

Content Analysis of a Congenital Cataract Social Media Support Group

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Purpose: Social networking sites are an increasingly popular source of health information and a natural place for connection and support among patients and their loved ones. This study analyzes the content of a Facebook support group for congenital cataracts to understand the concerns, informational needs, and support-seeking behaviors in this community.

Methods: A qualitative evaluation was conducted on the Facebook group Children with Congenital Cataracts, the largest group for congenital cataracts on the platform. The most recent 150 discussion posts were selected for review. Posts were categorized into one of 5 themes: surgery, contact lens, disease related, tips/advice, and miscellaneous. Additional information recorded included the identity of the post's author (caregiver/patient) and level of engagement. Two investigators reviewed the posts.

Results: The majority of posters were mothers of children with congenital cataracts (142/150 or 94.67%), with two posts from adults with the condition. The average number of replies per post was 9 (range: 0–63). Posts with image attachments had more engagement in terms of reactions obtained compared to posts without images ($p = <0.001$). The majority of posts were questions, followed by news sharing. Discussion post topics fell under the following categories: tips/advice, surgery related, contact lens related, miscellaneous, and disease related. The most common topics within each category were questions regarding surgical complications ($n=12$, 8%), inserting and removing (usage of) contact lens ($n=12$, 8%), etiology of disease ($n=3$, 2%), and advice on patching ($n=13$, 8.67%) and glasses ($n=13$, 8.67%).

Conclusion: Awareness of the community and knowledge sharing in the online social space is important for pediatric cataract surgeons. Understanding parental knowledge gaps can help healthcare providers address concerns and improve patient education strategies. Community-driven resources, such as unused contact lens resale, highlight impressive grassroots efforts to assist in care.

Plain Language Summary: Parents of children with less common conditions such as congenital cataracts often turn to the internet for answers, support, and advice. One of the largest Facebook groups dedicated to this topic is Children with Congenital Cataracts, where caregivers share their experiences and ask questions. This study looked at 150 of the group's most recent posts to better understand what kinds of support parents are looking for and what concerns they commonly face. Most of the posts were written by mothers, and nearly all were focused on asking questions. Often, the questions were about surgery, using contact lenses, or how to manage daily care like patching and glasses. Posts that included images received more reactions and likes, showing that visuals may help others connect or offer support. Some parents also used the group to share news, explain their child's diagnosis, or offer tips that have helped them. By learning more about what parents talk about in online spaces like this, healthcare providers can better understand the kinds of challenges families face and what information they may be missing. Doctors and care teams can then use this insight to improve how they communicate with families and support them over time. This study also showed how families help one another directly, demonstrating how powerful online communities can be in filling gaps in care.

Keywords: congenital cataracts, childhood cataracts, cataract surgery, caregiver experience, facebook, peer support, social media

Introduction

Congenital cataracts present at birth or develop in early infancy and are a rare but serious cause of childhood visual impairment, with an estimated global prevalence of between 1 and 15 per 10000 children.¹ Early diagnosis and timely

surgical intervention are essential to prevent amblyopia and promote normal visual development. However, postoperative care can be complex and prolonged, often involving patching regimens, contact lenses, or aphakic spectacle use, and frequent follow-up visits. For parents, navigating the emotional and logistical demands of this diagnosis can be challenging and isolating, especially when facing uncertainties about treatment options and long-term outcomes.

In response to these challenges, many caregivers seek information and community through social media platforms. In a systematic review of social media in child health, users, especially older children and parents, were most drawn to the ability of social media to facilitate the development of a support network. This need for connection highlights the valuable role social media can play, though effectiveness in improved health outcomes was not shown.² Social media platforms like Facebook have emerged as accessible online spaces for peer support, resource sharing, and open discussion among families facing similar medical conditions, such as congenital anomalies.³

Studies exist focusing on ophthalmology-related content on social media. Misinformation has been a growing concern, as it has been reported that most ophthalmology content on Instagram is authored by non-ophthalmologists.⁴ Unmoderated social media sites have been shown to contain more misleading information, especially regarding non-evidence-backed therapies/treatments.⁵ At the same time, online forums allow patients to communicate with peers and share their experiences, offer support, learn about conditions like glaucoma and its treatment and management strategies.⁵

