsenti management, clubfoot, financial, social and coping mechanism.

## **Introduction**

There are many views that have been stated concerning the management of clubfoot using non-surgical methods and how long a surgeon should wait before ruling the method as unsuccessful. Congenital malformations are a global burden especially in the developing countries. In the whole world, there are about 25 million disability adjusted life which affects children with clubfoot. 150000 to 200000 newborns are born with the club foot annually [1]. In India, every ten minutes a baby is born with the deformity, which adds up to one baby in every 500 [2]. If it is not treated, there will be a lifelong disability [3]. However efforts to alleviate the burden of congenital anomalies are limited to population based data. Ponseti management has been gaining popularity in low and middle income countries, where most children are born with clubfoot [4]. The children not treated end up not accessing quality education or employment [5].

In developed countries, club foot is treated with surgeries [5]. The studies done on the follow up after surgery, there has been poor results which include weakness, stiffness and early onset of arthritis [6]. Dr. Ignacio Ponseti developed a method of clubfoot management which is effective and less costly [7]. Studies done on follow up after this method have showed that the feet are flexible, pain free and strong. It has been stated to be best for all cultures and countries [7]. Ponseti method of clubfoot management is the gold standard in African countries. The children that are treated with Ponseti management experience no delay in motor milestone achievements such as sitting or crawling [8]. In Kenya, about 1200 children are born with club foot annually. Many of these children are left untreated as the trend in the rest of the developing countries [9]. Moi Teaching and Referral Hospital has several parents who bring their children to the clubfoot clinic many of who are born in the same facility. However, we have others who are referred from the surrounding healthcare facilities, whereas others are delivered at home. The club foot clinic works under the orthopedic department in conjunction with CURE international (CCK).

## **Statement of the problem**

Disability remains an issue of global concern. Clubfoot management can be done effectively, but it does not come without its challenges [4]. The healthcare professionals have a responsibility of making an assessment and identify newborns that have deformities and refer them accordingly for further management. The parents have a responsibility to take care of these children and ensure that they acquire for them the best management. There are also limited training organized by the government to facilitate the management of clubfoot. CURE international meets the cost of Ponseti management in Moi Teaching and Referral Hospital (MTRH) at no cost. The parents travel from their homes at their own cost, they are also expected to fit into the society which has different view on the clubfoot and its causes. From the books of attendance at the clubfoot clinic, there was a 22% loss of follow up which was 180 cases of clubfoot management lost. Also there was a relapse of 2% of the clients which came up to a total of 17 cases [10]. This informed on the gap of the management which was to assess for burden of children with clubfoot to parents and caregivers at MTRH. This study aims at finding out how Ponseti management of clubfoot has impacted on the life of the parents or caregivers.

## **Justification**

In Kenya, parents have a responsibility to take care of their children and meet their societal roles. These roles are affected when they get children with deformities. The parents' lives are impacted by the added responsibility of bringing their children to the hospital and take additional care for them at home. Currently, there is 22% loss of follow up of children being treated with Ponseti and 2% relapse rate [10]. There is a need to identify why the parents fail to come on follow up clinic.

The results from this research will inform the hospital and the organizations dealing with clubfoot on the challenges that the parents with clubfoot children face, inform the policy developers on the importance of screening the embryo intrauterine to rule out such deformities for early intervention [11]. Strategies can be developed to ensure that the parents bringing children to the clinic are not

incapacitated in other unnecessary ways which can be overseen by the social worker department and the orthopedic department to ensure total compliance to the treatment regimen.

## **Objectives**

### **Main Objective**

To assess the financial, social and psychological burden of Ponseti management on parents and caretakers of children with clubfoot at Moi Teaching and Referral Hospital.

### **Specific Objectives**

- 1) To determine the financial factors affecting parents or caregivers of children with clubfoot undergoing Ponseti management at MTRH.
- 2) To identify the perceived social support factors affecting parents or caregivers of children with clubfoot undergoing Ponseti management at MTRH.
- 3) To assess the coping factors affecting that parents and caregivers of children with clubfoot at undergoing Ponseti management MTRH use.

