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.

Level of evidence: IV

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Introduction

Clubfoot is the most common congenital foot deformity, affecting one in every 1000 live births. 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. 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. As the internet continues to impact every aspect of the modern world, it has become an alternative source for healthcare information for many patients. 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. 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.

Patients utilize social media to seek advice on specific diseases, share personal experiences and gain knowledge about specific treatment processes. 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.

Families of children requiring orthopaedic services are turning to the internet to gain health-related information as a source for alternative opinions. Ranade et al 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. 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.

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. 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. 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 323.3 (13 to 1065)) were identified. 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).
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 9,834 followers (mean of 983.4 (59 to 4,395)) and 11,922 comments (mean of 1,192.2 (18 to 3,349)) 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,
but may be currently underutilized by paediatric orthopaedic surgeons. 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

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.

**Fig 4.** Social media accounts categories.
Table 2  Thematic analysis of overall comments across social media platforms

| Themes                          | Prevalence (%) | Description                                                                 | Selected Comments                                                                 |
|--------------------------------|----------------|----------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| Sharing information and advice | 38.70          | Sharing day-to-day care and helpful information regarding the treatment process of children with clubfoot based on personal experiences. | “…. My son (4 months old) just got his last casts (after his heel clips) off yesterday morning and we were given the [Brand] brace system with the only instructions to “keep his heel down” and “make sure he wears them 24hrs a day for 4 months””.

| Appreciation and success stories| 12.81          | Sharing success stories of treatment, positive results from surgery and thanking others for providing help. | “thank you so much for sharing this. I’m having my first born in march and just found out she has club foot, we don’t know to what degree and won’t until she gets here but I’ve been so scared and nervous because it’s something I know next to nothing about. This brought me a lot of comfort. thank you”.

| Emotional support               | 12.71          | Building relationships based on shared emotional difficulties while taking care of a child with clubfoot. | “….I’m struggling to hold it together after finding out at my 21 week scan that my third child has bilateral club foot …. I am just so afraid of the syndromes that club foot can be associated with. I spend half the time fearing it’s more than clubfoot, and the other half the time panicking about the impact of club foot itself…. how on earth did you keep it all together?! I am just hoping that it’s “just” club foot and all will turn out okay”.

| Social media as a second opinion| 11.93          | Offering or receiving recommendations regarding clubfoot management. | “I need advice. My five year old son left foot is regressing… again. He spent all of October in a full leg cast and all of November on a cast just below the knee. He spent an additional 2 weeks in a cast in January. I really want to avoid the tendon transfer surgery but I am not sure at what cost, I feel like he is spending his childhood in casts. Can anyone relate? Please post advice/opinions”.

| Advertising services            | 10.10          | Advertising for clubfoot-related accessories and equipment. | “Our springs have been redesigned to allow the shoes to be attached without engaging the springs or weighing down the springs. This means when the child is at rest, they will not exert enough strength to engage the springs, leaving the foot in permanent dorsiflexed position…. We are giving you the ability to increase the resistance when you notice your child is overpowering the springs while resting in the bar”.

| Challenges and difficulties     | 9.31           | Challenges and negative experiences during casting, bracing or post-surgery. | “….My son is 11. He has aches and pain in his legs. He has had tenotomy and the two tendon transfers to both feet. Lately he hasn’t been able to go to school because he cant put any weight through his heels and his ankles are in so much pain.”.

| Techniques and anatomy          | 2.70           | Offering technical surgical details regarding clubfoot corrective surgery, sharing details regarding the structural anatomy and pathophysiology of clubfoot. | “The indication for [tendon] transfer is dynamic supination. In the absence of dynamic supination there is no reason for a transfer. There are reasons to exclude a transfer: connective tissue disorder, stiff feet, neurological feet. We could not have it and had day and night ADM instead”.

| Inequities and access issues    | 1.74           | Inability to afford or access treatment for clubfoot. | “Just wanna ask if clubfoot surgery is available in the Philippines [because] my grandson who was born 1 day old is having [this] condition particularly his right foot….is there any foundation who can help us to cure [this] kind of condition??”.

Fig 5. Word cloud of YouTube comments; larger size indicates more frequent words.

potential avenue for physicians to create educational content that engages millions.

Overall, 165 out of 177 (93.2%) social media platforms had a known country of origin. Accounts and videos were located in 25 countries (Table 1). Interestingly, despite the fact that 80% of all clubfoot cases are born in developing countries,24 more than half of social media accounts were located in the United States. This distribution likely reflects the fact that 80% of all clubfoot cases are born in developing countries.
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.23 ‘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 |
| Sharing information and advice           | 160.00          | 132.2          | 56.00          | 141.20  | 127.69          | < 0.0001 |
| Appreciation and success stories         | 151.35          | 129.9          | 57.76          | 139.85  | 106.10          | p < 0.0001 |
| Challenges and difficulties              | 157.70          | 119.8          | 62.11          | 127.60  | 106.31          | p < 0.0001 |
| Advertising services                     | 146.05          | 108.4          | 70.41          | 95.40   | 71.06           | p < 0.0001 |
| Inequities and access issues             | 130.60          | 107.02         | 72.13          | 97.90   | 51.06           | < 0.0001 |
| Social media as a second opinion         | 152.90          | 106.07         | 70.28          | 99.60   | 46              | < 0.0001 |
| Techniques and anatomy                   | 134.40          | 125.49         | 63.20          | 115.70  | 74              | < 0.0001 |

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)

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.

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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AUTHOR CONTRIBUTIONS
GH: Study design, Data collection, Statistical analysis, Manuscript preparation.
BBB: Study design, Manuscript preparation.
JP: Manuscript preparation.
JF: Data analysis, Manuscript preparation.
FE-O: Study design, Manuscript preparation.

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