

## Problems Faced by Parents in Care of Children with Congenital Clubfoot

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### ABSTRACT

**Objective:** This study aims to identify physical, psychological, social and financial problems faced by parents in care of children with congenital clubfoot. **Methods:** A cross-sectional study among 52 parents of congenital clubfoot child was commenced purposively who attended Hospital and Rehabilitation Center for Disabled Children (HRDC) outpatient department for treatment. The self-constructed tool with 22 item 5-point Likert scale questionnaire was used for interview. Confidentiality and privacy of the participants was maintained. The internal consistency of the tool after pretesting was as high as 0.887. Descriptive statistics i.e. frequency, percentage, mean, standard deviation was used for data analysis. **Results:** The study revealed that most of the clubfoot children had bilateral clubfoot (55.8%). Parents (57.7%) had “quite a bit” problem with cutting down work time, (61.5%) “very much” worried about their child’s future, (19.2%) “a little” problems with interaction with other people and (48.1%) had “quite a bit” decreasing source of income. **Conclusion:** The parents got less time for work and had decrease in income. The parents faced fewer problems in financial aspect due to free hospital services and were also worried about their children’s future. An awareness and counseling program about free health services and health condition is recommended.

**Keywords:** Congenital Clubfoot, Children

### INTRODUCTION

Congenital club foot or talipes is a non-traumatic deformity of the foot. The foot is twisted out of shape or position. The most common type of club foot is talipes equinovarus (95%), in which the foot is in planter flexion and deviated medially. The exact etiology of club foot is not known. The suggested contributing factors are familial tendency (about 10% cases) and primary arrest or anomalous development of foot in the fetal life. Intrauterine mal position of fetal foot due to less amniotic fluid and defective neuromuscular development of fetus may also found as important contributing factors of club foot. Club foot is found in 1 to 3 per 1000 live birth. Half of these cases are bilateral. Boys are two times more affected than girls. Club foot may be associated with spinabifida, meningocele and myelodystrophy (Parul, 2009).

The treatment of club foot begins soon after the birth of child. The deformity is fully correctable if proper treatment is

instituted in time. The treatment can be non operative by plasters for supple feet or operative for rigid feet. Once a foot gets corrected, it is maintained in a splint called Denis Brown Splint or shoe called congenital talipes equinovarus shoe (Van Bosse, 2011).

Clubfoot is a congenital deformity affecting approximately 200,000 children worldwide each year (Global Clubfoot Initiative). The Ponseti method is a treatment technique for clubfoot which has been found to be up to 98% effective when started in babies. An estimated 80% of these are born in under-resourced nations with limited capacity for identification and treatment of clubfoot (Penny et al., 2009).

In Uganda the incidence of clubfoot is 1.2 per 1,000 live births. The prevalence of clubfoot in East Africa, Central Africa and Polynesia the prevalence is at 8 per 1,000 live births. The prevalence of clubfoot in East Africa, Central Africa and Polynesia the prevalence is at 8 per 1,000 live births. Congenital clubfoot can be treated, however, if untreated, causes physical impairment and defect which affects the individual’s gait and results in disability. This disability negatively affects productivity, and leads to reliance on other persons within the family, which has immense impact on financial, social economic status and reduces the standard of living for the family and the community at large. Similarly; the physical deformity caused by clubfoot is coupled with stigma, which has a detrimental mental effect on the sufferers (Mathias et al., 2010; Mayo et al., 2007).

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A pilot study on continuing Ponseti treatment conducted in two rehabilitation centers in Madagascar revealed that fifteen out of twenty families had financial problems: 7 incurred debt, 2 sold possessions, 4 parents stopped work and 2 did not give any further details. All mothers experienced distress; 9 hid their child's foot, and 8 were accused of wrong doing during pregnancy. Three families traveled more than 500 km to the treatment center and journeys were costly and difficult. Repeated travel to the clinic resulted in financial and social burden on the families, which reduced their ability to engage in treatment (Ramahenina, O'connor, & Chamberlain, 2016).

The various problems faced by parents of clubfoot child remains unknown as previously there are no such studies have been found. So, the current study aims to identify physical, psychological, social and financial problems faced by parents in care of children with congenital clubfoot.