### **Research questions**

- 1) What are the financial factors affecting parents or caregivers of children with clubfoot undergoing Ponseti management at MTRH?
- 2) What is the perceived social support factors affecting parents or caregivers of children with clubfoot undergoing Ponseti management at MTRH?
- 3) What are the coping factors affecting that parents and caregivers of children with clubfoot at undergoing Ponseti management MTRH use?

## **Conceptual framework**

### **Financial factors**

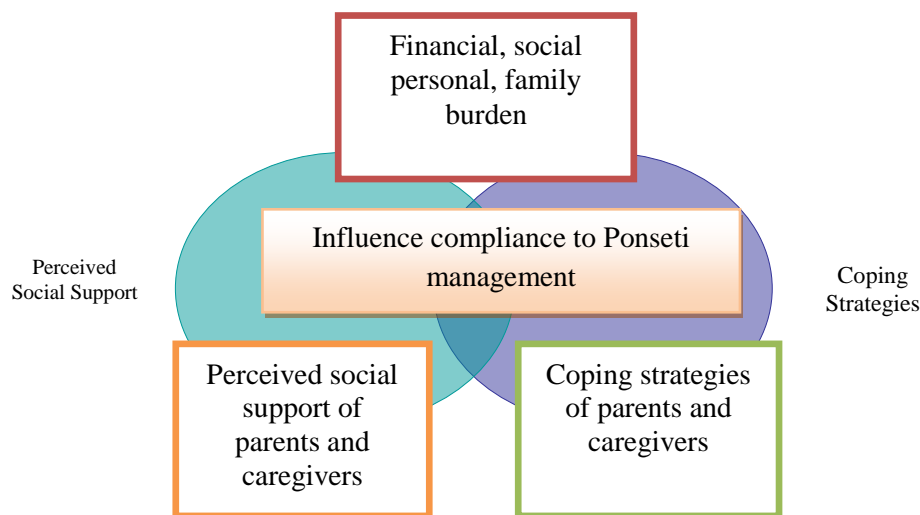
When the parents or caregivers bring the children to the clinic, they have to spend money on the transport and other logistics such as food to ensure that the children needs are met. For the low and middle income family settings, that is an extra heavy burden. Their performance might also be affected because of the burden of clubfoot on their lives [12].

### **Social factors**

Due to a child with clubfoot, the social events have to be put aside, and the time with friends and other family members is also strained [13].

### **Coping factors**

The parents of the child with clubfoot might feel that they have to make decisions together. There is a greater burden when a parent is one and has to make major decisions concerning the care of the child with clubfoot. While others might feel the condition of the child have made them stronger, there are those that will feel that they have not had enough time for other children or spouse due to the child with clubfoot. Other siblings might be treated differently by the society due to the ill child, which affects them negatively. Every person wants to feel supported while they are facing some challenges in taking care of a child who is ill.



**Figure 1. Conceptual Framework:**  
(van Wijck, Oomen & van der Heide, 2015).

## **Literature Review**

### **Ponseti method**

It is a method that is used to correct foot deformity in various stages. The first stage is manipulation of the foot to a better position and then casting it using plaster of Paris to get a desired improvement. The cast is removed after a week, it is then manipulated again and put in another cast. This is usually done for about eight weeks for the severe deformity or up to six times for mild deformity. Therefore the number of casts used depends from one individual to another. The first time a cast is put is aimed at placing the forefoot in alignment with the hind foot. The forefoot is said to be pronated when compared to the hind foot. When the forefoot is supinated the first metatarsal is elevated improving the alignment. The other casts are applied by stretching the foot and focusing on the abduction of the forefoot and applying pressure at the talus. The navicular is brought laterally to improve the alignment of the talonavicular joint. The abduction is increased with every casting to move the hind foot from varus to valgus. The ankle is left equinus till the forefoot and hind foot is corrected. In the final stage the equinus is corrected through attempt to dorsiflex the ankle.

