

# Assessment of awareness and barriers to clubfoot treatment in the Indian scenario

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#### Abstract

**Background:** We undertook this study to evaluate the awareness of the Primary Caregivers of children with clubfoot aka Congenital Talipes Equino Varus (CTEV) and their familiarity with the disease, their beliefs, knowledge and compliance to treatment, and barriers encountered during the treatment process. **Settings and design:** Cross-sectional, analytical study. **Materials and methods:** A standard questionnaire in the local vernacular language was prepared, on which 108 respondents were interviewed. Data were analyzed by using Statistical Package for the Social Sciences (SPSS) software program, version 21.0. Chi-square test was applied wherever suitable as a parametric test. **Results:** Approximately 57.40% of participants had no prior knowledge of clubfoot at all, till they had a child born of the deformity in the family. Superstitions like lunar eclipse (37.96%), punishment from God (37.03%), solar eclipse (34.26%) and black magic (26.85%) were widely prevalent as the perceived cause of the deformity. Only 25% of the participants believed that any kind of treatment should be started immediately after birth and 20.37% of the study population felt the first line of treatment should be a visit to a spiritual healer or to a shrine of a saint. Approximately 68.52% of the study participants were satisfied with the explanation of the disease process and treatment plan offered by the treating doctor. Approximately 52.77% perceived social stigma as an obstacle to treatment, whereas 58.33% had difficulties adjusting to change of home or workplace routines. **Conclusion:** The awareness level regarding clubfoot in the primary caregivers in the Indian scenario is low and has an implication on successful treatment and compliance.

Keywords: Awareness, barriers, caregivers, clubfoot, CTEV

#### Introduction

CTEV (Congenital Talipes Equino Varus or Clubfoot) is a birth defect in which the heel is in the equinus position and the foot is adducted and supinated. It is a relatively common congenital defect, with an incidence of about 1 to 7 per 1000 live births.<sup>[1]</sup> Male children are twice as likely to be affected with CTEV than

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females, with a ratio of 2.5:1.<sup>[2]</sup> Although various modalities of treatment, including nonoperative and operative, are available for the treatment of CTEV, the neglect of this condition is quite common.<sup>[3]</sup>

Primary Caregivers play a pivotal role in the treatment of CTEV, as the affected children often must go through repeated surgical procedures, physiotherapy and must wear orthopedic braces for extended periods of time, which needs a high degree of compliance to treatment and follow up. This compliance is directly related to the awareness, knowledge, and practices of these primary caregivers as regards the disease in question. These caregivers are under tremendous mental stress and consult many sources (medical personnel/relatives/traditional healers) for cure of their wards.

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This study was aimed to understand clubfoot from the perspective of the primary caregiver and to map their knowledge of this disability, their attitude towards it and what steps they took in this scenario (Practice).

### **Materials and Methods**

This study was conducted over a 3-month period from September 2018 to November 2018 in the Orthopaedics outpatient department of a tertiary hospital affiliated to Armed Forces Medical College, Pune as an ICMR Short Term Studentship (ICMR-STS) research project. The study was a cross-sectional analytical study, with an aim to assess the awareness about CTEV and its treatment in primary caregivers of children suffering from CTEV.

The objectives of this study were to help identify the environmental and social beliefs associated with this disability, to detect compliance to treatment, to ascertain existing knowledge amongst primary caregivers, and to recognize the difficulties which the caregivers face during treatment of CTEV.

#### Ethical considerations and consent

The study was approved by the Institutional Ethics Committee of Armed Forces Medical College, Pune (No. IEC/2018/107, dated August 8, 2018). Participation in this study was voluntary, and a written informed consent was obtained from each study participant after a detailed description of study objectives and methodology. The study participants could have refused or discontinued participation at any time.

#### **Inclusion criteria**

1. Primary caregivers, defined by the Oxford dictionary as the person who provides most of the care or guardianship, especially to a child or an infirm person, of children with CTEV and were more than 18 years of age.

