DOI: https://doi.org/10.30795/2595-1459.2018.v1203

ORIGINAL ARTICLE

Scientific Journal of the
Foot & Ankle

Congenital clubfoot: parents' considerations about the disease and its treatment

Pé torto congênito: considerações dos pais sobre a doença e seu tratamento

Eli Ávila Souza Júnior[1], Guilherme Ferreira Simões[1], Sabrina Versuti Nunes[1], Davi Coutinho Fonseca Fernandes Gomes[1], Túlio Vinicius de Oliveira Campos[2], Marco Antônio Percope de Andrade[2]

1. Hospital das Clínicas da Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil.
2. Faculdade de Medicina, Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil.

ABSTRACT

Objectives: To learn parents' impressions regarding the diagnosis of congenital clubfoot and its treatment. This information may favor persistence with treatment, breakdown of taboos and therapeutic success.

Methods: A qualitative and descriptive study with 10 parents whose children have congenital clubfoot. The tabulation of the data occurred through the use of three methodological figures: central idea, key expressions and collective subject discourse.

Results: When asked about impressions generated when their child was diagnosed with congenital clubfoot, 70% reported feelings of sadness, fright and worry, and only 30% showed a calm acceptance of the diagnosis, devoid of fear and worry. When asked about the treatment that was being done, 100% of the parents showed optimism and satisfaction with the results presented, 40% mentioned the comfort level brought by the therapeutic methods and 20% mentioned the importance of the involvement of the entire health team in the therapeutic approach.

Conclusion: Fear and concern were common feelings, which improved with the best elucidation by the health team regarding the disease. Regarding therapy, the parents' satisfaction was unanimous.

Level of Evidence V; Expert Opinion.

Keywords: Clubfoot; Bioethics; Foot diseases; Child health; Maternal health.

RESUMO

Objetivos: Conhecer quais as impressões dos pais em relação ao diagnóstico do pé torto congênito e seu tratamento. Essas informações podem favorecer a persistência ao tratamento, quebra de tabus e sucesso terapêutico.

Métodos: Estudo qualitativo e descritivo com 10 pais cujos filhos são portadores de pé torto congênito. A tabulação dos dados ocorreu por meio da utilização de três figuras metodológicas: ideia central, expressões-chaves e o discurso sujeito coletivo.

Resultados: Quando indagados sobre a impressão gerada quando o filho foi diagnosticado com pé torto congênito, 70% referiram sentimento de tristeza, susto e preocupação, sendo que apenas 30% demonstraram uma aceitação tranquila do diagnóstico, desprovida de medo e preocupação. Quando indagados em relação ao tratamento que estava sendo feito, 100% dos pais demonstraram otimismo e satisfação com os resultados apresentados; ainda, 40% opinaram em relação ao nível de conforto trazido pelos métodos terapêuticos, e 20% citaram a importância do envolvimento de toda a equipe da saúde na abordagem terapêutica.

Conclusão: Medo e preocupação foram sentimentos frequentemente apresentados, que melhoravam com a melhor elucidação por parte da equipe de saúde em relação a doença. Em relação à terapêutica, a grande satisfação por parte dos pais foi unânime.

Nível de Evidência V; Opinião de Especialista.

Descritores: Pé torto; Bioética; Doenças do pé; Saúde da criança; Saúde materna.

How to cite this article: Souza Júnior EA, Simões GF, Nunes SV, Gomes DCFF, Campos TVO, Andrade MAP. Congenital clubfoot: parents' considerations about the disease and its treatment. Sci J Foot Ankle. 2018;12(1):18-23.

Work performed at the Hospital das Clínicas da Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil.

Correspondence: Eli Avila Souza Júnior. Alameda Libânio, 72, Alfenas, Minas Gerais, Brazil – CEP 37130-000. E-mail: elijr42@yahoo.com.br

Conflict of interest: none. **Source of funding:** none.
Date Received: September 12, 2017. **Date Accepted:** December 14, 2017. **Online:** March 23, 2018.

INTRODUCTION

A newborn with a congenital anomaly of a limb presents a challenge to his parents and the team of professionals responsible for the child's treatment(1-4). Congenital clubfoot is defined as a deformity characterized by poor complex alignment of the foot involving soft and bony parts, with equinus and varus deformity of the hindfoot, cavus of the midfoot and adduction of the forefoot.

