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Assess perception, practice and lived experiences on use of corrective braces among parents of children diagnosed with clubfoot: A mixed method study

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Abstract:

BACKGROUND: Congenital talipes equinovarus (CTEV) is a congenital musculoskeletal deformity, which further leads to abnormal alignment of the feet in children. The aim of the present study is to assess perception and practice and explore lived experiences on the use of corrective braces among parents of children diagnosed with clubfoot.

MATERIAL AND METHODOLOGY: A mixed method study approach with convergent parallel research design was used on 100 parents of children with clubfoot. For the quantitative strand, a total enumerative sampling technique was used to collect the data using self-structured tools—a 5-point Likert scale on perception and a checklist on practice at the clubfoot clinic of a selected tertiary care hospital, Rishikesh. For the qualitative strand, a purposive sampling technique was used to conduct the in-depth interview until data saturation from 17 participants using a semi-structured questionnaire. Analysis was done using the SPSS 23.0 software, descriptive statistics with the use of frequency %, whereas for correlation, Pearson's correlation coefficient was used.

RESULTS: The mean age of participants was 31 years with a mean score of 30.54 ± 4.97 . Among parents, 93% showed positive perception with a mean score of 67.16 ± 6.23 and 64% followed appropriate practice with a mean score of 12.44 ± 1.45 . Coefficient correlation showed a statistically weak positive correlation between perception and practice ($P < 0.001$). The lived experiences of parents were reflected under six main themes, i.e., “personal experiences with wearing braces for correction,” “encounters and barriers,” “effects on one's social and personal life,” “perceived answers,” “any other previous practice,” and “awareness about clubfoot.”

CONCLUSION: Present study concluded that parents had a positive perception and appropriate practice on the use of corrective braces, but there were a few issues such as relapse due to non-adherence, financial burden, and traveling distance, and noticeably more, which need to be addressed. Parental information is a very essential component that should be addressed by all treating physicians and nursing officers before starting treatment for clubfoot.

Keywords:

Clubfoot, lived experiences, parents, perception, ponseti's method, practice

Introduction

An estimated 1.3 billion people—or 1 in 6 people—experience significant disability worldwide (ranging from 0.4 to 12.7%) according to data from the World

Health Organization (WHO) and World Bank.^[1-4] Congenital anomalies or birth defects are serious conditions that result in long-term disability; these may have a significant impact on people, families, the healthcare system, and society.^[5] Out

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of these, clubfoot is the most common congenital musculoskeletal defect. Clubfoot is an unusual alignment of feet because of abnormal tendon and muscle development and is an anatomical deformity.^[6]

The incidence of clubfoot varies around the world. In the entire world, 150,000–200,000 babies are born with clubfoot annually. Out of them, around 80% are in low- and middle-income countries.^[7-9] In India, the total prevalence of clubfoot is probably about 1.19 per 1,000 live births^[10] and 7 per 10,000 live births in Uttarakhand state.^[11]

The Ponseti method has gained acceptance all over the world. In the current scenario, the Ponseti method is the most effective and least expensive treatment for clubfoot. The main phases of treatment with the Ponseti method are casting and bracing.^[12] There are 2.6 times more reasons for noncompliance in a girl child than in a boy child in regards to less use of braces and fewer visits to hospitals for follow-up in India.^[13]

The prevalence of sensitive misery and child-rearing stress among the close relative of children at the early stage when they know the diagnosis and starts taking treatment and they also concluded that the level of stress severity increases with the increase in the age of the child.^[14]

In India, there are less data available by perception, practice, and lived experiences in this scenario. The novelty of study results helps to know help to know the main non-adherence factors, which lead to the recurrence of clubfoot, which can help future researchers to plan a strategy for parents of children diagnosed with clubfoot to overcome this problem. Thus, this can help the future researcher to plan counseling sessions or educational programs to create a positive perception, and appropriate practice, and resolves the issues explored by parents while caring for their children with corrective braces. This study aimed to gather data on positive and negative perceptions and practices of parents toward the use of corrective braces and lived experiences among parents while putting in corrective braces.

