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ORIGINAL ARTICLE

The role of social media in selective dorsal rhizotomy for children: information sharing and social support

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Abstract

Purpose Selective dorsal rhizotomy (SDR) is a surgical treatment for spasticity, primarily in cerebral palsy (CP). There is a growing trend for patients to seek medical information from their peers on social media platforms. This study qualitatively and quantitatively assessed the use of social media as an information-sharing and support-seeking tool by patients and caregivers.

Methods A search was performed on Facebook, Twitter, and YouTube. Public information was quantitatively assessed by category, users, year of creation, and country of origin. Representative samples of comments and posts were then qualitatively assessed by thematic analysis.

Results One hundred eighty-five Facebook groups and pages, 97 YouTube videos, and 14 Twitter accounts were identified, based in 13 countries. SDR and CP groups had a mean membership of 3063 and 2339, respectively; SDR and CP pages had a mean number of "likes" of 1650 and 10,711, respectively. Total YouTube video views were 593,135 (mean 6115). Total Twitter followers were 62,609 (mean 2160). Qualitative analysis identified seven categories of comments: emotional support and forming connections (22.34%), sharing information and advice (15.96%), appreciation and successes (31.91%), challenges and difficulties (8.51%), advertising/offering services (4.79%), inequities and access (4.79%), and social media as a second opinion (11.7%).

Conclusions This study outlines the use of social media platforms in the distribution of information regarding SDR. We highlight the importance placed by patients and caregivers on the advice of their peers. The current report should inform healthcare providers' interactions with patients with respect to information seeking and provision of support.

Keywords Social media · Selective dorsal rhizotomy · Cerebral palsy

Introduction

Selective dorsal rhizotomy (SDR) is a surgical technique performed for the treatment of spasticity in cerebral palsy (CP). SDR is not a new procedure [1], but has seen a recent surge in popularity, and is increasingly sought-after by a patient and parent population that is both more connected and better informed than ever before. The local and regional availability of SDR for children with CP in the developed world has been rapidly increasing in recent years, having been initially popularized by Peacock and Arens [2].

Social media has become an increasingly important and prevalent part of modern life. Facebook has over 2.2 billion monthly active users, comprising almost 30% of the estimated global population [3]. Similarly, YouTube has approximately

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1.9 billion active users, and Twitter, with a relatively smaller user base, boasts 326 million active accounts [3]. Healthcare professionals have recently adopted a greater social media presence to provide information and interact with patients [4, 5]. In addition, patients and their families use social media to connect with each other in ways that were not possible in the recent past [6]. These online interactions among patients and their families facilitate information sharing, advice giving, and support [7]. Much information about surgical procedures is gleaned from the Internet and from peers across the globe via social media platforms, rather than from physicians [8]. In addition, social media has specifically been shown to be an important part of information flow in several neurosurgical spheres [8–11].

It was hypothesized that social media would be a significant source of information and support for families considering or preparing for SDR. The surgery is aimed at improvements in gross motor function and consequently quality of life; it was felt likely that patients and families involved in the process would place a high value on the views of their peers. Social media platforms provide a ready-made tool to access those peers across boundaries. We aimed to assess the use of social media by SDR stakeholders both quantitatively and qualitatively, as well as study their global footprint on popular social media platforms.

Methods

Search strategies

Searches were carried out on three popular social media platforms well known for information sharing and social connectivity—Facebook, Twitter, and YouTube. The search terms *selective dorsal rhizotomy*, *sdr*, and *cerebral palsy* were used. A secondary query was performed using the search term *cerebral palsy*. The secondary search strategy yielded additional information on SDR on the Facebook platform. On YouTube and Twitter, the *cerebral palsy* search term yielded no SDR information in the midst of hundreds of unrelated results, and so, this search term was iteratively incorporated for Facebook only.

