

Perception about braces in parents of children with clubfoot

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Abstract

Objectives: To access the acceptability of Steenbeek brace by children undergoing clubfoot correction and their parents to ensure long-term compliance.

Methods: The cross-sectional study was conducted at the Indus Hospital, Karachi from October 2013 to March 2014. A trained researcher interviewed the person primarily responsible for bracing the child using a pre-coded questionnaire. Modified Orthotics Prosthetics User Survey for satisfaction with either the Mitchell brace of the Steenbeek brace was used. It included 11 questions in the Parent Bracing Satisfaction Survey. SPSS 21 was used for statistical analysis.

Results: Interviews were completed with 110 primary caregivers among whom 90(81.8%) were mothers. Overall, 32(29.1%) children were using the Mitchell brace, 30(27.3%) the Steenbeek brace, 46(41.8%) had shifted from Mitchell to Steenbeek brace, and 2(1.8%) had shifted from Steenbeek to Mitchell brace. Median duration of current brace usage was 4 and 3.5 months for Steenbeek and Mitchell braces respectively. The mean age of the child was 1.4 ± 0.7 years, and the mean of 4-point Likerts scale score of parent bracing satisfaction was 28.7 ± 2.2 in children on the Mitchell brace versus 28.5 ± 1.9 for those on Steenbeek brace ($p=0.505$). Overall, 82(74.5%) parents had favourable attitude towards braces in general, but there were no significant differences in the items except "brace is easy to put on" ($p=0.040$) and "durability between Mitchell and Steenbeek groups" ($p=0.017$).

Conclusions: There were no differences in satisfaction levels between the two types of brace users.

Keywords: Mitchell brace, Steenbeek brace, Clubfoot brace parent satisfaction survey. (JPMA 64: S-131 (Suppl. 2); 2014)

Introduction

Clubfoot presents early in neonatal life and, if not treated, becomes more disabling with age. It causes physical impairments that result in decreased ambulation and inability to perform basic household activities and inability to go to school. This leads to dependence on family and significant economic hardship for the patient. In addition, the structural differences in children with clubfoot are associated with social stigma, which has a psychological effect on the child.¹ Clubfoot occurs in every 1.2 in 1000 live births, more commonly affecting boys than girls. Up to 50% cases are bilateral.²

There is increasing evidence that surgical release for clubfoot results in painful, arthritic feet in adulthood.³ In recent years, the Ponseti method has become the worldwide standard for treating this deformity. This method is safe, quick, effective, economical and easy-to-teach, and could have an enormous impact on the lives of thousands of children born with clubfoot.⁴ This method has become the standard of care and completely eliminates the need for extensive operative correction in

over 98% patients if applied correctly.

The Ponseti method uses a combination of manipulation and casting to correct the deformity.⁵ A clinic-based procedure, in some cases it requires Achilles tenotomy under sedation.⁶ After the casting period, the child wears a foot abduction brace (FAB) until the age of about four years to prevent relapse. These braces consist of shoes attached to a bar of approximately the length between the child's shoulders.⁷ The key to maintaining initial correction of the foot lies in educating and encouraging parents in the proper use of the brace.⁸ The brace consists of a bar with shoes attached to hold the affected foot at approximately 70 degrees of external rotation. For the patient with unilateral deformity, the unaffected foot is positioned at 30 degrees of abduction. The shoes are placed at shoulder width for comfort. The end of the bar may be bent or adjusted to allow 5 to 10 degrees of dorsiflexion. Parents need to be aware that this treatment lasts several years and also requires a serious commitment from parents to make it successful. Most recently, Haft et al. reiterated that compliance with the post-correction abduction bracing protocol is crucial to avoiding clubfoot recurrence.⁹ Reports on failures with the Ponseti method have shown that the decisive factor that led to recurrence of the clubfoot deformity in 50% of the cases was non-compliance with the FAB protocol.¹⁰

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Several types of clubfoot braces based on the same principle are available. The Pehla Qadam Clinic at the Indus Hospital has used two different types of braces. Both are standard models known as the Mitchell brace and Steenbeek brace.¹¹

The Mitchell-Ponseti brace is the product of collaboration between John Mitchell and Ignacio Ponseti. This brace was found to be particularly helpful in patients who were considered difficult-to-brace with limited dorsiflexion. The brace consists of shoes made of very soft leather and a plastic sole that is moulded to the shape of a child's foot. It is very comfortable, easy-to-use and widely distributed in developed countries, but it is quite expensive.¹²

The Steenbeek brace was developed in Uganda by Micheal Steenbeek and David Okello and matches the recommendations endorsed by Ponseti. The shoes are attached to a simple metal plate that is riveted to the bar. This brace is easy-to-fabricate, low-cost, effective in maintaining correction and is locally manufactured using various designs in several developing countries.

