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Original Study Article

Usefulness and accessibility of information on the treatment of children with congenital clubfoot: results of a survey of parents

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ABSTRACT

BACKGROUND: Treatment of congenital clubfoot remains controversial from both specialists and parents regarding the details of its practical application, individual effectiveness, and follow-up, rehabilitation treatment, prevention, and treatment of relapses. The assessment of parental attitudes using an online survey optimizes doctor–patient interaction. Information available to parents regarding the diagnosis and treatment of children with congenital clubfoot is lacking.
AIM: This study aimed to assess the usefulness and accessibility of information for parents about the treatment of children with congenital clubfoot.
MATERIALS AND METHODS: To assess the usefulness and accessibility of information about the treatment of congenital clubfoot, a survey of the patients' parents was conducted using an electronic fillable form proposed for anonymous completion in a thematic group dedicated to the treatment of congenital clubfoot on the social network "VKontakte"; the study included 5500 participants at the time of the survey (2 weeks), with 328 responses received.
RESULTS: Most parents noted a lack of information regarding clubfoot treatment before it actually began. The preferred source of information was Internet resources (i.e., websites of medical institutions and social networks). Achilles tenotomy and wearing braces raised the most questions, requiring additional information from both doctors and alternative sources. The possibility of errors and complications in wearing braces caused the greatest concern among parents, as well as possible relapses and the correctness of prescriptions during the rehabilitation treatment. Online parent communities and physician blogs are considered significant information sources. Most parents prefer to expand information about congenital clubfoot on the Internet, including social networks and popular resources.
CONCLUSIONS: Analysis of the results of an anonymous survey of parents of children with congenital clubfoot showed a significant demand for high-quality, accessible information regarding the diagnosis, treatment, and rehabilitation of children with congenital clubfoot. Significant interest in the information provided by social media and other Internet resources determines the need for competent representatives of the professional community to participate in this process.

Keywords: congenital clubfoot; parents; availability of information; social networks.

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Оригинальное исследование

Оценка полноценности и доступности информации о лечении детей с врожденной косолапостью: результаты анкетирования родителей

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АННОТАЦИЯ

Обоснование. Лечение врожденной косолапости продолжает вызывать вопросы как специалистов, так и родителей относительно нюансов применения методов в клинической практике, индивидуальной эффективности, а также последующего наблюдения, восстановительного лечения, профилактики и лечения рецидивов. Изучение отношения родителей с помощью интернет-анкетирования позволяет оптимизировать взаимодействие между врачами и пациентами. Мы предположили, что существует дефицит доступной для родителей информации по диагностике и лечению детей с врожденной косолапостью.

Цель — оценка полноценности и доступности информации для родителей о лечении детей с врожденной косолапостью.

Материалы и методы. Для оценки полноценности и доступности информации о лечении врожденной косолапости нами проведен опрос родителей пациентов с помощью электронной формы, предложенной для анонимного заполнения в тематической группе в социальной сети «ВКонтакте», посвященной лечению врожденной косолапости. Группа включала 5500 участников на время анкетирования (2 нед.), при этом было получено 328 ответов, которые были обработаны с применением статистических методов.

Результаты. Большинство родителей отмечали недостаток информации, касающейся лечения косолапости, полученной до его начала. В качестве источника информации предпочтение отдавали интернет-ресурсам (как сайтам медицинских учреждений, так и социальным сетям). Ахиллотомия и ношение брейсов вызывали наибольшее количество вопросов, требующих дополнительной информации как со стороны врачей, так и из альтернативных источников. Возможность ошибок и осложнений в процессе ношения брейсов порождали наибольшую тревогу родителей, наряду с возможными рецидивами и правильностью назначений в процессе восстановительного лечения. Родительским интернет-сообществам и блогам врачей делегируется значительная роль в качестве источников информации. Большинство родителей считают целесообразным расширение информации о врожденной косолапости в интернете, включая социальные сети и популярные ресурсы.