#### **Exclusion criteria**

- 1. All individuals who were not involved directly in the care of the affected individuals irrespective of age or relationship to children with CTEV.
- 2. Any primary care giver who had a pre-existing psychiatric illness or was on medications for the same.

All participants were subjected to an indigenously developed questionnaire based on the lines of a standard Knowledge, Attitude and Practices study format. This questionnaire was prepared in English and the local vernacular language which the participants could understand, and pilot testing was done on 30 individuals who were not part of the study but satisfied the inclusion criteria; the questionnaire was found to be feasible and easily administrable and reproducible.

Data for this study were collected by a single interviewer using this questionnaire. The interview was a structured interview. The interviewer was not involved in data analysis to eliminate observer bias.

Based on the study performed by Alam *et al.*<sup>[4]</sup> the percentage of population aware of CTEV and its management was 7%. Hence, using the formula below, the sample size (N) was calculated with an  $\alpha$  error of 5%, *P* (expected proportion) of 0.07, *q* (1–p) of 0.93 and d (expected deviation) of 5%:

$$N = (Z-1/2)^2 \ge p \ge q$$

 $d^2$ 

The minimum sample size for this study was determined to consist of 100 subjects.

STROBE guidelines for cross-sectional studies were followed for reporting our study. Chi-square test was applied as a parametric test to analyze the data and Statistical Package for the Social Sciences (SPSS) software program, version 21.0 (SPSS, Chicago, Illinois) was used to conduct data analysis.

#### Results

A total of 108 participants were recruited for this study. The socio-demographic profile of the study cohort is given in Table 1.

Figure 1 summarizes the participants' perceived causes regarding clubfoot. Although all respondents were primary caregivers of children with clubfeet, 62 (57.40%) participants had no prior knowledge of clubfoot or its treatment at all, till they had a child born of the deformity in the family. For analysis of different

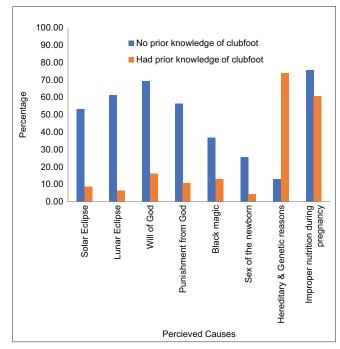


Figure 1: Perceived causes of clubfoot

Table 1: Socio-demographic characteristics of the study participants ( <i>n</i> =108)					
Variables	Frequency (n)	Percentage (%)			
Sex					
Male	37	34.26			
Female	71	65.74			
Age Group					
18-25 years	62	57.40			
25-35 years	20	18.54			
35-45 years	10	9.25			
45-55 years	16	14.81			
Marital Status					
Married	102	94.44			
Widowed	6	5.56			
Education level					
Uneducated	22	20.37			
Primary	4	3.70			
Secondary	28	25.93			
High School	40	37.04			
University	14	12.96			
Employment Status					
Employed	36	33.33			
Self Employed	10	9.25			
Unemployed	2	1.85			
Homemaker	58	53.75			
Retired	2	1.85			

factors, we divided the study population into two groups; Group 1 had no prior knowledge of clubfoot and Group 2 had some prior knowledge of clubfoot before they had to care for a child with this disability. Overall, the cause most perceived to be responsible for development of clubfoot was improper nutrition during pregnancy (69.44% in all). Other causes in descending order of belief were Will of God (49.07%), hereditary inheritance (38.89%), lunar eclipse (37.96%), punishment from God (37.03%), solar eclipse (34.26%), black magic (26.85%) and sex of the newborn (16.67%). Applying multiple response dichotomy analysis with Chi-square test, these causes were found to be statistically significant in the two groups.

Table 2 shows the perceived attitudes regarding treatment in the study population. Only 25% of the participants believed that any kind of treatment should be started immediately after birth, and this difference of opinion was statistically significant in the two groups. 20.37% of the study population felt the first line of treatment should be a visit to a spiritual healer or to a shrine of a saint, which was statistically significant on Chi-square test of association.

