



# Social media communities for patients and families affected by congenital pediatric surgical conditions

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## Abstract

**Background** Social media has become a means to allow individuals affected by rare diseases to connect with others. This study aimed to characterize the use of three popular social media platforms by individuals affected by common pediatric surgery index conditions.

**Methods** A systematic search of Instagram, Facebook, and Twitter was performed using standardized terms for the following pediatric surgical conditions: anorectal malformation, biliary atresia, bronchopulmonary sequestration, congenital diaphragmatic hernia (CDH), congenital pulmonary airway malformation, duodenal atresia, esophageal atresia/tracheoesophageal fistula (EA/TEF), gastroschisis, Hirschsprung disease (HD), and omphalocele. Accounts active within the last year were analyzed and assessed.

**Results** A total of 666 accounts were identified. Instagram was the most common platform, but accounts dedicated to support and story sharing were most common on Facebook. Biliary atresia and CDH had the largest communities identified. Support groups were most common among those dedicated to EA/TEF (43.3%,  $p < 0.001$ ). Most accounts were created by parents, but accounts dedicated to HD had the greatest proportion founded by patients (22.4%,  $p = 0.04$ ).

**Conclusions** Social media use is common among patients and families affected by congenital surgical conditions. Certain diseases have larger communities and support networks. Knowledge about their existence may allow surgeons to direct patients towards supportive communities and resources.

**Level of evidence** IV.

**Keywords** Neonates · Infants · Index pediatric surgeries · Social media

## Abbreviations

AAP	American Academy of Pediatrics
AMA	American Medical Association
ARM	Anorectal malformation
BPS	Bronchopulmonary sequestration
CDH	Congenital diaphragmatic hernia
COMIRB	Colorado Multiple Institutional Review Board

CPAM	Congenital pulmonary airway malformation
EA/TEF	Esophageal atresia/tracheoesophageal fistula
HD	Hirschsprung disease
IQR	Interquartile range

## Introduction

Social media has emerged in recent years as an interactive platform for individuals to gain knowledge, seek medical advice, and share personal experience about their own or their family member's medical conditions [1–3]. There has been a recent interest in studying patient engagement on social media. Of substantial concern is the spread of health-related misinformation and the reliance upon social media for medical information in lieu of medical resources [4, 5]. However, social media does have positive effects, specifically through the creation of online support groups, which have been shown to create a sense of community and

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improve health literacy for patients [6–9]. For those individuals affected by rare medical conditions, connecting with others who are experiencing similar concerns and challenges within their direct community is difficult, but the availability of online platforms has allowed for the creation of these important connections [10].

Many surgical problems that are diagnosed prenatally or in the neonatal period and addressed by pediatric general surgeons are rare. Though rates vary based on the specific surgical condition, they generally range from 1:2000 to 1:5000 [11]. With advances in prenatal testing and imaging, some of these conditions can be identified before birth of the fetus, which has the advantage of preparing patients and their families for expectations during the first days, weeks, and months of life. However, some patients are diagnosed after birth. Regardless of the time of diagnosis, it is known that parents of sick neonates feel isolated and poorly supported [12].

In most cases, parents are usually the primary caregivers of their children, and there is growing evidence that the condition of parents both directly and indirectly affects the health and wellbeing of their affected child [6, 13, 14]. Social support is proven to be protective of distress and has been studied in a variety of illnesses and conditions [4, 14, 15]. Social media has been studied previously to show that it allows for the existence of supportive social networks for individuals affected by congenital anomalies [3, 6, 16].

Research has shown that there is a strong online community for individuals affected by pediatric colorectal problems [3]. However, there are a variety of other congenital anomalies treated by pediatric surgeons that also require lifelong multidisciplinary care. The purpose of this study was to perform a quantitative and qualitative analysis of three popular social media platforms to characterize the use of social media among patients and their families with a variety of congenital pediatric surgery problems. We hypothesize that social media platforms provide a substantial source of supportive communities for patients and their families, but such communities may differ based on disease type.

