Article 6

CARING FOR A CHILD WITH CLUB FOOT IMPACT ON FAMILY: A CROSS SECTIONAL STUDY

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Abstract

Background

Clubfoot is a treatable abnormality that can be managed with early interventions. Parental support is important for the compliance of the management and to achieve good outcome. Identifying and quantifying the family impact due to this condition is important when addressing the caregivers of these children. The aim of this study was to determine the financial, familial social impact, personal strain, and coping strategies of parents of a child with CTEV and explore any associated factors.

Method

A descriptive cross-sectional study was carried out on 48 families presenting to the club foot clinic at Lady Ridgeway Hospital, Sri Lanka. A self-administered questionnaire with the Impact to Family Score and selected demographics was filled out by the selected participants.

Results

Mean age of the children in the study sample was 21.4 months. 65.96% of the sample were families where only one parent was working and 64.6% of the total sample were living with extended families. The perceived mean total impact was 53.9 (SD=11.59) (range 34 to 78) and implying to be significantly lower than a USA study measuring impact for other chronic illnesses in children (M=48.03, SD=8.2, t(47)=3.53, p<0.01). Total impact in only one parent working (M=50.42, SD=9.80) implied to be significantly higher than both parents working (M=59.88, SD=12.51) t(45)=-2.87, p<0.01.

Conclusion

Except for personal strain domain, all other domains of the family impact are perceived less when caring for a child with clubfoot than when caring for a child with chronic medical illness. Instances with only one working parent, and those living with extended family were identified to have a higher perceived impact when compared to their counterpart groups. Coping strategies of the parents were more favourable within nuclear families. This can be taken as a baseline study which demonstrates caregiver and family burden when caring for a child with club foot.

Introduction

Congenital talipes equinovarus (CTEV), commonly known as club foot is the most common congenital orthopaedic deformity encountered in the lower limbs [1]. Usually, the diagnosis is made soon after birth, but it can be detected by ultrasound scan from the third trimester of the gestation. This deformity affects males more than females and can occur unilaterally or bilaterally. Globally, prevalence of clubfoot is between 0.6 to 1.5 live births and about 80% of all the babies with clubfoot are from low- and middle-income countries [2]. When considering the South Asian region, clubfoot prevalence in India is 0.9 per 1000 live births [2] but no documented data on prevalence was available for in Sri Lanka. However, for Sri Lanka, The male to female ratio of clubfoot was identified to be 2.7:1, and bilateral deformity was seen in 48% of the cases[3].

Serial casting and manipulations followed by bracing, which was introduced and popularised by Dr Ignacio Ponseti, is the widely practiced treatment modality for clubfoot in the current practice [4]. This technique is based on addressing to the patho-anatomy of clubfoot. In Dr Ponseti's technique, the casts are numbered one to six and the first two casts are applied with the forefoot supinated, to bring it into alignment with the hind foot [5]. Then the third cast is applied using the head of the talus as the fulcrum point keeping simultaneous counterpressure over that with the forefoot abducted. In the fourth cast, the forefoot is further abducted. Usually, before the fifth cast, the degree of dorsiflexion is assessed and if dorsiflexion is not possible beyond neutral, then a percutaneous Achilles tenotomy is performed. The tenotomy, if required, is done under local anaesthesia as an outpatient procedure. However, in most Sri Lankan centres it is done under general anaesthesia in an operation theatre setting. The casts before the tenotomy are changed at weekly intervals while the cast after the tenotomy is removed at the end of three weeks. Following the removal of the last cast, irrespective of whether a tenotomy is done or not, the patient is placed in a modified Foot Abduction Orthosis (FAO). This FAO is used for 23 h a day in the initial four to six months and subsequently during bed time up to three to four years of age[6]. The average number of casts with the Dr. Ponseti technique is only 5.4. According to Dr. Ponseti, the clubfoot usually recurs until four years of age and parents should be warned of this possibility [5].

In Sri Lanka, care for children with club foot is currently offered free of charge at all National hospitals, teaching hospitals and district general hospitals, where a Consultant Orthopaedic Surgeon is on duty. Orthopaedic unit 1 of Lady Ridgeway Hospital was the only specialized paediatric orthopaedic unit established in Sri Lanka up until 2019. Currently in this unit the Sri Lanka Clubfoot Program, in collaboration with the International Clubfoot Registry offers services for babies with clubfoot. It offers braces, continuous support, follow up and educational materials for the caregivers of babies with clubfoot free of charge.