Despite their wide-spread use by caregivers, few studies have explored how platforms like Facebook function in the context of pediatric ophthalmic conditions. One study on parents of children with congenital cataracts found significant improvements in reported parental anxiety, knowledge, and satisfaction with the use of an interactive, multifaceted education approach, which incorporated various technology-based activities including video and social media.⁶ Although not focused on social media, the value of accessible, interactive, and peer-led resources was highlighted. Understanding the types of information shared in these online spaces can provide valuable insights into the unmet needs, concerns, and priorities of caregivers. It may also reveal knowledge gaps that could be addressed by clinicians and public health professionals through more focused counseling.

This study aims to conduct a content analysis of posts within a Facebook group focusing on the themes of discussion, frequency of specific topics, and the ways in which caregivers use the platform to seek and offer support. By characterizing the content of this digital community, we hope to inform future patient education efforts and strengthen clinician–family communication surrounding the diagnosis and management of congenital cataracts.

Methods

Using Facebook’s built-in search engine and the term “congenital cataracts”, the largest group was identified based on the number of members. The Facebook group *Children with Congenital Cataracts* was selected for content analysis. The last 150 posts under the Discussion tab were extracted on November 29, 2024, with the oldest post being published on October 22, 2024 and these posts were aggregated into Microsoft Excel. A descriptive content analysis of posts and discussions within the support group was conducted. A thematic analysis was employed using an inductive approach and posts were systematically categorized based on recurring topics identified by the study team, which were the following: surgery, contact lens, disease related, tips/advice, and miscellaneous. Within each theme, posts were further classified into broad categories. Advice related posts included questions on surgeon selection, use of eye drops, patching, and social resources and services. The surgery related questions were broadly focused on surgery complications, questions for during the postoperative period, the experience of and expectations related to surgery, and questions from people considering surgical intervention. Posts related to contact lenses were often regarding cleaning, usage, and acquiring them. Disease related questions included etiology related posts asking if there have been associations between congenital cataracts and other factors, such as alopecia, exposure to mold, and preventative asthma inhalers. Miscellaneous posts consisted of parents sharing news, progress, or pictures. Posts in the Facebook group were evaluated by two reviewers (A.Z. and C.L.K.). Posts were reviewed in their original format within the group (including text, images, and comments). Each post was coded according to parameters including (1) content category, (2) presence of images or multimedia, and (3) level of engagement (number of likes, comments; this closed Facebook did not allow for shares). Discrepancies in coding were resolved through discussion, and consensus was reached for all posts. Statistical analysis of engagement levels was performed using the Mann–Whitney U-test (Table 1).

Table 1 Levels of Engagement in Posts with and without Images

Engagement Type	Image (n=52)	No Image (n=97)	P Value
Likes	17.8	2.0	1.48E-06
Comments	10.7	10.3	0.58

This study was approved by the Johns Hopkins Institutional Review Board (IRB00358503). Explicit permission was sought and granted from the group moderator to access and use the data for research purposes on August 23, 2023 using the Messenger application. Research concepts and goals were explained, and all questions were answered. No personally identifiable information was collected, and no posts are being published. Stipulations from both the IRB and Facebook were adhered to. Informed consent was waived given the nature of the social media platform.

Results

Created in 2010, *Children with Congenital Cataracts* is a group for parents of children with congenital cataracts. To share ideas and help each other deal with children who have congenital cataracts, and how to cope with the challenges that this condition brings.

At the time of the data search, the group had 111 posts in the preceding month, and 13 new members in the preceding week. Among the posts reviewed, the majority of authors were mothers of children with congenital cataracts (142/150 or 94.7%), with two posts from adults with the condition and four from fathers.

Most posts were questions, followed by news sharing. The poll feature on the platform was utilized once to survey members on when they found out their child had congenital cataracts: there were 342 votes, with 35% responding “at birth” and 27% responding “after discharge.” The latest age of diagnosis based on the poll was 3 years old, with 1% of respondents selecting that as the answer.