## Methods

### Search strategy and data collection

All information collected for analysis was publicly available and no personal information was recorded. The Colorado Multiple Institutional Review Board (COMIRB) deemed this research study exempt, and no institutional review board approval was required.

Social media platforms reviewed in this study included Facebook, Twitter, and Instagram. These platforms were selected because they are commonly used by patients and

families of a variety of medical conditions. [1–3, 17] Though they function differently, and Facebook is the only platform with the functionality for dedicated groups and pages that multiple members can join, they all allow for sharing of information and interaction between users. A systematic search was performed on all social media platforms using standardized search terms for the following pediatric surgical conditions and associated index operations: “anorectal malformation” (ARM), “Posterior sagittal anorectoplasty” (PSARP), “biliary atresia”, “Kasai procedure”, “bronchopulmonary sequestration” (BPS), “congenital diaphragmatic hernia” (CDH), “congenital pulmonary airway malformation” (CPAM), “duodenal atresia”, “esophageal atresia/tracheoesophageal fistula”(EA/TEF), “gastroschisis”, “Hirschsprung disease” (HD), “pull-through”, and “omphalocele”. Both standard searches and hashtags of these search terms were utilized. These conditions were selected by the authors as they are the result of a congenital anomaly diagnosed prenatally or in the neonatal period and are often isolated anomalies in otherwise healthy infants. All online searches were conducted during September 2021 in English and analyzed by a single research member to maintain consistency. Accounts with activity within the last year were included in analysis. To maximize the most active accounts, Facebook groups and pages with less than 100 members or followers and Twitter accounts with less than 50 followers were excluded. Given the lack of previous studies on Instagram, no cut-off was applied to these types of accounts. As the analysis of social media is still in its infancy in pediatric surgery, we drew on the methodology of other studies in other disciplines to determine these cut-offs [1–3].

### Categorization and thematic analysis

Each social media account was assigned a functional category based on activity, but, due to the aim of this study to specifically characterize caregiver and patient social media involvement, only general information, personal story, or supportive/sharing accounts were included. Definitions and examples of each category are presented in Table 1. Functional categories have only been used once in the pediatric surgery literature but are based on and adapted from functional categories previously published in social media studies on different medical topics [1–3]. A significant number of social media accounts utilized by patients and parents were identified as being used for fundraising purposes, so this functional category was created and retrospectively applied to all relevant accounts.

### Quantitative data collected

Accounts were classified by platform. Facebook groups were divided into public or private groups. Due to the number of

**Table 1** Functional categories of social media accounts included in study

Category	Definition	Examples
General information	Communication for general information to promote awareness and education about a pediatric condition	Facebook page promoting awareness about congenital diaphragmatic hernia by providing articles and links to medical information for families and patients Twitter account promoting awareness and understanding for individuals born with anorectal malformations
Personal story	Content dedicated to a single individual’s personal journey with disease process	Instagram account dedicated to journey of infant with biliary atresia managed by patient’s mother Facebook page managed by parents sharing story of baby born with gastroschisis and his medical journey into childhood Twitter account managed by individual sharing personal story of experience living with Hirschsprung disease
Supportive/story sharing	Multiple members of specific disease community generate content sharing personal experience and provide support to each other	Private Facebook support group for parents of babies born with EA/TEF in the US Private Facebook support group for parents of babies born with biliary atresia in Australia
Fundraising	Account created to raise funds to support patient’s medical costs associated with disease	Private Facebook support group for adults living with Hirschsprung’s disease Facebook page dedicated to raising funds for baby born with omphalocele Instagram account sharing medical information about baby born with biliary atresia and requesting donations for medical expenses

private accounts that do not allow members of the medical community to join, a request was not made to join the group. Only publicly available data were collected for these accounts, which includes descriptions of account purposes and information shared, country of origin, and details of founding members. Quantitative data were collected including type of social media platform, number of members of a Facebook group, number of “likes” for a Facebook page, number of followers for Instagram and Twitter accounts, number of Tweets for a Twitter account, number of posts on Instagram, and country of origin. Account activity was grouped by likes, tweets, and posts for analysis. Each account was assigned information sources by the abstractor based on identifying information: medical institution, healthcare provider, company, nonprofit organization, support group, or personal account, as consistent with prior studies [1, 2]. Furthermore, the founding individual(s) of each account was categorized as a parent, patient, or healthcare provider, if such information was available. Accounts that were self-categorized as “adult support groups” were also indicated.

