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Research Article

LIVED EXPERIENCES OF PARENTS IN REARING CHILD WITH CLUBFOOT IN NORTHERN STATES OF INDIA: A QUALITATIVE STUDY

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ABSTRACT

Congenital Talipes Equinovarus (CTEV), is a congenital structural deformity characterized by abnormal tendon and muscle development which leads to abnormal alignment of the feet. The study aimed to explore lived experiences on use of corrective braces among parents of children diagnosed with clubfoot in Northern states of India. A phenomenological research design was used to collect the qualitative data by adopting a purposive (maximum variation) sampling technique. In-depth interviews method used until data saturation from 21 parents of clubfoot children in AIIMS, Rishikesh. The findings of the study showed that the lived experiences among parents of children diagnosed with clubfoot on use of corrective braces reflected under six main themes which were "Personal experiences of using corrective braces", "Challenges and barriers while applying corrective braces", "Impacts of corrective braces on personal and social life", "Perceived responses of parents & children towards corrective brace", "Any other experience" & "Knowledge about clubfoot". The study concluded that parents were facing few issues namely relapse due to non-adherence, financial burden because of lack of awareness regarding its free treatment, traveling distance, and noticeably more, which needs to be attended by health care professionals.

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INTRODUCTION

Congenital Talipes Equinovarus (CTEV) i.e. clubfoot, is a structural deformity that grows and develops in the mother womb during intrauterine life characterized by abnormal tendon and muscle development which leads to abnormal alignment of the feet¹. According to an estimate by the global clubfoot initiative in 2014, the prevalence of clubfoot in Sweden is 1.4 per 1000 live births. In Australia, the prevalence is higher among the aboriginal population (3.5 per 1000 live birth) than Caucasian population 1.1 per 1000 live births². The prevalence of clubfoot in India is estimated at around 1.19 per 1000 live birth¹. The challenges and barriers to clubfoot treatment in developing countries are different all around the world and especially the female child with a greater number of children in the family are prone to be neglected and non-adherence to use braces, lost treatment follow-up as compared to boys in India³. Findings suggested that the Parents/caregivers of children with clubfoot come across enormous challenges i.e. "long travelling distance, cost of treatment & travelling, poverty, stigmatization, lack of family support, lack of education, childcare difficulty, aesthetic purpose, parents think braces cause pain to their child and the problem with abduction

braces"^{4,5}. By exploring the lived experiences among parents of children diagnosed with clubfoot,⁶ concluded in his study that the parents caring of children with Ponseti method experience negative emotions and perception. The need of the study is that it helps to explore the lived experiences of parents with clubfoot children using corrective braces as a second phase of treatment of CTEV.

METHODOLOGY

Phenomenological qualitative research design used in this study. The sample of the study were parents and caregivers (grandparents and their relatives) caring clubfoot children. The data collected by use of purposive (maximum variation) sampling technique until data saturation from 21 parents from Aug 2020 to Feb 2021 every Thursday, attending clubfoot clinic of AIIMS Rishikesh during COVID 19 pandemic and taking treatment under second phase of ponseti method i.e. corrective braces having children diagnosed with clubfoot attending clubfoot clinic. In-depth interviews of all participants by using the purposive sampling technique with diversity in a sample from caregivers of different age groups children, genders of child and parents, religion and geographical areas of North India. The Inclusion criteria were children having ages from 3

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months to 14 years along with all those caregivers of children diagnosed with clubfoot using corrective braces. Children with syndromic clubfoot (cerebral palsy, spina-bifida) and parents who had left their treatment in-between due to their personal reasons excluded from the study.

A semi-structured questionnaire interview schedule was used to explore lived experiences on use of corrective braces from parents of children diagnosed with clubfoot. It contained five open-ended questions. The interview was conducted in a separate room, arranged for conducting the interview in Hindi language and interviews were recorded by using audio-taped method after making parents comfortable and taking consent signed from them after giving them full explanation about the research study protocol among all participants with their understanding level. The interview was conducted in Hindi language by using semi-structured interview schedule after taking written consent from participants in separate room with audio recorder after explaining about study. The recorded interview duration was 15 to 20 minutes with transcribed verbatim. After collecting data by conducting all interviews till saturation, Transcription of verbatim was done firstly from Hinglish to Hindi and finally to English language. The validation of English language was done by English expert for objectivity along with guide and co-guides for the study. Data coding was done by using NVivo Software. Thematic analysis of the data done after taking the word cloud image (Fig 1). Qualitative data were analyzed by using thematic representation under various Themes, Categories & Subcategories formed on corrective braces from parents of children with clubfoot done. The reliability and validity were checked to ensure trustworthiness of qualitative data in the study, Criteria of Lincoln and Guba's framework were used i.e. Credibility, dependability, approaches used to ensure credibility and transferability (Fig 2). The Ethical clearance was taken from the independent institutional ethical committee of the AIIMS Rishikesh with letter no. 46/IEC/M.Sc./2020.