Заключение. Проведенное нами исследование, основанное на анализе результатов анонимного анкетирования родителей детей с врожденной косолапостью, показало существенный запрос на качественную доступную информацию по диагностике, лечению и реабилитации детей с данным заболеванием. Значительный интерес к информации, предоставляемой социальными медиа и другими интернет-ресурсами, определяет необходимость участия в этом процессе компетентных представителей профессионального сообщества.

Ключевые слова: врожденная косолапость; родители; доступность информации; социальные сети.

Как цитировать

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BACKGROUND

Treatment of congenital clubfoot has a centuries-long history, with numerous milestones of advancement in the medical community that suggested imminent success in conquering this disease [1]. However, in contrast to these expectations, the etiology of clubfoot remains unknown, the pathogenesis is poorly understood, and the treatment is challenging. The Ponseti method, which is recognized worldwide, offer a standardized approach to typical idiopathic congenital clubfoot [2, 3]. However, there is no consensus among the medical and parental communities regarding the specific aspects of its practical application, individual efficacy, follow-up, rehabilitation, prevention and treatment of relapses [4].

Awareness is an essential aspect of modern medical practice. Patients deliberately seek out health-related information, use various sources, and are inclined to verify and re-verify the opinions and recommendations of medical professionals [5]. There may be differing perceptions of the situation between doctors and patients. As a result, patients are increasingly seeking information from alternative sources, including a ‘*collective wisdom*’ of online communities and social media [6].

Analyzing the attitude of parents to various health aspects using online surveys is becoming an increasingly important tool in medical research. These surveys, distributed via email lists or integrated into online platforms, facilitate the critical assessment of patient awareness and optimization of doctor-patient communication [7].

We hypothesized that currently, there is a paucity of accessible information for parents regarding the diagnosis and treatment of congenital clubfoot.

The study aimed to assess the completeness and accessibility of information available to parents on the treatment of congenital clubfoot.

MATERIALS AND METHODS

The completeness and accessibility of information on the treatment of congenital clubfoot was assessed through an online survey conducted among parents who had experience treating children with this disease. The respondents were offered to complete an anonymous electronic form in a congenital clubfoot community on the social media platform VKontakte. At the time of the survey, the community consisted of 5,500 members. As a closed community, it was unlikely that there were any unregistered members who were not directly involved in the matter under discussion. To facilitate the data collection and analysis, the survey form included single-select multiple-choice questions, where respondents were asked to pick only one answer. Multi-select multiple-choice questions (more than one answer from the proposed list were allowed) were presented to ascertain parents’ awareness of congenital clubfoot. The survey included a series of yes/no questions designed to elicit the feedback from parents of children with congenital clubfoot regarding the distribution of information about the disease. These questions were limited to one possible answer.

The wording of the questions was discussed during the planning stages of the study. It was intended that the questions should make minimal reference to medical aspects and terminology, with a preference for literary style of presentation. The basic medical terms and concepts used in communication with parents (such as Achilles tenotomy, braces, and relapse) are commonly used in discussions of congenital clubfoot. Therefore, we deemed it appropriate to include these terms in the questions and assumed that parents would have sufficient understanding of them. The survey was conducted over a 2-week period, after which the access was closed and the results were analyzed. The survey was made available to all community members via a link. Prior to initiating the survey, respondents were requested to consent to the voluntary provision of depersonalized data regarding their child’s treatment (under the condition of their own anonymity). They were further required to confirm that they were at least 18 years old and that they were the parents of a child with congenital clubfoot. The survey would only be initiated if a respondent answered ‘yes’ to all of the above questions. It was necessary for all fields to be completed before the form could be submitted. Consequently, all received forms were used to further processing. A preliminary testing of the survey form showed that the average completion time was approximately 10 minutes, which should have provided a sufficient number of responses. Over the 2-week survey period, 328 responses were received.

The responses were entered into Microsoft Excel tables for subsequent analysis. The data were analyzed using SPSS V.24.0. Categorical variables are presented as absolute values (number of responses) and proportions in each category. Correlations between categorical variables were assessed using Pearson’s χ^2 test. *P*-values of <0.05 were considered statistically significant.

