

The role of social media in clubfoot: information sharing and social support

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Abstract

Purpose Clubfoot is the most common congenital foot deformity in children. Caregivers often seek medical information on the internet. The aim of the study was to characterize how social media is used by caregivers to access medical information.

Methods A search was performed on Facebook, Twitter and YouTube platforms. Information was quantitatively assessed. Comments were qualitatively assessed, and the Kruskal-Wallis test was used to study thematic comment distribution.

Results In total, 58 Facebook groups and pages, 109 YouTube accounts and ten Twitter accounts related to clubfoot were discovered from 2007 to 2019. Facebook groups and pages had a collective 56 123 members and 80 544 total likes, respectively. YouTube had a collective 3 280 454 views, with 54 969 total comments throughout the accounts. Comment themes most commonly included sharing information and advice (38.7%), appreciation and success stories (12.8%), emotional support (12.7%) and social media as a second opinion (11.9%). Facebook groups contained a significantly higher number of comments related to 'social media as a second opinion' compared with Facebook pages ($p = 0.001$), Twitter ($p = 0.016$) and YouTube ($p < 0.0001$) while YouTube contained a significantly lower number of comments related to 'sharing information' compared with Facebook groups, pages and Twitter ($p < 0.0001$).

Conclusion Social media continues to be a growing tool for information sharing and the findings of this study highlight the importance placed by caregivers on the advice of their peers. The online presence of caregivers may represent an opportunity for orthopaedic surgeons to communicate with patients and help them make informed decisions.

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Introduction

Clubfoot is the most common congenital foot deformity, affecting one in every 1000 live births.¹ In addition to the burden of potential complications of surgical intervention, untreated clubfoot can result in skin and bone infections, difficulty with standard shoe wear, foot pain and limitations in mobility and economic opportunities.² Families of children with clubfoot endure major difficulties including the stress and emotional response to the diagnosis, coping with serial casting schedules and prolonged bracing.

It is estimated that as of 2019, nine out of ten adults in the United States use the internet.³ As the internet continues to impact every aspect of the modern world, it has become an alternative source for healthcare information for many patients.^{4,5} With an estimated 2.95 billion users worldwide, social media platforms reach more people than ever and allow regular users to share content and interact with each other across the globe.⁶ As of April 2020, Facebook (FB) had 2.5 billion active users, followed by YouTube and Twitter, with two billion and 386 million active users, respectively.⁷

Patients utilize social media to seek advice on specific diseases, share personal experiences and gain knowledge about specific treatment processes.⁸⁻¹⁰ YouTube has been used by patients to view videos describing anatomy, symptomatology and treatment options, while Facebook has been used to share experiences of disease management. Twitter has been used by patients to share information regarding treatment and provide psychological support.¹¹⁻¹⁴

Families of children requiring orthopaedic services are turning to the internet to gain health-related information as a source for alternative opinions.¹⁵⁻¹⁸ Ranade et al¹⁹ performed an analysis on YouTube videos pertaining to clubfoot and found hospital-created videos to be of higher information quality than private videos.

Social media can be an important source of information for parents of children with clubfoot regarding the treatment process.²⁰ The aim of our study was to perform a quantitative and qualitative analysis of three social media platforms in order to characterize how social media can be used by caregivers of children with clubfoot.

Materials and methods

Search strategies

No institutional review board approval was required for this study. All information collected was publicly available and no personal information was recorded.

A search was performed on Facebook (pages/groups), YouTube and Twitter using the keyword 'clubfoot'. An additional search was done for Twitter using the term 'talipes equinovarus' to maximize the results.