In some children, it is not possible to do this without tenotomy. This is a procedure that is aimed at releasing the percutaneous heel cord. Many times, it is done with sedation or monitored sedation. The Achilles tendon is divided and a dressing applied before casting the clubfoot for the last time. This cast remains in place for three weeks or thereabout. The parents are then required to start the child on foot braces. With this procedure, the parents are expected to keep up with the clinic follow ups and to support their children all through the treatment. It is a procedure that affects the financial status, personal status, social status and family status of the parents while the child undergoes the treatment. Secondly, it is a procedure where the parents will need a lot of support from the hospital and the community while at the same time develop positive coping mechanism.

### **The impact of Ponseti management method on the lives of the parents or caregivers of children with clubfoot**

#### **Financial factors affecting lives of parents and caregivers of children with clubfoot**

The parents and caretakers need resources such as money for transport and food on those particular days they attend the clubfoot clinic for assessment and change of casts. Some come from far and getting transport on those days is hard. In a research done in Madagascar, the families that were

undergoing Ponseti management had financial issues which included debts incurred by 7 families, stopping to work by 4 parents. There were families that had to travel for more than 500km to the center for treatment which was difficult and costly for them [13]. In another research, financial constraints, methods of transport, care of the casts and braces lack of resources and lack of knowledge and skill were some of the barriers that were found to be common [14].

In another study done in Indonesia and South Africa, many parents had to travel far for the treatment incurring cost of travel and causing missed working days, which led to increase in poverty. There were other parents who found it difficult to travel with their children in public transport while they were on splints making them end up using private means. This also contributed to neglected clubfoot at the start of the treatment regimen [12].

### **Social factors affecting lives of parents and caregivers of children with clubfoot**

In the research done in Madagascar, 9 mothers felt ashamed of their children and hid the child's foot, while 8 others were blamed of having done a wrong thing while they were pregnant, hence the punishment on their children in Madagascar [13]. Many parents lack the knowledge and skill in care of casts and braces. The braces need to be kept on during some period while the casts have to be monitored frequently and cared for so that the method is effective [14]. There were parents who were isolated due to their child's clubfoot. Others had to hide their children's condition from other people because they feared they will be rejected. There were others that were advised to take their children to traditional healers for treatment [13].

### **Family factors affecting lives of parents and caregivers of children with clubfoot**

The Ponseti way of management was acceptable but taking care of the splints was a problem for many families. All mothers were distressed of the situation during the study in Madagascar [13]. Some parents perceive themselves as being defective in one way or another when they give birth to a child with clubfoot [14]. In a study that was done in Madagascar, some parents had to stop schooling other children in order to care for the child with clubfoot. Other parents had left work because of fear that they might be denied permission to take their children for treatment [13].

### **The perceived social support factors affecting parents or caregivers of children with clubfoot**

From a study that was done in South Africa showed that the parents from there who had children with clubfoot perceived a high social support when compared to those that were in the United Kingdom. The parents were comfortable receiving support from friends and family. The children in South Africa had more casts done than for those in the UK [15]. In a study done in Madagascar, there were parents who perceived that they were isolated and left out by the society because of their children's clubfoot. They also were blamed of wrongdoing during their pregnancy. There were others who found support by the friends and relatives, especially in families where there was history of clubfoot or those that had been treated for the condition before.

### **The coping strategy factors affecting the parents and caregivers of children with clubfoot**

The parents of the children with clubfoot at South Africa applied more coping strategies than those in the United Kingdom. This was according to a Brief COPE that was used. They had an active coping, denial, instrumental, venting, planning, emotional support, positive reframing, religion and acceptance of the condition and the treatment regimen [15]. According to Ramahenina, O'connor and Chamberlain [13], all mothers identified a stressful period during the Ponseti management. In the study done in Madagascar, there were parents who were distressed and unhappy because of clubfoot of their child. They felt guilty and rejected hence ended up being despaired.