As per my best knowledge, after a literature search, the mixed method design has not been used in this North Himalayan belt as I have conducted this study for the first time and also during data collection, I came to know that its prevalence is high in this belt. I have explored the difficulty faced by parents by conducting interviews, making this study more novel.

Materials and Method

Study design and setting

A mixed method (quantitative and qualitative) approach was used with a convergent parallel research

design (total enumerative and purposely) to conduct this study.

Samples were selected from the outpatient department (OPD) of a clubfoot clinic at a tertiary care hospital, Rishikesh, from 2020–2021. This hospital explores areas of the complete state of Uttar Pradesh (U.P), Uttarakhand (U.K), Saharanpur, and Roorkee. This study was performed in a tertiary care center and had patients from different states even during the COVID-19 pandemic to enhance the possibility of generalization of study findings.

Study participants and sampling

Parents of clubfoot children attending special clubfoot clinic were selected as sample. The total samples size using the formula $n = N / (1 + Ne^2)$ {Here, n = Number of samples, N = Total population, e = Error margin (0.05) was 96, with 20% attrition rate of total sample size using total enumerative/consecutive sampling technique for generalization. After the completion of data collection, 100 samples were included in the data analysis of the quantitative strand. For the qualitative strand, a sample of 17 parents with a maximum variation using the purposive sampling technique was selected to conduct in-depth interviews until the thumb rule of data saturation for generalization.

Data collection tools

In the quantitative strand, data were composed using a self-structured questionnaire including a socio-demographic profile of parents with 13 items, a socio-demographic profile of children with 8 items, a 5-point Likert scale on perception with 16 items under three domains, that is, knowledge of parents about the use of corrective braces, importance, benefits of using braces, and regarding compliance on using braces, and checklist on practice with 16 items.

Orthopedics and nursing experts were consulted. There was 97.5% agreement from the experts on the items from the quantitative tool, the rest 2.5% were improved and incorporated into the final draft under the guidance of a guide and co-guide. The changes were done after consultation with a guide. The reliability of the questionnaire was represented by Cronbach's alpha as 0.91 and 0.99.

Qualitative strand, data were collected using a semi-structured questionnaire to all those parents who had given consent to talk freely and share their opinion by conducting an in-depth interview. Seventeen interviews were conducted until the saturation point (with a maximum variation such as parents of different age groups of children). The investigator was trained in conducting the in-depth interview (10–20 min) and interviews were recorded and typed later on.

During data collection, we used different questionnaires for qualitative and quantitative designs. For final reaching a decision, we used the meta-matrix method where any discrepancies were found. A meta-matrix method was used to reach the final conclusion of both strands to reach the final conclusion.

Ethical consideration

The study was approved by the Independent Ethics Committee at a tertiary care hospital, with IEC with letter no. 46/IEC/M.Sc./2020. Written informed consent was taken from each participant before enrolling in the study. All ethical standards of IEC, Rishikesh, Declaration of Helsinki, ICMR, and good clinical practices were followed in the study.

Data collection procedure

Patients were selected using a purposive sampling technique. Informed consent was taken from each subject to enroll in the study. A semi-structured questionnaire having two sections of the quantitative and qualitative strands was used for data collection. Tools consisted of socio-demographic variables of the participants and questionnaires.

Data were analyzed using SPSS version 23.0^[15] based on research objectives. The analysis of quantitative data was performed using descriptive and inferential statistics. Normality testing was done using the Kolmogorov–Smirnov test, which showed that the data were normally distributed; thus, the correlation between perception and practice on the use of corrective braces was calculated using a parametric test, that is, Pearson’s correlation coefficient. The association of perception and practice on the use of corrective braces with selected demographic variables was sought by parametric test one-way analysis of variance (ANOVA) and independent *t*-test.