Criteria and variables

On Facebook, groups with greater than 500 members and pages with greater than 500 "likes" were searched for. On Twitter, accounts related to SDR were searched for. On YouTube, non-personal videos and channels with greater than 500 likes were searched for. Data was collected on group, page, account, video titles, number of members/likes/views, creation date, public or private status, and country of origin (if available). Each individual result was then categorized according to its purpose or aim, based on title, "about" information or bio, and the creating user. Only publicly available pages and groups were accessed. Private groups were not included in the current study.

Thematic and "word cloud" analysis

To better understand the content of social media related to SDR, qualitative research methodology was leveraged. A sample was taken of 50 posts, tweets, and comments, from each account category. It was decided not to use solely the most recent posts, as previously described [9], to avoid including irrelevant posts and comments; instead, we selected a series of representative, illuminating, and information-rich comments following purposive and iterative sampling methods [12, 13]. The number of posts, tweets, and comments was selected to the point at which saturation was reached, where no novel themes emerged from analysis of further data; some categories had less than 50 comments extracted. Each comment was then assigned to a category by two of the authors independently. Posts and tweets were examined using a modified thematic analysis, using open and axial coding methods to develop overarching themes or "core categories" [12]. The open coding method involved line-by-line analysis attributing words or phrases (i.e., a code) to represent commonalities under that code [12]. Axial coding subsequently categorized all comments within each coded area based on overarching themes, ideas, and links. For example, posts from users asking about individual variations in cerebral palsy (CP), or treatment options in spasticity, would be open coded as "inquiring about symptoms" and "queries regarding treatment," respectively. The axial code/theme under which these open codes would fall under would be "information seeking or sharing." Data was analyzed until new themes did not continue to emerge and saturation was reached. Discrepancies in coding between evaluators were discussed until a consensus was reached. All words from posts and tweets were included for text analysis to generate a word cloud using a free online application (http://www.wordclouds.com).

Statistics

Descriptive statistics were calculated (sum, mean, median, and interquartile range [IQR]) for each variable. Cohen's kappa was calculated to assess for variation in users between different categories [11].

Ethical considerations

All material retrieved was publicly accessible and available via the relevant social media platforms. No information on user names or other identifiable data was sought or retained. For this reason, no ethical approval was sought for the purposes of this exploratory study.

Results

Quantitative analysis

Facebook

One hundred eighty-five Facebook pages and groups met the inclusion criteria, based in 13 countries. SDR groups had 27,563 members (mean of 3063; median of 697). CP groups had 133,312 members (mean of 2339; median of 1150). SDR Facebook pages had 67,672 likes (mean of 1650; median of 908). CP Facebook pages had 835,479 likes (mean of 10,711; median of 1150). Forty-nine were closed groups; of these, 16 (32.65%) had no geographical data available. Closed groups had 112,701 members (mean of 2300, median of 997). There were 136 open groups, which had 951,325 members (mean of 6995, median of 1614.5).

YouTube

Ninety-seven YouTube videos met the criteria, based in four countries; in just under half the videos, it was not possible to determine the country of origin. There were 593,135 video views in total (mean of 6115; median of 2934).

Twitter

Fourteen Twitter accounts met the criteria, and a further 15 accounts were found using a hashtag search, to give a total of 29. These accounts had a total of 62,609 followers (mean of 2160; median of 466) (Figs. 1 and 2).

Qualitative analysis

Five categories emerged from the initial analysis: story sharing, promotional information, medical institution, news, and non-profit organization. Through an iterative and collaborative thematic analysis, seven axial codes/themes emerged: emotional support and forming connections, sharing information and advice, appreciation and successes, advertising/offering services, challenges and difficulties, inequities and access, and social media as a second opinion. One hundred eighty-eight comments were coded in total. Cohen's kappa score was 0.77, indicating good agreement. The proportions of comment categories, with a description and representative quotes, are shown in Fig. 3 and Table 1. The generated word cloud is illustrated in Fig. 4.