Discussion post topics fell under five categories (Figure 1). Advice related posts made up 42.7% of the posts that were evaluated. The surgery related questions were broadly focused on surgery experience, complications, and questions regarding the postoperative period and from those still considering surgical intervention. The cleaning, usage, and acquisition of contact lenses made up another category. Disease related questions (n = 5) included etiology related posts asking if there have been associations between congenital cataracts and other factors. Two posters asked about the need for genetic testing and seeing a geneticist based on what their doctor has told them. Overall, the most common questions that

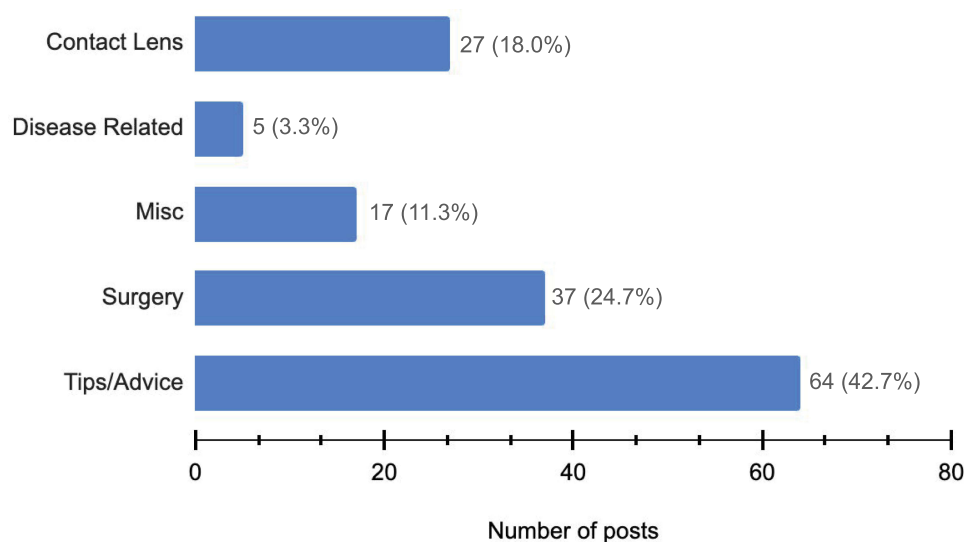


Figure 1 Themes of discussion posts in the congenital cataracts Facebook group.