The Mitchell braces were initially provided to Indus Hospital as a donation. At a later stage when these braces ran out of stock, the Steenbeek brace was manufactured locally. The plans are available for free download on the internet. Therefore, the initial Pehla Qadam programme patients used the Mitchell brace and subsequently the Steenbeek brace was introduced.

However, since Steenbeek braces are locally manufactured and cheaper to produce, it was found important that we determine early on in the programme its acceptability among parents since acceptability in the population is important for increasing adherence and ultimately the success rate of the treatment.

Factors that were important to assess included the cost of the brace, whether parents had knowledge regarding the proper use of braces, any barriers to following bracing instructions and knowledge of the length of bracing.

The current study was planned to gather parent perceptions about braces and knowledge of their use as well as to identify any factors that may indicate potential for non-adherence.

Subjects and Methods

The cross-sectional study was conducted at the Indus Hospital, Karachi, from October 2013 to March 2014, after approval from the institutional review board. Consecutive patients in the bracing phase were approached and it was checked if the person accompanying the child on the day was also the primary caregiver responsible for bracing the

child daily. In case she/he was not, a request was made that at the next appointment, the primary caregiver should accompany the child. The request was followed up with a telephone call prior to the next appointment.

If the person accompanying the child was also the one responsible for bracing, the caregiver was explained the objective of the study. Those who signed informed written consent were included in the study and were interviewed by a trained clinical/research officer using a pre-coded questionnaire. A study ID was allocated to each respondent, and the identifiers were kept confidential.

Modified Orthotics Prosthetics User Survey (OPUS) for satisfaction with either the Mitchell brace or the Steenbeek brace was used. It included 11 questions in the Parent Bracing Satisfaction Survey (Annexure) also. Besides, the survey also covered broad thematic areas, including knowledge of the bracing protocol, potential factors of non-adherence, child's reaction to bracing as well as assessment of the healthcare providers' interaction with the family.

Data was analysed using SPSS 21. Mean \pm standard deviation (SD) was computed for all quantitative variables, like duration of clubfoot brace (months), duration of current brace (months) and age of the child. Frequency and percentage were evaluated for all categorical variables like gender, type of brace, and questions related to satisfaction of braces, knowledge of bracing protocol, adherence, child's reaction and satisfaction scores.

The broad themes of information collected were analysed. Scores attained using the survey were correlated with the broad thematic areas. Compliance with bracing protocol was defined as 'full-time brace use' if the child was in the first three months of bracing, and night-time and nap-time use of bracing for those in the 2nd bracing phase.

Annexure

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- 1- The brace fits well.
 - 2- The weight of the brace is manageable.
 - 3- The brace is easy to put on.
 - 4- The brace looks good.
 - 5- The brace is durable.
 - 6- The brace does not affect clothing.
 - 7- Skin is free of abrasions and irritations.
 - 8- The child seems free of pain when the brace is on.
 - 9- We can afford to purchase this brace. (Mitchell: Rs. 37,500/- Steenbeek: Rs.3000/-).
 - 10- We can afford to repair or replace this brace as needed.
 - 11- I know about other braces that are better.
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Results

Interviews were completed with 110 primary caregivers who belonged to a range of ethnic backgrounds (Table-1). Among the primary caregivers, 90(81.8%) were mothers. Overall, 32(29.1%) children were using the Mitchell brace, 30(27.3%) the Steenbeek brace, 46(41.8%) had shifted from Mitchell to Steenbeek brace, and 2(1.8%) had shifted from Steenbeek to Mitchell brace (Table-2). Median

Table-1: Ethnic Background.

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
1- Sindhi	11	10.1	10.0	10.0
2- Urdu	51	46.4	46.4	56.4
3- Punjabi	15	13.6	13.6	70.0
5- Saraiki	6	5.5	5.5	75.5
6- Pushto	14	12.7	12.7	88.2
66- Other	13	11.8	11.8	100.0
Total	110	100.0	100.0	

Table-2: Types of brace used.