Table 3 sums up the attitudes of the study population with respect to treatment visits to the hospital for definitive care. Most of the hospital referrals for treatment of clubfoot (35.19%) were from medical personnel (doctor, nurses, and medical assistants) followed by referrals from friends/relatives, self-referrals and by Dais/Midwives. 76.85% of the study participants felt that the treatment cost was affordable, whereas others felt it was expensive and unaffordable, but still went ahead with the same. 58.33% of the study population experienced a disturbance in the routine of their daily home/work life, whereas others did not have any problem in adjusting their daily routines. Approximately 70.37% of the participants ensured that they took proper care of the plaster casts, whereas the rest had difficulty in maintaining the casts and needed more frequent changes of the same. Approximately 74.07% of participants were aware of the importance of maintaining the corrected foot in abduction braces/orthotics, whereas others were either unaware or noncompliant. Approximately 66.67% of the study population believed that stopping treatment would cause a worsening of the deformity, 20.37% felt the deformity would remain static and 12.96% thought it will correct itself.

Table 4 lists the barriers to treatment faced by the primary caregivers during treatment. Travelling for treatment was a major barrier faced by the study participants. 43.52% of the participants had to travel more than 10 km for seeking hospital treatment and 84.26% of the total participants faced financial difficulties in catering to the transportation costs and logistics. Although 24.07% of the participants had some financial difficulties in providing for cost of treatment per se, the majority faced no such barrier. No statistically significant difference was noted on Chi-square test for these parameters. Approximately 52.77% perceived social stigma as an obstacle to treatment, whereas 59.29% felt an uncooperative child was a barrier that could not be overcome, 52.77% of participants faced resistance from family members, whereas 58.33% had difficulties with adjusting to change of home or workplace routines, all of which were statistically significant barriers noted in the two groups.

## Discussion

We hypothesized that the prevailing knowledge about clubfoot amongst primary care givers of children affected by this disorder would be low, as previous research reported the knowledge to be totally lacking or filled with misconceptions. Alam et al.[4] in his study of parents of clubfooted children found that 93.3% of parents knew nothing about CTEV before they had a child suffering from this condition. Our study revealed that more than half of primary caregivers were totally unaware of this condition till they had to care for a disabled child. Studies have reported a lack of adequate knowledge as one of the contributing factors for poor treatment compliance and the resulting complications.<sup>[5]</sup> However, no analysis was done to assess the association between caregivers' knowledge about clubfoot and its treatment and their long-term compliance to treatment in our study, due to its cross-sectional nature. Despite this, the importance of knowledge and understanding regarding clubfoot cannot be sidelined and assumes a pivotal role in successful management of this condition.

In our study, the most prevalent perceived cause of clubfeet was improper nutrition during pregnancy, followed by Will of God, hereditary inheritance, lunar eclipse, punishment from God, solar

Table 2: Perceived attitudes regarding tree	0 0			
Perceived attitudes regarding treatment	Awareness about clubfoot			
	(No=62) n (%)	(Yes=46) n (%)		
Timing of Treatment				
When should treatment be started for this condition?				
At birth	10 (16.13)	17 (36.96)	0.02	
Birth-6 months	17 (27.42)	13 (28.26)	0.9	
6 months-12 months	23 (37.10)	10 (21.74)	0.09	
1 year-5 years	12 (19.35)	6 (13.04)	0.4	
First line treatment				
What is the first line of treatment you think was best when starting treatment of this condition?				
Spiritual healers and visiting holy shrines	19 (30.65)	3 (6.52)	0.001	
Massaging	25 (40.32)	10 (21.73)	0.1	
Bandaging	14 (22.58)	12 (26.09)	0.9	
Cast application	2 (3.23)	16 (34.78)	0.2	
Surgery	2 (3.23)	5 (10.87)	< 0.001	
Follow up				
Do you think regular follow up is required for success of any treatment undertaken?			< 0.001	
No	43 (69.35)	7 (15.22)		
Yes	19 (30.65)	39 (84.78)		