Figure 1 Word cloud image by Nvivo Software



Figure 2 Trustworthiness of Qualitative data

RESULT

Upon analysis of data, the lived experiences on use of corrective braces among parents of children diagnosed with clubfoot were explored and grouped under six main themes, which were enumerated in the table 1 below:

Table 1 Qualitative data analysis of lived experiences on use of corrective braces among parent of children with clubfoot

Sr.No.	Themes (f)	Categories & Sub-categories	N=21	f
1	Personal experiences of using corrective braces (21)	I. Check for proper placement, movement and circulation	3	3
		II. Comfort with using the type of braces		7
		III. Growth of child & milestone		1
		IV. Insecure to adhere to treatment protocol		10
		V. Practice & instruction about treatment protocol		5
		i. Missing to put braces as per treatment protocol		4
2	Challenges and barriers while applying corrective braces (8)	ii. Size appropriate to age	17	4
		VI. Relapse due to not wearing braces		3
		I. Financial burden		4
		II. Follow up visit problem		3
		III. Leave sectioning problem		3
		IV. Non-availability of medical facility nearby		2
		V. Problems associated with daily activities		11
3	Impacts of corrective braces use on their personal and social life (1)	VI. Problems during travelling	10	4
		VII. Visiting to relatives		4
		I. Blaming mother for her negligence		10
		II. Family support		5
		III. Give education & enhance awareness regarding available treatment		5
4	Perceived response of parents and children towards corrective braces (16)	IV. Improvement in child's feet	13	10
		V. Effects on social life		7
		I. Perception of parents of using corrective braces		6
		II. Personal beliefs		1
		III. Siblings support to child		8
5	Any other experience (1)	IV. Social taboos regarding solar eclipse	7	7
		i. Social beliefs		7
		I. No use of normal shoe in correction of clubfoot		1
		II. Use of triangular clothes		2
6	Knowledge about clubfoot (12)	I. Hereditary	6	4
		II. Medical personnel's have lack of awareness about diagnosis and its management		4
		III. Medical treatment support		6
		IV. Medically unfit due to unequal size of foot		2



Figure 3 Major Themes and Subthemes identified area wise by NVivo software

THEME 1: Personal experiences of using corrective braces (21)

All of the parents had shared their personal experiences of using the corrective braces/shoes for their children and stated that:

“In the beginning, the child has a lot of difficulty in moving his feet together, the child used to cry a lot & As he had to wear the shoe for at least 23 hours a day. So, I faced a lot of difficulty in handling him.”

“I had removed stitching of all her pyjama, whenever she passes urine or stool, those pyjama became comfortable to put on and put off without removing braces/shoes each time. During night, I had used diaper to her.”

CATEGORY 1-I: Check for proper placement, movement and circulation (3)

Parents had explained that how they were following the steps to put on these braces and how they were checking braces that they had tied that properly as per their statement:

“In summer, we always used to cut his socks at fingertips, so that check can be kept to observe finger movement and for its tightness. During winter season, we were using normal warm socks for him and checking for its proper tying was doing from the hole on heel of shoes for the settlement that it is touching the shoe heel.”

CATEGORY 1-II: Comfort with using the type of braces (4)

Few numbers of participants had shared their experience with the type of braces they were comfortable to put on these braces as their viewpoints were:

“We don't want shoes connected with iron rod. I find plastic bar shoes comfortable because it is designed in such a way that firstly, you can put on a shoes on child's feet and afterwards you can attach them with the plastic bar. These types of shoes remain comfortable during night also. As whenever child cry's during night, you can detach the bar without removing the shoes. Whenever he sleeps, you can comfortably can attach the bar in the shoe without disturbing the child. However, we are comfortable this time as I have received plastic bar shoes, whenever he starts to cry, I just detach the bar stand only and

shoes remain in place. When he sleeps, I attach the bar stand without his knowledge.”