Recorded interviews were translated from Hinglish to Hindi and then to English language with the help of an English expert. To validate the interview’s data, the data were reviewed after coding by peer reviewers and faculty members, and the coding process was re-conducted to ensure accurate results can be obtained. To ensure the credibility of qualitative data in the study, “Criteria of Lincoln and Guba’s framework were used, that is, credibility, dependability, and approaches used to ensure credibility and transferability. Four techniques were credibility, transferability, trustworthiness, and dependability, and three independent researchers collected and coded the data. Coding was performed by three independent researchers. Coding of data into the theme, categories, and subcategories was done and the final thematic analysis was derived from data using the NVivo software. Figure 1 depicts the phases of the study using the following diagram.

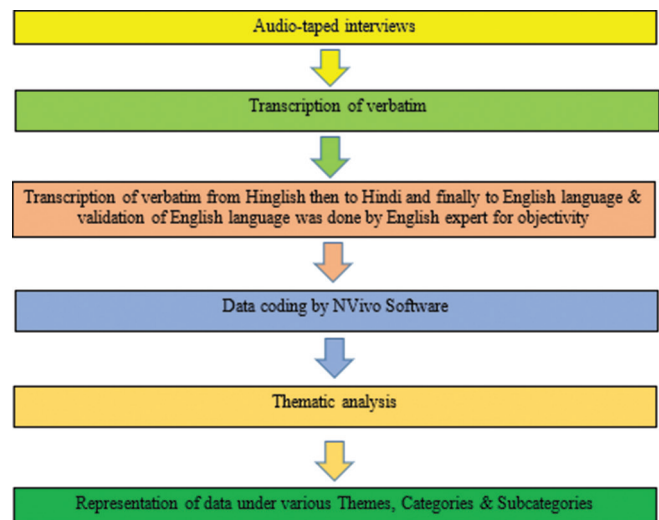


Figure 1: Processing of qualitative data

Results

For 100 participants, whole data were analyzed using SPSS version 23.0. The results were divided into two sections-quantitative and qualitative strands.

Section-I Quantitative strand

Table 1 depicts the sociodemographic variables of participants, 40% of the parents belonged to the 25–30 years of age group with a mean age of 30.54 ± 4.97 years with a range of 20–45 years. Interestingly, most enrolled caregivers (51%) were males, and more than half, that is, 59% belonged to the rural area. It was observed that in the education status of both parents, 45% were from the graduate and above group. The majority of the mothers 86% were housewives and were primary caregivers, that is, 94%. More than half, that is, 71% of children were male with congenital clubfoot, among them 95% had no history of a sibling with any congenital anomalies. Eighty percent of children underwent a surgical procedure (tenotomy) for the correction of rigid clubfoot before the prescription of braces.

Mean ± SD (range): The number of family members was 6.26 ± 3.23 (3–18). The height of the child in inches was 33.74 ± 4.57 (24.00–55.51), weight in pounds was 25.71 ± 7.67 (12.12–77.16), and body mass index (BMI) was 15.75 ± 2.18 (12.91–23.62).

Figure 2 depicts the distribution of the distance of available health facilities for regular follow-up, in which the majority of parents (39%) were found to travel above 100 kilometers.

Figure 3 depicts that the majority of children, that is, 59% who were bearing braces belonged to the 1–3 years of age group with a mean age of child 2.70 ± 1.43 (6 months–11 years).