## METHODS

The research setting was Hospital and Rehabilitation Center for disabled Children (HRDC). Self-constructed structured questionnaire with 22 items 5-point Likert scale was developed to assess the problems faced by parents on physical, psychological, social and financial aspects. The established reliability (Cronbach alpha) after pretesting was 0.887.

The written consent was taken prior data collection. Total 52 parents of children with clubfoot attending OPD of HRDC were selected and interviewed for data collection. Diagnosed clubfoot child with age above 6 months and up to 15 years were included in the study. Parents' confidentiality and privacy was maintained during data collection.

The collected data was entered and analyzed using SPSS version 20. Descriptive statistics were used for data analysis.

## RESULTS

**Table1 Socio-demographic Information of the Children**

| Variables   | Frequency | Percent |
|---|-----------|---------|
| <b>Age (year)*</b> Mean age = 3.31, Standard Deviation = 3.10 |           |         |
| Up to 5   | 44        | 84.6    |
| More than 5   | 8         | 15.4    |
| <b>Sex of child</b>   |           |         |
| Male  | 28        | 53.8    |
| Female  | 24        | 46.2    |
| <b>Religion</b>   |           |         |
| Hindu   | 44        | 84.6    |
| Others  | 8         | 15.38   |
| <b>Cast</b>   |           |         |
| Brahmin/Chhetri   | 21        | 40.4    |
| Janajati  | 29        | 55.8    |
| Dalit   | 2         | 3.8     |
| <b>Number of family members</b>                               |           |         |
| Up to 6   | 32        | 61.5    |
| More than 6   | 20        | 38.5    |
| <b>Types of family</b>  |           |         |
| Nuclear   | 21        | 40.4    |
| Joint   | 31        | 59.6    |

The study result regarding socio-demographic information of the children showed that most (84.6%) of the children were up

to 5 years of age, majority (53.8%) children were male. Regarding religion, most (84.6%) of the children belonged to Hindu religion, majority (55.8%) was Janajati ethnicity, majority (61.5%) had family members of 6 and higher percentage (59.6%) children had joint family.

**Table 2 Socio-demographic Information of the Respondents**

| Variables                          | Frequency | Percent |
|------------------------------------|-----------|---------|
| <b>Relation with child</b>         |           |         |
| Mother                             | 40        | 76.9    |
| Father                             | 12        | 23.1    |
| <b>Age of parents</b>              |           |         |
| 15-25 years                        | 9         | 17.3    |
| 25-35 years                        | 31        | 59.6    |
| More than 35                       | 12        | 23.1    |
| <b>Number of live Children</b>     |           |         |
| Upto 2                             | 37        | 71.2    |
| More than 2                        | 15        | 28.8    |
| <b>Parent's Educational Status</b> |           |         |
| Illiterate                         | 13        | 25.0    |
| Literate                           | 39        | 75.0    |
| <b>Level of education (n=39)</b>   |           |         |
| Primary level                      | 11        | 28.20   |
| Secondary level                    | 15        | 38.46   |
| Higher Secondary and above         | 13        | 33.33   |
| <b>Occupation</b>                  |           |         |
| Agriculture                        | 34        | 65.4    |
| Business                           | 5         | 9.6     |
| Service                            | 8         | 15.4    |
| Homemaker                          | 5         | 9.6     |
| <b>Family monthly income</b>       |           |         |
| Insufficient                       | 16        | 30.8    |
| Sufficient                         | 36        | 69.2    |

Regarding respondents' socio-demographic information, the majority of the parent (71.2%) had altogether 2 children, majority (59.6%) were from age group 25-35 years, all (100%) were married, most of them (75%) were literate with highest proportions (38.4%) with secondary level education. Majority of parent (65.4%) had occupation as agriculture.

The general information of children with clubfoot showed that most of the parent (84.6%) visited hospital up to 6 times for treatment of their child, most (55.8%) of the children had bilateral congenital clubfoot deformity and most parents (78.8%) had up to Rs.10000 expenses per hospital visit.