Success rate of Ponseti casting rates 80 % - 94% in the current literature [7, 8]. However, the recurrence rate is around 20% and if not treated or neglected the foot will undergo complete equines and varus deformity hindering normal ambulation and requiring complex deformity correction surgeries with variable outcomes [9].

In this context, understanding of the caregivers about the long course of treatment, the nature of the treatment, the necessity to attend to the clubfoot clinic on exact given dates to replace casts and after serial casting, making the child wear the abduction foot orthosis for 23 hours a day for several months and essential night time wearing up until 3-4 years of age is utmost important to prevent recurrence of the disease and to get a better outcome. Nevertheless, this is a challenging task for the child and as well as for the caregivers.

Knowledge of any chronic ailment or a visible deformity of a new-born is distressing to any family. Caring for a child with such a condition can affect the family dynamics. Along the course, the special care that the family and parents should give to the child with clubfoot may affect the entire family. Certain aspects of this impact can be measured in terms of personal strain to the parents and caregivers, financial burden, effect on social interactions. This special context will eventually create unique coping strategies for the caregivers of the affected baby and the family.

Caregiver support is extremely important to achieve a successful outcome in the clubfoot treatment. If the family support is minimal, the child's condition can worsen, and it further imposes a negative impact on the family, and this may go on as a vicious cycle. Identifying the factors determining optimal family support and assessing the impact this condition has on the family can be considered a first step to plan methods of improving compliance. Suitable measures can then be tailormade for the families affected by clubfoot. Furthermore, quantifying this impact into a numerical figure where we it can be compared with the impact caused by other diseases also allows better understanding and documentation.

The main objective of this study is to quantify the family burden when caring for a child with club foot and to quantify other aspects such as financial burden, familial and social burden, personal strain, and the coping/mastery mechanisms the parents or caregivers develop due to the child's health condition. The secondary objective is to explore any relationship between family burden and selected demographic factors.

Methodology

A descriptive cross-sectional study was carried out on 50 families accompanying their children with clubfoot deformity to Orthopaedic unit 1 of Lady Ridgeway Hospital for children (LRH), Sri Lanka. The sample was randomly selected using every 3rd patient attending the clinic. The clinic is held once a week and the sample of 50 was collected from June 2022 to August 2022. The questionnaire comprising the translated IFS scale and the demographic data extraction sheet was given to the families to complete by themselves during the waiting time and was collected just prior to leaving the clinic.

Impact to family scale (IFS) is a 27-item questionnaire with Likert scoring which measures the impact the child's health condition has on the family. This tool assesses financial hardship, work changes, travel, social interactions with friends, social interactions with family, family dynamics, finding caregivers, stigmatization, opportunity costs, worry, fatigue, depression, marital or family strife, grades, and school impact. These components are re-categorized to four areas of family impact. Namely, economic impact on family, social impact, familial impact, and personal strain/coping. All these areas together is considered the overall family impact. Lower scores indicate a greater negative impact or disability on the family.

This scale was originally developed to assess the family burden of chronic childhood illnesses by Prof. R. E. Stein and her team [10]. This scale was used in Paediatric Ambulatory Care Treatment Study in 1984, and this study is the hallmark of quantifying the family impact and other subscales using this study instrument.[11]

Mininder S. Kocher, et al (2022) used this for their study on Impact on Family Functioning of Immediate Spica Casting for Paediatric Femur Fractures: An Ecological Study, which revealed spica cast for femur fractures imposes greater overall impact on the family than taking care of a child with chronic medical illness. [12].

The original study instrument (IFS) was translated to Sinhala following standard protocols of forward and backward translation by sworn translators. It was finally checked by the original author and approved to be used in the study. The Sinhala version of the impact to family scale questionnaire is yet to be validated (validation process underway by the same author of this article) to the Sri Lankan context.