Table 1: Socio-demographic data of parents and children n=100

Variables	Frequency (f) and (%)
Age (years)*	
<25	11 (11)
25–30	40 (40)
31–35	37 (37)
>35	12 (12)
*Mean age (yrs.)=30.54±4.97 with range (20–45 years)	
Gender of parents	
Male	51 (51)
Female	49 (49)
Habitat	
Urban	41 (41)
Rural	59 (59)
Education status of father	
Primary education	12 (12)
Higher secondary	42 (42)
Graduate and above	45 (45)
No education	01 (01)
Education status of mother	
Primary education	12 (12)
Higher secondary	42 (42)
Graduate and above	44 (44)
No education	02 (02)
Occupational status of father	
Government job	16 (16)
Private job	33 (33)
Business/self-employed	39 (39)
Unemployed	02 (02)
Others, specify	10 (10)
Occupational status of mother	
Government job	05 (05)
Private job	01 (01)
Business/self-employed	86 (86)
Housewife	02 (02)
Not alive	
Caregivers at home	
Father	92 (92)
Mother	94 (94)
Grandfather	26 (26)
Grandmother	48 (48)
Other relatives	07 (07)
Monthly income of family (INR) (as per modified KuppuSwami scale 2019	
>39092 (upper class)	11 (11)
29,200–39092 (upper middle class)	16 (16)
19516–29199 (middle class)	13 (13)
11708–19515 (lower middle class)	16 (16)
3908 – 11707 (poor class)	37 (37)
<3908 (very poor class)	7 (7)
Attended educational activities	
Yes	01 (01)
No	99 (99)

Contd...

Table 1: Contd...

Variables	Frequency (f) and (%)
Socio-demographic data of children	
Clinical variables	
Gender of child	
Male	71 (71)
Female	29 (29)
Siblings with congenital anomalies	
Yes	05 (05)
No	95 (95)
Previous history of orthopedic surgery	
Yes (tenotomy)	80 (80)
No	20 (20)

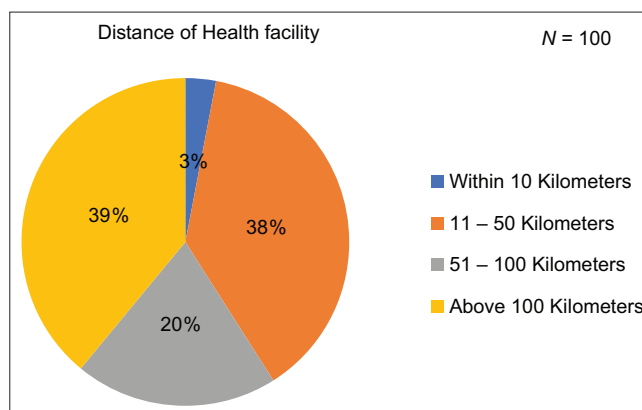


Figure 2: Available health facilities for regular follow-up

In the present study, the majority of parents, that is, 93% of parents were found with positive perception in the direction of the use of braces as a treatment for their children diagnosed with clubfoot as compared to 7% who showed a negative perception toward this treatment with a mean score of 67.16 ± 6.23 .

In Table 2, the majority of parents agreed with all the steps that they were following while putting braces on their children’s feet, which reflects that they were following the appropriate level of practice, that is, 64% with a mean practice of 12.44 ± 1.45 (range = 7–15).

The current study had shown a significant weak positive correlation between perception and practice among parents of children on the use of corrective braces, which was statistically significant $P = 0.001$ with an r -value of 0.334.

In Table 3, parent’s perception of the use of corrective braces showed a significant association with their age ($P = 0.038$), educational status of mothers ($P = 0.025$), occupation of the mother ($P = 0.006$), and educational activity attended ($P = 0.0001$). Furthermore, in regards to parent’s practice on the use of corrective braces, a significant association with the gender of parents ($P = 0.050$), educational status of mothers ($P = 0.0001$), occupational

status of mothers ($P = 0.0001$), and distance of available health care facility for follow-ups ($P = 0.001$) was observed.

Section-II Qualitative strand

The analysis was done using the Nvivo software to explore the lived experiences among parents of children on the use of corrective braces diagnosed with clubfoot and grouped under six main themes along with their frequency as depicted in Table 4. Frequencies were calculated using the SPSS 23.0 version software. Each theme written in the text contains a one-one example for better understanding; we have added in the table to show frequency.