**Statistical analysis**

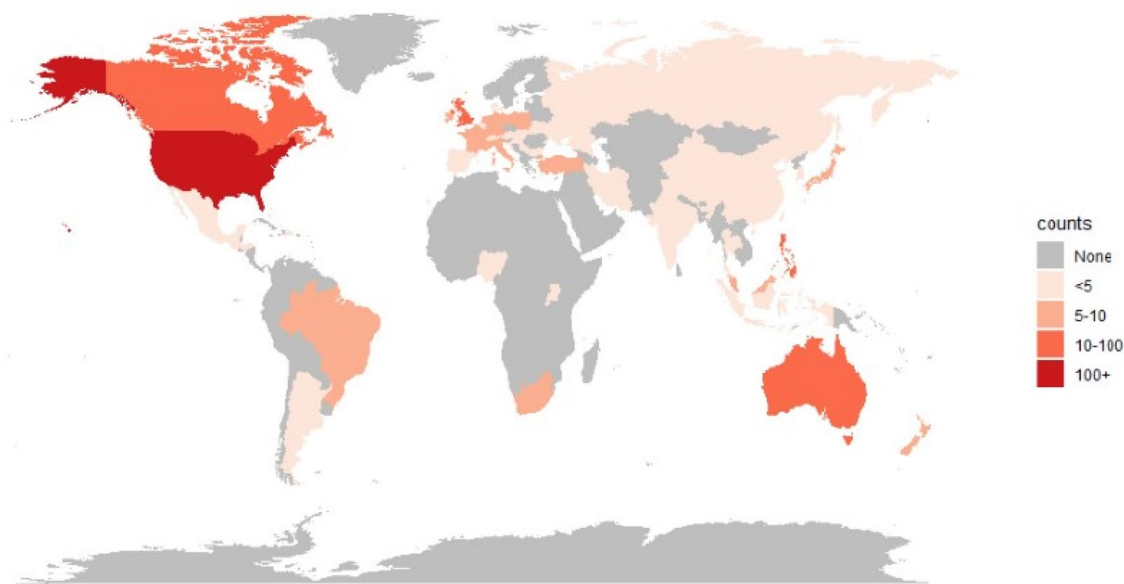
Descriptive statistics were summarized for continuous variables with medians and interquartile ranges (IQR) and for categorical variables with frequencies and proportions. Group differences are tested via *t*-test or Kruskal–Wallis test for continuous variables and Chi Squared test or Fisher’s Exact tests for categorical variables. If an overall significant difference was observed, pairwise comparisons were made with Bonferroni adjustment for multiple comparisons. Missing data were treated as missing at random. Significance was set at 0.05. Data analyses were conducted using R version 3.4.1 software (R Foundation for Statistical Computing, Vienna, Austria, <http://www.R-project.org/>).

**Results**

**Overall cohort**

There were 666 active accounts identified. The most common social media platform used was Instagram (54.6%). Accounts were identified in 49 different countries (Fig. 1). The most common countries of origin were the United States (337), United Kingdom (68), Canada (35), and Australia (25). All remaining countries had less than 15 accounts identified. Country of origin could not be identified for 46 (6.9%) accounts.

The most common information source was personal account (74.5%). Instagram had the greatest proportion of personal accounts (94.2%) compared to Facebook (50.7%)



**Fig. 1** Geographic heat map of social media accounts, by density

and Twitter (54.2%) ( $p < 0.001$ ). Parents were the most common founders of accounts overall (82.9%). This remained true regardless of platform (Table 2).