## **Material and Methods**

### **Research Design**

Quantitative non explorative research design was applied to give a description so as to answer the research questions. Hence it was descriptive cross sectional study design. The data that was

researched and collected at a specific time was applied as a representative of the population at the clubfoot unit of MTRH. The data was used to describe the financial, social and coping strategies burden on parents who have children on Ponseti management for clubfoot at MTRH, their perceived social support and coping strategies applied by parents and caretakers of children with clubfoot at MTRH. The studies therefore met the objective of assessing the burden of Ponseti management on parents and caretakers of children with clubfoot at MTRH.

### **Population**

The population of children with clubfoot at MTRH every three months is averagely 120 children. The study population were parents and caretakers who are attending the clubfoot clinic and have undergone Ponseti management. Convenience sampling was applied to select the participants in the study approached to fill the questionnaire. All the parents and caretakers of children was given an opportunity to be included in the study.

### **Sampling frame**

MTRH offers its services to populations in the western part of Kenya, the Rift Valley, Part of Uganda and even Southern Sudan.

MTRH has a clubfoot unit under the orthopedic department that caters to the children who have clubfoot. They work in conjunction with the CURE international (CCK) hence the services currently are free of charge. The CURE international provide the materials used in Ponseti management hence reducing the cost of care. Other costs indicated for parents and caretakers are transport costs and also because of the children and the long ques, they have to incur meal costs before going back home.

### **Sample and Sampling Technique**

Convenience sampling was applied to carry out the study in the institution that the researcher has identified the gap. The participants were selected as they attended the clubfoot clinic. In a period of three months, there are 360 children with clubfoot who are seen at the clubfoot clinic. The three months was adequate to collect data of a representative sample of 120.

The sample size was calculated using the following formula as per Cochran [20]

$$n = (Z^2) P(1-P) / d^2;$$

where; n=the desired sample where population < 10 000

z=standard normal deviate (1.96) corresponding to 95% confidence limit.

d=degree of precision usually set at 0.05

P= prevalence/proportion (Estimated proportion 0.5). Since the burden of Ponsenti management of clubfoot on parents and caregivers of children with clubfoot is not known, P taken as 50%

$$1.96^2 \times 0.5 \times 0.5 / (0.05)^2 \text{ hence; } n = 384$$

The study will be adjusted for finite population as follows, Fishers' et al. [21] as stated by Cochran [20].

Since the population is small then the sample size was reduced slightly. This is because a given sample size provides proportionately more information for a small population than for a large population. The sample size (n) can be adjusted using the formula below. Where n is the sample size and N is the population size.

$$n = no / [1 + (no-1)/N]$$

Hence the sample size was 105 participants. After adding the 10 percent of error probability, the sample size was 120 participants. On calculation, every participant was given a chance to participate in the research till the target population was achieved. The parents or caretakers who participated were those that were eligible by meeting the inclusion criteria.

## **Inclusion and Exclusion Criteria**

### **Inclusion Criteria**

- ✓ Parent or caregivers with children with clubfoot.
- ✓ Parents or caregivers with children who were going through the Ponseti management of clubfoot.
- ✓ Parents or caregivers who attended outpatient clinic at MTRH
- ✓ Parents or caregivers who consented to participate in the study.
- ✓ The caregiver had to be a person who was staying with the child for a period of more than three months.

### **Exclusion Criteria**

- ✓ Parents or caregivers with children with clubfoot in the inpatient.
- ✓ Patient or caregivers who were treated with other methods of management of clubfoot.
- ✓ Relatives or friends who were bringing the children to the clubfoot clinic in place of the parent and they are not primary caregivers of the child.