Table 2: Correlation between perception and practice among parents on the use of corrective braces n=100

Items	Parents		
	Mean±SD	Pearson's correlation	P
Perception	67.16±6.23		
Practice	12.44±1.45	0.334**	0.001*

** and *.Correlation is significant at the 0.01 level (2-tailed)

From Table 4 Qualitative data analysis of lived experiences on the use of corrective braces among parent of children with clubfoot

“Personal experiences of parents with wearing braces for correction”

Altogether, the caregivers shared their personal experiences with their children about using

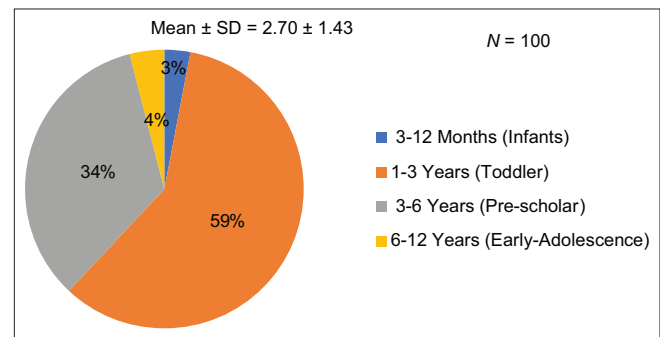


Figure 3: Distribution of children according to age

Table 3: Association of perception and practice on use of corrective braces with selected socio-demographic variables n=100

Sociodemographic variable	Perception		Practice	
	F/t-test	P	F/t-test	P
Age (in years) ^a				
• <25	2.913	0.038*	1.149	0.33
• 25-30				
• 31-35				
• >35				
Gender of parents ^b				
• Male	1.117	0.267	1.987	0.050*
• Female				
Education status of mother ^a				
• Illiterate	3.269	0.025*	0.517	0.000*
• Primary education				
• Higher secondary				
• Graduate and above				
Occupational status of mother				
• Dead	3.857	0.006*	6.857	0.000*
• Government job				
• Private job				
• Business/self-employed				
• Housewife				
Attended educational activities ^b				
• No	3.897	0.000*	0.716	0.476
• Yes				
Distance of available health facilities for				
• Regular follow-up ^a	1.586	0.198	5.782	0.001*
• Within 10 kilometers				
• 11–50 kilometers				
• 51–100 kilometers				
• Above 100 kilometers				

ANOVA, Independent 't' test, *P-value considered as level of significance* ≤0.05. ^adenotes ANOVA test for categorical data and ^bdenotes t-test for binomial categories

Table 4: Qualitative data analysis of lived experiences on the use of corrective braces among parent of children with clubfoot n=17

Themes	f (%)
Personal experiences of parents with wearing braces for correction	17 (10)
Encounters and barriers faced during the corrective braces phase	7 (41)
Effects of wearing braces for correction on one's social and personal life	10 (59)
Perception of parents and child's answers or response while wearing corrective braces	15 (88)
Any other previous practices of parents	11 (65)
Awareness about the clubfoot	11 (65)

the corrective braces/shoes and had given the statements:

"For this, I have to cut all the pajamas from one side and put the buttons on both sides and put them in all pajamas, so there was no need to open a shoe again and again. So, that time has passed well. Now, the child is on night-time shoes only."

"Encounters and barriers faced during corrective braces phase"

The parents had faced enormous challenges and barriers while putting on corrective braces as they had shared their difficulties as:

"After putting on shoes, then there are a lot of problems while the child is passing urine and stool. If we wash the feet, there may be chances of getting water into shoes, as shoes are of leather material, that's why preventing spoilage is a big problem. Therefore, I faced a lot of difficulty in handling him."

"Effects of wearing braces for correction on one's social and personal life"

Parents had shared their personal and social impacts of using corrective braces on several aspects of life and stated that:

"People are still unaware of clubfoot in our Indian society; It is still a social stigma in our society. This will have a negative impact on our child's life. Maybe this negative thinking of stigma will change in the future with awareness. Whenever we visit a hospital, we bring her by completely covered in a scarf otherwise people keep asking on the way, why this child has such feet."