Statistical analysis was performed using SPSS 25.0. Overall mean scores and standard deviations were determined for overall scores and subscales. Normalcy of data was confirmed using the Shapiro Wilk test. Inter-group comparisons were made using the independent samples t-test and ANOVA or their nonparametric equivalents.

Results

Cohort Characteristics

Of the 50 families the questionnaire was given to only 48 families returned after proper completion (response rate: 96%).

Mean age of the chid with clubfoot was 21.4 months (range, 3 weeks to 8 years). Figure 1 demonstrates the distribution which was not normally distributed (W (47) = 0.74 p<0.001).

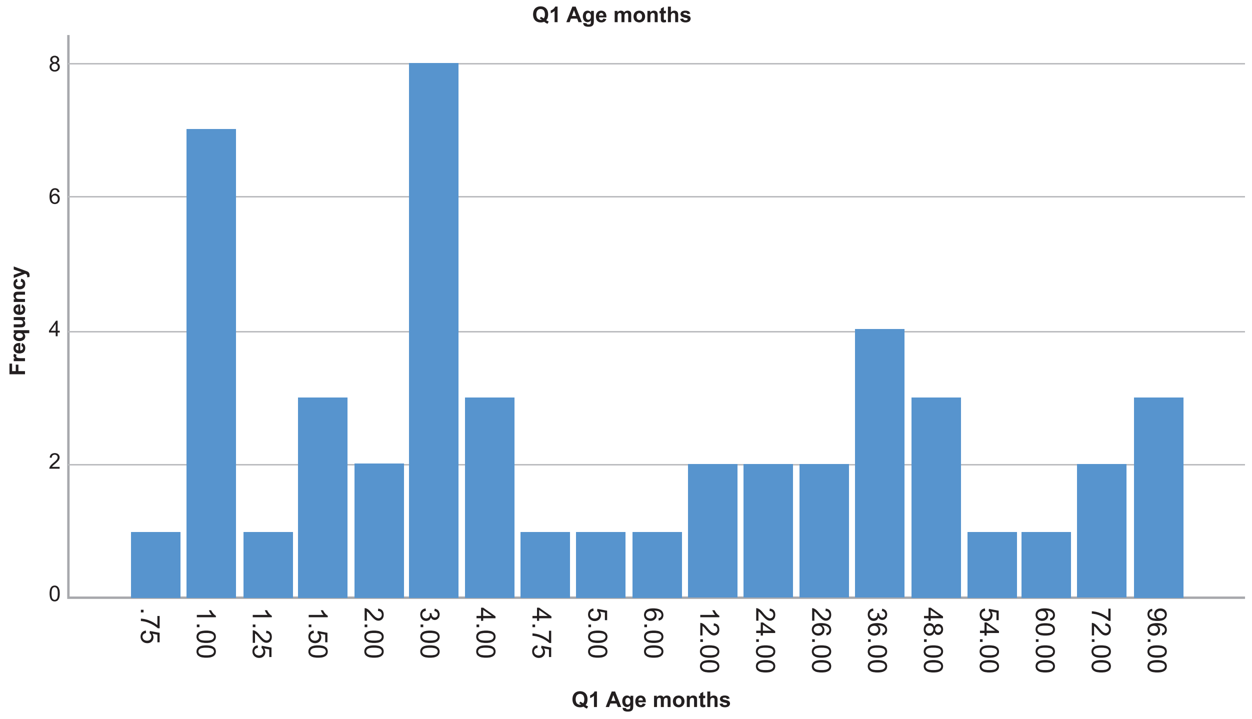

Figure 1 *- Histogram showing distribution of age*

Characteristics of illness

According to Table 1, 91.6% (n=44) of the sample was diagnosed at birth, and only one was diagnosed at 3 years of age. The mean time from diagnosis of the illness to completion of the survey was 4.26 years (51.17 months). However, the mean treatment duration was 1.58 years (18.99 months). None of the illness related statistics measured on a continuous scale were normally distributed as the Shapiro-Wilk statistic was significant in all cases.