### **Instrument**

The tool that will be used to collect data is a questionnaire that was in four parts. The first part is the demographic data that gave information on the demographics of the participants. Secondly it looked at the impact of Ponseti management on the lives of parents or caregivers of children with clubfoot; it looked at the financial, personal, social, and family impact. This applied the Impact on Family Scale (IOFS) research tool. The third part of the research tool looked at the perceived social support that they received from the society. It applied the Multidimensional Scale of Perceived Social Support (MSPSS) tool. The fourth part looked at their coping strategies while taking care of children with clubfoot. This used the Brief COPE tool.

All these data collection instruments were adjusted to adapt to the research topic. They are tools that are validated to collect data on chronic illnesses. They collected the expected data from the sample. Every questionnaire was administered having a number as identification so as to be able to guide the analysis.

The questionnaires that were filled 100% will be scored as that. Those that will be incompletely filled will be scored according to the number of questions answered. The questionnaires that were 90% filled will be included in the study.

## **Data Collection Procedures**

### **Ethical Considerations**

**Informed consenting:** After explaining to the participants what the study entails, they were given a chance to choose whether they wanted to be included in the study. They were not forced to participate. There was an informed consent form to sign after fully understanding the study. They were explained to what it is and why they should be involved in the study. They were told of its benefits and harmful influence. Moreover, they were reassured that failure to participate would not influence them negatively.

They were informed that:

- ✓ There would be no incentives provided for them during the study hence it is voluntary.
- ✓ There are no anticipated harm; physical or mental or psychological to the participants.

**Confidentiality of data collected:** the information that was provided by the participants would only be used for the study purposes and hence it will be necessary to have the information remain confidential and it would not be released from the storage unless the participants give permission. Anonymity would be observed throughout the study and during publication.

**Respect:** Respect for the participants would be expressed by having them recognize their right to self-determination in making decisions and judgment for themselves as well as their autonomy.

**Approval:** It is the right of every participant to be treated with utmost respect. Hence according to expectation of the constitution of Kenya, it is only fair that there would be approval from the institutional IREC of MTRH and NACOSTI (National Commission of Science and Technology Institute) before the data was collected.

### **Pilot Test**

So that the researcher gets to understand the questionnaire, there was a pilot study that was carried out in the occupational therapy department who also deal with parents of children who have chronic musculo-skeletal conditions and have to be in the hospital often for therapy. It would enable the researcher to get the potential responses that they are likely to be given in the questionnaire during the study. This mock data collection would also ensure that the information provided flows in an efficient and effective manner. The questionnaire would take up to 20 minutes to be filled by the research participants.

The research was conducted between October and December 2019.

### **Data processing and analysis**

#### **Data Analysis**

The information in the questionnaire was assessed to check for how complete they are before the researcher enters it into the computer software. The raw data provided by the participants was cleaned, coded and then entered into the SPSS software. Version 20 of the software was used. The data was analyzed by using descriptive statistics, and Pearson's correlation where P-value was set at  $<0.05$  to show significant association.

### **Dissemination of Research Findings**

The results from the research were provided to the clubfoot unit of MTRH as well as the Ethics committee. They were also provided to the various departments of MTRH as abstracts. The report will be presented in various seminars and conferences as well as get published in particular journals.

### **Findings**

#### **Demographics**

The age of the child ranged from 2 days to 6 years old with a median age of 0.78 years (IQR 0.31, 2.01). Where males were slightly more (54.7%) compared to females (45.3%) giving a male to female ratio of 1.2:1. The age of mother ranged from 18 to 55 years with a median age of 27 years (IQR 24, 32). Majority (77.7%) of the mothers were married where single constituted 16%. Only 33.3% of the mothers had completed college level of education with only 1 who reported not to have attended formal education.