**Table 3 Physical Problems Reported by Respondents**

| Problems                      | 1             | 2        | 3       | 4        | 5        |
|-------------------------------|---------------|----------|---------|----------|----------|
|                               | Frequency (%) |          |         |          |          |
| Malaise                       | 8(15.4)       | 17(32.7) | 1(1.9)  | 15(28.8) | 11(21.2) |
| Travelling long distances     | 19(36.5)      | 15(28.8) | 0(0.0)  | 12(23.1) | 6(11.5)  |
| Felt headache                 | 1(1.9)        | 14(26.9) | 2(3.8)  | 19(36.5) | 16(30.8) |
| Tiredness                     | 2(3.8)        | 19(36.5) | 0 (0.0) | 20(38.5) | 11(21.2) |
| Accomplished less work        | 5(9.6)        | 28(53.8) | 0 (0.0) | 14(26.9) | 5(9.6)   |
| Difficulty in performing work | 10(19.2)      | 26(50.0) | 0 (0.0) | 9(17.3)  | 7(13.5)  |
| Reduced time on work          | 9(17.3)       | 30(57.7) | 0 (0.0) | 6(11.5)  | 7(13.5)  |

1 = Very much, 2 = Quite a bit, 3 = Undecided, 4 = A little, 5 = Not at all

Concerning physical problems faced by parents of clubfoot child, highest proportion (32.7%) faced malaise “quite a bit”, highest proportion (36.5%) had to travel long distances “very much” to health facilities, highest proportion (38.5%) felt “a little” tired, highest proportion (36.5%) “a little” headache. Majority (50%) parent had “quite a bit” difficulty performing work, and majority (57.7%) had “quite a bit” problem of cut down amount of time on work or other activities.

**Table 4 Psychological Problems Reported by Respondents**

| Problems                 | 1             | 2        | 3        | 4        | 5        |
|--------------------------|---------------|----------|----------|----------|----------|
|                          | Frequency (%) |          |          |          |          |
| Sad                      | 25(48.1)      | 20(38.5) | 0 (0.0)  | 4(7.7)   | 3(5.8)   |
| Loss of interest in life | 1(1.9)        | 5(9.6)   | 12(23.1) | 14(26.9) | 20(38.5) |
| Worry for child's future | 32(61.5)      | 18(34.6) | 0 (0.0)  | 1(1.9)   | 1(1.9)   |
| Irritated                | 0 (0.0)       | 10(19.2) | 6(11.5)  | 16(30.8) | 20(38.5) |
| Guilty                   | 24(46.2)      | 10(19.2) | 0 (0.0)  | 2(3.8)   | 16(30.8) |

1 = Very much, 2 = Quite a bit, 3 = Undecided, 4 = A little, 5 = Not at all  
Concerning psychological problems face by parents of clubfoot child, highest proportion (48.1%) felt “very much” sad, highest proportion (38.5%) had “no” loss of interest in their life, majority (61.5%) were “very much” worried for child's future, highest proportion 38.5%) were “not” irritated and highest proportion (46.2%) felt “very much” guilty for clubfoot child.

**Table 5 Social Problems Reported by Respondents**

| Problems           | 1             | 2        | 3       | 4        | 5       |
|--------------------|---------------|----------|---------|----------|---------|
|                    | Frequency (%) |          |         |          |         |
| Social Interaction | 22(42.3)      | 19(36.5) | 0 (0.0) | 10(19.2) | 1(1.9)  |
| Social activities  | 21(40.4)      | 22(42.3) | 0 (0.0) | 9(17.3)  | 0(0.0)  |
| Family Support     | 42(80.8)      | 6(11.5)  | 0 (0.0) | 4(7.7)   | 0 (0.0) |

1 = Very much, 2 = Quite a bit, 3 = Undecided, 4 = A little, 5 = Not at all  
As regards to social problems faced by parents, the highest proportion (42.3%) had “very much” change to interact with other people apart from taking care of clubfoot child, highest proportion (42.3%) had “quite a bit” participation in social, religious and entertaining activities and most (80.8%) had “very much” family support to take care of child.