Table 1 - Descriptive statistics of the illness

Characteristic	N (%)	Mean (SD)	Range	Shapiro Wilk statistic
Age of Diagnosis (days)	48 (100)	28.02 (184.12)	1-1277 days	0.13***
1	44 (91.7)			
7	2 (4.2)			
10	1 (2.1)			
1277	1 (2.1)			

Characteristic	**N (%)**	**Mean (SD)**	**Range**	**Shapiro Wilk statistic**
Laterality				
Unilateral	10 (20.83)			
Bilateral	38 (79.17)			
Recurrence				
Yes	6 (12.5)			
No	42 (87.5)			
No of episodes	48 (100)	1.21 (0.58)	1- 4	0.38***
1	41 (85.4)			
2	5 (10.4)			
3	1 (2.1)			
4	1 (2.1)			
Period of illness (months)	48 (100)	51.17 (66.36)	1.79 - 239.92	0.75***
Treatment duration (months)	48 (100)	18.99 (26.29)	0.03 - 96.00	0.73***
Defaulted treatment				
No	10 (20.8)			
Yes	9 (18.8)			
No data	29 (60.4)			
Cast Number				
1	6 (12.5)			
3	9 (18.8)			
4	7 (14.6)			
5	8 (16.7)			
6	3 (6.3)			
Brace	15 (31.3)			

***p<0.001

Characteristics of Family

The family characteristics of the sample are summarized in Table 2. One child is cared for by the grandparents since the mother is working abroad to support the family and the father is separated. This entry was removed during some inferential analysis in some further analyses and the total sample shows n=47. This entry was not included where the descriptive statistics of occupation are shown. In all other families where only one parent was working it was always the father.

The maternal and paternal ages were normally distributed. Data was collected on other children of the family suffering with clubfoot. Of the seven families that had more than one child none of the other children had club foot. All parents in the sample had received secondary education or above.

Table 2 - Characteristics of family

Characteristic	**N (%)**	**Mean (SD)**	**Range**	**Shapiro Wilk statistic**
Mother's age	48 (100)	30.02 (4.76)	22- 44 years	0.96a
Mother's education				
Up to Grade 10	9 (18.8)			
Up to Advanced level	25 (52,1)			
Diploma and above	14 (29.2)			
Father's age	47 (100)	33.19 (4.98)	25 – 47 years	0.96a
Father's education				
Up to Grade 10	5 (10.4)			
Upto Advanced level	19 (39.6)			
Diploma and above	23 (47.9)			
Family Type				
Nuclear	17 (35.4)			
Extended	31 (64.6)			
Other children				
No	41 (85.4)			
1 other child	4 (8.3)			
2 other children	2 (4.2)			
3 other children	1 (2.1)			
Parental occupation	47 (100)			
Both parents working	16 (34.04)			
Only father working	31 (65.96)			

[a] – The Shapiro Wilk statistic was not statistically significant; hence these were normally distributed.

Other demographics

The distance from the hometown to the hospital was less than 50km for 58.3% of the sample (n=28), and an equal number (n=10) belonged to each 50-100km and >100km categories.

Overall satisfaction of the family regarding the service received at Lady Ridgeway Hospital for Children was, very poor n=1, (2.1%), neither good bad n=1 (2.1%), good n=9, (18.8%), very good n=18 (37.5%) , extremely satisfied n=19 (39.6%).

The main objective of this study was to quantify the family burden when caring for a child with club foot and to quantify the subscales namely, financial burden, familial and social burden, personal strain, and the coping/mastery mechanisms the parents or caregivers develop due to the child's health condition.

Table 3 shows the descriptive statistics of the 4 subscales of the IFS and the total IFS score. The main IFS scores and all the other sub scores except the Family and Social impact score, were normally distributed. The total mean score of 53.94 (±11.59) is significantly higher than the total mean score obtained in the PACTS study (M=48.3, SD = 8.2) ($t(47) = 3.53$, $p<0.01$).

Table 3 - Descriptive statistics of the total IFS score and four subscales

	N	Maximum possible score	Minimum	Maximum	Mean	Std. Deviation	Shapiro-Wilk (df=48)
Financial	48	16	4	16	9.23	3.08	0.97
Family & Social Impact	48	36	14	34	21.44	5.44	0.93*
Personal Strain	48	24	7	22	14.15	4.31	0.95
Coping/ Mastery	48	20	5	13	9.12	1.81	0.97
Total Impact	48	96	34	78	53.94	11.59	0.96

*p<0.05

The histograms showing the distributions of the total IFS scores and the four subscales are displayed in figures 2 to 6.