In order to select more 'active' Facebook groups, pages and YouTube videos; an arbitrary cut-off of 500 members/likes was selected. There were many search results with fewer than 500 members/likes; these results did not generate enough comment traffic to conduct a meaningful analysis and were excluded. On the contrary, due to the overall low number of Twitter accounts pertaining to clubfoot and more dynamic and interactive nature of communication via tweets, we felt that including all accounts would provide a representative sample of comments on the subject matter. Facebook groups were divided into public or private groups. A special request was sent to join all private groups. Data was collected on the number of likes, number of members, followers, total number of comments or tweets, country of origin, private or public status and year of creation. Based on identifying information, each search result was classified into one of five categories: medical institution, news, nonprofit organization, promotional information or story sharing.

Thematic analysis

To avoid any selection bias, all existing comments on YouTube, Facebook and Twitter were qualitatively analyzed, including main posts and post responses. The qualitative analysis was constructed in order to better understand common themes, topics, ideas and patterns of meaning as described by Kuckartz.²¹ Comments were assigned to a category by two authors independently (GH and BDB). The senior author (FEO) evaluated the comments for any discrepancies and made a final decision. Comment themes were determined using axial and open coding systems as described by Canty et al.²² The comment themes included sharing information and advice, appreciation and success stories, emotional

support, social media as a second opinion, advertising services, challenges and difficulties and inequities and access issues. A text analysis was performed on YouTube comments (10 066 words) using the online programme Wordcloud generator (www.wordclouds.com). The global geographical distribution of social media platforms was traced via a frequency-based heat map (www.heatmapper.ca/).

Statistical analysis

The Kruskal-Wallis test was used to study thematic comment distribution between social media platforms. When making multiple comparisons, the Bonferroni correction adjusted the p-value for multiple comparisons; $p < 0.05$ was considered significant for all statistical analyses (SPSS; IBM, Armonk, New York).

Results

Quantitative results

Overall, 177 social media accounts were identified from 2007 to 2019, located in 25 countries with a total of 54 969 comments. The majority of the accounts were from the USA (51.2%) (Fig. 1). The number of social media accounts created per year increased steadily until a peak of 32 accounts in 2016 (Fig. 2a).

Facebook pages

In all, 37 Facebook pages with a total of 80 544 likes (mean of 2176.9 (509 to 15 236)) and 11 962 comments (mean of 323.3 (13 to 1065)) were identified. Out of the 37 pages identified, 12 (32.4%) were located in the USA (Table 1). The incidence of clubfoot Facebook page creation was highest in 2014 with seven pages created (Fig. 2b).

Facebook groups

A total of 21 Facebook groups with a total of 56 123 members (mean of 2672.5 (515 to 7501)) and 30 551 comments (mean of 2182.2 (281 to 4752)). Out of the 21 groups identified, 20 private groups with 49 447 total members (mean of 2472.3 ± 1908.8 ; median of 2339; range 515 to 7501) and 27 159 total comments (mean of 2089.2 ± 1136.07 ; median of 2187; range of 281 to 4752) were identified along with only one public group with a total of 6676 members and 3392 comments.

Out of the 20 private groups identified, 13 were successfully joined with a membership total of 34 702 (mean of 2669 (515 to 5470)) and seven private groups could not be joined with a total of 14 745 members (mean of 2106 (561 to 7501)). Out of the 21 groups identified; ten (47.6%) were located in the USA (Table 1).