Perceived attitudes regarding treatment visits	Awareness al	oout clubfoot	Р
	No=62 n (%)	Yes=46 n (%)	
Who referred you to the hospital for treatment?			
Self	8 (12.90)	14 (30.43)	0.031
Friend/Relative	17 (27.42)	10 (21.74)	0.6
Dai/Mid-wife	15 (24.19)	6 (13.04)	0.2
Medical Personnel	22 (35.48)	16 (34.78)	0.9
Were you satisfied with the explanation offered by the treating doctor regarding the disease and its treatment?			0.035
Yes	48 (77.42)	26 (56.52)	
No	14 (22.58)	20 (43.48)	
Is the treatment offered expensive/unaffordable for you?			0.6
Yes	13 (20.97)	12 (26.09)	
No	49 (79.03)	34 (73.91)	
Is your daily life/work routine affected by regular hospital visits for treatment?			0.002
Yes	28 (45.16)	35 (76.09)	
No	34 (54.84)	11 (23.91)	
Do you take adequate care of the plaster cast and report to the hospital in case it is damaged?			0.001
Yes	52 (83.87)	24 (52.17)	
No	10 (16.13)	22 (47.83)	
Do you ensure that your child wears the requisite orthotic (Abduction brace, DB splint, etc.) at prescribed times?			0.5
Yes	44 (70.96)	36 (78.26)	
No	18 (29.04)	10 (21.74)	
What do you think will happen to the deformity if left untreated?			0.015
Deformity will become more disfigured	37 (59.68)	35 (76.09)	
Deformity will remain the same	12 (19.34)	10 (21.74)	
Deformity will correct itself	13 (20.98)	1 (2.17)	

eclipse, black magic, and sex of the newborn. In a study carried out in Pakistan by Burfat *et al.*,<sup>[6]</sup> many misconceptions related to apparent causes of clubfeet were evaluated qualitatively. Although not quantified, their study noted eclipses, including the actual event of eclipses (Solar/lunar), activities which the mother did during an eclipse and mother's movements during an eclipse, to be a leading cause to be responsible for ultimate development of this deformity. *Also notable were religious beliefs like will of God*, punishment from God and witchcraft, along with a view that maternal nutritional deficiencies during pregnancy, consumption of tobacco during pregnancy and genetic and hereditary causes, to be amongst the perceived causes for occurrence of clubfeet in affected children. It is clear these perceived causes are rampant in the Indian subcontinent and it is important that the public receives proper knowledge about the etiology so that caregivers can seek proper, timely treatment from health facilities.

Table 4: Barriers and difficulties experienced by primary caregivers during treatment					
Perceived Barriers and difficulties during treatment	Awareness a	Р			
	(No=62) n (%)	(Yes=46) n (%)			
Travel distance			0.9		
<5 km	9 (14.52)	8 (17.39)			
5-10 km	26 (41.94)	18 (39.13)			
>10 km	27 (43.55)	20 (43.48)			
Financial difficulties associated with cost of treatment	17 (27.42)	9 (19.57)	0.4		
Financial difficulties associated with cost of travel	53 (85.48)	38 (82.61)	0.8		
Social stigma attached to the disease	47 (75.81)	10 (21.74)	< 0.001		
Frequent changing of casts and cast care	24 (38.71)	15 (32.61)	0.5		
Uncooperative child	46 (74.19)	18 (39.13)	< 0.001		
Resistance from family members/elders	34 (54.84)	23 (50.00)	0.7		
Family/work commitments and disruption of daily routine	42 (67.74)	21 (45.65)	0.03		
Improper explanation by treating doctor as regards disease and its treatment	24 (38.71)	12 (26.09)	0.2		

