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The impact of living with clubfoot on children and their families – Perspectives from two cultural environments --Manuscript Draft--

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Full Title:	The impact of living with clubfoot on children and their families – Perspectives from two cultural environments
Article Type:	Original Article
Funding Information:	
Abstract:	<p>Purpose. To study the physical, emotional and social impact of clubfoot on the lives of affected children and their families.</p> <p>Methods. A purposive sample of children with treated idiopathic clubfoot and their parents was recruited from two geographical locations – the United Kingdom (UK) and India. Children were divided into age groups of 5-7 and 8-11 years. Questionnaires were administered separately to children and parents; the former comprised of multiple-choice questions scored using an 'emoji' system, and the latter included open-ended questions divided into pre-defined themes of daily limitations, social life, general health, emotional barriers and family impact.</p> <p>Results. Thirty-four children and parents participated from UK; 96 children and parents participated from India. The majority of children (>80%) reported no problems in daily activities, although 32.8% reported having pain. Difficulty finding appropriate footwear and limitation in sports were more common among UK children, whereas difficulty in squatting was more problematic for Indian children. Self and emotional perceptions regarding their appearance/condition were lower among older as compared to younger children in both countries. Parents' responses mirrored those of children; additionally they reported emotional and financial difficulties during initial treatment phase, and ongoing concerns about the future during the maintenance phase.</p> <p>Conclusion. Treated clubfoot continues to impact the lives of affected children and families. Perceptions of the condition and its impact vary between population groups; this needs to be appreciated when collecting and analysing outcomes.</p>
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Author Comments:	To, The Editor

Indian Journal of Orthopaedics

Respected Sir,

Sub: Submission of Manuscript for publication

We intend to publish an article entitled 'The impact of living with clubfoot on children and their families – Perspectives from two cultural environments' in your esteemed journal as an Original Article.

On behalf of all the contributors I will act as guarantor and will correspond with the journal from this point onward.

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Yours sincerely,

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Declarations

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Ethics approval: This study was registered as a service improvement project (ID2960).

Consent to participate: Informed consent was obtained from all individual participants included in the study.

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Author Contributions: DGL, YG, AA and DME contributed to the study conception and design. Material preparation and analysis were performed by DGL. The first draft of the manuscript was

written by DP and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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4 **The impact of living with clubfoot on children and their families – Perspectives from two cultural**
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12 **ABSTRACT**
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21 choice questions scored using an ‘emoji’ system, and the latter included open-ended questions divided into pre-
22 defined themes of daily limitations, social life, general health, emotional barriers and family impact.
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4 embracing of the Ponseti principles of serial manipulation, casting and bracing [2]. However, some or all
5 components of the deformity are known to recur with treatments often involving repeat casting, and surgical
6 procedures such as limited soft tissue releases and tendon transfers.
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10 Several outcome studies have highlighted the success of the Ponseti method of treatment in the short-term;
11 however long-term outcomes, especially in terms of relapse rates, remain uncertain [3]. Although there has been
12 substantial research into several aspects of the management of clubfoot in the past few decades, reporting of
13 outcomes has not been uniform. Most commonly-reported outcome measures are quantitative and focus on a static
14 assessment of the foot [4]. Only a few consider day-to-day function, patient and/or parent satisfaction, and the
15 psychological impact of the disorder on the child and their family. Furthermore, most outcome tools have originated
16 from high-income countries [4] and thus draw from factors relevant to their lifestyle. However, perceptions of
17 musculoskeletal symptoms and disability vary between different cultural settings [5,6]; and practices specific to
18 certain cultures may pose unique difficulties to children with clubfoot.
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28 The aim of the present study was to study the physical, emotional and social impact of clubfoot on the lives
29 of affected children, and the impact it had on their families. We also sought to analyse the differences in the
30 perception of this disorder between families belonging to two different cultural backgrounds. This study was part of
31 a larger project which determined a Core Outcome Set (COS) for clubfoot research and treatment [7,8].
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41 PATIENTS AND METHODS