RESULTS

The parents’ responses were analyzed to assess their general awareness, subjective perception of information sources, and opinions on how to optimize the information support in congenital clubfoot treatment. The questions were divided into two groups. Group 1 implied general information that parents had been made aware of congenital clubfoot (Table 1), while Group 2 consisted of parents’ recommendations regarding the diagnosis and treatment of congenital clubfoot (Table 2).

Table 1. Parents' awareness of congenital clubfoot

Questions	Answers
When did you first learn your child had congenital clubfoot?	During pregnancy, 95 (29%). During maternity hospital stay, 182 (55.5%). Upon discharge from the maternity hospital, 45 (13.5%). I cannot say, 6 (2%)
Before the initiation of treatment, what level of detail was available about clubfoot and its treatment options?	I had all the information I needed, 16 (5%) There was enough information, but some issues needed to be discussed with the doctor, 29 (9%) There was not enough information, so most issues were discussed during treatment, 198 (60%) The information available was insufficient or lacking, 74 (23%) I cannot say, 11 (3%)
Which additional sources of information did you use to choose a treatment method and a doctor? (Please provide no more than 3 answers)	Original research articles in scientific medical journals, 54 (16.5%) Plain language medical publications targeting non-specialist audiences on the healthcare websites, 211 (64%) Patient stories presented by parents on social networks and blogs, 59 (18%) Parent communities on social networks and other electronic resources, 233 (71%) Communication with other doctors, 97 (29.5%) I cannot say, 18 (5.5%)
At what treatment stage did you feel you did not get enough information from your doctors and other sources, including social networks?	Plaster casting, 73 (22%) Achilles tenotomy, 121 (37%) Bracing, 134 (41%)
Which of the potential complications that you were aware of at the beginning of treatment caused you the greatest concern and necessitated further information or a consultation with a doctor? (Please provide no more than 3 answers)	Bedsores and skin injuries associated with a plaster cast, 43 (13%) Cast-related hygiene problems, including bathing and changing clothes, 72 (22%) Potential complications of Achilles tenotomy, 132 (40%) Issues related to applying and wearing braces properly, 230 (70%) Adequate rehabilitation treatment (in an outpatient clinic, etc.), 204 (62%) Mastering basic motor skills, 179 (62%) Choosing footwear, 119 (36%) Risk of potential clubfoot relapse, 217 (66%) Risk of potential flatfoot, 39 (12%) I had no questions, 17 (5%) I cannot say, 9 (3%)
Which source of information do you consider the most important for parents who have a child with congenital clubfoot? (Please provide no more than 3 answers)	Maternity hospital doctor, 83 (25%) Outpatient pediatrician, 74 (22.5%) Orthopedic surgeon, 237 (72%) Healthcare websites, 266 (81%) Parental communities on social networks, 219 (67%) Doctors' websites and blogs on social networks, 61 (18.5%) Other, 28 (8.5%)
What types of information sources would you recommend, based on your personal experience, for parents who find themselves in a similar situation for the first time? (Please provide no more than 3 answers)	Original research articles in scientific medical journals, 77 (23%) Plain language medical publications targeting non-specialist audiences on the healthcare websites, 249 (76%) Patient stories presented by parents on social networks and blogs, 59 (18%) Parent communities on social networks and other electronic resources, 226 (69%) Personal communication with doctor 44 (13%) I cannot say, 15 (4,5%)

The data presented have demonstrated that most parents became aware of their child's congenital clubfoot diagnosis immediately after birth. However, relatively many cases were diagnosed upon discharge from the maternity hospital, suggesting the need to enhance awareness of this disease among neonatologists.

Most parents surveyed reported that before treatment initiation, they had received limited pre-treatment information related to the range of clubfoot treatment options. As evidenced by the data presented in Table 1, parents of children treated for congenital clubfoot tend to rate the quality of the information provided throughout the treatment period as relatively low. However, the respondents demonstrated a notable degree of criticism of the information received from 'official' healthcare channels (i.e., directly from medical professionals responsible for the diagnosis and treatment). Most of the parents surveyed indicated a preference for online resources. However, no significant difference was observed in the assessment of 'official' (healthcare websites) and 'non-official' (social networks and doctor blogs) sources. This finding corroborates the successful personal commitment demonstrated by medical professionals and parent communities. The quality of the information provided by these resources may be regarded as satisfactory. However, the lack of monitoring, control, and responsibility for the information provided on these resources does not preclude a risk of misuse (e.g., for the promotion of commercial products, braces, etc.) or ineptitude. It is notable that quite a considerable proportion of parents express interest in the findings presented in original research articles published in scientific medical journals. The accessibility of this information via online platforms makes it an essential resource for communication with parents.