CATEGORY 1-III: Growth of child & milestone (7)

Some of the parents had explained regarding how growth of children had changed their experiences while putting on the corrective braces as they stated that:

“I didn't keep him brace free. He used to crawl on knee. However, now he has grown up. He is now turning to be 3 years old. Now he walks too.”

CATEGORY 1-IV: Insecure to adhere to treatment protocol (1)

One of the participant told that *“Initially, I was insecure whether I would be able to follow this treatment for my child or not.”*

CATEGORY 1-V: Practice & instruction about treatment protocol (10)

Parents had reported regarding the instructions received and how they were practicing to put on these shoes/braces to their children as they had told about duration and some of them had demonstrated the steps they were following which are as follows:

“These are initial days of her treatment of second i.e. of bracing period, we have to put on shoes/ braces for 23 hours up to 3 months. It is very important that at least after 5 years you will have to wear it during night. After this, the foot will be completely cured.”

SUB-CATEGORY 1-V-a: Missed to put on braces as per treatment protocol (5)

Some of the parents explained the reasons of missed to put on braces. According to the treatment protocol as they mentioned that:

“When, the lockdown happened due to COVID pandemic, the shoes became tight and smaller. When I put on shoes to her, she gets swelling in her feet after wearing the braces.”

SUB-CATEGORY 1-V-b: Size appropriate to age (4)

Parents were aware enough regarding assessing the correct size of corrective braces but its unavailability due to COVID Pandemic according to their age as per their statement:

“Because of COVID Pandemic, we were unable to visit to get proper size shoe. Whenever her fingers come out of her shoe, we used to visit to get a new shoe.”

CATEGORY 1-VI: Relapse due to not wearing braces (4)

Parents had shared their experience that their child can face relapse if not adhere to treatment protocol as per their viewpoints:

“When he started to walk on toes. Then I checked it from his mother, whether she put on these shoes to him, and then she told me that she was not putting the shoe properly to him, now problem has increased. My son did not wear these shoes/braces properly; his feet didn't corrected.”

THEME 2: Challenges and barriers while applying corrective braces (8)

The parents had faced different types of challenges and barriers during the corrective brace phase as they had shared their problems encountered as:

“When child passes urine or stool, so this becomes very big problem in the starting three months’ treatment, as shoes must be put on at least for 23 hours a day. That time was very problematic as compared to now a day, because she is wearing only night-time shoes now. Now only you have to keep a check on child 2 to 3 time in the night.”

CATEGORY 2-I: Financial burden (17)

Majority of parents had reported about financial burden they encountered while receiving treatment and they had provided the information that they were unaware about its free treatment availability as they stated:

“We were facing a money problem because of travelling cost as we need to spend a lot of money for taxi service that was also one reason that I took decision to make arrangement regarding their stay in my relative’s residence. Otherwise, there is no burden of treatment from hospital side. It is completely free of cost.”

CATEGORY 2-II: Follow up visit problem (3)

Some parents who have given their point of view regarding follow up visit are as follows:

“Because it was very difficult to bring the child from distance of 300 kilometres in every 15 days for follow-up visit.”

CATEGORY 2-III: Leave sectioning problem (4)

Some of parents had faced problems in getting leaves who are working as they have mentioned:

“I faced many problems in taking leave from office. Therefore, my head always scolded me, as I needed to visit here fortnightly.”

CATEGORY 2-IV: Non-availability of medical facility nearby (3)

Parents have acknowledgement of problem faced due to non-availability of medical facility nearby their home as they stated that:

“This hospital is far away from ours. The distance is about 300 kilometres from home. It is very troublesome for people to come to AIIMS Rishikesh from Uttarakashi for the treatment, if treatment is supposed to run for so long. The most important challenge for us was to visit such a long distance from Uttarakashi to AIIMS Rishikesh. There should be a primary service in Uttarakashi, if people get this treatment in Uttarakashi itself, so it will definitely give a great relief to general population residing there.”

CATEGORY 2-V: Problems associated with daily activities (2)

Two participants had given their comments as:

“I am unable to perform work of daily routine. He becomes more annoying in-between. I faced a problem even with cooking.”