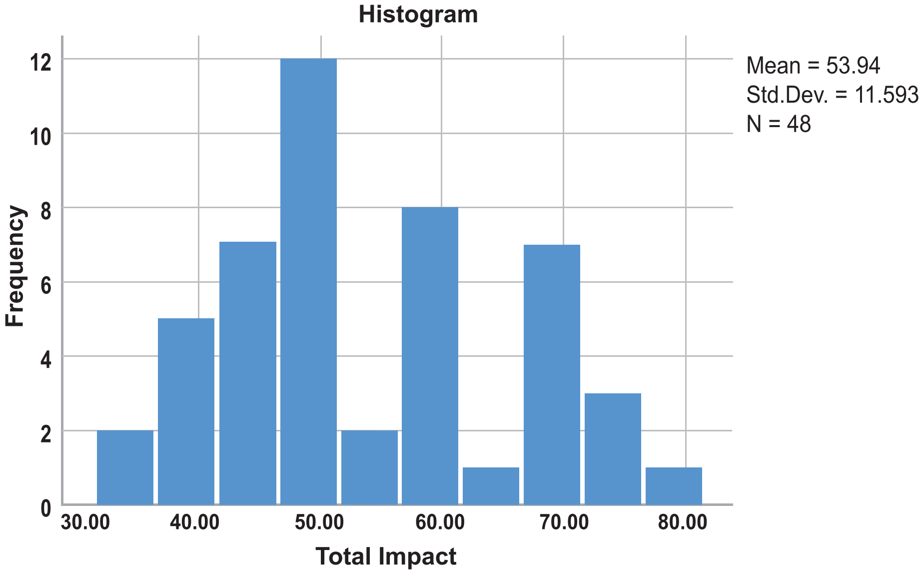

Figure 2 - Histogram of Total IFS scores

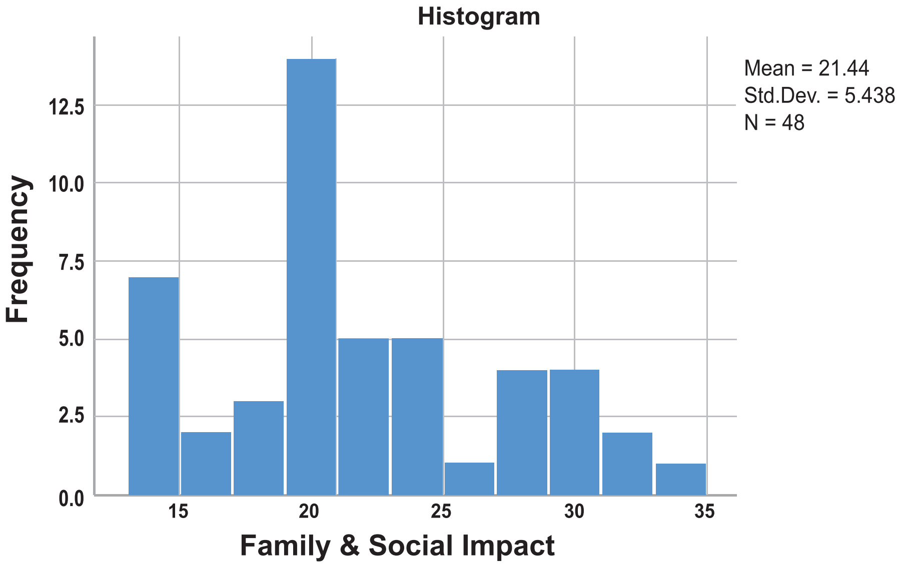

Figure 3 - Histogram of Family and Social impact distribution

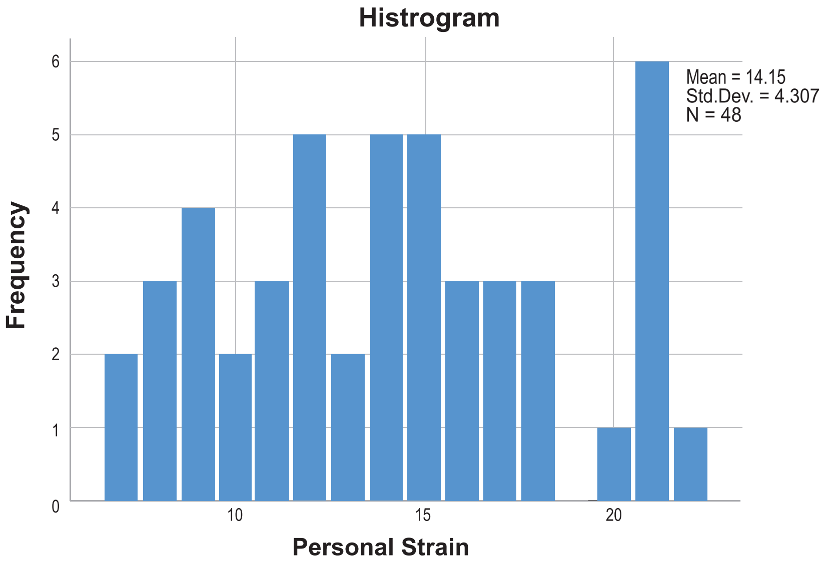

Figure 4 - Histogram of Personal strain

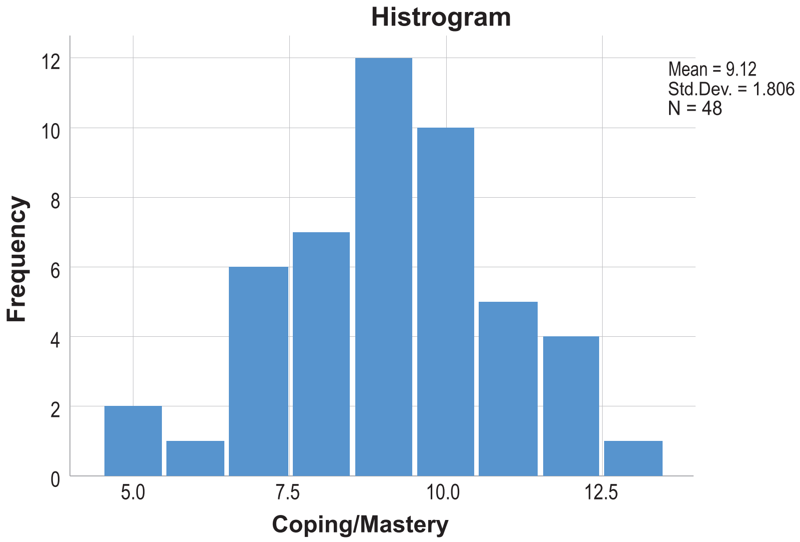

Figure 5 - Histogram of coping/ mastery subscale

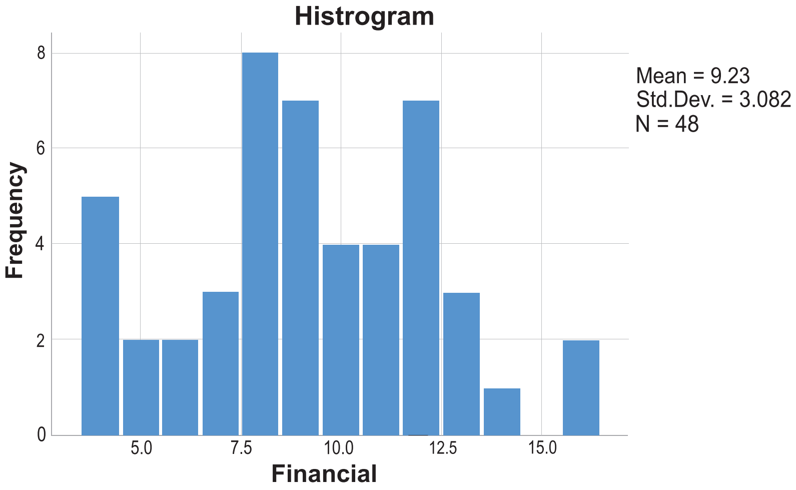

Figure 6 - Histogram of Financial subscale

Table 4 compares all the subscales of the IFS score with the means obtained from the PACTS study. Only the personal strain in the study sample was found to be significantly lower than the mean of the PACTS study implying that the personal strain was higher in the study population caring for a child with club foot. All other domains had mean values higher than that of the PACTS study, and the mean differences were significantly higher in all domains except in family and social impact domain.

