

Social Media Perceptions of Clubfoot Treatment: A Global Observational Study

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Abstract

Background: Clubfoot is a debilitating congenital anomaly that is often under treated in lower- and middle-income countries. There exists an active social media community with regards to clubfoot on both Instagram and Twitter. The purpose of this observational study was to investigate shared content related to clubfoot on social media.

Methods: A search for public posts on social media regarding clubfoot was performed from October 31st, 2018 to October 31st, 2019. Three hashtags on Instagram and Twitter were analyzed: #clubfootsurgery, #clubfoot, and #clubfootmommamas. Data was analyzed using Chi-squared tests with significance set to $p < 0.05$.

Results: Overall, 2050 posts with clubfoot-related hashtags were identified as publicly shared on these social media platforms over the 12-month period. 1992 met the inclusion criteria. Pictures consisted of 93.9% of posts which overwhelmingly had a positive tone, while only 16 posts were explicitly negative. On Instagram, personal accounts authored 95.5% of posts and on Twitter, organizations shared 99.4% of posts. Content related to active treatment was shared 32.7% of the time - of these posts, 94.8% showed Ponseti casting or Ponseti bracing. Chi-squared analysis was performed comparing Instagram with Twitter for media format, timing, tone, author, content, visibility, and topic reference. Statistically significant differences between the two ($p < 0.001$) groups were found in each of these categories.

Conclusions: Clubfoot treatment has a large social media presence with contributions from patients, treatment organizations, and physicians. Personal accounts on Instagram emphasize the patient experience, whereas organizations on Twitter focus primarily on education and increasing overall awareness.

Introduction

In recent years, the prevalence of clubfoot treatment has increased significantly as training programs around the globe have expanded, technology has improved, and available materials and providers have increased. Clubfoot, also known as congenital talipes equinovarus (CETV), has a global prevalence between 0.6 and 1.5 per 1,000 live births [1]. Of nearly 200,000 new cases per year, 90% occur in lower- and middle-income countries (LMIC) [2]. While widely regarded as a treatable congenital abnormality with the gold standard treatment the Ponseti method, clubfoot continues to leave many with lifelong deficits [3,4]. Contributing to this is the lack of early intervention, as only an estimated 15% of the diagnosed in LMIC start treatment with the Ponseti method [2]. Deficits that persist later in life have been shown to lead to lifelong negative effects such as difficulties finding a marital partner, experiencing limited educational opportunities, and increased poverty [5,6].

Social media provides a unique and powerful lens to examine the patient experience for those affected by clubfoot [7–9]. The use of social media is not limited to high-income countries (HIC) and continues to rise in LMIC [10]. The purpose of this observational study was to analyze publicly shared content on social

media platforms, specifically Instagram and Twitter, to gain an understanding of patient, physician, and organizations perspectives regarding clubfoot treatment. Specifically, we evaluated posts for (1) media format (picture, text, or video); (2) tone (positive, negative, or neutral); (3) perspective (personal account, hospital, professional organization, physician, or other); (4) timing (active treatment, post-treatment, non-treatment); (5) content (education, advertising, research, news/media updates, or patient experience); (6) post visibility (number of hashtags); and (7) location. We hypothesized that Instagram would cultivate an environment for individuals to share daily updates with a relatively positive tone, and Twitter would focus more on scientific advances and have a higher influence of physicians.

Methods

Search

A search of public posts on Instagram and Twitter was performed on November 1, 2019 for posts from a 1-year time period: October 1, 2018, to October 1, 2019. Posts were identified by use of three hashtags: #clubfoot, #clubfootsurgery, and #clubfootmommas. A quantitative approach was taken to identify the hashtags that were most relevant to clubfoot and related treatment using the Symplur Healthcare Hashtag Project. [11] Other hashtags such as #clubfootsurgery, #clubfoot, #clubfootmommas, #equinovarus, #ponsetimethod, #ponseti, #talipesfoot, #talipes, #birthdefects, and #miraclefeet were considered; however, the three included hashtags had the most specific and highest yield in regards to number of posts and relevance to the clubfoot treatment. The query of Instagram and Twitter resulted in a total of 1992 posts across both platforms including at least one of the three selected hashtags.

