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OBSTACLES ENCOUNTERED BY PARENTS DURING TREATMENT OF CLUBFOOT.

Orthopaedics

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ABSTRACT

Introduction: Idiopathic clubfoot affects approximately 50,000 children each year and is one of the leading causes of disability in India. The aim of the study was to investigate barriers encountered by parents of clubfoot children in desert area of India. Unfortunately, the Ponseti technique is very slowly picking up in our country in spite of its ease of usage and compatible results

Material and Method: In this prospective study of 215 patients enrolled from July 2014 to Dec 2016 In our study total 37 (17.2%) parents encountered obstacles and discontinued the treatment. The most frequent obstacles in our study were Parents related (45.95%), poor transportation and distance to treatment centers (40.54%), and Caregivers related (13. 5%).Lack of education and poor transportation services and distance from treatment centers had more obstacles for patient In India there are several patients and distance related factors in desert area influencing the outcome. There is lack of awareness programs in media (TV/ newspaper), schools, colleges and in public meetings. Poor transportation in Remote, hard desert areas producing hurdle for weekly serial casting and regular follow up.

KEYWORDS

Club Foot, Ponseti's Technique, Indian population.

INTRODUCTION:

Clubfoot or Congenital Talipes Equino Varus (CTEV) is a common complex congenital deformity of the foot. It is a three-dimensional deformity having four components: equinus, varus, Adductus and cavus. Many cases are associated with neuromuscular diseases, chromosomal abnormalities, Mendelian and non Mendelian syndromes and in rare cases with extrinsic causes. The incidence differs in different races. Idiopathic clubfoot affects 1-2children per thousands live birth(1), and is one of the leading causes of disability worldwide. Primary aim of our study was to find out the obstacles encountered by parents during treatment of ctev by ponsti method and Enlighten the solutions for obstacles to achieve 100% acceptability for treatment.

MATERIALAND METHOD-

This was a prospective observational study conducted in our center after ethical clearance. The study period was from July 2014 to Dec 2016.All idiopathic clubfoot were included in study and treated according to ponseti's casting technique (2,3). Data in the form of Questionary format (see Appendix 1) collected from parents of clubfoot children after written consent. Pirani's severity scoring system using for initial assessment of the severity and for evaluation of feet after each casting and tenotomy. Pre &Post procedure complication like plaster sore, skin excoriation, blister's formation, excessive bleeding following tenotomy. Inclusion criteria - Parents/principal caregivers of clubfoot affected children who attend the clubfoot clinic. Children with clubfoot of all age undergoing plaster casting treatment. Exclusion criteria - parents of syndrome clubfoot child, clubfoot children whose parents not attending the clubfoot clinic. Parents who did not return after their first appointment at the clubfoot Centre. The questionnaire consisted of 20 closed ended questions. At the time of attending clinic primary data taken from patient and rest of question taken as feedback from the parent's continuation and asked reason for discontinuation (dropout) children parents. Questionnaire made with the help of paper of Grogan, Conner, Norman, Willits and Porter (2000) in Scotland 3.and Dr. Patrika study Uganda2006 4 .out of 20 question 1-12 question related to parents related problems and 13-18 question related to medical persons, and 19-20 questions related to distance. The 20 questions of the instrument were developed based, firstly, on a review of literature on compliance/adherence of parents/caregivers to treatment regimens and, secondly, on the experience of the researcher within the field of clubfoot treatment.

We divide obstacles in 3 groups to study the difficulty faced by the parents as-

1st -group was parents related factors
2nd- group was poor transportation and distance to treatment centers
3rd- group of difficulty faced from medical facility

RESULTS-

Out of the 215 patients treated 139 patients (65%) were from a rural background and 76 patients (35%)belonged to urban areas .90% of the parents had attended weekly clinic with 67% indicating that they did not know about clubfoot and its treatment. In our study 37 (17.2%) patients encountered obstacles and discontinue in the treatment of ctev. (Table.1) and results trends shows in graph.1

1ST GROUP STUDY RESULTS-

In patient related factors 17 (45.95%)- 14 (82.35%)parents had lack of awareness of clubfoot and its treatment. These patients missed follow up and serial casting weekly, parents did not know the role of early treatment, what is clubfoot treatment, they missed follow-up regularly these patients are non compliant to clubfoot treatment.