According to Clifford, when faced with the birth of a child with congenital malformation, parents are taken by emotional shock, denial of the defect, anger, sadness, anxiety, anguish at not being able to properly care for the baby and guilt, which can be addressed to either themselves or the medical staff(5). There are also difficulties in adapting the child to special care and reorganization of life. Professionals, in contacting the parents, should identify the emotions and difficulties that these parents are experiencing so that care can be more adequately and effectively performed(6).

The objective in the treatment of this pathology is to obtain flat, painless feet with good mobility and that do not require special shoes (7).

The family is seen as a unit of health or disease; therefore, it is necessary to look at it as an object of care in a process of relationships and interventions that goes beyond the barriers of clinical care, including special care, such as children with congenital malformation and their families(8). During the last decade, interest in assessing how patients perceive the impact of the disease has increased, which is commonly referred to as health-related quality of life. Health-related quality of life is defined as a multidimensional construct that captures the impact of health status, including disease and treatment in three domains: physical, psychological and social function(9).

In our institution's pediatric orthopedic department, in addressing parents regarding their child's diagnosis and in explaining the various stages of treatment, physicians are often faced with feelings of insecurity, disagreement, distress and frustration. In the daily follow-up of these parents, it is often noted that they have doubts about the treatment. Examples of such situations include the impression that casts and orthotics hurt children and that the child's development is not compatible with what is expected.

The treatment of congenital clubfoot requires intensive follow-up with commitment of the guardians so that all of the steps are fulfilled. In this context, knowing the parental impressions about the congenital clubfoot will provide the orthopedist with more information to perform a quality explanation to the parents regarding the malformation. In this way, persistence with treatment, therapeutic success and breaking of taboos can be strengthened.

METHODS

This work was approved by the Research Ethics Committee with registration in the Brazilian Platform under CAAE number 64094416.9.0000.5149.

Considering the nature of this study, qualitative research of the exploratory type was employed, adopting as methodological reference the Theory of Social Representations (TSR). To know and describe the parents' considerations regarding congenital clubfoot and its treatment, under the RS reference, the Collective Subject Discourse (CSD) was chosen because it allows an approach to the phenomenon under study.

First, the subjects of the research were informed about the ethical issues of this work, which was followed by the signing of a consent form, obeying Resolution 466/12 of the Brazilian *National Health Council* (which addresses research involving humans).

The study, conducted from April 1, 2016 to November 1, 2016, had, as subjects, 10 parents who accompanied their children with congenital clubfoot in the pediatric orthopedic outpatient clinic.

Individual interviews were conducted to investigate the parents' concerns regarding the diagnosis of congenital clubfoot and its treatment using two semi-structured questions. Each interview was recorded on tape and then transcribed. For the analysis and presentation of the results, we used the CSD, written in the first person singular, composed of key expressions (KEs) that had the same central ideas (CI) and same anchorage (AC), strictly following the order of the following steps:

- 1st stage: the answers were heard several times and, only after total comprehension of the general idea and the discourse, were transcribed literally.
- 2nd stage: total reading of the answers of each of the interviewees, followed by a separate reading of all the answers to the analyzed question.
- 3rd step: transcription of the answers for each question. The KEs were highlighted in italics, and the CIs, which represent the description of the KEs and not their interpretation, were highlighted.

- 4th stage: individual transcription of each CI with their respective KE.
- 5th stage: extraction of the theme from each of the questions, grouping with their respective CI, the subjects, represented by the number of parents interviewed, and the frequencies of ideas through tables. Finally, construction of CSDs separately from each central idea with their respective KE.

RESULTS

We interviewed 10 parents of children with congenital clubfoot. In relation to schooling, 50% of parents declared incomplete elementary school, 10% completed primary education, 30% completed high school and 10% had completed higher education.

Most of the subjects (50%) reported having 1 child, with an average of 2 children per subject studied.

The sample characterization results are listed in Table 1.

Table 1. School and family profiles

Subject	Schooling	Number of children
1	Complete high school	2
2	Complete high school	1
3	Incomplete elementary school	3
4	Incomplete elementary school	4
5	Incomplete elementary school	3
6	Complete Higher Education	1
7	Incomplete elementary school	1
8	Complete high school	1
9	Complete primary education	3
10	Incomplete elementary school	1

The first question was: What was your impression when your child was diagnosed with congenital clubfoot? The central idea mentioned by 70% of the respondents was fright and worry, while 30% of the parents showed a clear acceptance of the diagnosis, devoid of fear and worry. Among the parents, 40% reported that with better understanding of the disease, either through the internet or by medical contact, there was better acceptance of the diagnosis; 20% were unaware of the diagnosis at the time of delivery due to the inability of ultrasonography to detect this change.

