

## Original Article



# Role for Social Media in Pediatric Liver Disease: Caregiver and Provider Perspectives

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## ABSTRACT

**Purpose:** To better understand the benefits and harms of engagement with online pediatric liver disease communities within social media.

**Methods:** We conducted a survey of caregivers of children with liver disease participating in online pediatric liver disease communities within social media, as well as a survey of healthcare providers (e.g., physicians, surgeons, nurse coordinators) from this field to better understand the perceived benefits and harms of participation.

**Results:** Among 138 caregivers of children with liver disease that completed the survey, 97.8% agreed social media was a good place to learn about patient experiences and 88% agreed it was a good source of general information. Among caregivers, 84.8% agreed social media helps them to better advocate for their child. While 18% agreed that the information over social media was equal to the information from their healthcare team and 19% neither agreed/disagreed, only 3% indicated they would use this information to change care without telling their provider; in contrast, among 217 healthcare providers, 55% believed social media may lead caregivers to change management without telling their team.

**Conclusion:** Engagement with online disease-specific communities in social media yields several benefits for caregivers and, in contrast to healthcare providers' concerns, participation is unlikely to lead to problems including caregivers changing the treatment plan without first discussing these plans with their team. Openness between caregivers and medical teams about the role for social media can help to improve trust and maximize the potential benefits of engagement with these groups.

**Keywords:** Social media; Facebook; Patient participation

## INTRODUCTION

Social media is defined as internet-based platforms that allow for the engagement and exchange of user-generated content that is used by approximately 90% of adults in the United States [1]. Social media platforms are increasingly used for health-related activities, with a survey suggesting up to 90% of individuals would engage with social media and trust the

health information they receive over these platforms, and 80% of individuals would be likely to share their own health information [2]. Both general social media platforms (e.g., Facebook and Twitter) and health-specific platforms (e.g., Patient's Like Me) facilitate individuals coalescing in groups with shared interests to exchange experiences and information.

For people with rare diseases, defined by the Rare Disease Act as occurring in less than 1 in 1,500 individuals, engagement with social media may be an especially useful mechanism for connecting with other individuals with similar experiences. Nearly all pediatric liver diseases are classified as rare with total incidence of all pediatric liver diseases estimated to be approximately 1 in 2,500 births [3]. These diseases develop as a consequence of a range of congenital, genetic or acquired conditions that are often life-threatening and associated with significant impact on morbidity and quality of life [4]. One of the most common diseases is biliary atresia, which occurs in approximately 1 in 14,000 births, and is characterized by a rapid destruction of the bile ducts requiring a liver transplant in nearly all affected children [5,6]. Given the rarity of these diseases and that they are frequently life-threatening, this leads to tremendous parental anxiety. Therefore, it is not surprising that caregivers of children with liver disease frequently participate in online social media communities. It remains unclear if participation in these communities may be problematic or harmful including leading to tension with other members, increasing anxiety, and obtaining incorrect information about their health condition.

We surveyed both caregivers that participate in Facebook pediatric liver communities and healthcare providers with expertise in pediatric liver disease to better understand the perceived benefits and harms associated with patient engagement in these online spaces. We hypothesized that caregivers perceive significant benefits to engagement in these communities (e.g., being better informed about the disease, gaining emotional support, improved ability to advocate for the child) with little harm while at the same time, any specific concerns on the part of providers' would be largely unfounded. These data would serve to better inform whether participation in online communities can be formally and consistently recommended by healthcare providers to support their patients and families.

## MATERIALS AND METHODS

### Study population and demographics

The study population for the caregiver survey was a convenience sample of parents/guardians of pediatric (<18 years) liver transplant recipients or caregivers of children with liver disease or liver transplant recipients. Only caregivers that were over 18 years old and that speak English were eligible to participate. The survey was divided into three parts: (1) questions addressing sociodemographic characteristics; (2) general attitudes about the role of online health communities; and (3) their perceived benefits and harms of participation in these communities. The study population for the healthcare provider survey was a convenience sample of experts in the field of pediatric hepatology and gastroenterology. This study was approved by the Institutional Review Board of the Johns Hopkins University School of Medicine.

### Instrument design and administration

Survey instruments for caregivers of children with liver disease and healthcare providers in pediatric hepatology were developed by a transdisciplinary team including members with expertise in transplant medicine, epidemiology, and family advocacy. The instruments

were tested for clarity and understanding by three caregivers of children with liver disease. The final instrument for caregivers consisted of 48 closed-ended questions and the final instrument for healthcare providers consisted of 17 closed-ended questions. The survey was administered using Qualtrics (Provo, UT, USA).