"Perception of parents and child's answers or response while wearing corrective braces"

Most caregivers trust that their children remain

completely uncomfortable after putting on these prescribed shoes/braces as they have given the following statements:

"Now he is facing a problem during sleep. Especially, when he is stuck in a bedsheet, he becomes disturbed and feels irritated. He starts crying as he watches his shoes/braces. He does not like to wear these shoes/braces at all. After just watching his shoes/braces, he gets angry and irritable."

"Any other previous practices of parents"

Parents had a variety of issues, including child care following previous surgeries and child walking with a limping posture issue after wearing these shoes/braces, as they stated:

"I have recognized that his feet are in the early phase of inversion, but due to the COVID pandemic, we were unable to visit and meet the doctor. Now his feet completely returned to the position same as were at the time of his birth. We were more uncomfortable with the shoes phase as compared to the plaster phase."

"Awareness about the clubfoot"

Further, most caregivers had no knowledge about clubfoot; they became aware of clubfoot after the diagnosis of the child as they commented as:

"When we were blessed with the baby girl, the doctor told us about the treatment that the first phase would be plaster casting followed by the second phase of wearing shoes then your child would be okay. There is nothing to worry about. In addition, on reaching the hospital immediately, we got complete information in the hospital in detail."

"Meta-matrix of both strands"

Overall, the majority of parents had a positive perception and were following the appropriate practices on the use of corrective braces/shoes for their children diagnosed with clubfoot.

Most parents came to know about clubfoot after the diagnosis of the child; before that only parents who had a family history were found to be aware of its diagnosis and management. Medical personnel was also found to have a lack of awareness regarding clubfoot and its management.

All parents believed that if they will continue to be strongly compliant with the treatment protocol, their child's feet would become this much correct that no one will be able to differentiate their child in the future that they had clubfoot problem during childhood.