Due to poor socioeconomic status 3 patients (8%) discontinued treatment. These parents couldn't afford expenditure of treatment and discontinued treatment. In our study because of less expenditure due to government policy, all casting material were free provided to the patients, therefore only expenditure on transportation borrowed by parents so fewer parent's discontinued the treatment because of economic burden.

2nd Group Results-

In our study 10.79% of rural parents discontinued the treatment only due to distance from treatment centers. Due to Poor transportation services and more distance to treatment centers 15(40.54%) parents faced obstacles. In our study more patients came from rural desert area were 70 parents from about >50-100 kms, 2 parents from 100-150 kms,37 parents from >150-200 kms, 22 parents from >200-250 kms,and 8 parents from 250 kms, 8 patients from 300 kms , poor transportation and distance to treatment centers which led to parent's not returning back till full correction.

In our study out of 15 parents ,4 (50%)parents from >250 kms ,6(27.2%) parents from >200-250 kms,3(8%) parents from >150-200kms, and 2 (4%)parents from >50-100 kms discontinued treatment. In our study distance was the major factor which affect the outcome of ponseti. Distance from treatment center is one of the major factor for discontinuation in western Rajasthan.

3rd group study-

5 parents (13.5%) had complications Due to during serial casting, out of which 2 patient had loose cast because of fatty child, due to soaking in urine cast may loosened. 2

children had excessive crying after casting. And 1 patient had tight cast, which discouraged patient's families and they discontinued treatment in between. There was some other factors which contributed to poor outcome were like skin blisters, lack of written reminder and late presentation.

DISCUSSION-

Parents compliance to the clubfoot treatment and awareness to parents

for treatment playing the major role in good outcome in treatment. In our study most important hurdle was patient related, lack of awareness was the most prominent, parents did not know the need of clubfoot early treatment requirement, and ponseti treatment methods. Socioeconomic obstacles in study was not major factor because of free government supply of casting material. And distance had the major factor for discontinuation in our study 50% patients of >250 kms discontinued the treatment due to poor transportation and far treatment centers .and due to casting application problems may also discontinuation of treatment. Only one study Scott and Evans (1997) (5) was found on the compliance of parents of children with clubfoot to treatment during the plaster casting stage. our study shows the factors that appeared to contribute to the poor continuation of treatment of early Ponseti treatment for clubfoot. The findings in our study parallel those from Latin America (6), Uganda (7) and Malawi (8). Madagascar (9) in these studies correlation between poor socioeconomic status &distance to treatment centers and family as well as society support needed for best results, In Peru (10) physicians report up to 30% of patients do not complete treatment. The most frequent obstacles, to the Ponseti method in Peru reported by physicians included lack of physicians trained in the Ponseti method in the country, patient transportation and distance to treatment centers, and lack of parental knowledge of the Ponseti method. The predominant cause of failure to complete treatment in desert area of Rajasthan are lack of awareness and poor education illiteracy rate in Rajasthan Literacy rate 66.11%Male Literacy79.19 %Female Literacy 5 2. 1 2 %(11). Due less female literacy rate, awareness about clubfoot treatment less, and because of unemployment, male populations of the community are out migrants in rural areas for work therefore couldn't took them for early clubfoot treatment. Lavy et al. (8)

recognized the barriers created by lack of good splint materials and staff with the necessary technical ability in Malawi. Infants born in rural area pose a problem. Normally they haven't the benefits of an examination of newborn by trained healthcare workers. in 4 of 7 our study 20% of children born by untrained dais's so they missed early diagnosis of the clubfoot. In summary, these findings indicate that family support in form of financial or physical support during care, which results in family well being and functioning, is a strong predictor of adherence to treatment requirements, good communication between the patient/caregiver and the health provider during clinical encounters and consultations is important for mutual understanding and agreement and is a good predictor of compliance to the prescribed care. Limitation of our study is question based study which have some limitation in clinical use and may be biased by parents by giving incorrect information.

CONCLUSION:

In spite of Ponseti casting technique becoming a common method to treat clubfoot worldwide, in India there are several patients and distance related factors in desert area influencing the outcome. There is lack of awareness programs in media (TV/ newspaper), schools, colleges and in public meetings. In our country there is no national health programme for clubfoot deformity, so diagnosis of clubfoot deformity is frequently missed at delivery points like sub centers, phc, chc and district hospitals. Poor transportation in Remote, hard desert area producing hurdle for weekly serial casting and regular follow up.

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