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
1- Steenbeek only	30	27.3	27.3	27.3
2- Mitchell to Steenbeek	46	41.8	41.8	69.1
3- Mitchell Only	32	29.1	29.1	98.2
4- Steenbeek to Mitchell	2	1.8	1.8	100.0
Total	110	100.0	100.0	

duration of current brace usage was 4 and 3.5 months for Steenbeek and Mitchell braces respectively. The mean age of the child was 1.4 ± 0.7 years, and the mean of 4-point Likert scale score of parent bracing satisfaction was 28.7 ± 2.2 in children on the Mitchell brace versus 28.5 ± 1.9 for those on Steenbeek brace ($p=0.505$). None of the Mitchell brace parents agreed that they could afford the brace, whereas 9(11.8%) of the Steenbeek brace parents agreed that they could afford it ($p=0.055$).

Overall, 82(74.5%) parents had favourable attitude towards braces in general, but there were no significant differences in the items except "brace is easy to put on" ($p=0.040$) and "durability between Mitchell and Steenbeek groups" ($p=0.017$).

Discussion

Clubfoot presents an ever-expanding spectrum of problems for the patient as an individual and for the physician as a disease. Recently the treatment of clubfoot has moved more towards a conservative approach rather than an extensive surgical procedure. This recent reappraisal has been due to the work of Dr Ponseti and

availability of long-term follow-up of his patients whom he treated with his manipulation and casting technique.

During the maintenance phase he employed braces to keep the corrected feet in a desired position so as to prevent relapse. Many braces have been developed since the inception of this treatment regimen.

One important barrier to bracing is the issue of physical satisfaction of the parent and child with a particular type of brace. Since our programme for clubfoot treatment has transitioned from donated Mitchell brace to self-manufactured Steenbeek brace, the evaluation of this important barrier was imperative to maintain the desired results in the programme.

Our study showed insignificant difference in satisfaction between the two groups ($p=0.505$). Satisfaction from the brace directly related with compliance, financial aspect of the brace being one of the most important factors as postulated in many previous studies.¹³ To remove this confounding factor, all treatment provided at the clinic starting from casting and progressing to bracing was provided free of cost. Additionally, financial assistance was provided to patients to cover their commuting expenses.

However, in our sample, which comprised low-income families, none of the parents agreed that they could afford the Mitchell brace whereas only 11.8% with Steenbeek brace agreed that they could afford the brace ($p=0.055$).

Our results interpret a very low patient non-compliance with bracing. This has been accomplished with the help of a dedicated team which has kept records of all the patients enrolled in the Pehla Qadam clubfoot programme, and any patient falling out of programme is brought back to follow-up by getting in touch with them through telephone contact. This also reflects in our study questionnaire which included questions like, "have you come on every visit", "is there anybody who discourages you from bracing", and also questions pertaining to Pehla Qadam team's interaction with the families. Counselling and education of patient's family has been cited as an important factor in previous studies.¹³

It is imperative to look at the survey point by point on each question to understand the difference of usage in both braces. Of particular interest in this regard are questions pertaining to the weight, appearance of the brace and whether it affects clothing or not. Families had insignificant difference of opinion in the two groups. However, there was a significant difference when asked whether the brace was easy to put on, as 97% in the Mitchell group had no difficulties versus 82% in the

Steenbeek group ($p=0.040$). Similarly, when asked whether the brace fits well, 93% parents had no difficulty in fitting the Steenbeek brace versus 100% for the parents with Mitchell brace. Both these problems could be attributed to the fact that the Mitchell brace has a detachable shoe which can be removed from the crossbar while putting it on the foot. However, since the initial follow-ups of the patients are kept at close interval when the bracing phase is started, the parents have a close chance of discussing the brace application with the team. This translates in the results by the fact that eventually only 7% parents had some problem with the fitting of Steenbeek brace.

Our results have to be interpreted cautiously as there are few limitations. Our patients were not randomly allocated to one or other type of brace. They had been prescribed either of the two braces on logistical availability of either of the braces at that point in time. Another limitation was that the survey scale did not include the neutral option, thus forcing the parents to either agree or disagree with the statement. However, our study shows equality of satisfaction in both groups.

Conclusion

Steenbeek brace is an economical and sustainable option for clubfoot bracing in financially-constrained programmes of low-income countries. The brace satisfaction survey was found to be similar for both braces, but to achieve such results, increased interaction and continued education of the parents and physicians is required.

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