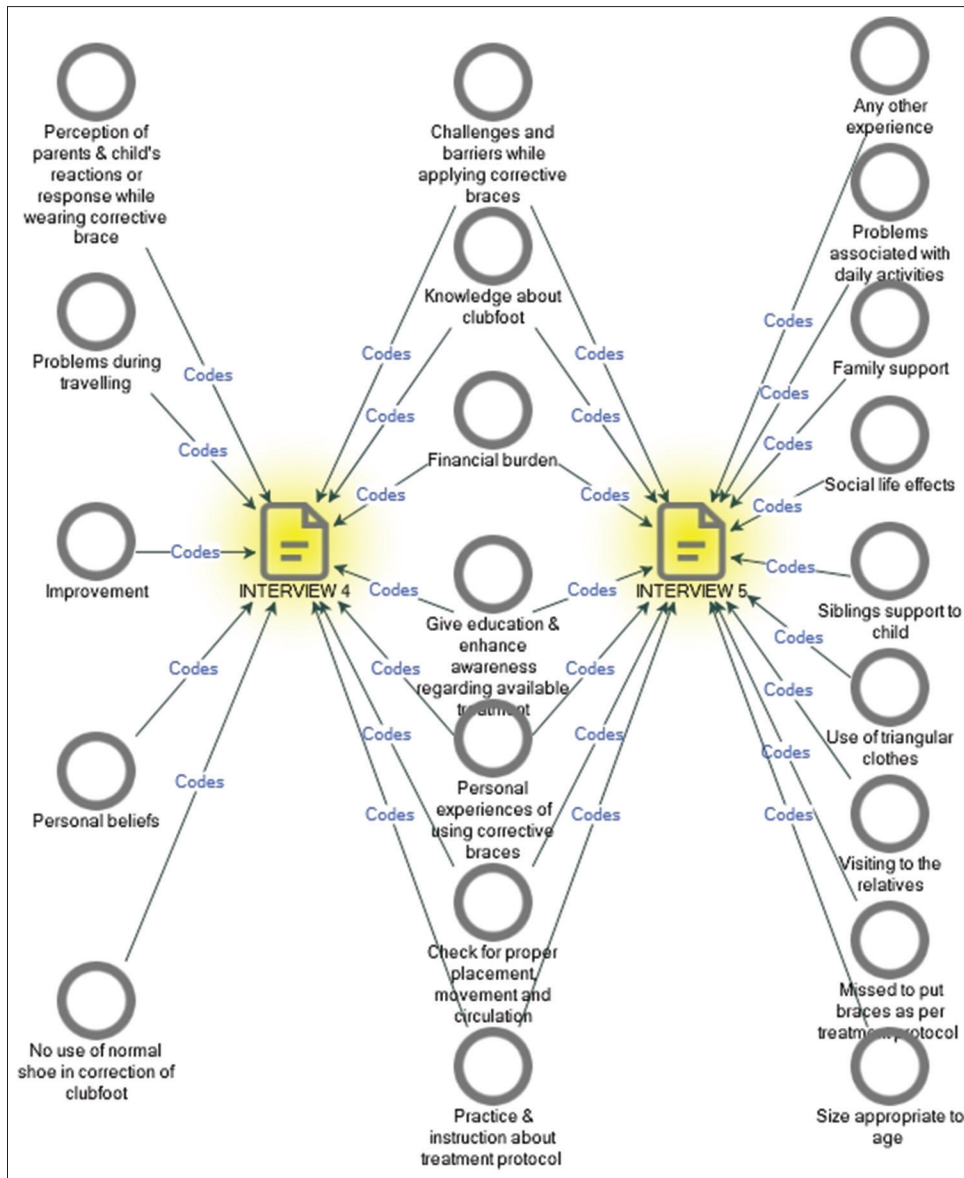


Figure 4: Relationship of theme and categories between interviews 4 and 15

Figure 4 depicts the relationship of theme and categories between interviews 4 and 15. We have calculated every theme and category relationship, which found that they had a relationship in all interviews; however, we have mentioned only one theme and category for example to explain the relationship.

Discussion

In the current scenario, the Ponseti method has become the most accepted and popular treatment globally for clubfoot management in two phases, that is, the plaster cast phase followed by the braces/shoes putting phase.

Of the study participants, 40% were from 25 to 30 years of age with a mean age of 31.10 ± 6.22 years. In view

of the educational background, fathers and mothers of children diagnosed with clubfoot, 44% had graduation and above educational status. Most fathers of children, that is, 39% with clubfoot were having their own business/self-employed, and the majority of mother participants were found to care for their children with clubfoot as caregivers and were housewives, that is, 94% followed by fathers, that is, 92%. The majority of male children were found with congenital clubfoot, that is, 71% as supported by Esan O *et al.*'s study.^[14]

The majority of siblings were not having any congenital anomalies, that is, 95% as compared to a study^[14] where 70.7% of patients had siblings with clubfoot. The mean age of children was 2.70 ± 1.43 (6 months–10.6 years) and most of them belonged to the 1–3 years of age group (toddler), that is, 59%. The majority of parents

were found to travel above 100 kilometers, that is, 39% for regular follow-up in healthcare facilities followed by 38% coming from 11–50 kilometers, but if we compare it with three studies,^[14,16,17] then, the mean age of participants was 18.43 months with a standard deviation (SD) of 22.26 and majority of them, that is, 55.2% had visited in their first year of life. One of the studies^[18] has shown a similar finding to the present study, where the majority of children who were bearing braces before undergoing a surgical procedure a surgical procedure (tenotomy) for the correction of rigid clubfoot before the prescription of braces as the next step, that is, 80%.

In the current study, the majority of parents were from the middle class, that is, 45% and 99% of parents had not attended any informative activity/program related to clubfoot management.