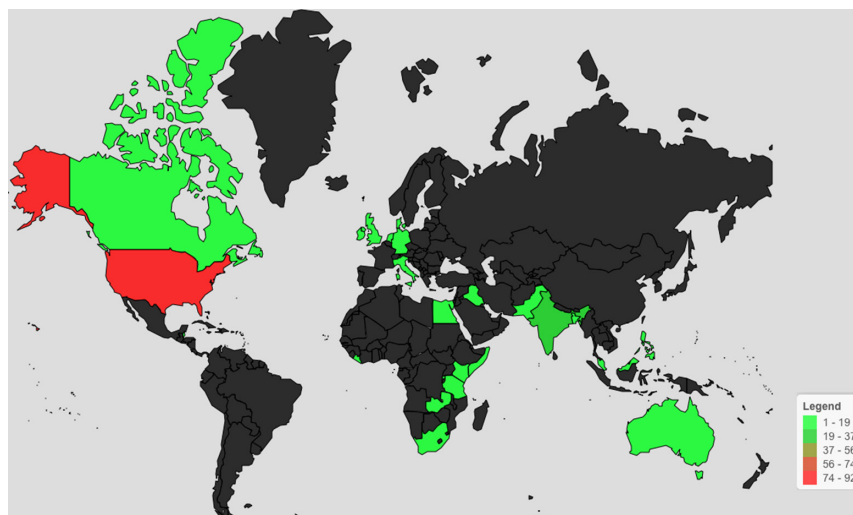


Fig 1. Geographic heat map of social media accounts distribution, by density.

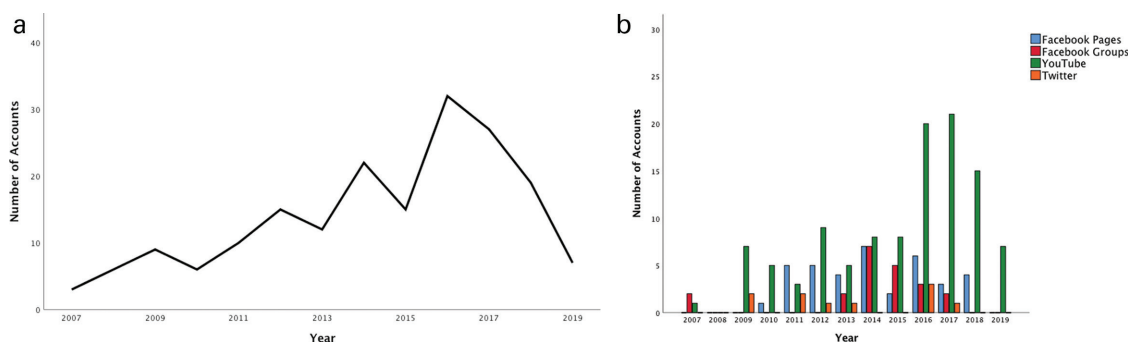


Fig 2. a) Social media accounts created per year; b) social media accounts created per platform per year.

YouTube

A total of 109 YouTube videos with a total of 3 280 454 views (mean of 30 095.9 (524 to 396 663)) and 534 comments (mean of 4.9 (0 to 72)) were identified. YouTube videos accounted for (60.6%) of total social media accounts (Fig. 3). Out of the 109 YouTube videos identified, 66 (60.6%) were located in the USA (Table 1).

Twitter

Ten Twitter accounts with a total of 9834 followers (mean of 983.4 (59 to 4395)) and 11 922 comments (mean of 1192.2 (18 to 3349)) were identified. Out of the ten Twitter accounts identified, four (40%) were located in the USA (Table 1).

Qualitative results

A total of 177 individual accounts were classified into five main categories (Fig. 4). A total of 54 969 comments were coded into eight themes (Table 2). Sub-thematic analysis of a total of 54 969 comments was conducted (Table 3). A word cloud was generated using a total of 534 YouTube

comments and the frequency distribution of the top ten words was plotted (Figs 5 and 6, respectively).

Thematic comment distribution

Social media platforms were significantly different in terms of number of comments related to the identified themes ($p < 0.0001$). Pairwise comparisons showed that Facebook groups contained significantly higher number of comments related to ‘social media as a second opinion’ compared with Facebook pages ($p = 0.001$), Twitter ($p = 0.016$) and YouTube ($p < 0.0001$) while YouTube contained significantly lower number of comments related to ‘sharing information’ compared with Facebook groups ($p < 0.0001$), Facebook pages ($p < 0.0001$) and Twitter ($p < 0.0001$) (Table 4).