Table 4 - Comparison of means against the PACTS study

	Sample Mean	PACTS scores mean (SD)	T (df=47)
Financial	9.23	7.7 (1.77)	3.44**
Family & Social Impact	21.44	20.8 (4.13)	0.81
Personal Strain	14.15	25.45 (4.83)	-18.18***
Coping/ Mastery	9.12	7.9 (1.55)	4.7***
Total Impact	53.94	48.03 (8.2)	3.53**

**p<0.01

***p<0.001

Objective 2

The secondary objective was to explore any relationship between this quantified burden and selected demographic factors.

Analyses of associations between total IFS score and subscales with the continuous variables

Only the maternal age showed a statistically significant weak negative correlation with the financial subscale. (r=-0.29, p<0.05). This implies that with advancing maternal age the financial burden is perceived more.

No other illness related, or family related continuous variable showed a statistically significant association with the total IFS score or any of its subscales.

Table 5 - Correlation Coefficient of the subscales and other demographics with scalar variables

	Period of illness	Age months	Mother Age	Father Age	Siblings	No of episodes
Financial	-0.02	-0.04	-0.29*a	-0.23 a	-0.15	0.00
Family & Social Impact	-0.18	-0.18	-0.07	-0.08	0.04	0.13
Personal Strain	-0.05	-0.06	-0.10 a	-0.14 a	0.16	0.13
Coping/ Mastery	-0.08	-0.1	0.03 a	-0.12 a	-0.18	-0.13
Total Impact	-0.09	-0.10	-0.15 a	-0.19 a	0.00	0.11

*p<0.05

^{a}-Pearson Correlation was used since both corresponding scales were normally distributed

Parental employment and impact to family

The entry filled by the grand parents in which both parents were deceased was removed from the analysis where the impact of parental employment was assessed.

According to Table 6 the total impact score in the group where only one parent is working is significantly lower in the group where only one parent is working hence the perceived burden in this group is higher compared to the group where both parents are working. Same was observed in all domains but the difference was not significant in the personal strain and coping/ mastery domains.

Table 6 - Mean differences of the burden among categories of parent occupation

	Only one working (N=31)	Both parents working (N=16)	Statistic of Mean difference (df=45)
	Mean (SD)	Mean (SD)	
Financial	8.35 (2.37)	10.81 (3.75)	-2.749**
Family & Social Impact	20.06 (4.7)	23.75 (6.07)	148.5a*
Personal Strain	13.26 (4.04)	15.63 (4.53)	-1.83
Coping/ Mastery	8.74 (1.73)	9.69 (1.74)	-1.77
Total Impact	50.42 (9.70)	59.88 (12.51)	-2.87**

Living with an extended family versus nuclear family

According to Table 7 the mean for coping/ mastery domain within those in nuclear families (M=9.88,SD=1.17) is significantly higher than the mean coping/mastery domain of those in extended families(M=8.71, SD=1.97). Equal variances were not assumed in the comparison of means for the two groups within this sub scale (F=5.89, p<0.05) t (45.64) = 2.59, p<0.05.

Table 7 - Comparison of means of IFS scores between nuclear and extended families

	Nuclear (N=17) Mean (SD)	Extended (N=31) Mean (SD)	Statistic of Mean difference
Financial	8.71(2.89)	9.52(3.19)	-0.87
Family & Social Impact	21.24(4.78)	21.55(5.84)	-0.19
Personal Strain	14.24(4.27)	14.10(4.40)	0.11
Coping/ Mastery	9.88(1.17)	8.71(1.97)	2.59*
Total Impact	54.06(10.80)	53.87(12.18)	0.05

*p<0.05

There were no consistent significant differences in overall IFS scores or its domains among the subgroups of maternal education, paternal education, or distance from the residence to treating hospital.

Discussion

In the management of paediatric orthopaedic conditions, the impact treatment has on the entire family is important to consider. Assessment of the family impact overall and the subgroups is important so that the interventions, we made can be tailormade to each family and to a population.