### Caregiver recruitment

Respondents were recruited over Facebook from November 29, 2018 to August 21, 2019 through two mechanisms. First, respondents were recruited through Liver Space, a Facebook-integrated “app” that is free and available on the Apple and Android stores and that has been described elsewhere [7]. Briefly, Liver Space provides users with several functions such as the ability to receive the latest news of interest to the user, ask-an-expert questions, locate other members of the community to arrange meetups, and track laboratory results. At the end of the study period, Liver Space had 604 users including 206 (34.1%) caregivers and 333 (55.1%) patients, and 128 (21.2%) individuals were listed as transplant recipients. Second, two posts were made on the Liver Space Facebook page that currently has 1,960 followers and one post was made on a second group directed towards the pediatric liver community with more than 500 members at the start of the period. Respondents were informed that participation was voluntary, and they would not be reimbursed for completing the study.

### Healthcare provider recruitment

Healthcare providers were recruited from two settings. First, healthcare providers were asked to complete the survey following a presentation on social media at the Annual Meeting of the Society of Pediatric Liver Transplantation on September 13, 2018 in Atlanta, Georgia. Second, the survey was shared over the Pediatric Gastroenterology “listserv” (pedGI@list.UVM.edu) on February 19, 2019. This listserv has been available to the pediatric gastroenterology community since February, 1995 and contains approximately 2,700 individuals.

### Statistical analysis

Data were summarized using frequencies, percentages, medians and interquartile ranges (IQRs). Associations between categorical variables were tested using a Fisher's exact (when  $n < 5$ ) or chi-squared tests. Questions utilizing a 5-point Likert scale were ultimately consolidated to compare the two affirmative responses (i.e., “strongly agree” and “somewhat agree”) and the two negative responses (i.e., “strongly disagree,” “somewhat disagree,”) with the “neither agree nor disagrees.” Statistical significance was assessed at the  $\alpha = 0.05$  confidence level. All analyses were performed using Stata 14.0/MP for Apple (College Station, TX, USA).

### Missing data

Among 153 eligible caregivers that started the survey, 90.2% ( $n = 138$ ) partially completed the survey and 15 left the survey entirely blank. All demographic data (i.e., age, gender, disease and transplant status) was available for 91.3% ( $n = 126$ ) and 12 (8.7%) respondents missed 1–4 questions. Complete data, including responses to questions about social media as well as demographics, was available for 87.0% ( $n = 120$ ). A missing indicator variable was created in order to test whether individuals with missingness affected responses to a random selection of questions from the domains. In all instances, missingness was not associated with the response and subsequent analyses were therefore made with all available data without imputation of missing data. For the healthcare provider survey, 99% of respondents completed the survey in its entirety.

## RESULTS

### Caregiver characteristics

Among 127 caregivers that provided demographic data, the median (IQR) age was 38 years (34–43 years) and 94% were female (**Table 1**). Regarding their children's underlying disease, 69.3% had biliary atresia and 60.6% were liver transplant recipients. Nearly half used technology to access the internet for 1–4 hours per day whereas 7.1% accessed the internet for less than 1 hour per day. Social media was used by 62.2% of individuals for 1–4 hours per day and 15.7% used it for less than one hour. When asked to describe their primary means of engagement with social media, 36.5% responded that they primarily read other people's posts, 45.2% responded to other people's posts, and 18.3% would start conversations/threads.

### Information from online communities

When caregivers were asked to respond to whether online liver communities were a good source of information, 88.4% agreed it was a good source for general information compared to 5.8% that disagreed and 5.8% that neither agreed/disagreed (**Table 2**). Nearly all caregivers agreed (97.8%) that online communities were a good place to learn about patient stories. Seventy-nine percent agreed that online communities can be a good place to learn things that will help them manage their child's health condition, whereas 8.0% disagreed and 13.1% neither agreed/disagreed. Similarly, 77.4% agreed online communities were a good place to hear about different centers approach to care, 8.0% disagreed, and 14.6% neither agreed/disagreed. A smaller percentage of caregivers responded that online communities were a good source to find out about other resources or organizations, with 70.3% agreeing, compared to 11.6% that disagreed and 18.1% that neither agreed/disagreed.