CATEGORY 2-VI: Problems during travelling (11)

Most of the parents have faced problem during travelling that they have to carry their child by completely covering with scarf from people travelling along with them as they have stated:

“Always have to travel by keeping the child’s feet covered with a scarf. When we go out, after seeing the child’s feet, people keeps on asking repeatedly, what has happened to your child? Why have you worn such shoes? There is problem even when we travel in the bus to come to the hospital. Even then, people ask repeatedly. Then, I tell them that there is problem in my child’s feet bone that is why he is wearing it.”

CATEGORY 2-VII: Visiting to the relatives (7)

Parents have belief that they should avoid visiting unnecessarily as per their statement that:

“If we visit to any of our relatives, they keep on asking about child’s feet problem and use of shoes/braces so, we don’t prefer to go anywhere. I advise to other parents that they should also avoid visiting unnecessarily.”

THEME 3: Impacts of corrective braces use on their personal and social life (1)

Parents explained the effects of using corrective braces on their personal and social life as per the statement:

CATEGORY 3-I: Blaming mother for her negligence (4)

People believes that the Mother remains responsible for the development of clubfoot to the child as they have different opinions:

“Even some of the people used to blame his mother for his deformity as they thought it was heredity problem, but the problem is only from mother’s side. They would not have told you about this before her marriage.”

CATEGORY 3-II: Family support (10)

Parents explained the role of family in following this treatment protocol as they have given the statement:

“To manage him, I went to my mother’s home. Because there both my mother and sister were also residing. So three of us used to take care of her alternately. For last 7 months, my mother was helping me in managing him.”

CATEGORY 3-III: Give education & enhance awareness regarding available treatment (5)

Parents told the role of imparting education regarding clubfoot and its treatment to general population could play a vital role in making them aware as they stated:

“I also told other people about this treatment. So that they can also come to consult for their child. There are a number of children in our village with clubfoot deformity. We have explained to the people whose children too have clubfoot deformity in our village that, they can also visit the hospital for their children’s treatment. I also told them that treatment is free; you need not to spend any money. You have to spend only travelling cost.”

CATEGORY 3-IV: Improvement in child's feet (5)

Majority of parents have seen improvement in their child's feet after adhering with this treatment protocol as they have given their comments:

"His grandfather used to say why the child was wearing that shoe too much but after seeing improvement due to treatment, he supported it in putting these shoes again and again. Since then, the baby's foot had improved significantly. But, after observing improvement with treatment, I followed it for the correction in the feet of my child."

CATEGORY 3-V: Effects on social life (10)

Community people still consider clubfoot child as stigma and believe that it happens due to God's curse on couple and because of the past Karma's & destiny role as they stated that:

"It is still a social stigma in our society. This will have negative impact on our child's life. Maybe this negative thinking of stigma will change in future with awareness."

THEME 4: Perceived response of parents and children towards corrective brace (16)

Most of the parents have belief that their children remains completely uncomfortable after putting on these prescribed shoes/braces as they have given the following statements:

"In the beginning, the child has a lot of difficulty in moving his feet together, the child used to cry a lot & As he had to wear the shoe for at least 23 hours a day."

"We are trying to make her habitual with shoes, because she is not wearing it for long time. She starts crying only after putting on for 1 to 2 hours only, does not sleep & stop crying until we put off her shoes."

CATEGORY 4-I: Perception of parents of using corrective braces (6)

Majority of parents have positive perception on using corrective braces as a part of treatment as they have stated that:

"Even after completing first 23 hours course of three months, he has to only put on shoe during night; child also remains uncomfortable due to lack of sleep. When child goes into deep sleep, that period only remains comfortable but once he needs to do any movement as he remains in one position. So it is very difficult for a child to remain in one position overnight. That's why he becomes uncomfortable and in trouble."

CATEGORY 4-II: Personal beliefs (13)

Mostly parents have different personal believes regarding clubfoot and its management as they stated:

"We didn't bother about other people. I ignore to listen to people. I just say that it will cure. I have no other problem. So I just told them that this was in the hands of the God, we would do all for her as it is our moral duty. Moreover, we feel that he will be cured soon."

"I think it happened to me because of my own karma (actions)."