Discussion

Quantitative analysis

Social media has become an increasingly omnipresent and important part of provider engagement in healthcare. The current study demonstrates that it is also a highly utilized source of information, support, and even medical opinion for many patients and families involved in the SDR process. Various organizations have also identified the commercial opportunities in engaging with such a large and committed group, and active advertising of services was a clear theme that emerged in this study.

Facebook was the dominant social media platform in terms of number of groups and pages. This may have been due to the inclusion of an extra search term—"cerebral palsy"—for this platform alone. However, there were many YouTube videos sharing challenges, experiences, and outcomes of CP and

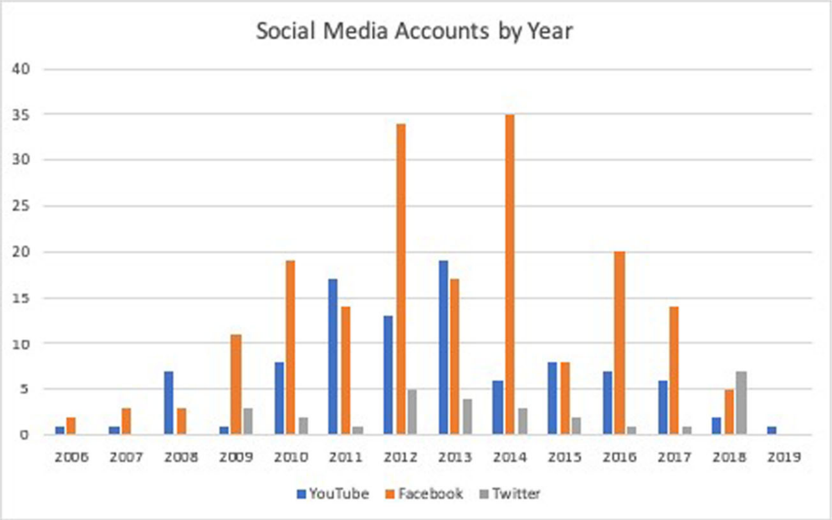

Fig. 1 Social media accounts by platform by year

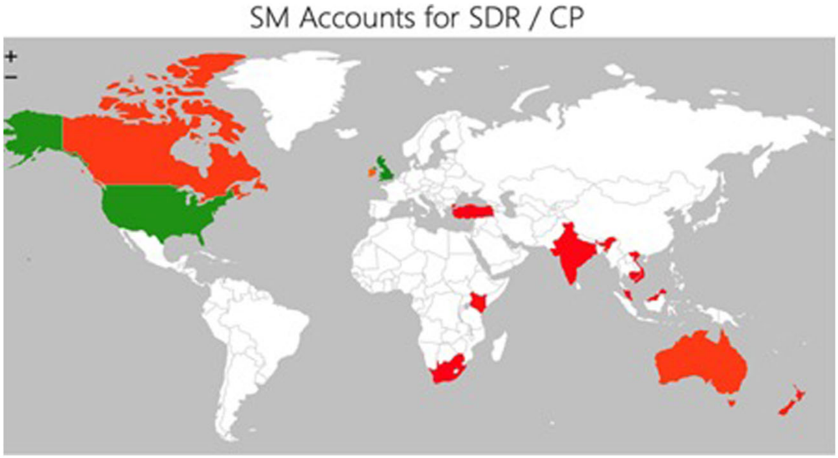

Fig. 2 Geographic heatmap of social medial accounts; the spectrum of red to green represents smaller (red) to larger (green) numbers

SDR. YouTube videos also had a higher total number of viewers than Facebook had members or followers.

Forty-nine of the identified Facebook groups were "closed," meaning they required an application and approval to join. These groups were included in the final summary statistics, but no comments from these groups were read or used in the thematic analysis. There were fewer members of these groups compared with open groups, and geographical data was available less often.