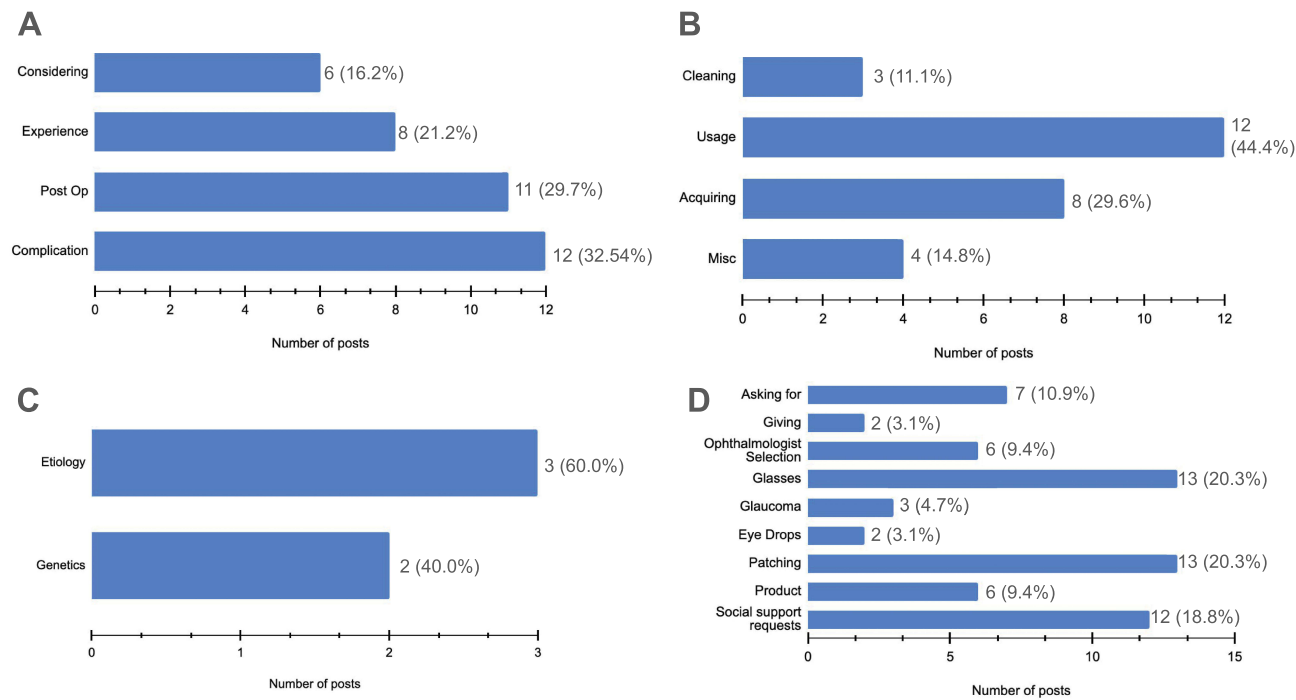


Figure 2 Common topics discussed within each theme in the congenital cataracts Facebook group. Popular types of questions are illustrated, including (A) surgery, (B) contact lens use, (C) disease-related concerns, and (D) tips and advice.

were posted in the group were advice on glasses and patching compliance (Figure 2). Images were most often attached to posts that were sharing news ($n = 10$) or that fell under the category of questions related to complications ($n = 6$).

The average number of replies per post was 9 (range: 0–63). 34.9% of posts in the group had images attached (Table 1). When assessing engagement in terms of the likes the post obtained (considered a proxy for “engagement”), posts with image attachments compared to posts without images (mean = 17.8 vs 2.0) had significantly more engagement ($p < 0.001$). No significant differences were observed when comparing the number of comments or replies to posts with images vs without images ($p = 0.580$). When engagement was stratified by discussion topic, the highest number of likes were observed in posts in the miscellaneous category that were news sharing ($n = 734$), while the greatest number of comments occurred in posts related to patching ($n = 164$) (Table 2). Overall engagement, measured as the sum of likes and comments, was greatest for posts on sharing news ($n = 893$), surgical complications ($n = 197$), and advice on patching ($n = 187$).

Table 2 Number of Posts with Image Attachments and Engagement Metrics by Theme

	Images		Engagement		
	No	Yes	Likes	Comments	Total
Surgery	23	14	81	369	450
Considering	6	0	5	47	52
Experience	5	3	15	53	68
Post Op	6	5	19	114	133
Complications	6	6	42	155	197

(Continued)

Table 2 (Continued).

	Images		Engagement		
	No	Yes	Likes	Comments	Total
Contact lenses	20	7	25	222	247
Cleaning	3	0	1	44	45
Usage	11	1	14	80	94
Acquiring	5	3	1	35	36
Misc	1	3	9	63	72
Disease related questions	2	3	42	85	127
Etiology	1	2	0	11	11
Genetics	1	1	42	74	116
Tips	48	16	231	709	940
Asking for	5	2	11	112	123
Giving	1	1	109	62	171
Ophthalmologist Selection	4	2	20	65	85
Glasses	9	4	10	80	90
Glaucoma	3	0	5	41	46
Eyedrops	2	0	2	26	28
Patching	10	3	23	164	187
Product	4	2	14	51	65
Social support	10	2	37	108	145
Misc (sharing news)	4	12	734	159	893

Discussion

This content analysis of the *Children with Congenital Cataracts* Facebook group highlights the central role that social media plays in providing support, guidance, and community for caregivers navigating a rare and complex pediatric condition. The majority of posts were authored by mothers, and most centered on practical advice, surgical concerns, and challenges related to contact lens use—underscoring the real-world difficulties families face after diagnosis and treatment.