CATEGORY 4-III: Siblings support to child (1)

Parents believe the role of sibling in adoption of child with use of corrective braces as they stated:

"I always encouraged my two children to play with him. I

taught my children to play by lifting your both legs together so that he could imitate them and learn to move his both feet together."

CATEGORY 4-IV: Social taboos regarding solar eclipse (8)

Most of people in Indian society have strong belief about the role of solar and moon eclipse in the development of clubfoot as they stated:

"Our elderly people have belief that this happens in eclipse. They keep on telling me that I might not have taken care of myself during pregnancy in the eclipse time, so this has happened."

SUB-CATEGORY 4-IV- i: Social beliefs (7)

People have different opinion regarding clubfoot as per their awareness level as they stated:

"Guiding us to take extra care during the solar eclipse and moon eclipse and give instructions not to do the use the knife to cut anything."

THEME 5: Any other experience (11)

Parents had faced different problems like care of child after other surgeries along with clubfoot, child will walk with limping posture, moisture problem after wearing these shoes/braces as they stated:

"Other children at home mimic that she will move with limping posture. So I explained to them that as she is receiving treatment from the hospital. As we are caring her and getting the treatment done properly before she starts to walk, she will also walk normally like you. Ladies also say that if we had not visited the hospital initially, she would have had crooked feet like this always."

"Another issue is of moisture formation during summer season in child's feet."

CATEGORY 5-I: No use of normal shoe in correction of clubfoot (1)

Parents were aware about the use of these special types of jointed shoes/braces importance in correction of clubfoot as compare to normal shoes, which they can purchase from market as they have stated:

"I just know that if I will purchase any type of normal shoes from market, it would not have any correcting effect, until the child's heel well fitted in the shoes. There will be no correction in feet from using that."

CATEGORY 5-II: Use of triangular clothes (2)

Parents have used the triangular cloth as a diaper to prevent shoes/braces from wetting in order to avoid the financial burden as they stated:

"Initially, I used to tie her a triangular cloth sling as diaper and put a cloth underneath so that the shoes can prevented from getting wet. It was summer season."

THEME 6: Knowledge about clubfoot (12)

Most of the parents were having no knowledge about clubfoot; they come to know about clubfoot and its treatment after the diagnosis of their own child after birth as they stated:

which is as follows:

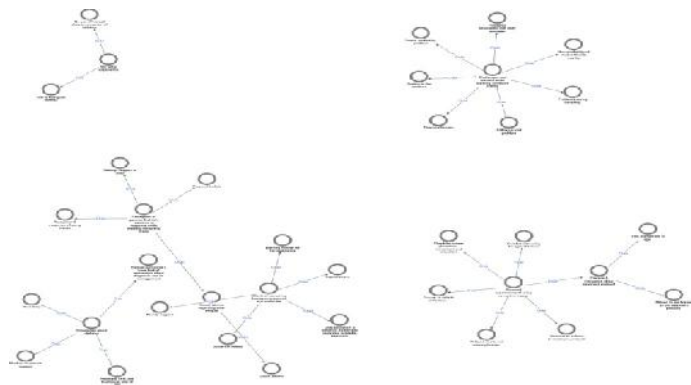


Figure 7 Project map showing association between themes, categories & subcategories

DISCUSSION

The clubfoot, musculoskeletal congenital anomalies of children, about which there is a little awareness about its treatment in Indian communities. The female child remains neglected in developing countries along with non-availability of health care services (clubfoot clinic) nearby as more preference to male gender. This disease can be successfully treated if remain compliant with the treatment upon the prescribed period along with its follow-up visits.

This study provides important insight into the lived experiences among parents on use of corrective braces. Parents had shared their experiences about how they choose correct size of braces, what kind of braces/shoes; they are comfortable to put on, their feeling about treatment protocol, how they had left to put on shoes/braces for their child. In addition, they had also explored the role of COVID-19 Pandemic for most of the relapse cases in the hospital due to non-availability of corrective braces/shoes timely.