The CI, KE and CSD for the first question are listed below:

CI: fright and worry (70%)

CSD: At first, as I did not know the subject, my first reaction was *worry*. I was very *scared* because I had never seen it, and I did not know if there was any treatment, if it would improve; we are from the interior region of Brazil, so we were *scared*, there is no treatment there; I *cried a* lot because I discovered that he would have to go through a treatment; I was very *apprehensive* when I saw his crooked legs, I thought he was not going to walk; it was something very *different* for me, I found it very *strange*.

CI: good acceptance of diagnosis (30%)

CSD: The first thing I thought was in the area of orthopedics, I thought *there is a way*, I thought about the boot. So, I felt *calm*; I already knew the disease, his father's family has cases of clubfoot, right? So, I was not scared, no; it did not bother me at all, I did *not worry too much*.

CI: comfort from better understanding (40%)

CSD. Although I did not know anyone who had clubfoot, doing *a* lot of *research* on the *internet*, I saw that it was a common malformation; we were scared until arriving here for the consultation, but then the *doctor* we saw told us that it was not something to be shocked by, and we were seeing the *other people* being treated for it, looking at the internet, becoming more *resistant to* the treatment; I already knew his father's *family* has it, right? Although in my city I never saw it, when I got here and *saw so many cases*, I found it normal.

CI: incompatibility with ultrasonography (20%)

CSD: It was a surprise, the *ultrasound* scans did not show *anything*, and when she was born, the doctor broke the news to us; I learned about it only at the time of birth, on the *ultrasound* I had not seen *anything*.

In the second question about the parents' opinion regarding the treatment made for the correction, 100% of the parents reported satisfaction with the results presented with the treatment. The level of comfort of the child with the treatment was one aspect mentioned by 40% of the parents, and 20% of the interviewees mentioned the importance of involving the entire health team in the therapeutic approach.

The CI, KE and CSD for the second question are listed below:

CI: good satisfaction with results (100%)

CSD: The treatment was *spectacular*; every week I think it *improves more*; the little foot is almost *in place*; is *improving* *a lot*, seeing the other children also improving, generates a great *relief*; with *confidence and discipline*, we see ever greater improvement; *wonderful results; great treatment* with *visible results*, it is hard to believe the way it was done.

CI: considerations on child comfort (40%)

CSD: I do not think it *hurts* anything; it *bothers* a little when the cast is removed, but do not think it *hurts;* the bad thing is to *change* the cast every Friday; he gets *used* to the cast, when Thursday arrives, upon removing the cast, his leg is lighter, he finds it *uncomfortable,* and he *cries a* lot at the time.

CI: attendance team involvement (20%)

CSD: The treatment is spectacular because the *staff is great*; they make us more *relieved*; all the care from the staff here was great.

DISCUSSION

The news

According to Manoni, when a child representing dreams is born sick, the realization produces a shock in the mother(10). This "reality shock" is often the product of uncertainty, which is defined as a psychological state characterized by insecurity and a lack of clear information(11). In this study, 70% of the parents referred to this "reality shock" and the emergence of uncertainties when they received the diagnosis of congenital malformation, demonstrated by the analogous expressions present in the "fright and worry" CI.

Parents of children with clubfeet face a complex situation: information regarding treatment may not be available or be inconsistent. This limited knowledge about the causes and long-term effects of the disease generates insecurity(12,13). Similarly, the "comfort from better understanding" CI reveals the lack of sufficient information regarding the disease by at least 40% of the parents, since not everyone can feel comforted, even with better understanding.

Other sources of uncertainty include the potential stigma of health status, the long-term effects on child development and the treatment efficacy(14,15), factors that are also related to CIs raised primarily by the first issue of this study.

The clarification

In a study conducted in Malawi and Uganda, there were a number of erroneous considerations about the causes of clubfoot, and people often did not seek treatment because they were unaware of their availability and did not consider clubfoot to be a correctable condition(16, 17). In a study conducted in Pakistan, it was found that the disease was often blamed on mothers, which may lead to stigmatization of families of children with clubfeet and can have a negative impact on the mothers of these children(18).