**Table 1. Demographics**

<b>Variables</b>	<b>Category</b>	<b>Frequency</b>	<b>Percentage</b>
Child's sex	Male	52	54.74
	Female	43	45.26
Maternal education	None	1	1.08
	Primary	35	37.63
	Secondary	26	27.96
	College	31	33.3
Maternal marital status	Married	73	77.66
	Single	15	15.96
	Separated	5	5.32
	Divorced	1	1.06
Child's age	Median (IQR)	0.78 (0.31, 2.01)	
Mother's age	Median (IQR)	27 (24, 32)	

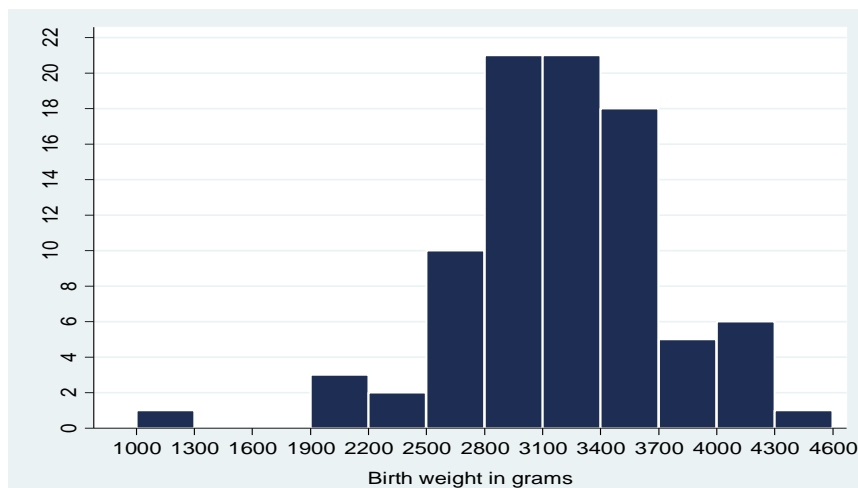


### Medical history

At birth, the weight of newborns ranged from 1000grams to 4600 grams with mean birth weight of 3148 (SD 547) where only 6(6.8%) were born underweight (less than 2500 grams). While gestation age ranged from 18 to 42 weeks with median gestation age of 40 weeks (IQR 38, 40) where 14(16.3%) were premature (born before gestation 37 week). Half of the patients (50.6%) had bilateral clubfoot while the other half only one foot was affected, where most 24(57.1%) affected right foot. Of these patients, 42(44.7%) had a family member who also had a clubfoot. Majority (83.2%) of the patient with clubfoot were delivered through SVD. Maternal or paternal history of alcohol, smoking or diabetes was negligible.

**Table 2. Medical history**

Variables	Category	Frequency	Percentage
Gestation at birth	Median (IQR)	40 (38, 40)	
Birth weight	Mean (SD)	3148 (547)	
Laterality	Unilateral	42	49.41
	Bilateral	43	50.59
Delivery mode	SVD	79	83.16
	C/S	16	16.84
Family history of clubfoot	None	52	55.32
	Yes	42	44.68
Smoking history	Paternal	1	1.06
	Maternal	1	1.06
Alcohol intake history	Paternal	5	5.26
	Maternal	3	3.23
Diabetes history	Paternal	1	1.05
	Maternal	1	1.05



**Figure 2. Birth weight**

### Perceived impact on family scale (IOPS)

The purpose of Impact-on-Family scale (IOPS) is to quantify the impact of childhood illness on a family. Stein and Riessman [22] developed a 33 items inventory to measure the impact of childhood illness on family which had a 4-level likert scale (strongly disagree to strongly agree). In this study the researcher didn't use the inventory as recommended by Stein and Riessman [22] (use of 4-level likert scale) instead used 2-level scale (0=no, 1=yes scale). Individual scores were calculated as a percentage of the questions answered yes for purpose of comparison across the five scales instead of total score. Financial burden was most sited impact of childhood illness on family with a mean score of 77.5% followed by mastery/coping with 75.3%. On the contrary impact on siblings was the least sited at 49.5% followed by personal strains.