Inclusion Criteria

Only posts relating to human participants were included. All posts referencing clubfoot were included, and those discussing other procedures were excluded. Only posts in English were included to avoid misinterpretation and the lack of funds to pay for an interpreter. Data was collected and analyzed by two independent reviewers (H.S. and L.Y) familiar with the Ponseti method and related clubfoot treatment. Interrater variability was resolved by review of original media and discussion with the first author (E.K) to achieve agreement. Data analysis was performed in Microsoft Excel. A binary categorical scoring scheme was used for media format, perspective, timing, tone, content, post visibility, and geographic location. Tone was determined by overall explicit positive, negative, or neutral expression in the text accompanying and media. In the majority of cases this referred to positive connotations to tackling the global burden of CTEV with positive accurate information on management and early detection. No posts were excluded for interrater variability.

Anonymity and Risk of Harm:

Much ethical consideration was given to use of the data of a potentially vulnerable population found within this study. The data aggregated was determined to be public and thus reasonable to be accessed as our research group only accessed public accounts that may be viewed by any user worldwide without

requesting specific access to the content. A thorough review of the terms and conditions of both Twitter and Instagram was performed to ensure the aforementioned methods aligned with site policies. Twitter explicitly states that any posted information is “viewable and searchable by anyone around the world” and Instagram states that posted information is “considered public information.”[12,13] In addition, only posts including the aforementioned hashtags were collected for analysis, indicating that these users desired their content to reach a larger population that is similarly interested in clubfoot related happenings; and thus, reasonably expected their content to be accessed by strangers. No private account information was accessed in any manner.

Given the potential sensitive nature of the subject matter, there is risk of harm if identifiable data were to be amplified more broadly than originally intended. As such, we sought to preserve the anonymity of the authors with the following methods. No direct quotes or account names were collected or are shared throughout this manuscript. Similarly, all data presented is deidentified and unable to be traced back to the original authors without complete replication of the study methods. Due to the sensitivity of the data, no public data sets will be made available. Upon analysis, no data was suspected to be shared by participants under the age of 13, however if encountered, any such data would have been eliminated from analysis. The data presented addresses key themes within each of the platform’s clubfoot related communities and does not intend to infer judgement on the study populations. Recommendations from the Social Media Research: A Guide to Ethics were closely followed.[14]

Results

Instagram

Table 1 summarizes the results of both Instagram and Twitter content. For Instagram, a total of 1499 posts met inclusion criteria. The posts were almost exclusively (1432/1499, 95.5%) shared from personal accounts. A majority of posts contained a positive tone (1157/1499, 77.2%), 330 posts (22.0%) contained neutral tones and only 12 posts contained an obviously negative tone. In terms of timing, 39.8% of posts showed active treatment, 9.34% showed post-treatment content, and 50.1% did not show any treatment types. Posts most commonly were focused on the patient experience (59.6%), followed by advertisements (21.9%), and education (18.6%). In terms of visibility, each post had an average of 16.5 hashtags. The location for 1,440 Instagram posts were able to be determined by either a location tag on the post or by analysis of the authors page. A total of 542 posts originated from the United States and 898 posts were from other 15 other countries. A total of 629 posts were from the United Kingdom, 149 from Australia, and 43 from Canada – making up the majority of international posts. Fig 1 demonstrates a representative post analyzed with the captions and author data removed.

Figure 1: Example of an Analyzed Image from Instagram (Author Details and Caption Removed)

(Table 1)

Twitter

Similarly, a summary of the content analyzed from Twitter is available in Table 1. A total of 493 tweets were included in the study. These tweets were almost exclusively (490/493, 99.4%) authored by organizations, with only three total posts authored by either a personal account or a hospital. A majority of the posts had a positive tone (87.42%), 11.76% had neutral tones, and only 0.81% posts having a negative tone. As for timing, 11.2% of posts showed active treatment, 4.26% showed obvious post-treatment content, and 84.8% of posts shared content unrelated to treatment. In terms of content, 75.9% of posts contained an advertisement, 28.2% referenced media or news, and patient experience was only represented in 16.9%. Each post had an average of 1.99 hashtags. The location of all posts was determined in the same manner as posts from Instagram. Posts originated predominantly from the United States (354/493, 71.8%). In total, 44 different countries from across the globe were represented.

Comparison: Chi-squared analysis was performed comparing Instagram with Twitter for media format, timing, tone, author, content, visibility, and topic reference. Statistically significant differences between the two ($p < 0.001$) groups were found in each of these categories, as depicted in Table 1.