44 **Participants**

45 A purposive sample of children with treated idiopathic clubfoot and their parents was recruited for this
46 study. Participants were recruited from two different geographical locations – London, UK and Mumbai, India.
47 XXXXXX & XXXXXX are National Health Service Trusts in London; the latter being a tertiary referral centre that
48 receives patients from all over the UK. XXXXXX is a public hospital in Mumbai mainly catering to children from
49 lower to middle socio-economic classes; and as tertiary referral centre, serves families not only from within the city,
50 but also from surrounding regions and distant parts of the country. Although specific data regarding ethnic origin
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4 was not collected in this study, the children treated at both these locations were believed to represent fairly
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6 ‘Western’ and ‘Eastern’ lifestyles respectively.
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8 At both these sites, children and their parents were approached for enrolment in the study during routine
9
10 follow-up visits. Children that had been treated for idiopathic clubfoot by the Ponseti method, aged more than five
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12 years at the time of participation in the study, and where the child and parents were willing to answer the
13
14 anonymised questionnaires were included in the study.
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18 **Questionnaire administration**

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20 The questionnaires were designed by members of the research team with relevant experience in qualitative
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22 research, after adequate analysis of the previous literature to identify relevant themes. Consultation with two parents
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24 of children with diagnosis of clubfoot before the start of the study helped to gather preliminary feedback on the
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26 questionnaires and they were “sense checked” in an iterative process throughout their development. The
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28 questionnaires were originally designed to help develop a COS for clubfoot, and examples of these questionnaires
29
30 can be found in the previously published papers describing disease impact in clubfoot and other paediatric
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32 orthopaedic conditions [7–9].
33

34 The questionnaires were either self-administered or completed together with a health professional / member
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36 of the research team who was not involved in patient care to reduce reporting bias (using it as a schedule for a semi-
37
38 structured interview). Self-administration was preferred, despite having several limitations, as it was perceived to
39
40 have greater anonymity, and therefore to potentially yield more genuine answers on sensitive questions [10].
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42 The children’s questionnaire comprised a series of multiple-choice questions, scored using an ‘emoji’
43
44 system for ease of completion by the children. Children rated their answers as either ‘*often*’, ‘*sometimes*’ or ‘*never*’,
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46 which were represented by the emojis ☺, ☹, and ☹ respectively. The questions were divided into three pre-defined
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48 themes, namely: (1) Daily limitations; (2) Self-perception; and (3) Emotional barriers. Children were asked to pick
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50 the emoji that best represented their feelings for each question. The children’s questionnaire concluded with an
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52 open-ended question where children could express their feelings about living with the condition in their own words.
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54 Younger children completed this section with the help of the parents.
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56 The parents’ questionnaire included a series of open-ended questions aiming to determine the impact that
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58 the condition had on the affected child and the family as a whole. The questions were divided into five pre-defined
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4 themes, namely: (1) Daily limitations; (2) Social life; (3) General health; (4) Emotional barriers; and (5) Family
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6 impact.

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8 A consent form was collected from all parents who agreed to participate, and permission was obtained for
9
10 their and their child's responses to be analysed and reported in an anonymised manner.
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12 13 14 **Ethics approval**

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16 This study was registered as a service improvement project (ID2960). Hence permission from the hospital
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18 administration was taken, and Ethics approval was not deemed necessary.
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21 22 **Analysis**

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24 The children's responses were analysed using descriptive statistics. For the parents' questionnaires, the
25
26 responses for each theme were grouped, summarised and interpreted using the reflexive thematic analysis developed
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28 by Braun and Clarke [11].
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31 32 33 34 **RESULTS**

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38 Seventeen children (three girls and 14 boys) and seventeen parents participated in the study from the UK
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40 and forty-six children (11 girls and 35 boys) and fifty parents participated from India. The children's ages
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42 ranged from 5 to 11 years (median 8 years, IQR 3, Q1 6.5; Q3 9.5) and they were divided into groups of 5-7 and 8-
43
44 11 years respectively. The initial plan had been to include children up to the age of 16 years, and a separate
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46 questionnaire was developed for the 12-16 years age group. However, just one child was recruited in the 12-16 years
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48 age group, and hence this group was excluded from further analysis. Parents participating in this questionnaire
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50 included both males and females, with ages ranging from 27 to 48 years. Time for completion of each questionnaire
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52 was about 15-20 minutes for parents and 10-15 minutes for children.
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57 **Children's questionnaire**

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4 The majority of the participants from all age groups and from both geographical areas reported that they
5 often had no problems in daily activities such as climbing the stairs (87.5%), squatting (82.8%) and wearing shoes
6 (90.6%). Only 67.2% of children answered that they were often pain-free in their foot/ankle, and 81.3% that their
7 movements were painless. Whilst 78.1% of the children reported that they were happy with the appearance of their
8 foot and 76.6% of children responded that they were ‘okay’ with the condition affecting their feet, when analysing
9 the two populations, some differences became apparent.