When asked about their trust in the information they receive over social media, 17.6% of caregivers agreed that it should be considered equal to information from the medical team

**Table 1.** Characteristics of caregivers of children with liver disease

Characteristic	Value (n=127)
Female	120 (94.5)
Age in years	38 (34–43)
Disease	
Biliary atresia	88 (69.3)
Autoimmune disease	5 (3.9)
Fatty liver	2 (1.6)
Malignancy	5 (3.9)
Acute liver failure	5 (3.9)
Other	22 (17.3)
Liver transplant recipient	77 (60.6)
Use of internet (hours per day)	
<1	9 (7.1)
1–4	60 (47.2)
>4	58 (45.7)
Use of social media (hours per day)	
<1	20 (15.7)
1–4	79 (62.2)
>4	28 (22.0)
Primary type of engagement with social media*	
Reader	46 (36.5)
Responder to other posts	57 (45.2)
Conversation starter	23 (18.3)

Values are presented as number (%) or median (interquartile range).

\*n=126.

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**Table 2.** Response of 138 caregivers regarding information from online communities

Response	Agree	Disagree	Neither agree/disagree
Online patient communities are a good place to learn about...			
1. General disease information	122 (88.4)	8 (5.8)	8 (5.8)
2. Other patient experiences*	134 (97.8)	3 (2.2)	0 (0.0)
3. Knowledge to help manage my child's illness*	108 (78.8)	11 (8.0)	18 (13.1)
4. Different centers approach to care*	106 (77.4)	11 (8.0)	20 (14.6)
5. Additional groups and organizations	97 (70.3)	16 (11.6)	25 (18.1)
Medical information over the internet and social media...			
6. Should be considered equal to information from team**	24 (17.6)	86 (63.2)	26 (19.1)
7. Is likely to be correct*	33 (24.1)	56 (40.9)	48 (35.0)
8. May lead me to change management without discussing with my team**	4 (2.9)	124 (91.2)	8 (5.9)

Values are presented as number (%).

\*n=137; \*\*n=136.

and 19.1% neither agreed/disagreed; 63.2% disagreed that information from social media was equal to information from the medical team. Similarly, 24.1% agreed that the information from the internet and social media is likely to be correct, 35.0% neither agreed/disagreed, and 40.9% disagreed. However, only 2.9% agreed that information over social media might lead them to make a change in the management of their child's disease without discussing it with their healthcare team; 5.9% neither agreed/disagreed and 91.2% disagreed that the information they receive over social media would lead them to make a change without first discussing it with their healthcare team.

**Benefits and harms of participation**

Among caregivers, 73.9% agreed that hearing about other people's experiences over social media decreases their anxiety, compared to 13.8% that disagreed and 12.3% that neither agreed/disagreed (**Table 3**). Nearly all individuals agreed that hearing other experiences helped them to realize there are other people with similar experiences. Eighty-five percent of caregivers also felt that participating in social media helped them to advocate for their child, compared to 2.2% that disagreed and 13.0% that neither agreed/disagreed.

Some concerns about social media were acknowledged by caregivers including 29.0% agreeing that hearing about other experiences can make them feel confused about the best course of action their child, compared to 43.5% that disagreed and 27.5% that neither agreed/disagreed. However, only 13.8% agreed that social media can lead to tension and conflict with other members of the group, compared to 64.5% that disagreed and 21.7% that neither agreed/disagreed. When asked about concerns about sharing of health information, 26.8% agreed they were worried that their health information could be shared inappropriately by the

**Table 3.** Response of 138 caregivers regarding benefits and harms of online communities

Response	Agree	Disagree	Neither agree/disagree
Hearing about other patient experiences online...			
1. Decreases my anxiety	102 (73.9)	19 (13.8)	17 (12.3)
2. Helps me to realize there are other people like me*	133 (97.1)	1 (0.7)	3 (2.2)
3. Can help me to better advocate for my child	117 (84.8)	3 (2.2)	18 (13.0)
4. Can leave me feeling confused about the best course of action for my child	40 (29.0)	60 (43.5)	38 (27.5)
5. Can lead to tension/conflict with other members	19 (13.8)	89 (64.5)	30 (21.7)
When sharing health information online, I worry that the information may be inappropriately shared...			
6. Between members of the community	24 (17.4)	82 (59.4)	32 (23.2)
7. With other companies or people outside the group	37 (26.8)	63 (45.7)	38 (27.5)

Values are presented as number (%).