**Table 3. Impact-on-Family Scale**

Category	Mean	Standard deviation
Financial burden (8 items)	77.5%	18.9
Familial/social impact (15 items)	70.1%	28.2
Personal strains (6 items)	62.7%	25.7
Mastery/coping (4 item)	75.3%	21.6
Impact on siblings (5 items)	49.5%	27.2

### Perceived social support

To measure where the parent/guardians got the support, Multidimensional Scale of Perceived Social Support (MSPSS) inventory was used. The questionnaire has 12 questions which are divided into 3 main subscales as recommended by Zimet et al. [23]. He also recommended that the scale can be divided into; low support (means scales 1–2.9), moderate support (means scales 3– 5), high support (means scales 5.1–7). In this study majority of parent/guardian of children with clubfoot perceived the social support to be from significant other followed by family, while friends were the last in terms of perceived social support.

**Table 4. Perceived social support**

Category	Mean	Standard deviation
Significant other	5.21	1.65
Family	4.99	1.93
Friends	3.88	1.97
Total SMPSS	4.74	1.60

Overall, those who were classified as having high support were 36(46.8%). Significant other subscale had the highest proportion (62%) of those perceived to have high social support compared to family sub scale (58.1%) and friends sub scale (31.0%).

**Table 5. Perceived social support**

Variable	Category	Frequency	Percentage
Significant other	Low support	8	8.70
	Moderate support	27	29.35
	High support	57	61.96
Family	Low support	15	17.44
	Moderate support	21	24.42
	High support	50	58.14
Friends	Low support	28	32.18
	Moderate support	32	36.78
	High support	27	31.03
Total SMPSS	Low support	9	11.69
	Moderate support	32	41.56
	High support	36	46.75

### Coping mechanism

To determine coping mechanism of parent and caregivers of children with clubfoot undergoing Ponsenti management at MTRH Brief COPE questionnaire was used. The questionnaire consist of 28 questions but for ease of interpretation, it has been divided into 14, two-item scales as recommended by Carver et al. [24].

The most used coping strategy is that of religion followed by acceptance and positive reframing. While the least used coping strategy is substance use followed by humor and behavioral disengagement.

**Table 6. Coping mechanism**

<b>Category</b>	<b>Mean</b>	<b>Standard deviation</b>
Religion, items 22 and 27	3.30	1.01
Acceptance, items 20 and 24	3.08	0.87
Positive reframing, items 12 and 17	2.91	0.93
Active coping, items 2 and 7	2.90	0.92
Planning, items 14 and 25	2.49	1.08
Use of emotional support, items 5 and 15	2.30	0.99
Use of instrumental support, items 10 and 23	2.20	1.00
Denial, items 3 and 8	2.02	0.96
Self-distraction, items 1 and 19	1.96	0.81
Venting, items 9 and 21	1.86	0.80
Self-blame, items 13 and 26	1.72	0.88
Behavioral disengagement, items 6 and 16	1.69	0.85
Humor, items 18 and 28	1.30	0.66
Substance use, items 4 and 11	1.18	0.44

## **Discussion**

### **Study sample**

This is a study that investigated the burden of Ponsenti management on the parents and caretakers of children with clubfoot in MTRH. The results in the study show that the sample of 94 parents and caretakers that brought their children to the facility for Ponsenti management and participated in the study. This sample size composed of 52 females and 43 males. The females dominating the clinic can be compared to a similar study that was done at Centre for the Rehabilitation of the Paralysed on barriers experienced by caregivers to access treatment of clubfeet patients of having consisted of 66.7% of mothers and 16.7% of fathers [16].

At Mbarara Regional Referral Hospital, a study was conducted on barriers experienced by parents/caregivers of children with clubfoot deformity attending specific clinics in Uganda where 98% were mothers and 2% were biological fathers of the children [17].

The dominance of females can be attributed to the fact that the women have a gender role of caring for their children and keeping appointments. It was noted that a good number of men were however interested in the care their children were receiving in this study compared to others. This can be attributed also to women in the society being increasingly educated and having become providers as well as caregivers which has led to change in gender roles [18]. 77% (73/94) were married while 15.9% (15/94) were single.