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16 Footwear concerns were less common among Indian children, with 96% reporting that they often used
17 ‘shoes’ without any difficulty, as compared to 78% of their UK counterparts. The difference in ability to participate
18 in sports was even more stark with 96% of children in India but only 44% in the UK stating they were often able to
19 play sports or take part in Physical Education (PE). The appearance of the feet was also more acceptable amongst
20 the Indian cohort (87%) as was acceptance of the condition itself (80%), compared to 56% and 67% in the UK
21 respectively. Finally, only 30% of children in India and 27% in the UK responded that they were happy to talk about
22 their condition to others.

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When comparing the age groups (5-7 years vs 8-11 years), responses related to daily limitations were similar between the two groups, however, self-perception (being ‘okay’ with the appearance of the feet) and emotional perception (being ‘okay’ with their condition) were both lower in the older age group.

Figure 1 displays the children’s responses from both countries, figure 2 the overall comparison between the two countries, and figures 3 and 4 the break-down of responses according to age groups.

Parents’ questionnaire

Daily limitations

Overall, most participants from both locations mentioned some limitations caused by the disorder on their children’s day-to-day lives. This included difficulties in running/jumping, problems with strength and co-ordination, and concerns with foot positioning. Frequently reported challenges were children getting tired easily with walking or running long distances/time (32 of 67 responses) and pain associated with walking/running long distances/time (25 of 67 responses). Respondents from India in particular mentioned that difficulty in squatting led to problems in using traditional Indian-styled toilets (four of 50 responses). Aside from limitations on activities, some participants

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4 also mentioned difficulty in finding properly fitting footwear (six of 67 responses). A couple also expressed
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6 concerns over difference in length/size of the affected limb (two of 67 respondents).
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10 *Social life*

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12 The second theme explored was whether the condition limited the children's ability to take part in social
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14 activities. A majority of the participants stated that their children's ability to take part in activities was not
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16 affected (52 of 67 responses). A proportion of participants, more so from the UK (10 of 17 responses) than from
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18 India (5 of 50 responses), stated that the condition did affect their children's ability to a certain extent, particularly
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20 with regards to PE. Children were noted to be limited either by pain, or by an inability to run as fast as their peers.
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24 *General health*

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26 In this cohort of idiopathic clubfoot, almost all participants (63 of 67 respondents) mentioned that their
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28 child did not have any co-morbidities. A few unrelated health conditions were mentioned (for example, asthma and
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30 autism).
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34 *Emotional barriers*

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36 Under this theme, we enquired about the children's emotional response to the limitations imposed by the
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38 disorder, and the parents' impressions about the appearance of their feet. The majority of parents reported that their
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40 children did not feel particularly negative emotions towards their condition (58 of 67 responses); but a few did
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42 mention that their children felt sad/worried/frustrated (nine of 67 responses) by their foot/feet. The most common
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44 cause for these feelings was the limitation in ability to participate in certain activities like PE. Others reported that
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46 their child often got worried about the appearance of their foot/feet when they noticed that it was different to that of
47
48 other children, or when they wore tights/shorts that revealed the affected limb(s). For participants from India,
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50 cosmesis was often mentioned as one of the parents' main concerns, particularly when the child was female (12
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52 responses).
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56 *Family impact*