In the present study, 93% of parents had shown positive perception with a mean score of 67.16 ± 6.23 toward the use of braces as the best treatment protocol for their children with clubfoot. If compared with another study, the participants had experienced negative emotions and perceptions as they had considered this diagnosis similar to other disabling conditions.^[19]

In this study, 64% of parents followed appropriate practice procedure steps while putting on braces for their children as a part of treatment protocol as compared to the study in which only half of the respondents had the knowledge to put on these braces properly.^[20]

Furthermore, it was found that the parent's practice on the use of corrective braces had a significant association with the gender of parents ($P = 0.050$), educational status of mothers ($P = 0.000$), occupational status of mothers ($P = 0.000$), and with a distance of available health care facility for follow-ups ($P = 0.001$).

The current study adds to our understanding of parents' perspectives on the use of corrective braces. Parents talked about in what way they chose the correct size of braces, what kind of braces/shoes they were comfortable wearing, how they felt about the treatment protocol, and how long it took them to put on their child's shoes/braces. They also looked into the involvement of the COVID-19 pandemic in the majority of re-occurrence cases in the hospital.

“Majority of parents had faced a lot of challenges and barriers such as financial burden, follow-up visit problems, leave-sanctioning problem, non-availability of medical facility nearby, problems associated with daily activities, problems during traveling, visiting relatives and managing child's toilet with the use of triangular clothes as supported by common challenges in three studies while caring their child with congenital clubfoot.^[21-23]

Moreover, in the current study, the parents had a lack of awareness of the treatment, they considered clubfoot deformity as a stigma and obtained treatment from religious places, and had a strong belief about it happening during solar and moon eclipses as supported by previous studies.^[10,20,24]

Results of the present study revealed that parents had shown an optimistic perception toward the use of corrective braces as compared to another study^[19] that showed they had poorer perception along with feelings of anger. Further, it was evident from the study that a mother's neglectful behavior during solar and moon eclipse, God's curse due to bad karma (religious beliefs), hereditary, and mother's negligence was considered as the causes of the development of clubfoot in Indian society as supported by studies.^[19,24]

Caregivers had their personal belief that if they will remain compliant with the treatment protocol, their child will walk like a normal child in the future as discussed in the study.^[18] In the present study, parents discovered their experiences that medical personnel was also found to be unaware and untrained regarding clubfoot diagnosis and its management.

This study has a few limitations as the researcher was not an expert to conduct this study in varying localities to enhance its generalizability. The data collection time was only 1 month and the researcher faced issues due to the COVID-19 pandemic; participants had feared visiting the hospital and a few of them were found to be reluctant to fill out the questionnaire and spare their time for the interview.

The strength of the study is the good sample size, which was appropriately calculated to generalize the findings of the study into other settings.

Limitations and Recommendations

The study designs can be better if the experimental design and control group can be adopted for better comparison of the results. A similar study can be recommended on a larger sample by adding other healthcare professionals to make the findings more generalizable and to plan a training development workshop as an intervention so that the practice of parents can be rectified by giving demonstrations and taking re-demonstrations to give them feedback.

Conclusion

Clubfoot diagnosis and its management are burdensome for parents and other caregivers of the child. This study has shown that the parents had a positive perception and appropriate practices among parents on the use of

corrective braces. Although a modest level of difficulty is faced by all caregivers while caring for their child at home according to the CURE India program^[25] under the second phase of the Ponseti method. Fulfilling the needs of the child, pose physical, psychological, financial, and social challenges and barriers for caregivers, which remain unnoticed. The participants felt that there should be proper awareness programs for the general population as a part of government policy so that the knowledge level of society can be enhanced and parents will not face any negative impact on their life. Thus, it is very important to understand the caregiver's role and its related challenges for the betterment of life of their children.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Authors declaration for this article

All authors have declared that this work originally belongs to AIIMS, Rishikesh.

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Conflicts of interest

There are no conflicts of interest

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