\*n=137.

platform or get “hacked” compared to 45.7% that disagreed and 27.5% that neither agreed/disagreed. A fewer number of people were concerned that their health information could be shared inappropriately by other members of the community, with 17.4% agreeing with this concern compared to 59.4% that disagreed and 23.2% that neither agreed/disagreed.

### Healthcare provider characteristics

Among 219 healthcare providers that started the survey, 99.1% (n=217) provided demographic information including 69.1% that were female (**Table 4**). Among healthcare providers, 84.8% were physicians/surgeons and 12.0% were nurses or physician assistants. Duration of practice varied with 23.0% still in training, 27.6% within the first five years after training, 27.2% practicing for 5–15 years, and 22.1% practicing for more than 15 years. With respect to the type of practice, 78.3% practiced in academic setting and 15.7% practiced in a hospital-based but non-academic setting. Nearly all individuals used computers and/or smartphones for at least one hour per day; 88% of individuals used social media at least monthly and 66.4% using social media daily; only 12% of healthcare providers never used social media.

### Healthcare provider attitudes towards social media

Ninety percent of healthcare providers agreed that social media can be generally helpful for families to manage chronic liver disease compared to 6.5% that were neutral and 3.2% that disagreed (**Table 5**). Among healthcare providers, 80.6% agreed that social media helps families to learn about their disease, 85.7% agreed it provides families with emotional support, and 88.9% agreed it helps families to identify other resources to manage their disease. At the same time, 55.3% of healthcare providers agreed that it may encourage families to make changes in the treatment plan without discussing these changes with the healthcare team and this was significantly more than the 3.2% of caregivers that indicated they would change plans without discussing with their team ( $p<0.001$ ). Among healthcare providers, 68.2% agreed that social media may provide patients with bad information. Healthcare

**Table 4.** Characteristics of 217 healthcare providers with expertise in liver disease

Characteristic	Value (n=217)
Female	150 (69.1)
Occupation	
Physician or surgeon	184 (84.8)
Nurse, nurse practitioner, or physician assistant	26 (12.0)
Researcher	6 (2.8)
Social work	1 (0.5)
Duration of practice	
Still training	50 (23.0)
<5 yr	60 (27.6)
5–15 yr	59 (27.2)
>15 yr	48 (22.1)
Practice	
Academic	170 (78.3)
Private	11 (5.1)
Hospital-based, non-academic	34 (15.7)
Other	2 (0.9)
Use computers/smartphones >1 hour per day	215 (99.1)
Use of social media	
Never	38 (17.5)
Daily	144 (66.4)
Weekly	24 (11.1)
Monthly	11 (5.1)

Values are presented as number (%).

**Table 5.** Attitudes regarding social media among 217 healthcare providers

Response	Agree	Disagree	Neither agree/disagree
1. Generally helpful	198 (91.2)	14 (6.5)	7 (3.2)
2. Help families to learn about the disease	175 (80.6)	15 (6.9)	29 (13.4)
3. Help families to get emotional support	186 (85.7)	13 (6.0)	20 (9.2)
4. Help families to find other resources	193 (88.9)	7 (3.2)	19 (8.8)
5. Encourage families to make changes in plan without discussing with team	120 (55.3)	46 (21.2)	53 (24.4)
6. Provide families with bad information	148 (68.2)	38 (17.5)	33 (15.2)
7. Lead to problems with sharing of information between the community	110 (50.7)	55 (25.3)	54 (24.9)
8. Lead to problems with privacy violations (e.g., hacking)	71 (32.7)	89 (41.0)	59 (27.2)

Values are presented as number (%).

providers were also more likely to agree that social media can lead to problems with sharing of health information between members (50.7% for healthcare providers vs. 17.5% for caregivers;  $p < 0.001$ ) and can lead to problems with sharing of information with third party companies or “hackers” (32.7% for healthcare providers vs. 27.2% for caregivers;  $p = 0.002$ ).

## DISCUSSION

In our survey of 138 caregivers of children with liver disease, most individuals thought that social media was a good space to learn about their disease, with nearly all individuals agreeing these groups are a good place to hear stories from people with similar experiences, and nearly 90% of individuals believing it was a good source for general information. While nearly 20% of individuals felt that information on social media should be considered equally to information from their healthcare team, only 3% acknowledged they would make changes in the child's treatment plan without discussing it with their healthcare team. Besides the information individuals receive over social media, 85% believed it helped them advocate for their child. However, one important harm was that nearly 30% felt that it could leave them confused about the best course of action for their child. These perspectives contrasted somewhat with those of healthcare providers in our survey of 219 healthcare providers, where most individuals agreed it can be a good source of information but more than half thought it may lead caregivers to change treatment plans and nearly two-thirds of individuals thought it would lead to sharing of bad information. Healthcare providers were more worried about the sharing of personal health information between other members of the community as well as third party groups or hackers.

