Microtia and Craniofacial Microsomia: Content Analysis of Facebook Groups

Abstract

Objective: An increasing number of patients use social media for health-related information and social support. This study's objective was to describe the content posted on Facebook groups for individuals with microtia and/or craniofacial microsomia (CFM) and their families in order for providers to gain insight into patient and family needs and experiences to inform clinical care. **Methods:** Two months of posts, images, comments, and 'like' responses from two Facebook groups in the US and the UK were recorded and analyzed using content analysis. A secondary analysis identified statements of emotion.

Results: Posts (N=254) had a total of 7,912 "like" responses, 2,245 comments, and 153 images. There were three categories of posts: seeking guidance (43%; 9 themes), promoting events/news (33%; 5 themes), and sharing experiences (24%; 3 themes). Across categories, 16% of posts had emotional content. Most comments were responding to posts seeking guidance, including medical care (20%), surgical care (9%), and hearing aids (5%). Promotional posts often aimed to increase CFM awareness. Posts sharing experiences were generally positive, with the highest number of "likes".

Conclusions: Facebook groups members frequently exchanged health-related information, suggesting value placed on input from other families and the convenience of seeking information online. Posts also promoted awareness and shared experiences. Clinical care implications include the need for easily accessible accurate and tailored CFM-related health education. Additionally, providers should demonstrate awareness of health information on social media and may address the potential emotional impact of CFM by facilitating access to resources for social support. **Keywords:** craniofacial microsomia; microtia; hemifacial microsomia; Goldenhar Syndrome; psychosocial experience; social media; online groups

1. Introduction

The internet is widely utilized as a source for health information, which can be perceived by patients and their caregivers as more readily accessible and straightforward than contacting health care providers [1]. Similarly, social media is used by at least 3.484 billion people worldwide [2], often to access healthcare information. Facebook ranked third for the world's most visited social media sites in 2019 [2]. In the United States, 7 in 10 adults have a Facebook account, 74% of which report using the site daily if not multiple times a day [3]. For patients with chronic medical conditions and their families, particularly rare diagnoses like microtia and craniofacial microsomia, Facebook groups provide a method to engage with each other, facilitate emotional support, affirm identity, facilitate fundraising, and promote awareness, all of which establish a sense of community [4-8].

Given the popularity of social media platforms like Facebook and online groups for individuals with specific conditions, there is an increasing need to understand how patients and their families use social media [9]. In a Facebook group for parents with a child with a tracheostomy, parents commonly sought emotional support, care advice, and medical supply resources [10]. Similarly, for parents of children requiring a tonsillectomy, social media use focused on their surgical experiences [11]. Until recently, little research has focused on social media use of individuals with craniofacial conditions. Studies by Khouri et al. [12] and Stock et al. [13] examined social media utilization of individuals with cleft lip and/or palate and similar themes were described, including seeking surgical or general healthcare information, treatment evaluations, and emotional support. In a study of the 100 most popular microtia webpages, Facebook and Twitter were rated similarly by physicians and patients, though neither were rated in the top 20 sites for the quality of the content provided [14].

Little attention has been paid to the content of social media in individuals with microtia and/or craniofacial microsomia (CFM). CFM occurs in 1 in 3500 live births and is associated with a wide range of features, most frequently microtia and mandibular underdevelopment [15-17]. CFM features can include malformations of facial soft tissue and nerves, dentition, vertebrae, heart, and kidneys [16,17]. CFM is the third most common diagnosis for children cared for by craniofacial teams with frequent otolaryngology and audiology follow-up. CFM can impact hearing, speech, breathing, feeding, neurodevelopment, and academic performance [15-20], which can contribute to parental concerns [21]. For example, one group of mothers of patients with microtia reported interpersonal concerns, depression, and anxiety [22]. Socially, many children with CFM demonstrate awareness of their facial differences at age three years and report that teasing and bullying may start at age four [23]. While teacher reports consistently indicated concerns for students with CFM with peer acceptance, internalizing behaviors, and social abilities [24], parent reports were more variable in their perceptions of how children with CFM differed from peers [24, 25]. Adaptive coping may develop during childhood, as suggested by a recent study, where no differences were found in behavioral concerns between adolescents with and without CFM [26]. Some children with these diagnoses also report better psychosocial outcomes following surgeries for ear reconstruction [27] or hearing loss [28].

Healthcare providers who work with families of children with CFM often address a range of concerns related to health, development, academic functioning, and psychosocial adjustment. Qualitative content analysis of topics discussed among patients with CFM and their families on Facebook groups can offer insight into real-time patient concerns that may not be apparent in routine clinical care [29]. This study examined topics discussed among members of two Facebook groups that support individuals with clinical conditions within the CFM spectrum.