Facebook groups or pages relating to SDR were created later than those relating to cerebral palsy; we also noted a peak in activity in terms of new groups, pages, or videos, between 2011 and 2014. This period coincided both with an increase in enthusiasm and demand for SDR, as well as a dramatic increase in popularity of social media platforms as a whole. The country of origin was identifiable on 171 occasions. Accounts and videos were distributed among 13 countries, almost all in the English-speaking world. The majority were in the USA and UK (38% and 35%, respectively).

The identified cohort of YouTube videos had amassed over half a million views, and were predominantly videos of patients pre- or post-surgery, or from institutions demonstrating their expertise and experience with SDR. The majority of videos from a patient perspective were updates on treatment or rehabilitation, and often demonstrated the extent of neurological impairment, or the degree of improvement post-treatment.

Twitter was a surprisingly shallow source of information sharing on social media, with a small number of accounts identified. In total, the Twitter accounts identified in our search had less than half the numbers seen in Facebook groups alone. Comments on Twitter generally were confined to messages of gratitude towards caregivers and institutions, or fundraising messages, and the platform did not seem to be a deep reservoir of story sharing for SDR patients and families. This led to the conclusion that patients and families use social media platforms differently: YouTube and Facebook for more personal interactions and Twitter for more "formal" interactions. One possible reason for this is the character limit on individual tweets.