The way in which news is communicated is an important factor; therefore, it should be more valued during the teaching of medicine or during the supervision of residents(19). In the study in question, it was demonstrated that when parents received better information about the disease, including clarification by the physician who also became responsible for the treatment, acceptance of the disease became easier.

Another relevant and current aspect observed in this study is the reference to the internet as a tool to better understand the disease, which, according to 40% of the parents, resulted in greater comfort in relation to the diagnosis. A study by the Pew Research Institute indicates that there has been an explosion of online health-related information, in terms of both production and consumption, because of the increase in internet access (74% of American adults use the internet) (20). A recent study published in the *Journal of Pediatric Surgery* evaluated the importance of social media for patients and families with congenital anomalies. When asked if they would like to participate in a Facebook group connected to the hospital in which they received care and be directly assisted by a health professional online, 83% of the participants answered yes (21).

A prenatal diagnosis of clubfoot has repercussions on the mother and on the psychological state of the family and, in some cases, can modify the course of the pregnancy. Even if the progress of the deformity cannot be changed in the womb, most mothers admit that it is useful to be aware of this before the birth of their children. While it is true that prenatal diagnosis leaves some issues unresolved and that a false positive remains a possibility, it allows the mother to initiate treatment soon after birth and seek genetic counseling(22). In the study in question, 20% of the parents cited absence of evidence on obstetric ultrasonography that suggested congenital clubfoot. The question raised is how much these parents were instructed about the probability of prenatal ultrasound evidence of the disease and about the rate of false negatives, which could minimize frustration. The incidence of clubfoot diagnosed before birth varies significantly in published studies, ranging from 0.43% to 59.8% (23,24).

The treatment

Bor et al. conducted a study in which 74 patients were treated with the Ponsetti method and were followed up for an average of 6.3 years. They assessed the foot movement and applied a questionnaire, in which all of the patients presented a high degree of satisfaction with the final result, and 89% presented good foot movement(25).

A recent study published in Norway compared the treatment of the disease in question using the method of Ponsetti and previously used methods, with two questionnaires administered to parents on function and satisfaction, which reported significantly higher results after using the Ponsetti method(26).

Similar findings are seen in the study in question, in which 100% of the parents reported satisfaction with the results presented, citing them as excellent, spectacular and wonderful.

CONCLUSION

Despite the limitations already mentioned in this study, it was possible to explore subjective aspects regarding congenital malformation of the foot by means of a method that is not used in the literature and should not be underestimated.

Thus, negative feelings, such as fear and worry, have been found in most parents when informed about a diagnosis of congenital clubfoot. It was also noted that greater comfort was brought to the parents by better understanding the disease, and the actions of all the health team were recognized as important in addressing this pathology with the parents.

Therefore, we believe this study can help improve and broaden the approach to addressing this pathology with parents.

Authors' Contribution: Each author made significant individual contributions to this manuscript: EAS (https://orcid.org/0000-0002-5054-874X)* has conceived and planned the activities that led to the study, interpreted the study results and has approved the final version; GFS (https://orcid.org/0000-0003-2141-6120)* has written the article, conducted interviews, interpreted the study results; SVN (https://orcid.org/0000-0001-7016-5714)* has written the study, revised the successive versions and participated in the review process; DCFFG (https://orcid.org/0000-0001-9866-2536)* has written the study or revised the successive versions and participated in the review process; TVOC (https://orcid.org/0000-0002-2522-7047)* has written the study or revised the successive versions and participated in the review process; MAPA (https://orcid.org/0000-0001-6284-213X)* has written the study or revised the successive versions and participated in the review process. *ORCID (Open Researcher and Contributor ID).