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4 Under this heading, we enquired about the effect the disorder had on the family during the initial
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6 treatment phase and during the current maintenance phase, as well as their concerns about the future.
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8 Most participants across both centres reported being heavily impacted during the initial diagnosis and
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10 treatment period. Several commented on being distressed on learning the diagnosis and being worried about other
11
12 possible abnormalities that their child might have. Difficulty in adjusting to the casts / boots was also a common
13
14 theme highlighted.
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16 Issues unique to Indian respondents were difficulty in reaching treatment centres (long distances to be
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18 travelled, more than six hours in some cases), financial burden imposed by the disorder (due to expenditure for
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20 weekly plaster changes, and need to take time off work for attending treatment sessions : 24 of 50 responses) and
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22 unsupportive family members (particularly elders, who considered the deformity a ‘bad omen’ and spread false
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24 information – 17 of 50 responses).
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26 The majority of participants across both centres responded that, at the present time (following correction of
27
28 the deformity), the child’s condition did not affect the family. Several did report concerns about the future, namely
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30 whether the deformity would recur needing further treatment (28 of 67 responses); whether they would experience
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32 pain; whether they would be limited in their activities; and whether they would face bullying in school due to the
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34 appearance of their feet (three of 67 responses).
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38 Selected statements by parents elaborating on the above themes are provided in table 1.
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44 **DISCUSSION**

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46 The Ponseti method has revolutionised the treatment of clubfoot, and it is now the ‘gold standard’ of care
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48 [2]. However, even with successful Ponseti treatment, affected children do experience certain limitations, and these
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50 can often be overlooked or underestimated. Studies have shown that children with treated clubfeet, both unilateral
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52 and bilateral, exhibit gross motor deficits and asymmetries as compared to typically developed children [12], and
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54 that they also show slightly decreased walking capacity [13]. Surprisingly, these findings have been similar in
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56 children treated by both Ponseti and other methods [14]. The psychological impact of these limitations on the child
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58 and their family is poorly understood. Another relatively overlooked aspect is that there is a significant cosmetic
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4 component to clubfoot. Even after appropriate treatment, affected children are left with relative hypoplasia of the
5 calf muscles and a smaller foot size. These are sequelae which persist into adulthood [15] and they can have
6 significantly adverse effects on patients' self-esteem.
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12 With this in mind, this study aimed to look at the physical, social and emotional impact of clubfoot, as
13 perceived by the affected children and their families. The study was conducted in two different population settings
14 in order to gauge differences in perceptions across different cultures. We have found that clubfoot and its treatment
15 presents several common concerns across both populations, as well as some that are unique to each population
16 group.
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22 23 24 *Impact of clubfoot on the child*

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26 The majority of children from both populations faced little limitation in their day-to-day activities.
27 However, pain was an issue for a third of all respondents, and almost a quarter of children answered that they were
28 unhappy to some extent with the appearance of their feet. The problem with cosmesis was more apparent in older
29 children, as it is often when approaching teenage years that children become more self-conscious and dislike
30 anything that makes them stand apart from their peers. Respondents from the UK were more likely to have problems
31 with finding appropriate footwear, likely due to the predominant use of closed shoes, whereas the open footwear
32 more commonly used in India is more adaptive to foot shape and size. In contrast, a slight limitation in ankle
33 dorsiflexion, a common sequelae of treated clubfoot, tends to be more of a problem for Indian children as use of the
34 traditional Indian-styled toilets requires them to be able to squat.
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45 Across both populations, we found a general unwillingness among affected children to talk about their
46 condition with others. This alludes to a persistent stigma attached to the disorder, possibly stemming from a lack of
47 awareness about the condition and its aetiology.
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53 *Impact of clubfoot on the family*

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55 Clubfoot treatment requires a considerable time/resource input in the initial manipulation and casting
56 phase, with prolonged intermittent contact with health-care professionals during the subsequent maintenance phase.
57 There may also be further interventions later in life. All this can place a considerable strain on the patient's family,
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4 the impact of which is often unrecognised. Parents across both populations mentioned the distress they experienced
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6 at initial diagnosis and how they found it difficult to adjust to the treatment with casts initially and braces later.
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8 Indian parents additionally faced hurdles in accessing and continuing treatment, due to financial burdens and
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10 distance from treatment centres. It is well known that a large proportion of the population in India and other such
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12 low-middle income countries lacks access to adequate healthcare [16], as a result of which many children either fail
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14 to receive treatment for clubfoot, or drop-out from treatment leading to increased likelihood of recurrence [17].
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16 Additionally, the social stigma attached to disorders like clubfoot is another hurdle caregivers encounter in order to
17
18 provide appropriate care for their child. The findings of our study reinforce this.
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22 *Differences in impact across cultures*