The most common functional category overall was personal story (73.3%), which was more common on Instagram (92.9%) compared to Facebook (49.6%) and Twitter

(52.5%) ( $p < 0.001$ ). Facebook had the greatest proportion of supportive/story sharing accounts (48.2%) compared to Instagram (7.1%) and Twitter (45.1%) ( $p < 0.001$ ). There were 45 (6.8%) accounts that were identified as fundraising accounts. The proportion of these was highest among Facebook accounts (9.4%) compared to Instagram (4.7%) and Twitter (8.3%) ( $p = 0.05$ ).

**Table 2** Characteristics of analytic cohort by social media platform

	Facebook ( $n = 278$ )	Instagram ( $n = 364$ )	Twitter ( $n = 24$ )	Total ( $n = 666$ )	$p$ value
Number of followers	451.5 (231.5, 1145.2)	542.0 (237.5, 1135.5)	398.0 (203.0, 1554.5)	482.0 (233.2, 1144.8)	0.886
Information source					
Medical institution	1 (0.4%)	0 (0.0%)	0 (0.0%)	1 (0.2%)	0.465
Nonprofit organization	26 (9.4%) <sup>a</sup>	14 (3.9%) <sup>b</sup>	10 (41.7%) <sup>c</sup>	50 (7.5%)	<0.001
Support group	110 (39.6%) <sup>a</sup>	7 (1.9%) <sup>b</sup>	1 (4.2%) <sup>b</sup>	118 (17.7%)	<0.001
Personal account	141 (50.7%) <sup>a</sup>	343 (94.2%) <sup>b</sup>	13 (54.2%) <sup>a</sup>	496 (74.5%)	<0.001
Functional category					
General information	44 (15.8%) <sup>a</sup>	13 (3.6%) <sup>b</sup>	12 (50.0%) <sup>c</sup>	69 (10.4%)	<0.001
Personal story	138 (49.6%) <sup>a</sup>	338 (92.9%) <sup>b</sup>	13 (54.2%) <sup>a</sup>	488 (73.3%)	<0.001
Supportive/story sharing	134 (48.2%) <sup>a</sup>	26 (7.1%) <sup>b</sup>	11 (45.8%) <sup>a</sup>	171 (25.7%)	<0.001
Fundraising	26 (9.4%)	17 (4.7%)	2 (8.3%)	45 (6.8%)	0.050
Founder type					
Parent	225 (80.9%) <sup>a</sup>	318 (87.4%) <sup>a</sup>	10 (41.7%) <sup>b</sup>	552 (82.9%)	<0.001
Patient	37 (13.3%)	32 (8.8%)	4 (16.7%)	73 (11.0%)	0.107
Healthcare worker	4 (1.4%)	0 (0.0%)	0 (0.0%)	4 (0.6%)	0.075
Adult support group	12 (4.3%) <sup>a</sup>	1 (0.3%) <sup>b</sup>	0 (0.0%) <sup>b</sup>	13 (2.0%)	0.002

Variables are reported as frequency (%) and tested via Fisher's Exact or Chi-Square Test; pairwise significant differences are represented by differing letter superscripts (a,b,c)

## Facebook

There were 278 Facebook accounts identified. Of these, 154 (55.4%) were Facebook pages, and 124 (44.6%) were Facebook groups. The median (IQR) number of followers was 451.5 (231.5, 1145.2). The most common types of accounts were personal story (49.6%) and supportive/story sharing (48.2%). The most common surgical disease addressed was biliary atresia with 34.9% (97) accounts dedicated to this problem. Both BPS/CPAM and duodenal atresia only have one active account on Facebook (Table 3). Among the Facebook accounts, 4.3% (12) were identified as adult support groups.

## Instagram

Instagram was the most common platform with accounts for patients and families. The median number of followers of these accounts was 542.0 (237.5, 1135.5). The most common functional category identified was personal story (92.9%). These accounts were most commonly managed by parents (87.4%). The largest proportion of these accounts were dedicated to CDH (26.9%) and biliary atresia (23.9%).