REFERENCES

1. Fernbach SA. Common orthopedic problems of the newborn. Nurs Clin North Am. 1998;33(4):583-94.
2. Mason KJ. Congenital orthopedic anomalies and their impact on the family. Nurs Clin North Am. 1991;26(1):1-16.
3. Garcia MG, Ferreira EAF, Oliveira FPSD. Análise da compreensão de pais acerca do teste do pezinho. Rev Bras Crescimento Desenvolv Hum. 2007;17(1):01-12
4. Abreu LC, Souza AMB, Oliveira AG. Incidência de hemorragia peri-intraventricular em recém-nascidos pré-termo e a relação com o peso ao nascer. Rev Bras Crescimento Desenvolv Hum. 2007;17(2):24-30.
5. Clifford E. Parental ratings of cleft palate infants. Cleft Palate J. 1969; 6:235-44.
6. Drotar D, Baskiewicz A, Irvin N; Kennell J, Klaus M. The adaptation of parents to the birth of an infant with a congenital malformation: a hypothetical model. Pediatrics. 1975;56(5):710-7.
7. Cummings RJ, Davidson RS, Armstrong PF, Lehman WB. Congenital clubfoot. J Bone Joint Surg Am. 2002;84(2):290-308.
8. Pinheiro AKB, Varela ZMV. Desmame precoce x cotidiano familiar de nutrizes adolescentes. In: Barroso MGT, Vieira NFC, Varela ZMV (orgs). Saúde da família: abordagem multirreferencial em pesquisa. Fortaleza: Edições UVA; 2002.
9. Leidy NK; Revicki DA; Genesté B. Recommendations for evaluating the validity of quality of life claims for labeling and promotion. Value Health. 1999;2(2):113-27.
10. Manoni M. A criança retardada e a mãe. São Paulo: Martins Fontes; 1985.
11. Brashers DE. Communication and uncertainty management. J Communication. 2001;51(3):453–629.
12. Babrow AS, Hines SC, Kasch CR. Managing uncertainty in illness explanation: an application of problematic integration theory. In: Whaley BB. Explaining illness: Research, theory, and strategies. Mahwah, NJ: Lawrence Erlbaum Associates; 2000. p. 41-67.
13. Babrow AS, Kasch CR, Ford LA. The many meanings of uncertainty in illness: toward a systematic accounting. Health Commun. 1998; 10(1):1-23.
14. Brashers DE, Neidig JL, Reynolds NR, Haas SM. Uncertainty in illness across the HIV/AIDS trajectory. J Assoc Nurses AIDS Care. 1998; 9(1):66-77.
15. Gundersen T. 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. Sociol Health Illn. 2011;33(1):81-95.
16. Bedford KJ, Chidothi P, Sakala H, Cashman J, Lavy C. Clubfoot in Malawi: treatment-seeking behaviour. Trop Doct. 2011;41(4): 211-4.
17. McElroy T, Konde-Lule J, Neema S, Gitta S, Uganda Sustainable Clubfoot Care. Understanding the barriers to clubfoot treatment adherence in Uganda: a rapid ethnographic study. Disabil Rehabil. 2007;29(11-12):845-55.
18. Burfat A, Mohammed S, Siddiqi O, Samad L, Khan MA, Chinoy MA. Understanding the knowledge and perceptions about clubfoot in Karachi, Pakistan: a qualitative exploration. Iowa Orthop J. 2013; 33:149-52.
19. Kübler-Ross E. Sobre a morte e o morrer: o que os doentes terminais têm para ensinar a médicos, enfermeiras, religiosos e aos seus próprios parentes. São Paulo: Martins Fonte, 1996.
20. Fox S. The Social Life of Health Information, 2011. Washington, D.C: Pew Research Center's Internet & American Life Project; 2011.

21. Jacobs R, Boyd L, Brennan K, Sinha CK, Giuliani S. The importance of social media for patients and families affected by congenital anomalies: A Facebook cross-sectional analysis and user survey. J Pediatr Surg. 2016;51(11):1766-71.

22. Radler C, Myers AK, Burghardt RD, Arrabal PP, Herzenberg JE, Grill F. Maternal attitudes towards prenatal diagnoses of idiopathic clubfoot. Ultrasound Obstet Gynecol. 2011;37(6):658-62.

23. Bakalis S, Sairam S, Homfray T, Harrington K, Nicolaides K, Thilaganathan B. Outcome of antenatally diagnosed talipesequinovarus in an unselected obstetric population. Ultrasound Obstet Gynecol. 2002; 20(3):226-9.

24. Treadwell MC, Stanitski CL, King M. Prenatal sonographic diagnoses of clubfoot: implications for patient counseling. J Pediatr Orthop. 1999;19(1):8-10.

25. Bor N, Coplan JA, Herzenberg JE. Ponseti treatment of idiopathic clubfoot: minimum 5-year followup. Clin Orthop Relat Res. 2009; 467(5):1263-70.

26. Sætersdal C, Fevang JM, Bjørlykke JA, Engesæter LB. Ponseti method compared to previous treatment of clubfoot in Norway. A multicenter study of 205 children followed for 8-11 years. J Child Orthop. 2016 Oct;10(5):445-52.