Secondary Analysis: Active treatment posts for both Instagram and Twitter were analyzed for the specific type of treatment shown, data visualized in Fig 2. Categories include (1) Ponseti bracing, (2) Ponseti casting, (3) rehabilitation, (4) progress photos, and (5) radiology. On Instagram, posts most frequently (379/1184, 32.0%) showed Ponseti bracing, followed by Ponseti casting (14.8%), and rehabilitation (1.9%). The most common type of treatment shown on Twitter was Ponseti bracing (34/88, 38.7%), followed by Ponseti casting (13.7%), and progress photos (9.1%). With four degrees of freedom, Chi-squared analysis revealed a statistically significant p value of < 0.001 comparing Instagram to Twitter.

Figure 2: Analysis of Specific Treatment Type Comparing Instagram and Twitter

Geographic analysis: Figs 3A and 3B visually represent the geographic location of the posts for Instagram and Twitter, respectfully. This geographic data is combined for a collective visual representation of all Instagram and Twitter posts in Fig 3C. The location of 1,933/1,992 posts were able to be determined via location tags on the posts or analysis of the author's page if available. Graphs were created within ArcGIS Online, v2.0 headquartered in Redlands, California.

Figure 3A: Clubfoot Social Media Activity on Instagram from Oct 1, 2018 to Oct 1st, 2019

Figures 3B: Clubfoot Social Media Activity on Twitter from Oct 1, 2018 to Oct 1st, 2019

Figure 3C: Clubfoot Social Media Activity on Instagram and Twitter from Oct 1, 2018 to Oct 1st, 2019

Discussion

CTEV is considered the most common serious musculoskeletal birth defect across the globe [5,15]. Considering the high prevalence of the disease, the low level of treatment within LMIC, and ability of the disease to harm in ways beyond the physical level, there is great opportunity for improvement in current management [6,16]. Multiple studies have been done comparing the Ponseti method to other treatment

types such as the French method; however, the Ponseti method continues to produce the best outcomes and satisfaction [17–22]. Despite an adequate method to treat clubfoot, patients and families continue to face uncertainty and fear when receiving this diagnosis [23,24]. One author described their experience as a “stressful, complicated journey.” Online social communities have the ability to provide an avenue of relief and connection with those across the globe [23]. The online community with respect to clubfoot has a presence in over 50 countries, spans multiple platforms, and unites the perspectives of organizations, families, and patients.

Instagram has an active social media clubfoot community. The authors of the posts predominantly (1,320/1,440, 92%) post from the United States, the United Kingdom, and Australia (Fig 3). Despite this, over 40 different countries were represented and thus giving this community a far-reaching influence. These posts were shared predominantly (1432/1499, 95.5%) from personal accounts and contained a positive tone (1157/1499, 77.2%). Given the positive nature of these posts and focus on the patient experience (893/1499, 59.6%), the stories shared on Instagram indicate the platform has provided individuals a forum to share the daily successes, updates, and obstacles. Posts are rarely shared by physicians and health professionals, which perhaps, has allowed those within the community to connect with others traversing similar hardships and allowed for a sense of vulnerability to develop within the Instagram community. One individual with a child diagnosed with clubfoot commented that Instagram has allowed her to see adults with clubfoot do “amazing things” and has given her confidence that one day her child will also be able to do those things (Anonymous, unpublished).

Twitter similarly has an active clubfoot community but with a different demographic. Many of the posts were made from within the United States, but as compared to Instagram, were not shared from personal accounts but primarily from organizations that are based within the U.S and have a large global reach. One public account for a large, international organization authored the highest number of tweets (168/493) and is based in the United States, however, also conducts work in 26 other countries across the globe thus showing that location data may be skewed towards higher income countries [25]. The included tweets were most frequently advertisements (374/493, 75.8%), many of which were focused on fundraising. With a much smaller influence from personal accounts and posts focused on patient experience, the Twitter community is one of education, awareness, and fundraising. Physicians had an underwhelming presence on Twitter but may be more active on other social media sites not included in this study [26]. It is also plausible that the content shared by the organizations on Twitter were authored by physicians and other providers working within the organizations and thus may represent a similar viewpoint. The demographics and topics represented within this platform form a pillar of the clubfoot social media community, one that emphasizes the scientific progress in the treatment and care for those with clubfoot [27].