Alsiddiky *et al.*<sup>[7]</sup> in their review of public awareness of clubfoot in the general population in Saudi Arabia noted that prior knowledge of clubfoot was significantly associated with awareness of the best time to initiate clubfoot treatment and that there was a statistically significant association between awareness and correct perception of first-line treatment for clubfoot, that is, respondents who believed cast application was the first line of treatment for clubfoot were significantly more aware of clubfoot. Alam *et al.*<sup>[4]</sup> reported that 11.8% of the parents of children with CTEV were unaware of the best time to initiate treatment. In our study, we found that the participants believed that treatment for clubfoot should be started before 6 months of age but not at birth (30.56% of the total study participants).

Bridgens *et al.*<sup>[8]</sup> reviewed the outcomes of surgery and casting (Ponseti) for clubfoot and found that 78% who were treated using the Ponseti method had an excellent or good result compared with 43% of the cases treated surgically. In our analysis, 16.67% of the respondents believed that casting was effective whereas a small proportion (6.48%) believed surgery was effective. The need for early referral to a specialist must be emphasized for successful outcomes following appropriate management,<sup>[9]</sup> as early presentation can usually be managed with casting alone and prevents the need for a surgical intervention and also helps prevent complications. *Our analysis also revealed that many caregivers firmly believe in the healing potential of spiritual healers and positive effects of visiting a holy shrine of a "peer" or a saint (20.37%)*, yet again exposing a lacuna in the existing knowledge in the population.

Hospital treatment visits constitute a major part of clubfoot treatment and most of the hospital referrals were provided by medical professionals in our study, primarily because our study was based in an urban area and almost all deliveries in urban India are being carried out in institutions due to good access and increased awareness of maternal morbidity and mortality. Shelton *et al.*<sup>[10]</sup> conducted a study in the UK on parents' experience of clubfoot diagnosis and found out that in most cases, the parents were generally satisfied with the outcome and with the way that they had been treated at the hospital they attended with their child. The most common suggestion for improvement was in

the provision of information by the healthcare professionals. Despite being a developing country, the satisfaction levels in our study population are good considering the limited health infrastructure (68.52% of participants were satisfied).

Compliance to treatment remains a prime cause of concern in prevention of relapses and recurrences of CTEV, which in addition to surgical treatment entails a prolonged treatment time increasing the caregiver burden. Alam et al.[4] reported a correct knowledge and importance of plaster cast care in 86.3% and application of orthotic braces in 52% of their study population. Our analysis revealed figures of 70.37% for cast care and 74.07% for orthotics which are consistent with his study statistics. A study by Evans et al.[11] underlined the fact that rates of dropouts during management of CTEV were dictated in large part by the emotions of the parents (e.g. guilt, shame, blame, fear) and the experience during initial casting of the clubfeet, as well as inadequate communication between the medical professionals and primary caregivers. A new finding of our research is the fact that 66.67% of our study population believed that the clubfoot deformity would worsen on treatment cessation, which highlights the importance of patient education by the healthcare institutions and proper follow-ups.

Perceived barriers to treatment are a fundamental roadblock to effective clubfoot treatment. Alyana *et al.*<sup>[12]</sup> in their study on barriers affecting clubfoot treatment in a Malaysian cohort described the lack of adequate knowledge, geographical terrain, logistical difficulties especially in transportation and financial difficulties in treatment and transportation costs to be major, statistically significant factors in deterring optimum treatment. Financial strain that the caregivers encounter during the treatment process includes weekly travel expenses for change of cast. The occult expense incurred during these weekly visits is quite high considering their income. This is further worsened by the fact that orthotic braces are very expensive and not all parents/caregivers can afford to purchase them.<sup>[13]</sup>

Studies conducted in the African continent in places like Malawi and Uganda have highlighted the importance of social stigma