**Table 6 Financial Problems Reported by Respondents**

| Problems                    | 1             | 2        | 3      | 4        | 5        |
|-----------------------------|---------------|----------|--------|----------|----------|
|                             | Frequency (%) |          |        |          |          |
| Family disputes             | 1(1.9)        | 19(36.5) | 0(0.0) | 7(13.5)  | 25(48.1) |
| Increased debts             | 1(1.9)        | 6(11.5)  | 0(0.0) | 32(61.5) | 13(25.0) |
| Marital disharmony          | 2(3.8)        | 6(11.5)  | 0(0.0) | 4(7.7)   | 40(76.9) |
| Decreased child's follow up | 0(0.0)        | 10(19.2) | 0(0.0) | 20(38.5) | 22(42.3) |
| Lack of time for earning    | 1(1.9)        | 17(32.7) | 1(1.9) | 17(32.7) | 16(30.8) |
| Decreasing source of income | 1(1.9)        | 25(48.1) | 0(0.0) | 15(28.8) | 11(21.2) |
| Burden for treatment        | 0(0.0)        | 6(11.5)  | 2(3.8) | 21(40.4) | 23(44.2) |

1 = Very much, 2 = Quite a bit, 3 = Undecided, 4 = A little, 5 = Not at all

With reference to financial problems faced by parents of clubfoot child, the highest proportion (48.1%) did not face family disputes, majority (61.5%) faced “a little” increased debts whereas most (76.9%) did not face marital disharmony at all. The highest proportion of parents (42.3%) did not had a problem of decreasing child's follow up because of financial constraints, highest proportion (44.2%) did not feel burden for expensive clubfoot treatment.

According to parents, among the burden of expenses transport (76.9%) remained the highest; among management of expenses salary (32.7%) and loan (30.8%) are common.

## DISCUSSION

This study revealed that highest proportion (32.7%) of the respondents faced “quite a bit” malaise. Highest proportion (36.5%) had faced “very much” problem of travelling long distances. This finding is supported by the cross-sectional study done at Nilphamari and Rangpur General Disability Clinics and in National Institute of Traumatology and Orthopedics Rehabilitation (Alam et al., 2014). Highest proportion (36.5%) of the respondents felt “a little” headache and (38.5%) “a little” tiredness while caring clubfoot child. Majority (53.8%) of the respondents had “quite a bit” problem of less accomplished work or activities. Half (50.0%) of the respondents had “quite a bit” difficulty performing work, and majority (57.7%) of the respondents had “quite a bit” problem of cut down amount of time on work or other activities. Concerning about psychological problems of parents' study shows that 48.1% of the respondents felt very much sad, lowest proportion (1.9%) of the respondents had very much loss of interest in their life. Majority (61.5%) of the respondents were worried about their clubfoot child's future. Minority (3.8%) of the respondents found they a little guilty for their children. This study is consistent with the study on mother's psychological well being: an empirical contribution on the clubfoot (Coppola et al., 2012).

**Table 7 Expenses and Burdens Reported by Respondents**

| Variables                  | Frequency | Percent |
|----------------------------|-----------|---------|
| <b>Burdens of Expenses</b> |           |         |
| Transportation             | 40        | 76.9    |
| Others                     | 6         | 11.5    |
| No                         | 6         | 11.5    |
| <b>Expenses Management</b> |           |         |
| Salary                     | 17        | 32.7    |
| Loan                       | 16        | 30.8    |
| Agency aid                 | 8         | 15.4    |
| Others                     | 11        | 21.2    |

1 = Very much, 2 = Quite a bit, 3 = Undecided, 4 = A little, 5 = Not at all

In regards to social problems of parents, the highest proportion (42.3%) of the respondents had “very much” chance to interact with other people apart from taking care of their clubfoot children. Highest proportion (42.3%) of the respondents had “quite a bit” participation in social, religious and entertaining activities. Most (80.8%) of the respondents had “very much” family support to take care of clubfoot child. This finding is inconsistent with the qualitative investigation on impact of disability in Kenya (Mayo et al.). It might be due to affordable cost for treatment provided by hospital in this study.