## Twitter

Twitter was the least frequently used social media platform by patients and their families with only 24 (0.3%) accounts identified. The median number of followers was 398.0 (203.0, 1554.5). The most common source was personal account (54.2%). Though personal story was the most common function category (54.2%), there was a similar proportion of general information accounts (50.0%). Anorectal malformations were the most common disease addressed on Twitter (29.2%). There were no accounts dedicated to BPS/CPAM, duodenal atresia, or omphalocele identified on Twitter.

## Analysis by disease

The most represented surgical disease on social media was biliary atresia (27.8%,  $n = 185$ ) followed by CDH (22.7%,  $n = 160$ ). BPS/CPAM was the least represented surgical disease on social media, comprising 0.8% (5) of all accounts. Duodenal atresia accounts had the greatest median number of followers 974.0 (394.5, 3108.5) ( $p = 0.002$ ). For every disease type, over half of accounts were dedicated to personal stories, with the greatest proportion among accounts for duodenal atresia (94.7%; 18 of 19) and biliary atresia (87.6%; 162 of 185). EA/TEF accounts had the greatest proportion of support groups (40.0%; 24 of 60), followed by HD accounts (36.2%; 21 of 58) ( $p < 0.001$ ). There were no differences in rates of accounts identified as fundraising accounts.

## Analysis by founder type

Founder type was identified for 94.4% (629) of accounts. Parents more commonly managed social media accounts regardless of platform. However, Twitter had the smallest proportion of accounts managed by parents (41.7%) compared to Facebook (80.9%) and Instagram (87.4%) ( $p < 0.001$ ). There were no differences in proportion of accounts managed by patients based on platform. When stratifying by disease, Hirschsprung disease had the greatest proportion of accounts managed by patients (22.4%) followed by ARM (19.4%) ( $p = 0.005$ ).

Adult support groups were identified among accounts dedicated to Hirschsprung disease, EA/TEF, biliary atresia, omphalocele, gastroschisis, and CDH. Accounts dedicated to EA/TEF had the greatest number of adult support groups (4). There were no adult support groups identified for duodenal atresia, or CPAM/BPS.

**Table 3** Frequency of representation of congenital diseases, stratified by social media platform

	Facebook ( $N = 278$ )	Instagram ( $N = 364$ )	Twitter ( $N = 24$ )	Total ( $N = 666$ )	$p$ value
Anorectal malformation	13 (4.7%) <sup>a</sup>	17 (4.7%) <sup>a</sup>	7 (29.2%) <sup>b</sup>	36 (5.4%)	<0.001
Biliary Atresia	97 (34.9%) <sup>a</sup>	87 (23.9%) <sup>b</sup>	1 (4.2%) <sup>b</sup>	185 (27.8%)	<0.001
BPS/CPAM	1 (0.4%)	4 (1.1%)	0 (0.0%)	5 (0.8%)	0.494
CDH	48 (17.3%) <sup>a</sup>	98 (26.9%) <sup>b</sup>	5 (20.8%) <sup>ab</sup>	151 (22.7%)	0.014
Duodenal Atresia	1 (0.4%) <sup>a</sup>	20 (5.5%) <sup>b</sup>	0 (0.0%) <sup>ab</sup>	21 (3.2%)	<0.001
EA/TEF	35 (12.6%) <sup>a</sup>	24 (6.6%) <sup>b</sup>	1 (4.2%) <sup>ab</sup>	60 (9.0%)	0.026
Gastroschisis	33 (11.9%)	68 (18.7%)	5 (20.8%)	106 (15.9%)	0.032
Hirschsprung disease	35 (12.6%) <sup>a</sup>	17 (4.7%) <sup>b</sup>	6 (25.0%) <sup>a</sup>	58 (8.7%)	<0.001
Omphalocele	18 (6.5%)	35 (9.6%)	0 (0.0%)	52 (7.8%)	0.150