In this study, majority of parents had faced a lot of challenges and barriers such as financial burden, follow-up visit problems, leave sectioning problem, non-availability of medical facility nearby, problems associated with daily activities, problems during traveling, visiting relatives & managing child's toilet with the use of triangular clothes. Similarly, studies conducted in Vietnam, India & Kenya respectively were facing common challenges like long traveling distances, cost of treatment & traveling, poverty, stigmatization, lack of family support, and a problem with abduction braces while caring for their child with congenital clubfoot.^{7,8&9}

Findings of the present study, parents were aware that they have to put on these jointed corrective braces/ shoes, normal shoes will not be going to help anymore which was supported by previous study findings.¹⁰ Parents had told that to remain compliant with the treatment protocol, which was noticed between male and female child during treatment same found in study conducted by previous study,¹¹ that female child remained neglected as compare to male child in India.

The present study findings suggested that 99% of parents had not attended any educational activity for clubfoot management so were found with no awareness before diagnosis of their children after visiting hospitals, similarly, previous study

findings revealed that 93.1% of parents did not know anything about clubfoot deformity before their child's diagnosis.¹²

The present study had theme named social stigma and impact on personal-social life includes different of treatment of clubfoot in our communities. They get their treatment from religious places, because they believe it is result of bad karmas. Similar findings reported in previous studies,^{2,13} concluded that parents were poorly aware of treatment, they consider clubfoot deformity as stigma & get treatment from religious places, both of these studies.

The present study also reported about the effects of corrective braces on the personal and social life, as parents still had to face negative effects on their social life as people consider this as social stigma telling that this happens during to solar, and moon eclipse supported by three studies.^{2,13}

Results of the present study revealed that parents had shown their positive perception towards the use of corrective braces was contradicted by previous study that they had been worse perception along with the feelings of anger.⁶

Further, it was evident from this study that mother's negligent behavior during solar and moon eclipse, God's curse due to bad karma (religious beliefs), hereditary, mother's negligence was considered as the causes of development of clubfoot in Indian society similarly, previous studies,^{6,13} where they had also noticed the causes of clubfoot development as they listed lunar and solar eclipses, religious explanations, health status and behavior of parents and genetics.

In the current study, ways to overcome some challenges were also explored where parents told that they are overcoming the financial burden by using triangular clothes instead of using the diapers. It was also come as challenge in present study that children will remain medically unfit for the defense services in future due to their unequal size of feet. A similar concern was discussed in the study conducted under the theme parent's concern about child's future their mother had reported concerns about different shoes size, fashion issues and its impacts on their child's confidence in future.⁶

Parents 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 supported by the study.¹³

In present study, parents had explored their experiences that medical personnel was also found to be unaware and untrained regarding clubfoot diagnosis and its management. The present study also reported about the effects of corrective braces on the personal and social life, as parents still had to face negative effect on their social life as people consider this as social stigma telling that this happens during to solar, and moon eclipse which is supported by previous studies.^{2,13}

Results of the present study revealed that parent's hereditary play a vital role that if any member has this disease before then the next generation will have more chances to get this as supported by similar study.⁶

Further, it was evident from this study that mother's negligent behavior during solar and moon eclipse, God's curse due to bad karma (religious beliefs), hereditary, mother's negligence was considered as the causes of development of clubfoot in Indian society. Similarly, two studies, where they had also noticed the

causes of clubfoot development as they listed lunar and solar eclipses, religious explanations, health status, and behavior of parents and genetics.^{6,13}

Additionally, present study, parents had explored their experiences that medical personnel was also found to be unaware and untrained regarding clubfoot diagnosis and its management. Researcher was unable to conduct this study in varying localities due to COVID-19 pandemic to enhance its generalizability. As participant's visits once in three months or later after braces becomes small in size, so difficult access to further participants within the short duration of data collection. By educating about C.U.R.E. International India, 2009 clubfoot program in nursing education as a free treatment protocol can contribute to aware people about its availability and will improve the compliance level of parents with the treatment. Nursing research further can contribute by finding the easy way to teach patients like by giving health education, workshops for awareness and demonstration of applying braces for parents and awareness camp for general community people of India. Overall, it will enhance the scope of nursing by contributing its knowledge to the existing body of nursing regarding clubfoot and its management. The researcher recommended conducting this type of study in varied localities of cities and community area of India like multispeciality hospital or hospitals of different regions, so that a protocol can be framed to teach parents about its application and can make them aware to decrease the compliance level of clubfoot in India. This study concluded that a modest level of difficulty faced by all parents/caregivers while caring for their child at home. The care of a child with clubfoot poses physical, psychological, financial and social challenges, and barriers on caregivers, which remains unnoticed.

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