Active treatment posts from both Instagram and Twitter were analyzed (Fig 2) for the type of content and treatment shown. Ponseti casting and bracing posts made up over 45% of active treatment posts on Instagram and over 50% of active treatment posts on Twitter. Post-treatment posts frequently showed children riding bikes, running, standing, and displaying their feet with a smile on their face. The

community often highlights positive content and is described by multiple individuals as an outlet to express thoughts and feelings related to present struggles. In a private conversation, one individual said "I find it so refreshing that I feel so connected to each of the [other] mom's journeys" in regard to how unifying the community can be in hard times (Anonymous, unpublished).

While the combination of these two platforms create the image of a holistic community with collaboration between physicians, patients, researchers, and families - the reality is that there is little communication between them. The differences in content posted about and the demographics of the posters highlight this point. With little representation of organizations on Instagram and a smaller portion of posts highlighting the patient experience on Twitter, a perception of divide has been created. Are these communities then at a loss for the lack of collaboration between one another? And can steps be taken to remediate this disunity?

Worth considering first is if this virtual distance between the two groups has been beneficial for those directly affected by clubfoot by creating an open space for vulnerability and community. Without the influence of healthcare providers and researchers this community may have been given the room it needed to develop. However, given the positive tone of many of these posts and numerous photos of patients and families smiling, it is reasonable to hypothesize that many have found their clubfoot management to be an overall positive experience. This in addition to literature demonstrating that patients using social media for health-related topics are often driven by a search for social support, health information, as well as exchanging advice supports the notion that collaboration between the two groups may be vital [28–30]. Unity between these two communities may be further explored through studies analyzing potential methods for connecting with patients through social media while maintaining patient anonymity in addition eliciting the desires from patients and their families. Physicians and health professionals ought not enter blindly into these communities with the intention of immediately connecting with patients and their families but may begin considering ways to incorporate social media connections into their practice to improve care for those with clubfoot.

Geographic representation: Given the distribution of both of the online social media communities represented in Figs 3A, 3B, and 3C, it is clear that the expanse of this clubfoot community is far-reaching. In an era where collaboration across the globe can be instantaneous, representation from individuals from different countries and their unique viewpoints could not be of higher importance. Within the clubfoot community, 53 countries had one or many individuals author at least one post. These 53 countries, however, only represent where the author is based in and does not include the numerous countries that individual or organization represent. If united perhaps through an online forum or another platform, the wide expanse of clubfoot in social media could be used to deepen the sense of community it already has started to develop [8].

Limitations

This study is not without limitations. Due to the nature of the social media platforms used, only public posts with the selected hashtags were analyzed. Thus, a large number of posts may have been excluded

if they were made private or did not include a relevant hashtag. Yet, the search across the two platforms included a total of 1992 posts over an extended study period of one year, generating a large sample for analysis. In general, social media users tend to highlight positive aspects of their subject, potentially creating a bias toward positive outcomes while failing to capture the negative experiences that patients may face [31]. Although other social media sites such as Facebook and Snapchat are popular among social media users, Instagram and Twitter were chosen for their ability to provide a large data set of public posts with relevant hashtags that could be objectively analyzed for content.

Conclusion

In conclusion, the social media community with regards to clubfoot represents numerous countries and individuals from diverse backgrounds. Social media provides unique insight into the patient experience that ought to be utilized [32]. With input from physicians, researchers, parents, patients, and organizations, the community represents many perspectives and backgrounds. The content shared is overwhelmingly positive and frequently focused on the patient experience. There does, however, exist a divide between the patient and family focused Instagram community and the education, awareness and fundraising focused Twitter community. Physicians, health professionals, and organizations ought to enter into the patient centric online communities with humility and a desire to learn. True connections and collaborations may be formed through intentional effort and evaluation of the unique specifics of their patient base and local influence. With such expansive reach and representation, these divided communities ought to collaborate to form a higher sense of unity for the continued improvement in the treatment and care for those with clubfoot.