Variables are reported as frequency (%) and tested via Fisher's Exact or Chi-Square Test; pairwise significant differences are represented by differing letter superscripts (a,b,c)

## Discussion

This study reveals that social media use is frequent among patients and families affected by congenital surgical conditions. Instagram was the most utilized social media platform, most commonly for personal story sharing, but Facebook had the greatest proportion of support groups. These platforms serve multiple functions, allowing for patients and their families to connect, share information, and even raise money for medical treatments. Certain diseases, such as biliary atresia and CDH, have larger communities and supportive networks, including those which are patient-driven.

The impetus for this research is related to our findings of social media use among the pediatric colorectal community. Prior research found that this community is very active on social media. Members of this community use social media in different ways, but notably, over two-thirds of the accounts within this community are categorized as “personal story” or “supportive/story sharing” [3]. The implications of being born with a congenital colorectal condition are well-recognized with patients and caregivers known to be at risk for impaired psychosocial functioning [6]. However, social support is known to be protective of distress. Given that many of the challenges of living with a congenital colorectal condition are shared by patients born with other congenital surgical diseases, it was of interest to investigate the utilization of social media for social support by caregivers and patients affected by other pediatric surgical conditions.

The use of social media in relation to rare surgical congenital anomalies is not well studied, but it is known this community feels they lack support provided by their current healthcare services and rely on social media as a platform to seek medical advice from individuals affected by similar conditions [16, 18]. This is especially true for rare pediatric diseases, for whom patients and caregivers may never meet another affected by the same condition [19, 20]. It is known that social media is a widely used tool by individuals affected by rare conditions to connect with others affected by the same condition [19]. Interestingly, some conditions were identified to have a more active presence on social media, with the most accounts dedicated to biliary atresia, CDH, and gastroschisis. Why some communities are more represented on social media than others were beyond the scope of this study, but these differences may highlight conditions that lack supportive communities overall and require increased resource allocation.

Our study showed that a variety of congenital surgical diseases are represented on social media, and that all these diseases had at least one social media account that were categorized as “supportive/story sharing.” This not only

underscores the importance of supportive communities for individuals affected by these conditions but also the need for them. Knowledge of their existence may allow healthcare providers to inform patients who seek supportive communities and resources that such communities exist. For parents of newborns with a congenital disease, being able to talk, see, and learn from an adult born with the same condition is an invaluable source of information that no healthcare provider could offer. Overall, 11.0% of the accounts were identified to be created by a patient, and, further, this study identified thirteen support groups dedicated to adults living with these conditions. These groups represented all conditions included in the study except for duodenal atresia and CPAM/BPS. Many congenital anomalies are associated with long-term morbidity and problems can persist beyond childhood. As children with congenital surgical diseases age, the need for transitional care from pediatrician to adult practitioners has been well-documented [21–23]. It is also known, however, that gaps in the transition to adult care exist for these patients [22]. It is possible that these online communities can serve an important role for such individuals and their parents, to not only provide supportive communities for adults born with congenital anomalies, but to also direct those in need of care to appropriate resources.

With any study on social media, it is important to address the ethical questions related to information sharing on the internet, specifically the concerns for sharing of erroneous information. Information shared on social media platforms is not subject to the same standards of information published in peer-reviewed medical journals or sources, and social media is known to be characterized by misinformation [5]. We have identified and provided a list of supportive groups, founded by both individuals and non-profit organizations, on social media that are active and have high membership that may benefit patients and their families (Table 4). However, as the purpose of this study was to identify the existence of supportive communities for patients and families, our study did not assess the validity or quality of the information shared by these social media accounts, but we recognize that false information is shared on social media accounts. Given the dangers and risks associated with false medical information and associated stress it may cause patients and their families, we caution that these resources not serve as a substitution for information from trusted medical sources, but instead offer a different resource a healthcare provider cannot provide. It should be noted that direct healthcare provider involvement in online support groups for patients and parents may undermine the supportive aspect these communities provide and, further, that moderation by a healthcare provider may never be feasible nor expected. However, awareness of these communities can ensure that doctors counsel their patients about the risks of misinformation sharing and emphasize