The level of engagement and the use of interactive features such as polls demonstrate the group's utility in providing peer support, disease specific information, and practical advice. Stratification of engagement by discussion topic highlights how different content resonated with group members. Posts involving personal experiences (sharing news) generated the most likes, reflecting strong peer support and solidarity. High overall engagement with sharing news, surgical complications, and patching underscores the dual role of the group in providing both emotional support and practical guidance. This supports other studies that have shown that many parents turn to social media, especially Facebook, to connect with other families and share experiences, providing not only emotional support but also advice and information that enhances their understanding and confidence in addressing their child's condition.^{7,8} The utility of social media in health care for parents of children with rare diseases is especially important given the isolation, stress, and lack of readily available resources and information for rare conditions.⁹

Understanding the commonly discussed topics within the Facebook group can help inform providers on the concerns and difficulties that children with congenital cataracts and their parents face. Many families struggle to achieve the prescribed hours of patching for their child with amblyopia, and the advice and solidarity provided by an online community has the potential to improve compliance. Some reasons for issues with compliance include skin irritation, social stigma, and lack of cooperation from the child.¹⁰ Among children with unilateral cataracts, high levels of maternal stress have also been associated with decreased patching adherence.¹¹ An online social network group offers a supportive community that can alleviate medical care-related

stress and offer productive. Supporting this idea, there was high engagement with content related to patching and emphasis among the comments the importance of consistent patching despite its challenges as well as helpful tips and encouragement.

Members of the group were also enthusiastic about offering recommendations for specialists and sharing their experiences with those in need of a pediatric cataract surgeon. There are marked disparities in access to pediatric ophthalmological care, with up to 90% of US counties with no pediatric ophthalmologist.¹² Furthermore, while all pediatric ophthalmologists can diagnose cataracts in children, not all of them perform cataract or glaucoma surgeries and in some practices, the surgeon does not perform postoperative glasses or contact lens management, necessitating additional appointments with partnering optometrists. This online community offers a network that can be theoretically advantageous for families relocating and living in smaller cities to find an eye care provider comfortable with their child's unique needs. It prepares families for preferred practice patterns of one surgeon compared to another practice, allowing caregivers to anticipate what to expect when meeting a new doctor.

Another offering in this Facebook group is contact lens resale, serving as a marketplace for people to pass on unused lenses that their child may have outgrown. Given the supply shortage of the popular SilsoftTM aphakic contact lens, its high cost, and variable insurance coverage, the creation of a social media marketplace is a unique offering for those in the rare disease community.

While social media is an important resource for parents seeking supplemental health information, turning to platforms like Facebook should not take the place of medical advice or seeing a physician. The administrators in the group list this as a rule, reminding members that parents are sharing their own unique experiences in the group and that they should ultimately contact their doctor for medical advice. Furthermore, all posts are screened and need to be approved before being posted. Administrators of the Facebook group help ensure that medical advice related questions with no mention of plans to consult a health provider do not get posted to the page. While advice was offered, often providing medical guidance, these comments were always followed by recommendations to see their ophthalmologist. Although the quality of information should always be a concern when evaluating social media-based medical content, providers seeking to support and educate parents should also recognize the emotional support and community-building that online platforms can provide.

One study found that almost 70% of parents used social media for health information, but only half of parents discussed information from social media with their physician.¹³ The benefit for health care professionals to engage with these online platforms is an area for future investigation. The potential benefits include more directly assessing the informational needs of this population and promoting accurate information sharing; however, without access to each child's medical history there are limits to what can be offered.

This study is limited by its short time frame and focus on a single social medial platform, capturing only a snapshot of the caregiver experiences and information exchange within the online community. As a result, these findings may not fully represent the dynamic nature of online exchanges or the diversity across forums and platforms. This also only captures one support group for one specific ophthalmic condition and therefore is biased towards the views of the moderators and participants. This group had strict rules preventing the discouraging of members from seeking established medical treatments, but that may not be true for all social media groups and platforms. Future research could expand to include a longer time frame across more social media platforms to gain a more comprehensive understanding of how caregivers seek and share support.

Conclusions

Awareness of the community and knowledge sharing in the online social space is important for pediatric cataract surgeons. By examining the experiences and conversations within this online community, we aim to shed light on the real-world questions and concerns parents face, and how social media serves as a tool for navigating a complex and lifelong pediatric condition. Community-driven resources, such as unused contact lens resale, highlight impressive grassroots efforts to assist in care. These findings may inform future directions in patient education and support resource development for families affected by congenital cataracts.

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Disclosure

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