

SHORT COMMUNICATION

PROBLEMS ENCOUNTERED BY PARENTS OF INFANTS WITH CLUBFOOT TREATED BY THE PONSETI METHOD IN MADAGASCAR: A STUDY TO INFORM BETTER PRACTICE

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Objective: Ponseti treatment for clubfoot is effective and inexpensive, improving children's social participation. Two rehabilitation centres in Madagascar piloted Ponseti treatment; however, at one centre 46% of infants failed to complete treatment. The aim of this study was to determine the causes of defaulting in order to facilitate subsequent improvements nationwide when treatment is rolled out to all centres.

Methods: Questionnaire-based interviews.

Patients: Twenty mothers of infants younger than 1 year were interviewed after 3 months of treatment in relation to difficulties they experienced with continuing treatment.

Results: Fifteen families of these had financial problems: 7 incurred debt, 2 sold possessions, 4 parents stopped work and 2 did not give any further details. All mothers experienced distress; 9 hid their child's foot, and 8 were accused of wrong-doing during pregnancy. Three families travelled more than 500 km to the treatment centre and journeys were costly and difficult. Ponseti splints were acceptable, but aftercare of the splints proved problematic.

Conclusion: Repeated travel to the clinic resulted in financial and social burden on the families, which reduced their ability to engage in treatment. The findings of this study are similar to work from other countries, but publications on rehabilitation from Madagascar are few. Improved support for parents, information, splinting with better materials and provision of treatment more locally are needed. Financial support for parents is key to enhancing children's life chances.

Key words: rehabilitation; clubfoot; orthotics; parents; service evaluation; environmental factors.

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INTRODUCTION

Clubfoot is one of the most common childhood developmental disabilities seen in the developing world. The incidence of clubfoot in sub-Saharan Africa is 1.2 per 1,000 births (1). The impact of

clubfoot is profound; it affects walking, participation in education and work, and reinforces the cycle of poverty and disability (2). Treatment of clubfoot seeks to realign the foot and balance the functionally of the musculature. In France, functional re-education was the reference treatment until 1999, after which the Ponseti technique was increasingly adopted, leading to improved results (3, 4). The Ponseti technique is a surgical technique used to straighten the foot and ankle involving tenotomies and serial splinting.

Madagascar is the fourth largest island in the world, with a population of 23 million, which is predominately rural and widely dispersed. The country's infrastructure, including health services, is underdeveloped. Systematic teaching using a locally appropriate rehabilitation syllabus was given to doctors and physiotherapists from 2011–2013, resulting in a cadre of rehabilitation doctors capable of providing modern rehabilitation in regional centres (5). Epidemiological data on disability is lacking in Madagascar, thus the exact incidence of clubfoot is not known and services cannot be planned in this light. Nevertheless clubfoot is reported frequently in all regional rehabilitation units, with children often presenting late when treatment is more difficult (personal communication; Sonia Andrianabela, Ministry of Health, Madagascar).

With the help of Christoffel-Blindenmission (CBM) 2 pilot centres (in Antananarivo, Madagascar) were established for delivering Ponseti treatment. These were Le Centre d'Appareillage de Madagascar (CAM), in the capital, Antananarivo, and Le Centre de Ré-éducation Motrice de Madagascar (CRMM), at Antsirabe, approximately 300 km further south. However, at CAM in 2012, it was found that 46% of the children did not complete the early phase of treatment.

In preparation for expanding the treatment programme nationally to the other regional rehabilitation centres, it was decided that the reasons for this situation should be determined. The aim of this study was to explore the reasons for this low concordance with treatment.

METHODS

Participants

Parents whose children were less than 1 year old when starting Ponseti treatment at CAM from 1 March 2013 and 30 May 2013 were

provided with information about the study and invited to participate when they returned for the first assessment following serial splinting and tenotomy. Parents of children with conditions other than clubfoot, or whose children were over one year of age at presentation, children who were brought by adults other than their parents, children whose records were incomplete or who defaulted before the first assessment, or who did not wish participate, were excluded.