As evidenced in Table 1, Achilles tenotomy and wearing braces were of the greatest interest to parents. Among the questions posed by parents, those pertaining to bracing were identified as the most crucial in terms of demand for supplementary information from both medical professionals and alternative sources. Among the concerns most frequently reported by parents is the potential for errors and complications associated with wearing braces. Other frequently mentioned concerns included those related to adequate rehabilitation treatment and a risk of relapse. The assessment of medical practitioners' competence was far from ideal, with only a small proportion of respondents being completely satisfied with this aspect. Parents demonstrated a comparable expectation from acquiring the relevant information from both medical professionals and online sources. It was deemed advantageous to obtain the information from a range of medical professionals, including orthopedic surgeons, maternity hospital doctors, and outpatient pediatricians (Table 2).

Summarized feedback from parents of children with congenital clubfoot regarding information about the disease and its treatment reveals that online parent communities and doctor blogs are considered a significant source of information. Most parents considered it appropriate to make more information related to congenital clubfoot available online, including social networks and popular resources. However, they acknowledged the risks associated with self-promotion of incompetent medical professionals and clinics, and promotion of ineffective methods and commercial products. In response to the question of where parents of children with congenital clubfoot could obtain information and advice, respondents most frequently cited parental communities and plain language medical publications targeting non-specialist audiences on healthcare websites. In general, most respondents highlighted that it would be beneficial to provide more information related to available treatment options on social networks and official healthcare websites.

From both theoretical and practical perspectives, the attitude of parents toward the information on prenatal clubfoot diagnosis is interesting. Although most parents

Table 2. Feedback from parents of children with congenital clubfoot regarding the distribution of information about the disease and its treatment

Questions	Yes	No	I cannot say
Should parents necessarily be informed if congenital clubfoot is identified on pregnancy ultrasound?	224 (68%)*	72 (22%)	32 (10%)
Should more information on congenital clubfoot be made available online, including social networks and popular resources?	267 (81%)*	31 (9.5%)	30 (9.5%)
Should parents be additionally informed of congenital clubfoot treatment options through social networks and official healthcare websites?	256 (78%)*	17 (5%)	55 (17%)
Are there any potential disadvantages to sharing the information on congenital clubfoot?	55 (17%)	239 (73%)*	34 (10%)

* $P < 0.05$.

believed it was important to be informed of the presence of this abnormality during pregnancy, a rather significant proportion of respondents considered this information undesirable, since awareness of the fetal pathology would not change the situation in any way. Some respondents found it difficult to answer.