Discussion

Quantitative analysis

Social media platforms can be influential in terms of patient education and guiding treatment considerations,

Table 1 Global geographic distribution of social media accounts

Country	Total social media platforms (%)	Facebook pages (%)	Facebook groups (%)	YouTube (%)	Twitter (%)
USA	92 (52)	12 (32.4)	10 (47.6)	66 (60.6)	4 (40.0)
India	22(12.4)	3 (8.2)	0 (0)	18 (16.5)	1 (10.0)
UK	11 (6.2)	1 (2.7)	3 (14.3)	5 (4.6)	2 (20.0)
Canada	6 (3.4)	1 (2.7)	4 (19.0)	1 (0.9)	0 (0)
Philippines	4 (2.3)	4(10.8)	0 (0)	0 (0)	0 (0)
Pakistan	4(2.3)	1 (2.7)	0 (0)	3 (2.8)	0 (0)
South Africa	3 (1.7)	1 (2.7)	1 (4.8)	0 (0)	1 (10.0)
Zambia	2 (1.1)	1 (2.7)	0 (0)	0 (0)	1 (10.0)
Malaysia	2 (1.1)	1 (2.7)	0 (0)	1 (0.9)	0 (0)
Italy	2 (1.1)	0 (0)	0 (0)	2 (1.8)	0 (0)
Germany	2 (1.1)	1 (2.7)	0 (0)	1 (0.9)	0 (0)
Australia	2 (1.1)	1 (2.7)	0 (0)	1 (0.9)	0 (0)
Tanzania	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Somalia	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Singapore	1 (0.6)	0 (0)	0 (0)	1 (0.9)	0 (0)
Rwanda	1 (0.6)	0 (0)	0 (0)	1 (0.9)	0 (0)
Netherlands	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Liberia	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Kenya	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Ireland	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Iraq	1 (0.6)	0 (0)	0 (0)	1 (0.9)	0 (0)
Egypt	1 (0.6)	0 (0)	0 (0)	1 (0.9)	0 (0)
Denmark	1 (0.6)	0 (0)	0 (0)	1 (0.9)	0 (0)
Belize	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
Bangladesh	1 (0.6)	1 (2.7)	0 (0)	0 (0)	0 (0)
N/A	12 (6.8)	2 (5.4)	3 (14.3)	6 (5.6)	1 (10.0)

N/A, geographical information not available

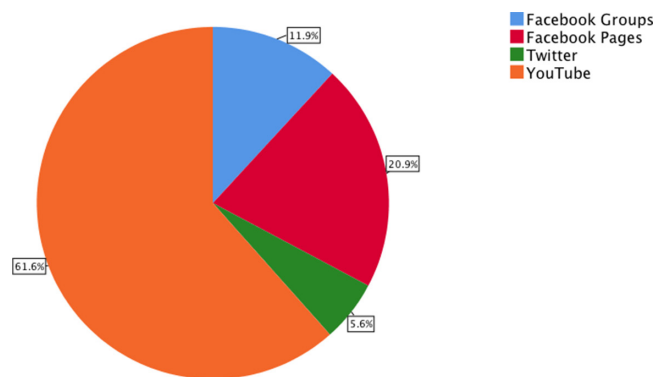


Fig 3. Social media accounts distribution by platform.

but may be currently underutilized by paediatric orthopaedic surgeons.²³ This study demonstrates that caregivers of children with clubfoot share an average of 4581 comments per year on Facebook, YouTube and Twitter.