The study received institutional review board approval by the Malagasy Ministry of Health and was considered to be a service development project. The study was part of a series of service development projects across the regional rehabilitation centres, which were requirements for training for a mid-level Rehabilitation Medicine diploma for the doctors in each centre (5).

Intervention

Consenting parents were interviewed by a single interviewer, the doctor in charge of the clinic, who was not involved in the day-to-day delivery of the Ponseti treatment. Interviews were conducted in Malagasy using a standardized set of questions developed by the researchers for the purposes of the study. Due to high levels of illiteracy in Madagascar, it was decided to administer all questions orally for consistency, even if a parent could read or write. The questions covered social and emotional problems arising during treatment, including interactions with the wider family and neighbours, finance, transport, access and work difficulties, problems with the treatment itself, both in the centre and with managing the child and splints after the family returned home. Answers to the questions were elaborated as needed.

Plan of analysis

Data were collated and analysed by the authors HR and MAC. Parents' responses were grouped into overarching themes, the numbers of respondents reporting each issue were noted and examples of the difficulty were selected to illustrate the points made by parents.

RESULTS

Participants

From 1 March 2013 to 31 May 2013, 38 patients presented for diagnosis and were assessed for treatment. Of these, 18 children were excluded from the study: 4 children were over 1 year of age, 2 had incomplete records, 2 had died of malnutrition before the first follow-up, 3 had not completed treatment, the parents of 1 would not permit tenotomy if needed, and 6 failed to return for the first follow-up.

All parents meeting the inclusion criteria agreed to participate; all 20 of these parents were the child's mother. Interviews were held in the rehabilitation centre and took less than 1 h. Fifteen families were classed as '*défavorisé*'; that is, working in the informal sector with irregular, low incomes; only 3 families had regular incomes.

Experiences of parents

All parents reported at least some difficulty in relation to the treatment that their children received. Difficulties were categorized as financial, transport-related, attitudinal and practical.

Financial issues. Fifteen parents needed help to finance the treatment: 7 of the parents had gone into debt, 2 had sold livestock and 1 family stopped the schooling of another child to pay for treatment. Four parents had temporarily stopped working to facilitate treatment. Two of these parents had been employed, but

they feared refusal of leave from work to take their children to hospital. Most parents had sought ways of financing continued treatment, principally from grandparents. One parent had received financial aid from a charity. Seven families reported difficulty with the costs, not only of treatment, but also of transport.

Transport difficulties. Although 13 families lived in the city, all experienced travel delays. Many parents travelled by bus, where overcrowding made it difficult to transport a baby wearing splints, thus some parents had to use taxis. Three families came from over 100 km away, which meant starting the journey at 04.00 h and catching the last returning bus by 15.00 h, curtailing the possibility of treatment in the afternoon. A further 4 families travelled more than 500 km due to lack of local treatment; as treatment was weekly they had recurrent costs of overnight stays, which were extremely burdensome for them. Costs of transport for some families could exceed the modest costs of treatment.

Social and attitudinal experiences. Twelve parents experienced social isolation in relation to their child's impairment. Nine mothers hid the child's foot, due to shame and fear of rejection from their extended families. Eight mothers reported being accused of wrong-doing during their pregnancies, such as attempted abortion, failure to observe local taboos or witchcraft, and 2 sustained verbal abuse. One parent was urged to bring her child to a traditional healer. Two parents were ostracised by their families; the children's feet had frequently been referred to as '*point d'interrogation*' because of their foot shape.

Eight parents did not experience negative reactions from their families, mostly because other children in the extended family had received such treatment in the past. Nevertheless, 15 mothers were sad, despaired about their situation, and felt rejected and guilty. Both rural and urban families reported these problems.

Practical difficulties. All parents had practical difficulties using the abduction splints. All found the splints difficult to don and cumbersome when travelling. All infants were said to have cried during plastering, some for up to 3 days afterwards. One infant had temporary oedema of the foot. Two infants had fever during the treatment, one due to respiratory infection, which the parent felt was due to the baby having to lie supine.