In concern with financial problems of parents of clubfoot child, the highest proportion (48.1%) of the respondents “did not” face family disputes due to clubfoot child related financial constraints. Majority (61.5%) of the respondents faced “a little” increased debt. This result is supported by the pilot study conducted in two rehabilitation centers in Madagascar (Ramahenina et al., 2016). It might be due to affordable cost for treatment of clubfoot in this study. Most (76.9%) of the respondents “did not” face marital disharmony at all. Highest proportion (42.3%) of the respondents “did not” have a problem of decreasing child’s follow up visit. This result is opposed by the quantitative cross-sectional survey done in Uganda in Talipes Clinics at Mbarara Regional Hospital and Mulago Hospital in Uganda (Kazibwe & Struthers, 2009). Regarding a problem of lack of time for job for earning, minority (1.9%) of the respondents felt it “very much”. Highest proportion (48.1%) of the respondents had “quite a bit” problem of decreasing source of income. This finding is supported by the cross-sectional study done at Nilphamari and Rangpur general disability Clinics and in National Institute of Traumatology and Orthopedics Rehabilitation (Alam et al., 2014). Highest proportion (44.2%) of the respondents “did not” feel burden for expensive clubfoot treatment. This finding is opposed to the pilot study conducted in two rehabilitation centers in Madagascar and World Report on Disability (Ramahenina et al., 2016; World Report on Disability, 2011).

## CONCLUSIONS

Higher proportion of parents had social and financial problems such as less accomplished work or activities and cut down amount of time on their work because of their clubfoot child. Majority of the parents had psychological problems such as they were worried about their clubfoot child’s future, higher proportion of parents felt very much sad and guilty for their clubfoot child. Most of the parents didn’t feel social problems as they got very much family support to take care of clubfoot child. Regarding financial problems, majority of the parents faced a little increased debts and higher proportion felt decreasing source of income because of their clubfoot child.

## REFERENCES

- Alam, Z., Haque, M., Bhuiyan, R., Chowdhury, S., & Huq, F. (2014). Barriers Facing by Parents During Clubfoot Treatment of Children with Clubfoot Deformity. *MedCrave Online Journal of Orthopedics & Rheumatology*, 1(2), 00008
- Coppola, G., Costantini, A., Tedone, R., Pasquale, S., Elia, L., Barbaro, M. F., & d’Addetta, I. (2012). The impact of the baby’s congenital malformation on the mother’s psychological well-being: an empirical contribution on the clubfoot. *Journal of Pediatric Orthopaedics*, 32(5), 521-526.
- Global Clubfoot Initiative. Clubfoot. Retrieved from : <https://globalclubfoot.com/clubfoot/>
- Kazibwe, H., & Struthers, P. (2009). Barriers experienced by parents of children with clubfoot deformity attending specialised clinics in Uganda. *Tropical doctor*, 39(1), 15-18.
- Mathias, R. G., Lule, J. K., Waiswa, G., Naddumba, E. K., & Pirani, S. (2010). Incidence of clubfoot in Uganda. *Canadian Journal of Public Health*, 101(4), 341-344.
- Mayo, E., Cuthel, A., Macharia, J., Lavy, C., & Mead, T. (2007). Creating a countrywide program model for implementation of a Ponseti method clubfoot treatment program in developing countries. Cure International. Annals of International Ponseti Symposium; 2007; Iowa
- Parul, D. (2009). *Pediatric nursing 2nd edition*. New Delhi.. Jaypee.
- Penny N, Lavy C, Mannion S, Mayo A, Morcuende J, & R., O. (2009). Integrating early intervention for clubfoot deformity into national plans in under-resourced nations Retrieved August 16, 2016, from Global Clubfoot Initiative
- Ramahenina, H., O’connor, R. J., & Chamberlain, M. A. (2016). Problems encountered by parents of infants with clubfoot treated by the Ponseti method in Madagascar: A study to inform better practice. *Journal of rehabilitation medicine*, 48(5), 481-483.
- Van Bosse, H. J. (2011). Ponseti treatment for clubfeet: an international perspective. *Current opinion in pediatrics*, 23(1), 41-45.
- World Health Organization & World Bank. (2011). World report on disability 2011. World Health Organization. Retrieved from: <https://apps.who.int/iris/handle/10665/44575>

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