Unlike in other orthopaedic conditions, like paediatric femur fractures [12] the child's age did not affect significantly over the impact in overall and in sub scales in our population. Hence, it can be assumed that the burden imposed on the family is independent of the child's age in cases of clubfoot.

Impact to family scale numbers is discussed in detail in the paediatric ambulatory care treatment study (PACTS) done in USA to assess the family impact when caring for children with chronic medical conditions such as asthma, diabetes, renal failure or juvenile rheumatoid arthritis. The total mean score in the PACTS study was (M=48.3, SD = 8.2) [11] was significantly lower than in our study (M= 53.94, SD ±11.59) (t(47) = 3.53, p<0.01). This shows that in the sample of parents taking care of a child with clubfoot and seeking treatment in the pioneer Centre in Sri Lanka, perceives less severe burden to the family when compared to USA sample caring for a child with a chronic illness. The reasons for this can be the availability of free healthcare facility in Sri Lanka and the predictable nature of the illness.

The other subscale values are considered as in table 4, Financial impact, family and social impact and coping domains shows greater scores than PACTS study, showing in Sri Lankan context when caring for clubfoot children these aspects are not severely affected as in USA when chronic medical illnesses are considered.

However, in personal strain domain our sample mean 14.15 is significantly lower than PACTS mean (M=25.45 SD=4.83) t(47)-18.18, p<0.01). This observation is important as it shows the caregivers personal burden is considerably higher. The reasons for this can be lack of teamwork within Sri Lankan family when caring for an ill child and the person, usually the mother of the family is expected to do all the household work and caring for the child on her own in Sri Lankan context. Although data was not directly collected on who filled in the questionnaire, it was almost always handed to the mother of the family. In USA, the cultural background is such that usually the family shares tasks hence one single person getting the burden all the time is minimal.

When considering coping/mastery domain, Sri Lankan families have adopted positive coping strategies. The cultural upbringing of acceptance of the illness and expecting positive outcome while giving continuous good care is seen in Sri Lankan context.

The financial domain shows significantly negative association with increasing maternal age. This means that the financial burden is felt more as the maternal age increases.

The children with both working parents (Figure 3) (n=16), total impact mean = 59.88 (SD=12.51) and the group with one working parent mean = 50.42(SD=9.70) t (45) = -2.87, p<;0.01. This was statistically significant. This implies that when a single parent is working the family experiences a severe impact. The reasons could be the parent at home (mother, in our study sample) has to take up the whole burden of caring for the baby as when both parents are working, they have other support to care for the baby so that a “timeout” is received to parents while they are at work and the financial support to the family is more when both parents are working. This observation is backed by the finding that financial impact mean was 10.81 (SD=3.75) significantly higher in the children with both working parents than in the group with one working parent where the financial impact mean was 8.35 (SD=2.37) t (45) = -2.75, P<0.01. . Although not statistically significant, the positive coping strategies are seen when both parents are working than a single parent working.

We explored whether living with extended family, (with parents, siblings, in-laws,) has any difference in the perceived burden felt by the family when compared to living in a nuclear family. Overall impact was not significantly different, but it was noteworthy that in coping and mastery domain, nuclear families have better positive coping strategies than living with extended family. The reasons could be when living alone, the parent and child bond is stronger and each other shares the psychological stress while when living with an extended family, there may be added responsibility of the family towards the other family members and in the Sri Lankan context, shared support and expectations through arranged marriages may add to it[13].

Limitations

Although the response from the parent/caretaker who accompanied the child to the clinic was recorded as a proxy for the entire family, he or she may not be the only respondent. If the response from both parents could be obtained the results would be more balanced with minimal disturbance to information from lack of communication between parents, unequal perception of the burden and other possible disturbances in the marital relationship.

Conclusion

In conclusion the perceived impact to the family of a child with clubfoot lies at less than 50% of the maximum impact. However, a considerable impact is felt by the families of these children with clubfoot, and all its subscales. In comparison to studies in other countries on impact due to and other illnesses the perceived personal strain was higher, but the impact of all other aspects was lower in our study sample. Out of the sociodemographic variables lower maternal age and both parents being employed affected positively in some aspects of measured perceived burden, while coping strategies were significantly better when parents lived as nuclear families.

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