Creation of clubfoot themed social media accounts has increased over time, with a peak in 2016 (Fig. 2a). An increase in YouTube video creation in 2016 might have contributed to this trend (Fig. 2b). Clubfoot social media accounts rose from 86 to 118 in 2016, a 37.2 % increase. Simultaneously, clubfoot-related YouTube videos rose from 46 to 66, a 43.5 % increase. Although the quality of the videos was not assessed, this highlights the ability of YouTube to influence a vast audience and become a

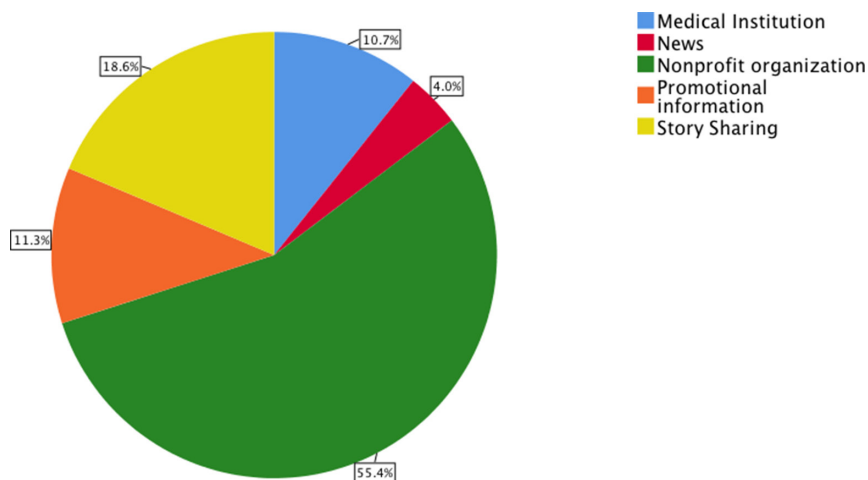


Fig 4. Social media accounts categories.

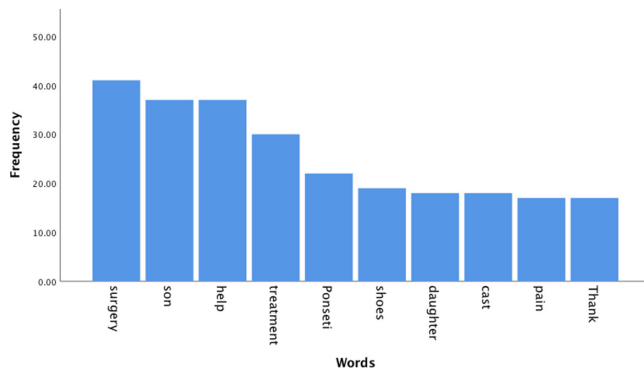


Fig 6. Frequency distribution of the top ten words in the word cloud (verbs, adverbs and common nouns not related to clubfoot were removed for clarity).

ing the total views. As such, no conclusion can be drawn as to the extent of engagement of caregivers on YouTube.

Facebook was the most interactive platform, accounting for 42 513 out of 54 969 (77.3%) total social media comments. A total of 22 out of 58 (37.9%) Facebook groups/pages were located in the United States. The year 2014 had the highest number of Facebook pages/groups created, 14 out of 58 (24.1%). In all, 20 out of 57 (35.0%) Facebook accounts were private and access was only gained to 13 (65%). Accessible private groups were the most interactive part of Facebook, accounting for 27 159 out of 42 513 (63.9%) total Facebook comments. The heavy caregiver usage and relative privacy of these groups may offer a strong starting point for information distribution by orthopaedic surgeons.

Twitter provided a negligible source of information in terms of the number of social media accounts, contributing only ten out of 177 (5.6%) total social media accounts (Fig. 3). A total of four out of ten (40.0%) Twitter accounts were located in the United States. The year 2016 had the highest number of Twitter accounts created, three out of ten (30.0%). Tweet text character limitation may limit caregivers from sharing detailed personal experiences making Twitter an undesirable medium for clubfoot-related conversations.

Thematic analysis

Comment analysis demonstrated a primarily informational role of social media platforms (Table 2). Comments seeking and distributing information categorized as ‘sharing information and advice’ accounted for 38.7% of all social media comments. Sharing advice comments were composed of personal day-to-day experiences caring for a child with clubfoot (Table 2). These experiences were depicted in words and uploaded images offering an educational usage of social media.