Declarations

Ethics approval and consent to participate: The authors recognize that social media analyses require careful review of ethical principles. In order to uphold the highest of ethical standards, the Ethical Guidelines for Internet Research from the British Psychological Society as well as the Economic and Social Research Council were carefully reviewed. Four main principals include: Respect for the Autonomy, Privacy and Dignity of Individuals and Communities, Scientific Integrity, Social Responsibility, and Maximizing Benefits and Minimizing Harm. In regard to these principals, no identifiable information or quotations were used throughout the study, when quotations were used from private discussion, they were identified as such throughout the text. No formal ethical approval was sought prior to this study. As stated in the ESRC's guidelines, we assessed the risk of making a discovery of illegal images or activities as low – as the main predicted authors of tweets and Instagram posts (inferred from previous studies) were likely to be professional organizations, healthcare providers, and patients who were sharing updates about treatment and unlikely would include any illicit information. With the addition of no specific patient information being shared, the authors felt it reasonable to proceed without formal ethical approval. Recommendations from the Rocial Media Research: A Guide to Ethics by Townsend and Wallace were also followed.

Consent for publication: Available upon request. Inclusion of parent social media posts approved from those that posted the included posts.

Availability of data and materials: The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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

Funding: There are no sources of funding to report.

Authors' contributions: SN and TN proposed the project idea. AD, LY, HS, and EK collected and collated the data. SSA, HS, and EK analyzed the data. CL and TN provided expert guidance in the analysis of data and with future suggestions. EK and SMN were major contributor in the writing of the manuscript. All authors read and approved the final manuscript and agree to be personally accountable for their contributions and accuracy of their work.

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Tables

Table 1						
Summary of Social Media Content						
Dates: October 31st, 2018 to October 31 st , 2019						
Categories		Instagram		Twitter		p-value
Media Format	Picture	1421	94.80%	450	91.28%	<0.001
	Text	0	0.00%	31	6.29%	
	Video	78	5.20%	12	2.43%	
Timing	Active Treatment	597	39.83%	55	11.16%	<0.001
	Post Treatment	140	9.34%	21	4.26%	
	Non-Treatment	762	50.83%	418	84.79%	
Tone	Positive	1157	77.18%	431	87.42%	<0.001
	Negative	12	0.80%	4	0.81%	
	Neutral	330	22.01%	58	11.76%	
Author	Personal	1432	95.53%	2	0.41%	<0.001
	Hospital	0	0.00%	1	0.20%	
	Organization	8	0.53%	490	99.39%	
	Physician	1	0.07%	0	0.00%	
	Other	58	3.87%	0	0.00%	
Content	Education	278	18.55%	64	12.98%	<0.001
	Advertisement	328	21.88%	374	75.86%	
	Research	0	0.00%	3	0.61%	
	Media or News	0	0.00%	139	28.19%	
	Patient Experience	893	59.57%	83	16.84%	
Visibility	# hashtags/post	16.53		1.99		<0.001



Table 2**Top Posters on Instagram**

Dates: October 31st 2018 to October 31st 2019

Username	Location	Category	Post Total	Percentage of Total Posts
@talipesbootsandbarcovers	UK	Personal	216	14.4%
@zachary_slade	USA	Personal	152	10.1%
@sloanesclubfootjourney	Australia	Personal	145	9.7%
@abiandthetwincesses	UK	Personal	128	8.5%
@themommabear512	USA	Personal	107	7.1%
@happy_footers	UK	Personal	80	5.3%
@baby_danyal_and_me	UK	Personal	80	5.3%
@talipesfrankie	UK	Personal	64	4.3%
@julietmcnew	USA	Personal	62	4.1%
@ashbridgejoy	USA	Personal	48	3.2%
Totals			1082	72.2%

Table 3				
Top Posters on Twitter				
Dates: October 31st 2018 to October 31st 2019				
Username	Location	Category	Post Total	Percentage of Total Posts
@miraclefeet	USA	Organization	168	34.1%
@TheClubfoot	USA	Organization	126	25.6%
@IowaBrace	USA	Organization	72	14.6%
@hopewalksorg	USA	Organization	69	14.0%
@GlobalClubfoot	USA	Organization	29	5.9%
@Hopewalksorgs	Rwanda	Organization	23	4.7%
@ArogyaAndhra	India	Organization	2	0.4%
@CarysMairJones1	North Wales	Personal	1	0.2%
@hopewalks	Mozambique	Organization	1	0.2%
@IndusHospital	India	Hospital	1	0.2%
Totals			492	99.8%

Figures



Figure 1

Example of an Analyzed Image from Instagram (Author Details and Caption Removed)



Figure 1

Example of an Analyzed Image from Instagram (Author Details and Caption Removed)