The benefits of social media reported here – improved knowledge, social support, and empowerment—should not be surprising. The role for caregiver-to-caregiver support in health conditions is well-established. A framework of social support by Cassel identified four major domains of support for which an individual would benefit including emotional (“being there”), instrumental (“doing things for the individual”), informational (“sharing knowledge and resources”), and appraisal (“helping individuals to see their stressors with more confidence”) [8]. Apart from instrumental support, social media provides a tremendous opportunity to connect with others to obtain much-needed support for caregivers in general, and for caregivers of children with rare and severe diseases specifically.

A role for social media in the management of health conditions has been reported both for a number of common diseases (e.g., diabetes, depression and food allergies) as well as rare disorders [9-13]. Participation in these groups is generally viewed favorably. Nicholl et al. [14]

surveyed caregivers of children with rare disease who use the internet and social media on how their use impacted their experience. The most frequently cited benefit from caregivers was that these resources improved their understanding of their child's health condition (72%) compared to nearly all individuals in our study. This same survey found that 16% felt these resources can reduce anxiety whereas nearly three quarters of respondents from our survey felt social media reduces anxiety. An even bigger contrast was seen with respect to whether these platforms can increase patient engagement, with only 2% of respondents in their survey indicating that the platforms help to empower caregivers whereas 85% of respondents in our survey indicated that participation increased caregiver ability to advocate for their child. It is not readily clear why our findings diverge significantly by those in the earlier study by Nicholl et al. [14], although one possibility may be that we sampled from groups with a narrower focus (i.e., disease-specific groups rather than an organization for all rare diseases). A second possible explanation may be that some characteristic unique to pediatric liver disease, such as their associated disease severity, leads to different perspectives about social media as these authors didn't characterize the etiology of the rare disease.

One limitation of our study is that it was only conducted among caregivers of children with liver disease; while we anticipate that our findings may be applied to other rare diseases with similarly significant morbidity, it is less clear if they are generalizable to more prevalent conditions where caregivers may have personal (i.e., face-to-face) acquaintances with similar diseases that can serve to exchange information and provide support. Likewise, there may be challenges in extrapolating our findings among caregivers, such as their reluctance to implement changes in their child's management without discussing with the healthcare team, to the practices of adults who themselves have medical conditions. Although our study highlights several potential benefits to social media to caregivers, it should also be noted that patients may themselves have different attitudes about how their health information is shared, and may not consider the potential benefits of online communities as sufficient to justify a loss of privacy. Another important limitation is that the caregivers that responded to our survey represent a small subset of individuals engaged in online communities and that a selection bias may exist with perspective from our study that do not reflect the larger community. A similar challenge in generalizing our findings to individuals that do not engage with online disease communities is that such individuals may be avoiding these spaces not because they are unaware they exist, but rather because their attitudes about the benefits and harms of social media are already formed and they are resistant to considering any potential benefits of social media. Finally, while our study does suggest that healthcare providers may consider routinely recommending these online groups for their patients, it should be noted that our study did not compare attitudes of caregivers between those who use and do not use social media. As such, the potential benefits may not extend to individuals who are currently reluctant to engage in social media as the possibility exists this later group would not benefit in the same way as those that use social media by their own accord.

Our study suggests that engagement with social media by caregivers of children with rare and severe diseases can be a valuable source of information and social support. Overall, people who use social media for these purposes reported positive experiences including increasing their ability to advocate for their child. While one-third of individuals agreed or were neutral in their belief that the information over social media was equivalent to information provided by the healthcare team, very few indicated they would make changes in the management of their child without first discussing it with their team. Consequently, while healthcare



providers generally understood the benefits of social media, their concerns that caregivers will make changes without first discussing it with them may be unfounded.

Whether providers like it or not, caregivers will be on social media and as such, it is important to have an open discussion about the benefits and risks. These findings suggest that healthcare providers may consider counseling patients to engage with social media platforms to identify individuals with shared experiences. Such participation is likely to be associated with improved understanding about the disease and emotional support. Individuals participating in these groups are not likely to experience significant tension with other individuals, to have increased anxiety, and to obtain information leading to changes in the management of their child's condition without first discussing it with their healthcare team.

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