The mean age of the caregivers was 28.5 years (SD=6.7) with the majority between 24 and 32 years of age. Most of the parents in this study were in the years that they are most productive to the society. This is comparable to other studies such where the parents who had children with clubfoot were in their most productive years [19].

### **Medical history**

Half of the patients (50.6%) had bilateral clubfoot while the other half only one foot was affected. This is comparable to a research by Esan et al. [19] where 50% of the patients had bilateral clubfoot. In this study it was noted that the boys (54.7%; n=52) were more affected than the females (45.3%; n=43) to a ratio of 1.2:1, which was comparable to findings of the study done in Nigeria by Esan et al. (19) which indicated that males were more (70.7%; n=41/58), and females were 29.3%, n= 17/58. Where most 24(57.1%) affected right foot. Of these patients, 42(44.7%) had a family member who also had a clubfoot. Majority (83.2%) of the patient with clubfoot were delivered through SVD. Maternal or paternal history of alcohol, smoking or diabetes was negligible.

### **Perceived impact on family scale (IOPS)**

Financial burden was most cited impact of childhood illness on family with a mean score of 77.5%. The parents experienced financial burden while taking care of the children born with clubfoot. Their finances get directed to clinic visits because they need transport to reach the hospital. The time that they would use initially to cater for family needs and work for money, once they have to cater for the needs of the child with clubfoot then they cannot be as productive as before. They left their work so as to care for the child. This finding could be expected considering the fact that 66.7% of the parents that participated in the study had no tertiary education which could translate to better earnings. However, this study did not investigate the income or employment status of the parents and primary caregivers of the children. This is comparable to other studies that have been done on Ponsenti management and financial implications to families [13]. In MTRH the clubfoot Ponsenti management is free but it was found that still the parents of children with clubfoot still face financial burden as the most barrier in during their children's management.

### **Perceived social support**

In this study majority of parent/guardian of children with clubfoot perceived the social support to be from significant other followed by family, while friends were the last in terms of perceived social support. Overall, those who were classified as having high support were 36(46.8%). Significant other subscale had the highest proportion (62%) of those perceived to have high social support compared to family sub scale (58.1%) and friends sub scale (31.0%).

### **Coping mechanism**

The most used coping strategy is that of religion followed by acceptance and positive reframing which are categorized as being in the approach coping. While the least used coping strategy is substance use followed by humor and behavioral disengagement. This was similar in a study that was done in South Africa and UK where it showed that the South African parents perceived a higher support socially [15]. They employed more coping strategies which can be attributed to the cultural and social practices in the South African region. The research showed that the South African felt more comfortable seeking help from the facilities when they felt encouraged by their friends and family. This can be compared to the current research where more people felt that they got support from their families and friends.

### **Family support**

Family support that is provided by the closest person in the family affects the perception of the parent and their behavior while making decisions on children undergoing Ponsenti management. Although in a study that was done in Uganda showed that physical and financial support had a significant association [17], in this study, the parent or caregiver felt that they received support from their significant others although they still faced financial challenges. It is likely that when the parents get support from the people close to them, they get relieved from burden of domestic responsibility and they would also received financial assistance from them helping them afford necessary costs and comply to the treatment regimen.

### **Summary and recommendation**

This discussion focused on major findings of the research in respect to the objectives of the study. They showed that the parents were facing financial challenges and also clubfoot condition impacted on their family and social activities in the society. The study provided information on factors that might be barriers of the parents complying with Ponsenti management at Moi Teaching and Referral Hospital. Just like other programs support the Kenyan Ministry of Health facilities where people in the society receive critical health services the CURE and other partners and stakeholders should collaborate and deal with clubfoot should devolve services across counties and sub-counties. Further strategies should be developed to provide services near the resident places of the children. Community devolvment of the CURE services will ensure that the parents do not spend a lot of money on transport and meeting other needs of the children while on the way.

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