Sub-thematic analysis revealed different dominant themes among platforms. Analyzing YouTube comments

revealed that ‘appreciation and success’ was the dominant theme accounting for 30.7% of all YouTube comments while other platforms played a significantly more prominent role in sharing information compared with YouTube ($p < 0.0001$) (Table 3). Most of the YouTube comments demonstrated the gratitude of users; they were uploading videos of their personal experiences and success stories of the treatment processes. The word cloud of YouTube’s comments (Fig. 5) contained the words ‘surgery’ and ‘thank’ among the top ten most frequent words with a frequency of 40 and 17, respectively (Fig. 6). This suggests caregivers felt comfortable sharing appreciation and success stories with other caregivers on YouTube.

The ‘personal touch’ of the comments was ubiquitous, and they were often describing personal experiences that facilitated caregiver-to-caregiver support. This trend can be explained by the powerful effect of caregiver-to-caregiver dialogue that enhances coping skills and acceptance of the child’s needs.²⁵ ‘Emotional support’ emerged as the third most common theme overall, accounting for 12.7% of total social media comments with Facebook groups/pages and Twitter playing a significant role compared with YouTube. In this comment type, caregivers shared their distress during clubfoot management and their emotional challenges facing the diagnosis (Table 2). As such, social media can serve as a way for caregivers of children with clubfoot to facilitate their emotional adjustment and ability to care for their children.²⁶

Notably, caregivers often sought a second opinion on Facebook groups which were the most significant source for such conversations compared with other social media platforms ($p < 0.05$). Under the ‘social media as a second opinion’ theme, caregivers usually posted their medical questions directed to other caregivers either as a case description, ultrasound results, images or videos. The responses ranged from offering medical advice based on previous experiences, referring caregivers to orthopaedic surgeons or redirecting them to health-related websites. In most cases, people without a medical background led discussions in this realm. While information sharing is valuable with regards to emotional support and experience sharing among caregivers, medical advice shared in this forum is at risk of being misleading and even dangerous for patients due to the absence of vetting by orthopaedic surgeons with specialized expertise.¹⁰

Information exchange regarding clubfoot was not only personal but also technical. A new theme that emerged from our analysis was ‘techniques and anatomy’. The majority of this comment type came from research-based Facebook groups, pages and Twitter accounts discussing pathophysiology and surgical techniques concerning clubfoot. Some Facebook pages discussed topics concerning aspects of the surgical correction of clubfoot. In addition, caregivers had the opportunity to submit ques-

Table 3 Sub-thematic analysis of comments across social media platforms

Themes	Facebook page (%)	Facebook group (%)	YouTube (%)	Twitter (%)
Emotional support and forming connections	794 (6.6)	4343 (14.2)	46 (8.6)	1801 (15.1)
Sharing information and advice	4781 (40.0)	12 401 (40.6)	141 (26.4)	3951 (33.1)
Appreciation and successes	2219 (18.6)	2432 (8.0)	164 (30.7)	2229 (18.7)
Challenges and difficulties	876 (7.3)	3311 (10.8)	14 (2.6)	916 (7.7)
Advertising/offering services	1958 (16.4)	1149 (3.8)	3 (0.6)	2440 (20.5)
Inequities and access	201 (1.7)	505 (1.7)	20 (3.7)	228 (1.9)
Social media as a second opinion	302 (2.5)	5993 (19.6)	93 (17.4)	172 (1.4)
Information regarding technique and anatomy	831 (6.9)	417 (1.3)	53 (9.9)	185 (1.6)

Table 4 Kruskal-Wallis test comparing mean ranks of the number of comment themes between social media platforms