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24 An important finding of this study was that the perception of clubfoot, and the expectations from its
25
26 treatment are not necessarily the same for families in the two cohorts. For example, limitations in sport were more
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28 apparent among children in the UK cohort, whereas difficulty in activities of daily living (such as squatting) were
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30 more of a concern for children in India. For the parents, it was apparent that accessibility to treatment and lack of
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32 support from relatives were challenges more commonly encountered in India. Solutions to some of these problems
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34 may lie in better communication. For example, restriction in participation in sport may to some extent be because of
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36 parental anxiety; it is important to emphasise that children with treated clubfoot can indeed participate in any sport
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38 they desire without adverse consequences. Inclusion of extended family members in the treatment process in India
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40 may bring in more buy-in and enhance support to parents in the more collectivistic Indian culture. Information
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42 campaigns may help change traditional mindsets and reduce the taboo surrounding congenital disorders like
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44 clubfoot. Limitations in activities important to certain lifestyles, such as the ability to squat, may require treatment
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46 modifications (for example, a lower threshold for treating residual equinus) and the need to include these activities
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48 when developing outcome tools that are contextual to the population being studied.
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53 This study has captured perspectives of children treated for clubfoot and their families, discussed the issues
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55 that they continue to face as well as their concerns for the future. A strength of the study was that it sought
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57 comments from both children and their parents, with the use of an open narrative to explore their perceptions on care
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4 and outcomes. The inclusion of two different cultural groups also allowed to capture a broader perspective on the
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6 disorder.

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8 This study does have limitations. Recruitment for this study was done from a single centre in India and two
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10 centres in the UK. This fact, as well as the small sample size at each centre, might have affected the ability to
11
12 capture the perspectives of the wider populations in these two countries. Information about socio-economic status
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14 and ethnic origin was not collected; London has a particularly diverse population and it is likely that one or more
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16 Indian-origin families were included in the UK group. However, the purpose of the present study was to provide a
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18 simple snapshot of patient and family perceptions in two different cultural environments, and in this respect the
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20 study did identify several interesting findings. Finally, participants were randomly selected from three clubfoot
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22 follow-up clinics and hence their baseline severity may have differed, which in turn may have had an impact on their
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24 perception. The assumption was that, overall, a clubfoot clinic will represent a similar mix of cases. The purpose of
25
26 this study was to identify and analyse the variables that determine outcomes in these children, rather than measuring
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28 the actual treatment outcomes in this cohort.
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31 The findings of this study highlight the need to use outcome measures for clubfoot, that are holistic, take
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33 into consideration both children's and caregivers' perspectives, and are contextualised to differing lifestyles.
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35 Variables such as the ability to squat, ease of use of footwear and aesthetic acceptability are important and have
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37 been incorporated into the new COS for clubfoot [7,8].
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42 CONCLUSION

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44 Idiopathic clubfoot, even following adequate treatment, continues to have physical, emotional and social
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46 impacts on the lives of affected children, as well as their families. Perceptions of the condition and the impacts it
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48 causes, can vary between different population groups and should be appreciated.
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54 CONFLICTS OF INTEREST

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57 On behalf of all authors, the corresponding author states that there is no conflict of interest.
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31 **FIGURE LEGENDS**

32 Fig1. Chart summarising children's responses from both countries.

33 Fig2. Chart showing comparison of responses from children in UK and India, across both age groups.

34 Fig3. Chart showing comparison of responses from children in UK and India in the 5-7 years age group.

35 Fig4. Chart showing comparison of responses from children in UK and India in the 8-11 years age group.
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44 **TABLE LEGEND**

45 Table1. Selected parents' statements.
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Table 1. Selected parents' statements

“Difficulty in walking and playing with other children. Currently gets pain when squatting and walking/running for long distances.”

- India, parent #05

“Often limited from taking part in PE activities. Teacher sometimes have to take child off the team (which makes her sad).”

- UK, parent #05

“Right lower limb a bit short so limp a bit”

- India, parent #03

“Frustrated, when child cannot participate in activities with friends”

- UK, parent #01

“Apprehensive regarding the deformity and the treatment procedures. No support from relatives and parents had to take care of the child by self - expenses of the weekly plasters and the procedures were difficult to manage.”

- India, parent #05