**Table 4** Examples of Informative and Supportive Groups Identified on Social Media

	Account name (platform)	
	Patient/family-driven	Non-profit
Hirschsprung's disease	Hirschsprung's disease families & friends (Facebook) <sup>a</sup> Hirschsprung's disease help group (Facebook)* Hirschsprung's disease family support UK (Facebook) <sup>a</sup> Adults with Hirschsprung's (Facebook) <sup>a,b</sup>	Research, Education & Awareness for Children with Hirschsprung Disease (REACH) (Facebook/Instagram) Pull-Thru Network (Facebook)
Biliary atresia	Biliary Atresia families. Pre and post transplant (Facebook) <sup>a</sup> Adult Survivors of Biliary Atresia (Facebook) <sup>b</sup>	Children's Liver Disease Foundation (Facebook/Twitter/Instagram) BAaware Biliary Atresia (Facebook)
EA/TEF	Kids born with Tracheoesophageal Fistula (TEF) & Esophageal Atresia (EA) (Facebook) <sup>a</sup> Esophageal Atresia/Tracheoesophageal Fistula (Facebook) <sup>a</sup> Esophageal Atresia—Tracheoesophageal Fistula Born unable to swallow (Facebook) <sup>a</sup>	Esophageal Atresia Global Support Groups (EAT) (Twitter)
Anorectal malformation	Imperforate Anus USA Support Group (Facebook) <sup>a</sup> Imperforate Anus/Anorectal Malformation International Support Group (Facebook) <sup>a</sup>	ONE in 5000 Foundation—Imperforate Anus/Anorectal Malformation (Facebook/Twitter) Pull-Thru Network (Facebook)
Omphaloceles	Mothers of Omphaloceles (Facebook) <sup>a</sup> Adult Omphalocele Survivors and Moos with Future Concerns (Facebook) <sup>a,b</sup>	
Gastroschisis	Gastroschisis Support Group (Facebook) <sup>a</sup> Gastroschisis Babies UK (Facebook) <sup>a</sup> Gastroschisis Answers from Survivors (Facebook) <sup>a,b</sup>	The Global Gastroschisis Foundation (Facebook) Avery's Angels Gastroschisis Foundation Parents of Pediatric Survivors (Facebook) <sup>a</sup>
Duodenal atresia	CHD, TEF/EA, Duodenal Atresia & other GI issues (Facebook) <sup>a</sup>	
Congenital diaphragmatic hernia	CDH Stars & Angels (Congenital Diaphragmatic Hernia Support Group) (Facebook) <sup>a</sup> Congenital Diaphragmatic Hernia Survivors (Facebook) <sup>a,b</sup>	CDH International (Facebook/Twitter) Tiny Hero (Facebook/Instagram)

<sup>a</sup>Denotes private account

<sup>b</sup>Denotes account dedicated to adult patients; CPAM/BPS omitted due to low number of accounts

the importance of relying on their medical providers for information related to their disease and illness. Interestingly, some of the patient and family-driven social media accounts provided in Table 4 specifically mention their purpose is not to provide medical information, indicating that medical misinformation on social media is also of a concern to patients and their families.

With the knowledge of these robust online communities and acknowledgment that misinformation can spread at an unprecedented speed, healthcare providers can engage with social media to combat this. This, however, raises the question of whether professional organizations should provide or regulate online resources for patients and families. Physicians and healthcare providers are known to engage on social media [3, 17]. Professional organizations, such as the American Academic of Pediatrics (AAP) and American Pediatric Surgical Association, both have active public Twitter and Facebook accounts. AAP also has an Instagram account. However, direct engagement with patients on social media

platforms may raise concerns regarding liability and patient protection [24]. The American Medical Association (AMA) has issued a statement on physician engagement on social media as well as developed a Continuing Medical Education course to “help physicians identify and understand how to maintain boundaries with their patients as well as boundaries for treating family, self and colleagues” [25]. This information largely emphasizes the maintenance of professional boundaries online and holds physicians accountable to the same ethical standards when interacting with patients on the internet. The AMA, the American College of Physicians, and the British Medical Boards all discourage accepting friend requests from patients on the internet [26].