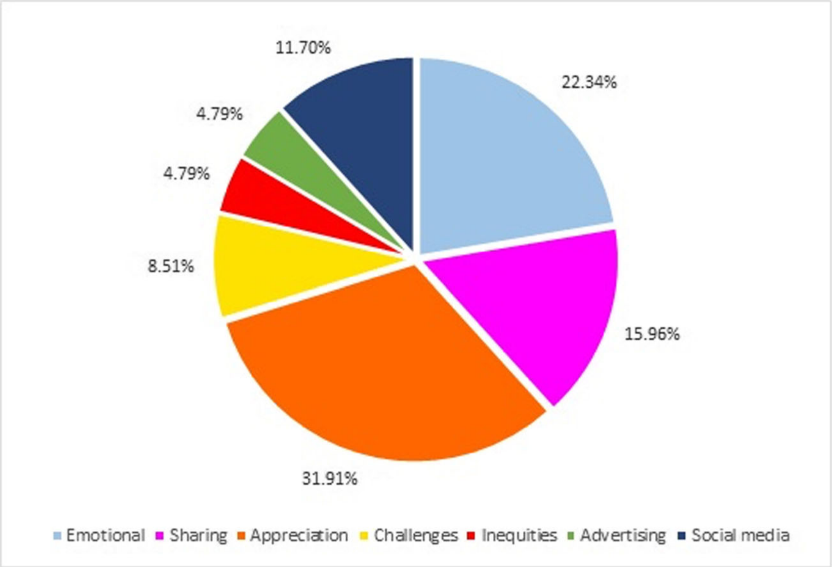

Fig. 3 Distribution of social media comments into each theme

Table 1 Prevalence, description, and representative quotes by theme

Themes	Prevalence (%)	Description	Representative quotes
Emotional support and forming connections	22.34	Seeking or offering support to others; building relationships based on shared experience	"...I'm so happy that I found this page. For me to share & read about that there are other parents in my shoes. It breaks my heart watching my little girl try so hard to walk & play with other kids... Her condition has really taken a toll on me. Physically, mentally, & emotionally. I cry a lot. I'm just relieved there's parents on here that I can open up to."
Sharing information and advice	15.96	Sharing personal experiences of the SDR process; logistical information about treatment and rehabilitation; advice on specifics of day-to-day care	"I would like to add that SDR is not just for independent walkers – I know of many children who used to walk with K-walkers and can now walk independently and also I know of many children who are wheelchair bound and SDR has had amazing results for them too. Anyone who would like to know more, please visit the Selective Dorsal [institution] Facebook page where many videos can be found and helpful advice from parents who have had the same journey as us."
Appreciation and successes	31.91	Expressing gratitude to caregivers and other commenters; communicating positive outcomes of SDR	"Thank you so much for posting this video of before and after... my daughter is going to have this surgery done in two days and I am so happy to see the outcome... God bless you."
Challenges and difficulties	8.51	Day-to-day problems in care; obstacles in care; negative outcomes of SDR	"My son had a selective dorsal and you need to be very careful that he does not get kyphosis of the spine later down the road. My son was bad that they tried to do rod surgery to straighten out his spine and could not. The rhys was wonderful for his legs but the after is hard. Good luck."
Advertising/offering services	4.79	Direct offers of services requiring payment, such as legal services	"My child's CP case has been turned down by a law firm, now what? If your case has been turned down by a law firm you should always get a second opinion. We have had successful recoveries on many cases that were turned down by other law firms. If you would like a second (or third) review please type 'yes' below and an attorney will contact you typically within 5mins."
Inequities and access	4.79	Funding problems; inability or difficulties in accessing SDR; geographic considerations	"Thank for God for making this boy can walk again... please help our son also, he is the same as the case of this boy completely, he cannot walk, please show me how can me to heal my son... how can I cross the seas and oceans to get to the same place in which to address this boy? His mother every day crying blood when she see how effort trying to walk."
Social media as a second opinion	11.7	Seeking or offering advice regarding a specific patient's condition or treatment, subsequent to real-life medical opinion	"The doctors that you have seen may have a narrower criteria than [surgeon] for the operation... Again, I do not know your child, and I'm not a doctor, but we have been down the road you are on... contact [surgeon]'s team directly at [institution] to talk about your child's suitability – he's seen more cases than anyone. Have a look on the Facebook page '[institution]' - you'll find lots of videos / cases that will probably be similar to yours."

Thematic analysis

Our comment analysis revealed a significant majority of Facebook, YouTube, and Twitter comments regarding SDR and CP to be positive. The largest category was "appreciation and success,", and this comprised many comments expressing gratitude to healthcare providers, thanks for support received, and communicating positive outcomes of SDR. There were also strong religious overtones to many of these remarks, with multiple commenters referencing or thanking a deity (example in Table 1). The strong positive nature of these contributions can be seen clearly in the word cloud generated from the pooled comments. A recurring feature of our analysis was the positive "spin" that many commenters had placed on what seemed to be suboptimal experiences or outcomes. This may suggest a significant emotional and psychological gain from being involved in the whole SDR process, or it may reflect the particular resilience of these patients and families in the face of setbacks or disappointments. Another possible explanation is that even if formal goals were not met (e.g., independent ambulation), any amelioration of symptoms following surgery, such as reduction in pain or spasticity, may produce a significant improvement in quality of life.

Fig. 4 Word cloud of all extracted comments; larger size represents a more frequently occurring word

In the theme of emotional support, many commenters eloquently expressed their feelings of isolation due to the strains of caregiving. These types of remarks also implied a benefit to the function of social media in facilitating connections with other caregivers in similar situations, as seen in other areas of medicine [14]. Caregivers in this study found comfort and solace in connecting with others who had shared experiences of difficulty. Therefore, social media platforms may act as a source of emotional support [15].

Contributions relating to sharing information or advice were typically parents sharing their experience of the SDR process, logistical information about treatment and rehabilitation, or advice on specifics of day-to-day care. Many of these commenters would direct those seeking advice to an alternative platform, creating a social media advice feedback loop; for example, we noted many comments on SDR YouTube videos directing others to Facebook groups. Some comments on YouTube videos were made by parents and caregivers a short time prior to their admission for SDR, and it seemed that they were using the platform to prepare for the hospital experience. Similarly, many posters sought specific logistic advice from social media accounts, such as availability of food, supplies, and travel times to their institution.