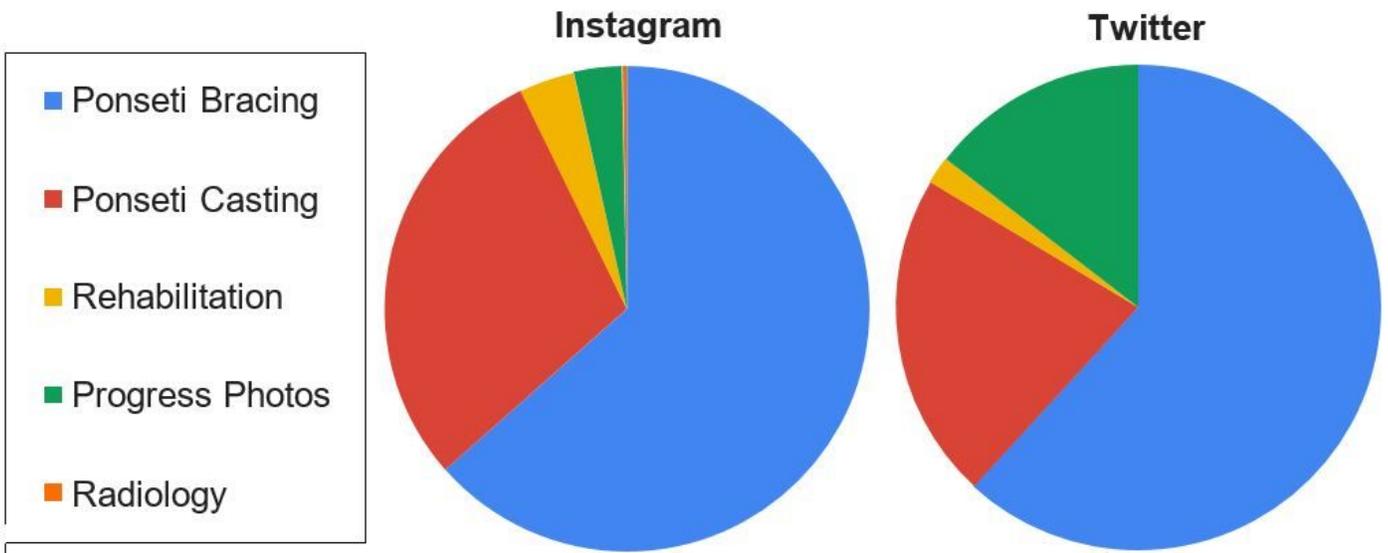


Figure 2

Analysis of Specific Treatment Type Comparing Instagram and Twitter

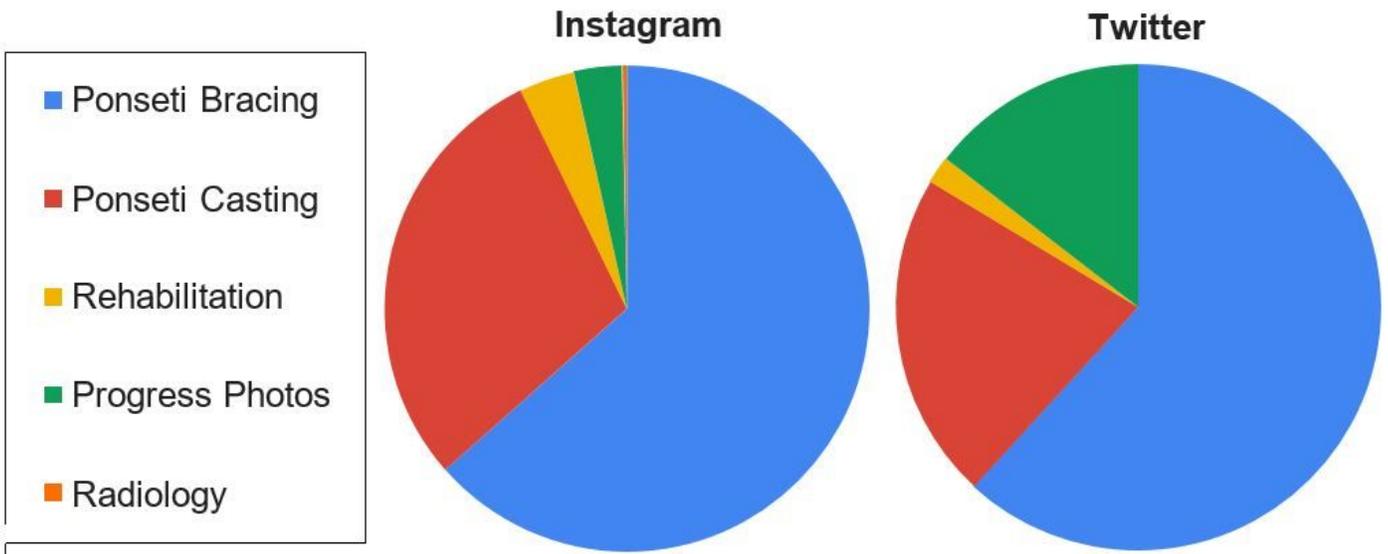


Figure 2

Analysis of Specific Treatment Type Comparing Instagram and Twitter



Figure 3

Figure 3A: Clubfoot Social Media Activity on Instagram from Oct 1, 2018 to Oct 1st, 2019
 Figure 3B: Clubfoot Social Media Activity on Twitter from Oct 1, 2018 to Oct 1st, 2019