Thematic categories	Facebook groups	Facebook pages	YouTube videos	Twitter	chi-squared test	p-value
Emotional support	160	121.24	59.89	144	115.12	< 0.0001 ^{a,b}
Sharing information and advice	160.00	132.2	56.00	141.20	127.69	< 0.0001 ^{a,b,c}
Appreciation and success stories	151.35	129.9	57.76	139.85	106.10	< 0.0001 ^{a,b,c}
Challenges and difficulties	157.70	119.8	62.11	127.60	106.31	< 0.0001 ^{a,b}
Advertising services	146.05	108.4	70.41	95.40	71.06	< 0.0001 ^a
Inequities and access issues	130.60	107.02	72.13	97.90	51.06	< 0.0001 ^{a,b,d}
Social media as a second opinion	152.90	106.07	70.28	99.60	46	< 0.0001 ^{a,d}
Techniques and anatomy	134.40	125.49	63.20	115.70	74	< 0.0001 ^{a,b,c}

Pair-wise comparisons were all significant at (p < 0.05) except as shown below:

^a Twitter versus Facebook pages (p > 0.05)

^b Twitter versus Facebook groups (p > 0.05)

^c Facebook groups versus Facebook pages (p > 0.05)

^d Twitter versus YouTube (p > 0.05)

tions regarding their concerns to board certified paediatric orthopaedic surgeons through the Facebook page of the Pediatric Orthopedic Society of North America, another excellent starting point for orthopaedic surgeons to engage patients online. Given patients' interest in learning about their condition in meticulous detail and their enthusiasm for physicians to join social media,²⁷ continued expansion of the presence of orthopaedic surgeons sharing content on clubfoot is anticipated. While this may serve as an avenue for physicians to educate parents and stimulate valuable discussion between their individual providers, it is important to consider the risk of providers prioritizing the use of this platform for marketing rather than education. These concerns highlight the importance of encouraging our well-respected orthopaedic societies, rather than individual physicians, to increase their presence to provide information that is mutually agreed upon by leaders in the field and supported by peer-reviewed evidence. An emphasis should be placed on posting information which is understandable at lower education levels and fostering enthusiasm for parents to be educated in their children's care.²⁸

A limitation of this study included the use of 'clubfoot' as the one keyword to search for clubfoot-related content, excluding results that may differ in nomenclature. Even though an additional search term 'talipes equinovarus' was used for Twitter, it did not result in any additional accounts. Another limitation is only English-based content was selected which prevented analyzing social media platforms of different languages. Access was not gained

to seven out of 20 (35.0%) private groups, which limited this study from capturing different types of discussions taking place in those groups. Word cloud analysis of only YouTube comments may have produced results not representative of all social media platforms. In addition, word cloud generators analyze word frequency only with no consideration for the context in which they were used.²⁹ Finally, this study represents only a snapshot of the current use of social media by caregivers. Reported numbers are prone to change due to the dynamic nature of social media platforms.

This study provides insight into the use of Facebook, YouTube and Twitter by caregivers of children with clubfoot as tools for information sharing. There was considerable variability among platforms and their use internationally. However, the presence of caregivers and nature of information being shared represent a potential opportunity for orthopaedic surgeons to share information supported by peer-reviewed evidence. Increasing the presence of surgeons and societies on these platforms should be with the goal of informing discussions between parents and their individual local providers who know their child and their condition personally. Information shared through social media does not supplant the patient/parent-physician relationship. Despite this, its heavy utilization by parents of children with clubfoot represents an opportunity to potentially improve patient care and health outcomes.

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OA LICENCE TEXT

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ETHICAL STATEMENT

Ethical approval: This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent: Informed consent was not required for this work.

ICMJE CONFLICT OF INTEREST STATEMENT

None declared.

AUTHOR CONTRIBUTIONS

GH: Study design, Data collection, Statistical analysis, Manuscript preparation.

BDB: Study design, Manuscript preparation.

JP: Manuscript preparation.

Jl: Data analysis, Manuscript preparation.

FE-O: Study design, Manuscript preparation.

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