All parents were unable to afford disposable diapers: they used small pieces of cloth as diapers, which were insufficient to contain the urine and thus did not keep the plaster of Paris splints dry. The centre's shoemakers had been instructed to make the Steenbeek abduction splints, but these were sometimes inadequate to maintain the foot correctly as the shoemakers were unable to obtain leather of sufficient quality.

DISCUSSION

This pilot service development project identified a number of factors that appeared to contribute to the poor continuation of treatment of early Ponseti treatment for clubfoot. Failure to complete this treatment will almost always mean that the foot

does not become plantar grade, thus potentially denying the child access to school, work and full participation in society. Malagasy doctors leading the developing rehabilitation centres are keen to understand these issues in order to develop effective and comprehensive services across the country.

The findings in this study parallel those from Latin America (6), Uganda (7) and Malawi (8). The predominant cause of failure to complete treatment in Madagascar is the considerable financial burden on families, many of whom are very poor. Most families tried to find the finances to help their children, yet were often thwarted by the costs of treatment, travel and staying overnight. Distances to a regional, rather than a national, centre would be shorter, thus costs would be substantially lessened and ability to continue treatment enhanced. However, many families live in very remote places that are inaccessible in the rainy season, therefore some practical difficulties will remain.

This study has a number of limitations. Studies with small samples may not yield results representative of larger populations. However, the current study identified several improvements that can be made to the services provided by the pilot centres in Madagascar, in addition to improvements to the services to be provided by the regional rehabilitation services, which it is anticipated will soon also provide Ponseti treatment.

The interviews were performed by a senior member of the staff of one of the rehabilitation centres. This may have biased the answers to the questions asked. However, parents were willing to participate in the interviews and were forthcoming with information that cross-references with data from work in other centres, suggesting that our findings are true. Finally, parents who did not return after their first appointment at the rehabilitation centre could not participate in the study. The project did not have the resources to contact these families to study the reasons why they were unable to return; however, since a comprehensive overview was made of the difficulties experienced by those who did return, it is likely that similar reasons applied to the families who did not return after the first appointment.

Three possible changes might improve concordance with treatment. If policymakers were able to ensure that the treatment of all infants was free, as in Guatemala (6), this would help families considerably. More treated children would then be able to access schooling and, subsequently, work, thus improving outcomes both for individuals and the community. Streamlined, local treatment, with supervised community-based rehabilitation using health assistants is used for the rehabilitation of torture survivors (9), but is unlikely to be feasible with the Ponseti treatment, as precise splinting is required. In addition, some overnight facilities will still be needed for families from remote areas, particularly in the rainy season.

Lavy et al. (8) recognized the barriers created by lack of good splint materials and staff with the necessary technical ability in Malawi; it is acknowledged that modern orthotic materials and training in modern orthotics are urgently needed in Madagascar and strenuous efforts are being made to secure these but for a country experiencing considerable poverty, but this is not easy. Most other practical clinic problems are organizational and can be resolved. Data collection is improving,

as this was addressed during the training of the doctors, who have established a national database for rehabilitation centres so that future audit, research and evaluation can be done (10).

Notwithstanding the limitations of the services in Madagascar, several positive developments have occurred since this project commenced, informed by the results of this work. Clinics are now better coordinated, which has improved waiting times for families in clinic. The environment of the clinic has also improved, with greater privacy for families. Parents of children who have successfully completed treatment are now invited back to talk to families commencing treatment, in order to emphasize the importance of concordance. Some financial help for families has now given by local charities to support their travel and living expenses while away from home. Finally, better leather has been obtained for the clinic. However, throughout the country rehabilitation centres are without modern splint materials, although this is acknowledged and a major effort is being initiated to improve matters.

In conclusion, this study identified a number of barriers to families completing Ponseti treatment of their children. These overwhelmingly relate to the costs of travel and splintage. The results of our work are informing the spread of early Ponseti treatment throughout the country.

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