 Figure 3C: Clubfoot Social Media Activity on Instagram and Twitter from Oct 1, 2018 to Oct 1st, 2019

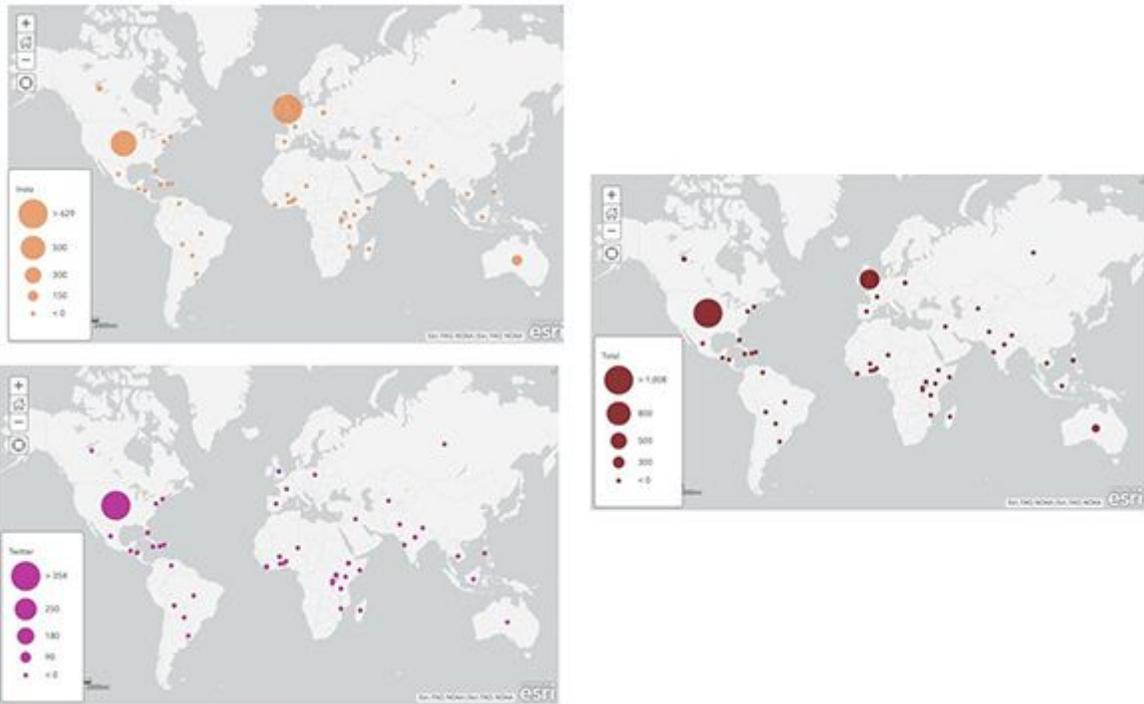


Figure 3

Figure 3A: Clubfoot Social Media Activity on Instagram from Oct 1, 2018 to Oct 1st, 2019 Figures 3B: Clubfoot Social Media Activity on Twitter from Oct 1, 2018 to Oct 1st, 2019 Figure 3C: Clubfoot Social Media Activity on Instagram and Twitter from Oct 1, 2018 to Oct 1st, 2019