2. Methods

2.1 Participants

Following guidelines for analyzing data from social networking sites [30-32], the researchers contacted the Facebook page administrators to receive permission for data collection prior to beginning the study. No identifiable information was collected to protect anonymity. Two Facebook groups were identified based on their focus on individuals with clinical conditions within the CFM spectrum and high level of group activity. The Ear Community Facebook page is based in the US with 8,349 followers and identifies as a Microtia and Atresia support group, as well as a nonprofit organization formed to help individuals and their families. The Goldenhar Syndrome Facebook page is based in the UK and consists of 2,739 members available to individuals with Goldenhar Syndrome and their families. Data were recorded from August to October 2019 using the computer program SnagIt [33], which records screen images. *2.2 Data Analysis*

Content analysis was used as described by Stock et al. [13] and shown in Figure 1. Data captured were read thoroughly, with notes made on potential data categorization. The number of posts, post comments, responses to posts (i.e., "like" responses, a Facebook functionality that shows appreciation of the post [34]), images within posts, and the creator of each post (e.g., adult with CFM, parent or relative of individual with CFM, community organizer/administrator) was recorded. The geographic location of the person posting was not available. The coder then categorized the content of the post, assigning a general category and a specific theme within the category. As a reliability check, a second coder reviewed the coded data and both coders discussed content from posts that differed in category and/or theme until consensus was met. Frequency counts with percentages rounded to whole numbers were calculated. As a secondary

analysis, both coders also identified posts with emotional content, including explicit statements about how the person posting or their child felt, such as feelings of anxiety, affection, or pride.

3. Results

3.1 Post and participant characteristics

During the two-month period on both Facebook groups, there were a total of 254 posts that fit into three categories (Table 1). Images were included as part of 153 posts and there were 2,245 comments and 7,912 "like" responses. Half of the posts were made by parents of individuals with CFM (n=127) with the remaining posts by community administrators (n=75), unspecified members (n=30), adults with CFM (n=20), and other relatives of individuals with CFM (n=2).

3.2 Seeking guidance posts

Table 2 provides a summary of the themes within each category. Most posts were in the category of seeking guidance (n=108), which generated the greatest number of comments (n=1,470), i.e., there were 13 times as many comments in response to the posted questions. These posts had few images (n=18) and a low proportion of 14% of "like" responses (n=1,090). Posts that were included in the seeking guidance category often included questions about general medical care (n=50). For example, one adult with CFM asked, "Does anyone else [have] problems breathing through their nose and have trouble smelling things, like your nose is blocked, but you don't have a cold or flu?" Surgical care (n=24) was a frequently posted topic, as illustrated by one parent: "We are considering canalplasty and Medpor reconstruction. What are the negatives and positives to look into especially with the canalplasty? Are they prone to have ear infections later or not?" There were several posts related to hearing aids (n=13), such as one parent's post: "Did your unilateral microtia child wear a hearing aid? When did they start and

what was your/their experience like? I'm sure they'll tell us more this upcoming visit but I couldn't stop thinking about it and sort of freaking out."

Other themes in this category included seeking additional information (n=5), such as CFM etiology, access to surgical care, and disability rights. Education questions were also posted (n=4), including how to navigate accessing school-based special education services. Posts asked about activity participation (n=4), such as protective sports helmets being customized to accommodate hearing aids. Posts about coping with diagnosis (n=4) asked for advice on how to discuss the diagnosis with their children. The remaining posts were related to speech delays (n=2) and asking for emotional support (n=2).

3.3 Promotional posts

The second most frequent category promoted various events or information (n=84), which had 616 comments, 1,620 "like" responses, and 78 images. Many posts focused on building CFM awareness (n=26), such as: "Artist with hearing loss honor[ing] the world of hearing loss with her works of art." Media sharing (n=18), included links to a video of American Sign Language for babies, music videos, and religious services. Users posted about products (n=15), including CFM-related shirts and wrist bands and manufacturing brands for prosthetic ears and hearing aids. Some posts shared scientific news (n=14), e.g., "In this new video, [doctor] demonstrates how a child with microtia and atresia can hear when there is an absence of an ear canal." Events of community interest (n=11) were also posted.

3.4 Sharing experiences posts

The third category of sharing experiences (n=62), had the highest number of "like" responses generated (n=5,202) and reflected 81 "likes" per post. There were few comments (n=159) and images (n=57). Users mostly shared positive messages (n=33), such as one mother

who posted a picture of her smiling daughter and commented, "I just wanted to say hello, show off my girl and say thank you to the group. I don't always post or comment, but I'm always following. This group has been so helpful in our journey." Advocacy and awareness events (n=15) were common in this category and included a post about community members who wrote a local congressperson about raising "awareness for the need to mandate private insurance coverage for bone conduction hearing devices." Other descriptions of experiences (n=14) were often related to healthcare: "I was born with just a lobe, no canal, this was very rare for our small country in 1977. I've had five surgeries in 1980s and 1990s and this is what I have [image], still no canal though." An adult with CFM posted an image noting: "This is me with my new glasses. My face isn't perfectly symmetrical but I am okay with that."