The challenge of medical misinformation on the internet has recently been amplified by the COVID-19 pandemic [27]. In fact, the World Health Organization held an Infodemiology Conference in June and July 2020 to provide measures and practices to better understand and control infodemics (defined as an overabundance of information) and build a

public health research agenda to address misinformation and disinformation online [28]. Though this an active area of research and concern, the obligation and expectation of physicians to manage such false information is vague. Furthermore, though it is clear that physicians are expected to uphold the same ethical standards for doctor–patient relationships online as they are in person, the legal implications and policies of patient involvement or information correction on the internet is less clear. The AAP Committees on Bioethics and Medical Liability and Risk Management have stated any answering of clinical questions posed by patients on social media creates a professional obligation similar to that of an in-person visit subject to associated liability, which may not be covered by malpractice insurance [26]. Therefore, we recommend physicians consult their own institutional policies prior to social media engagement and considering withholding from direct patient contact until policies are better delineated. Though they may feel compelled to correct false information shared by patients directly, the surgeon's involvement on social media may be best limited to publicly sharing information on the internet. In fact, prior research has shown that direct, public rebuttal of information by a physician can lead to harassment [29, 30]. To specifically address misinformation, a recent publication by Arora et al., suggested a three-step process to debunk misinformation, which involves stating a fact, then stating the related myth, and then explaining its fallacy [30]. Healthcare providers can further work to ensure their patients utilize social media as a resource for connecting with other patients and families experiencing similar challenges, not as a source for specific medical advice.

This study is not without limitations. First and foremost, all searches of social media platforms utilized the English language, and this methodology does not recognize any accounts without the specified English search terms. Therefore, our findings are biased by search language and likely do not reflect all social media accounts dedicated to the congenital diseases of interest. It is also possible that certain groups were not captured due to privacy controls that affect searchability. Additionally, we restricted our analysis to social media accounts serving supportive purposes. We recognize this results in the exclusion of important accounts managed by healthcare professionals that disseminate strictly medical information and contribute to online knowledge dissemination. We also acknowledge that our analysis was not inclusive of all congenital surgical diseases, and we recognize there is subjectivity in our selection of disease. Social media is also dynamic by nature and, therefore, our data are limited by its investigation during a specific period. Furthermore, the qualitative aspect of this study introduces methodology limitations inherent to this type of analysis. Finally, we recognize that the quality of medical information shared in these groups was not qualitatively assessed. Given that this

study aimed to identify supportive communities on social media for patients and families affected by specific diseases, such information is not subject to the same quality control as medical information. However, we recognize that medical misinformation is likely shared on these platforms and next steps would be to perform a quality analysis.

## Conclusion

Social media provides an important resource for individuals and their families affected by a variety of rare pediatric surgical problems. Supportive communities for patients and their families with anorectal malformation, biliary atresia, CDH, EA/TEF, gastroschisis, Hirschsprung disease, and omphalocele exist and are very active. Knowledge by healthcare providers can allow them to appropriately refer parents and patients affected by these conditions who may benefit from these online communities with the emphasis that they remain resources for support. Education and awareness of misinformation and disinformation will ensure appropriate counseling by members of the medical community for safe use of social media by patients and their families.

**Author contributions** MLR, JK and AB contributed to study conception and design. MLR, KP, and MNM were responsible for data acquisition. KP was responsible for data analysis and preparation of figures. MLR, DLT, LW, and AB were responsible for manuscript drafting. All authors critically reviewed the manuscript.

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## Declarations

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**Conflict of interest** The authors declare no competing interests.

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