An interesting theme to emerge from our analysis was that of social media as a second opinion. This theme was notable for the multiple incidences of parents seeking advice from others on social media regarding their child's condition or proposed treatment, sometimes in opposition to medical advice. There were many comments from responders offering specific opinions as to what kind of treatment should be sought and where it should occur, as noted in Table 1. The prevalence of such comments suggests an enthusiasm or even preference for the opinion of peers who have been through the SDR process in addition to, or even over, that of medical professionals. It may also reflect a lack of access to SDR specialists local to these users. We also noted a repeated pattern of recommendations for patients and parents to seek treatment at specific centers, as well as advice to send videos to such centers for further opinions when a local center had declined surgery. Some of these recommendations came directly from healthcare service providers within official social media accounts. We did not come across any examples of the converse situation, where a second opinion was advised due to surgery being offered.

Comments coded as challenges and difficulties predominantly consisted of day-to-day problems in care, rather than of dissatisfaction with treatment or outcome. Similar to observations made in other categories, even significant difficulties tended to be framed positively.

Given the large amount of Facebook pages and Twitter accounts devoted to fundraising, it was unsurprising to discover several comments about a lack of funding, or inability to access SDR. It was striking how passionate these commenters were about this difficulty, and it was clear how watching videos of SDR successes exacerbated these frustrations. Older comments from Canada, the UK, and Australia also focused on the lack of SDR availability in these regions; the difficulty in raising such significant amounts of money to travel (usually to the USA) for treatment appeared to evoke strong feelings of inequity.

An unexpected theme that emerged from the comment analysis was that of advertising/offering services. Several Facebook groups described themselves as support groups and provided a forum for discussion about cerebral palsy and its consequences. These groups were however run by legal firms and offered services to pursue compensation for possible birth injury. These posts were sometimes subtle, but often overtly commercial, such as that described in Table 1. While the majority of groups, pages, and accounts on social media were created by healthcare consumers, this small minority represented a commercial arm with the aim of profit; an extension of a "digital healthcare marketplace" was previously described [16]. The origin of these accounts was sometimes clandestine, and this represents a potential pitfall for patients and families. While such accounts represented only a small fraction of those surveyed, it would be wise for information consumers to be clear about the ownership and motivation behind groups they seek to join.

Limitations and future research

There were several limitations in the current study that were in accordance with previous publications on social media in neurosurgery [8, 9, 11]. Firstly, our sample was limited to English-speaking sections of the relevant platforms. As can be seen from the geographic heatmap, this significantly restricted our sample population and may have skewed the data, particularly with regard to themes such as inequities and access. Secondly, only publicly available data was collected, and due to social media privacy settings, it was not possible to determine whether there was an overlap in comments between or within platforms in a number of accounts. For this reason, there may have been fewer total users than our data would suggest. In addition, we did not access 49 Facebook groups listed as private, so we could not determine whether discussion within those groups was similar or different than those carried out on the public pages; it may be that users expressed different opinions or experiences on private pages.

The current study was also limited by our selected search terms. We cross-referenced our search strategy by using *cerebral palsy* as a search term for Facebook based on an iterative search strategy. This yielded many relevant accounts where SDR was a major topic and heavily discussed. However using the same term for YouTube produced a huge amount of irrelevant results or "noise" that were not analyzed within the scope of this project. This may have resulted in a bias towards Facebook data.

Lastly, from the current study, we were not able to discern how families interpret and make decisions based upon the information available to them. While many patients and families who undergo SDR use social media before and after surgery, they are a self-selected group. We intend to explore this further in a secondary qualitative study using interviews of families prior to and following SDR.

Conclusions

In conclusion, the current study delineates the use of three popular social media platforms in obtaining and disseminating information regarding selective dorsal rhizotomy. Patients and caregivers use these platforms in a variety of ways, and several themes emerged from our thematic analysis of comments made across the different platforms. There was a strong trend towards positivity in comments made, and a notable importance placed by patients and caregivers on the opinion of social media peers. With increasing numbers of users worldwide, and an increasing presence of medical institutions on these platforms, social media will continue to play a large role in the healthcare information climate. It is likely to be beneficial to patients for medical providers to further establish themselves on social media outlets as reliable and respected sources of information.

Compliance with ethical standards

Conflict of interest The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

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