3.5 Posts with emotional content

A secondary analysis identified 40 posts from the total of 254 posts that also included statements of emotions. Of the total posts, 21 included positive feelings, such as gratitude (e.g., "I appreciate that hospital soooo much!"), pride (e.g., "So proud of him!"), and affection (e.g., "I love her so much!"). Negative emotions were also found in 17 posts, such as, "[Insurance issues] destroyed me!" and "But this week was just hard...conversations with teachers and coaches left me drained." Other users noted anxiety, such as "I worry about her getting hurt constantly." A few posts included both positive and negative emotions (n=2), such as when one adult with CFM posted: "As a child, I always wanted to wear my hair up. Now I think it's silly that I didn't, but I was always self-conscious. I wanted to be [character] for Halloween, but thought I couldn't because she wears her hair in a bun. This year I will be her - I will wear my hair half down and half up in bun. There are ways to make your dream happen. Don't let this syndrome stand in your way."

4. Discussion

Based on posts from two Facebook groups used by individuals with microtia and/or CFM and their families, the most common category of posts was the exchange of health-related information, followed by promotion of CFM events and awareness and sharing CFM-related experiences, which is consistent with previous studies [4-8]. These findings suggest a need for easily accessible CFM-related health education and provide insight for providers about the topics of interest to individuals with CFM and their families.

The majority of posts inquired about medical topics applicable for healthcare teams to address, such as orienting families to treatment plans across systems, surgical decision making, CFM etiology, hearing aid management, insurance advocacy, and access to school-based services. While there is no formal monitoring for accuracy, group forums offer direct access to a pool of people to address specific questions relatively quickly, with a high level of trust often placed on firsthand patient experiences [35]. In contrast, journal publications and online educational resources require greater effort to locate and understand, may not address relevant areas of concern, and are not interactive. Compared to online information, access to healthcare providers generally requires greater effort, financial cost, and time to be seen [1]. Additionally, when compared to the expected compassion of a group member, there may be variability across providers in empathy and communication skills to address patient and family concerns [36], which has been the focus of medical education based on the impact of patient satisfaction on a range of health outcomes [37-39].

Taken together, these points highlight the central role of social media in healthcare and, as has been recently discussed, otolaryngologists may find benefits from professional social media use [40, 41]. For example, providers may address questions and provide education as part of structured and moderated online forums with clearly delineated healthcare and legal responsibilities. Multicenter collaborations and professional organizations can produce comprehensive online patient educational materials that minimize the potential for bias that can present from a single provider or center, which are currently the majority of microtia websites [14]. The demands of busy clinics often limit the time available to spend with patients and their families. When it is not feasible to include comprehensive education in clinic, healthcare providers may consider offering vetted sources of online information assessed as reliable and discuss the variability of CFM-related treatment to help establish appropriate expectations. Promoting information of interest to the CFM community may also be shared as part of clinic visits or on professional websites; for example, information about National Microtia Awareness Day and National Craniofacial Acceptance Month.

The groups also served the key function of exchanging information based on firsthand experience, like what to ask at medical appointments and personal recommendations for providers and manufacturing brands, such as for hearing aids. Sharing CFM experiences, which were mostly positive messages, were a quarter of posts and the high ratio of "like" responses per post reflected social support and positive reinforcement from the group. Participation in a diagnosis-based social media community is associated with feeling less isolated and more hopeful, as well as more knowledgeable about their diagnosis and following up with their providers [42-44]. There were a small proportion of posts with negative emotion that elicited support from the community. From a provider perspective, these posts reinforce the importance of demonstrating awareness of the potential emotional impact of CFM on patients and families [21-28] and to have local and national resources and referrals prepared. Although the current methodology allowed for the capture of large amounts of real-time information, other modalities, such as interviews or surveys, must be considered in future studies to gain a fuller picture of patient's healthcare needs and information seeking behaviors. Input from providers about effective approaches and challenges in CFM healthcare would also be valuable. The accuracy of medical information shared in posts was not evaluated, which would be useful for future studies to evaluate. The sociodemographics of users was not available, which represents a design limitation. Additionally, the users were a self-selected group motivated to join a Facebook group that may not represent the larger CFM population and were limited to those who were English-speaking and with computer literacy.

Future research should continue to examine how patients and families can access healthcare information that is user-friendly, accurate, and of interest to the population, an assertion supported by previous research with patients with CFM and their caregivers [23]. Another potential area of study is how social media can be used in interventions to promote positive psychosocial outcomes [8].

5. Conclusions

Social media, and particularly Facebook, is a key resource for information and support for patients and families. Patients with microtia and/or CFM and their families who were members of two Facebook groups in the US and UK most often exchanged health-related information. The medical information group members sought is appropriate for providers to address and should be integrated in routine care as well as referring to local and online resources. Otolaryngologists and other healthcare providers who care for patients with microtia and CFM may consider opportunities for engaging in online patient health education and professional social media activity. **Acknowledgements:** We extend our gratitude to the Facebook groups who took part in this study. We also acknowledge the International Craniofacial Clinical Research Consortium for their contributions.

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