#### Conclusion

as a major perceived barrier to clubfoot treatment.<sup>[14,15]</sup> Our study reveals an association between caregivers who did and did not have prior knowledge of clubfoot and experience of a social stigma acting as a barrier to treatment. These studies<sup>[14,15]</sup> have also shown that familial resistance and lack of moral and emotional support are factors that act as barriers against treatment. Caregivers are left with no choice but to give in to the wishes of the elders in the family, who disapprove of the treatment.<sup>[15]</sup> Family support assumes a key responsibility in determining the compliance to treatment.<sup>[14]</sup> Resistance from family members or elders is an important obstacle to treatment in our study and positive assistance from family members is vital to enhance treatment compliance. The same has been highlighted by Doris et al.[16] in which the authors have suggested tackling perceived social support, financial impact on the family, positive reframing as a coping mechanism, and family support to ensure a successful treatment outcome.

Caregivers' commitments and responsibilities are important factors affecting clubfoot treatment. Many respondents (58.33%) mentioned it was very difficult to bring their children for regular treatment as they had other obligations and duties. Leaving behind other family dependents and missing work while attending to the treatment was disturbing to the daily routines in the household and workplace. Alyana et al.[12] stated a negative effect of these family responsibilities on the treatment compliance because of which the children failed to receive opportune and satisfactory treatment. Comparable research done in Latin America showed family commitments and responsibilities the caregivers shouldered were one of the biggest obstacles in obtaining treatment for CTEV.<sup>[17]</sup> Nonetheless, this aspect has an enormous influence on the caregiver compliance to clubfoot treatment that leads to poor observation of the treatment protocol.

Strengths of our study include the fact that with a sizeable sample size, the results obtained carry a statistically relevant value which can be utilized for extrapolation to similar populations. We have not only analyzed the lacunae in the existing knowledge of clubfoot in the primary caregivers of this condition but have also tried to ascertain what are their attitudes to treatment and perceived barriers needed to overcome for successful management of these cases.

Our study is limited by the fact that as the results obtained are in a hospital setting and are of primary caregivers of children who have the disease, these cannot be generalized to the general population. Also, as the study was carried out in an urban setting, the results cannot be extrapolated to the rural populace as they have their own peculiar set of constraints. Our questionnaire could not be validated prior to start of the survey, as it was outside the scope of an undergraduate ICMR-STS project, although pilot testing was carried out to determine the feasibility of the same. We could not assess the impact of socio-economic status on the barriers or practices of the caregivers, as many respondents were reluctant or refused to divulge their income details. This study has highlighted that clubfoot is as much a social affliction as it is a medical condition. The variety of superstitious beliefs which are still widely prevalent surely hinder the treatment and counseling of the affected families.

There is a definite relevance of primary care physicians in the management of this disorder. A comprehensive knowledge of CTEV and ability to educate the primary caregivers of affected children will immensely increase the faith in the population as regards the healthcare setup and help in a significant reduction of the disease burden and associated complications, which mostly are directly related to lack of proper knowledge or a missed or misdiagnosis on the part of primary care physicians.

#### Summary

To summarize the research effort, it would be prudent to mention the following:

- a. This study has highlighted that clubfoot is as much a social affliction as it is a medical condition and awareness level regarding clubfoot in the primary caregivers in the Indian scenario is low.
- b. Various social variables play a role in the unsuccessful management of clubfoot in India, of which superstitions, financial handicaps, social stigma attached to the disease and deformity, resistance from family members, and general misinformation among the population regarding the disease.
- c. There is a distinct role of primary care physicians in achieving successful outcomes of the treatment, provided they have a basic but adequate knowledge of CTEV, identify the disease as early as possible, counsel the parents and primary care givers of the affected child in a manner as to dispel the prevalent myths like religious superstitions surrounding the condition and refer earlier to a specialist for effective management, be it casting or surgery, instead of primary caregivers resorting to services of local saints, *peers* and visiting shrines in hope of a cure.

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#### **Conflicts of interest**

There are no conflicts of interest.

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