DISCUSSION

Congenital clubfoot is a well-studied pediatric orthopedic condition, with numerous guidelines, studies, and textbooks providing detailed information on its treatment. Despite a plethora of information available, treatment methods and outcomes remain the subject of vigorous debate, controversial opinions and concepts. In recent decades, the worldwide use of the Ponseti method has brought about a consensus among professionals on the principles of congenital clubfoot treatment [8]. However, due to numerous specific settings, interpretations, and aspects of treatment regimens, there is considerable variation in treatment outcomes between countries, clinics, and medical professionals [9]. Furthermore, the feasibility of randomized clinical studies evaluating the efficacy of various treatment methods has been argued. As demonstrated by the Cochrane review, the available studies are characterized by low-certainty evidence [10]. This finding formally establishes a significant equivalence in the strength of recommendations for the use of both the Ponseti method or its modifications and other clubfoot treatment modalities. The current paradigm governing the development and approval of clinical guidelines presents a significant obstacle to establishing the standard of treatment based on the principles of evidence-based medicine. This limitation can be attributed to the paucity of high-level evidence studies. It is therefore crucial that parents are provided with comprehensive information related to the treatment process and the most effective treatment practices, as this will facilitate an informed decision-making process for both medical professionals and patients' parents. It is noteworthy that the Ponseti method, which was first developed in the 1960s, was not widely recognized as the 'gold standard' for congenital clubfoot treatment until the turn of the 21st century. This was largely made possible through contributions from the parent community, with the information available to parents of children with congenital clubfoot through online resources [11]. Awareness of the primary sources of information, understanding of the parents' decision-making logic, and analysis of their opinions regarding the availability and completeness of data on the treatment of congenital clubfoot from various sources (including official sources, such as medical professionals and healthcare facilities, and alternative sources, such as parent communities, etc.) facilitate the filling of informational gaps, optimization of decision-making process, and enhancement of treatment adherence [12, 13]. It should be borne in mind that the majority of parents of children with congenital clubfoot are people of the 'digital generation,' for whom online communication, social media, ratings, reviews, and assessments represent a normal practice of daily consumer behavior, which inevitably extends to medical aspects [14].

Our analysis has demonstrated that there is an unmet need for complete and high-quality information on congenital clubfoot treatment. The information provided by medical professionals during the diagnosis and treatment is not regarded as particularly valuable by responders, leading to recurrent demands for alternative sources of information, the quality of which is also a subject of concern for parents. Parents have quite reasonable expectations and are generally open to receiving plain language information from online sources associated with competent medical professionals and clinics. It is therefore important to enhance communication in this regard. It is crucial for the medical community to recognize the significant growth of social media-based interactions. As a popular leisure activity, social media has evolved into an effective tool to form the public opinion, including on medicine and health. Most of the parents surveyed reported that social media is one of the primary sources of information on the treatment of congenital clubfoot. It is also important to include medical professionals as expert members of these communities to ensure that medical information is interpreted correctly and that only competent opinions are published.

This study is limited by the specific data collection methodology. As the questions were closed-ended and prepared in advance, it was not feasible to provide further explanations or collect open-ended information or additional comments. To maintain respondent anonymity, it was not possible to exclude non-targeted respondents from the survey. However, an access to the community assumed to yield a high probability of relevant answers. The social media-based survey may be also associated with the prevalence of younger, socially active Internet users. As previously noted, most parents of newborns with clubfoot *a priori* belong to the generation that considers social media and Internet communication to be an essential part of everyday life. However, studies based on alternative data collection and analysis methodology and evaluating variables such as geographic region, social status, education, and family income can facilitate the identification of additional barriers to obtaining information on the treatment of congenital clubfoot.

CONCLUSION

The findings of our study, which analyzed the results of the anonymous survey of parents of children with congenital clubfoot, have demonstrated a significant demand for high-quality, accessible information on diagnosis, treatment, and rehabilitation of pediatric patients. The data obtained

indicate that parents not fully satisfied with the information provided by medical professionals. The significant interest in information sourced from social media and other alternative online resources has highlighted the need for qualified medical professionals' community to actively engage in this process.

ADDITIONAL INFORMATION

Funding source. The study had no external funding.

Competing interests. The authors declare that they have no competing interests.

Ethics approval. This study was discussed and approved by the Ethics Committee of the Turner National Medical Research Center for Children's Orthopedics and Trauma Surgery of the Ministry of Health of the Russian Federation (extract from Protocol No. 24-1-1 of April 19, 2024).

Consent for publication. By agreeing to participate in an anonymous survey, the respondents thereby consented to the processing of depersonalized data and its subsequent publication.

Author contribution. All authors made a significant contribution to the study and preparation of the article, and each read and approved the final version before it was published.

The largest contribution was distributed as follows. *V.M. Kenis* developed the concept, searched and analyzed the literature, performed data analysis, and prepared the manuscript; *A.G. Baindurashvili, P.S. Shpulev, A.V. Sapogovskiy, E.V. Melchenko, G.N. Rustamov, A.N. Kasev,* and *H.H. Rustamov* analyzed the data, edited and approved the final version of the manuscript.

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