

# Social Media Participation Among Parents and Caregivers of Children With Pulmonary Hypertension

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**Background:** Engagement in social media has risen nearly 60% over the last decade with consumers engaging in social media not only browse social networking websites, but also to share health information, view health-related videos, and contribute to online support groups. For parents and caregivers (PCGs) of children diagnosed with pulmonary hypertension, participation in social media can be one way to associate with others in a similar position as individuals can connect with others around the world and share information.

**Methods:** In this study, parental and caregiver involvement was explored through a cross-sectional study utilizing a survey method to evaluate current practices in social media groups. PCGs of over 300 patients from a large pediatric pulmonary hypertension center were approached for participation in the survey via their child's web-based messaging portal connected to the electronic medical record. The survey was created in REDCap and given to parents electronically or on paper. The survey was comprised of 4 sections covering child demographics, PH medications and hospitalization encounters, social media utilization among PCGs, and the "Big 5 Personality Survey."

**Results:** Eighteen PCGs completed sections 1-3 of the survey, and 6 PCGs completed the entirety of the survey (sections 1-4). The children represented in the survey had been diagnosed for an average of 5.5 years. Seventy percent of PCGs in the survey reported using social media as a support resource, utilizing 2-5 different social media platforms. PCGs reported feeling overwhelmed, connected, discouraged, depressed, supported, seen, and good when participating. Among respondents, the three highest-scoring personality traits were agreeableness (31.9), conscientiousness (27.2), and openness to experiences (26.7).

**Conclusions:** This is the first study that seeks to understand social media's role as a support resource and its impact on PCGs of children diagnosed with pulmonary hypertension. It offers insight as to why PCGs may utilize social media platforms and emphasizes its significant role as a support resource for these families. Healthcare teams should consider evaluation of social media and support its role as a resource and source of education.

Over the past decade, social media platforms and applications have become increasingly popular with now 7 in 10 Americans using some form of social media for connecting with others.<sup>1</sup> Platforms and applications are constantly evolving to offer new functionalities and invoke new patterns of use among consumers.<sup>2</sup> The 2019 Health Information National Trends Survey (HINTS) reports that social media involvement has grown from 27% in 2009 to 86% in 2019.<sup>2</sup> The survey finds consumers engage in social media not only to

browse social networking websites, but also to share health information, view health-related videos, and contribute to online support groups. With the rapid expansion of this technology over the last decade and the sharp rise in consumer engagement, the integration of social media technology must be further understood as it permeates various aspects of daily life and affects diverse demographics of people. For parents and/or caregivers (PCGs) of children diagnosed with a chronic illness, social media may be one way to associate with

others in a similar position as individuals can engage with others around the world and share information.

Pulmonary hypertension (PH) is a chronic disease that can affect children of all ages. It is characterized by elevated blood pressure in the lungs and can be related to a variety of cardiac, pulmonary, and other systemic disorders.<sup>3</sup> As a chronic disease, it may entail many hospital admissions for medication conversions or illness exacerbations, outpatient office visits with multiple different specialty providers, and/or many different medications with frequent administration times. Families may have to travel far distances to receive care at a PH center,<sup>4</sup> and local communities may

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not understand the disease given its low prevalence worldwide.<sup>5</sup>

In addition to navigating the medical care of pediatric PH, PCGs must also navigate every other aspect of the child's life: school, development, family, and community life. PCGs are frequently faced with nonmedical dilemmas and may be unsure of resources for help. Such situations include schooling modifications like an individualized education plan and educating their child about PH and prognosis. Evaluating support strategies for PCGs of children diagnosed with PH is an important aspect of ensuring family-centered care and working to optimize the overall quality of life of the patient and their family. Health care teams may be aware that PCGs are turning to social media for support and information but may underestimate the extent of social media's impact and therefore miss an opportunity to support or guide social media as a positive resource. In this paper, PCG involvement was explored through a cross-sectional study using a survey method to evaluate current practices in social media groups.

## METHODS

In this study, PCGs of over 300 patients from a large pediatric PH center were approached for participation in the survey via their child's web-based messaging portal connected to the electronic medical record. PCGs were also approached during their child's routine outpatient PH appointments and/or during their child's inpatient hospitalization. Surveys were available electronically and on paper. The surveys were completed in English. Inclusion criteria included a parent or caregiver of a child diagnosed with PH who was receiving care at the study site. Exclusion criteria included children not diagnosed with PH or cared for at another institution. The survey was limited to 1 per household, however PCGs were encouraged to complete the survey together, to reflect the collective feelings of all PCGs in the home. Data collection occurred from December 2020 to February 2021.

The web-based survey was created and housed through Research Electronic Data Capture (REDCap, v10.6.12, Vanderbilt University, Nashville, Tennes-

see). REDCap is a secure web application used for survey data collection. An e-consent was embedded into the survey for electronic signature and was stored within the database. Electronic signatures were obtained by participants typing in their full legal name or signing directly on the REDCap page under *signature*. For PCGs who preferred to complete a paper copy of the survey, the survey was printed out from REDCap, written consent was reviewed, and signatures were obtained in real-time. Data was then directly entered into REDCap from the surveys by the research team.

The survey was divided into 4 sections. Section 1 of the survey included information on demographics including the child's current age, number of individuals living in the household, number of caregivers assisting with the child's care, and the role of the individual(s) who was completing the survey. Section 2 asked about the child's PH including the number of medications for PH taken, length of time of diagnosis, and the number of hospitalizations related to PH or respiratory illness in the past year. Section 3 evaluated the support resources used, the social media platforms used, time spent each day on social media for personal use, changes in use patterns related to the COVID-19 pandemic, how the PCG finds social media groups, benefits of involvement, emotions when participating in social media groups, and other ways the parent or caregiver finds support. Section 4 involved the completion of the 50-question "Big Five Personality Survey."<sup>6</sup> The "Big Five Personality Survey" is based on the 5 broad traits of personality: extroversion, agreeableness, conscientiousness, neuroticism, and openness to experience.<sup>7,8</sup>

## LIMITATIONS

There were several limitations identified in this study. One limitation is that majority of the respondents were female and listed themselves as the mother of the child. There were also only 24 responses available for data analysis. Some incomplete surveys were still included in the results of the study as some participants completed the entire survey except for the 50-question "Big Five Personality Survey." This may be because of the

**Table 1.** Social Media Platform Use and Time Spent

Type of platform (N=24)	n (%)
Facebook	21 (87)
Twitter	1 (4)
YouTube	9 (38)
LinkedIn	2 (8)
Instagram	7 (29)
Snapchat	3 (12.5)
Reddit	1 (4)
Other	3 (12.5)
Daily time spent (N=24)	n (%)
Less than 15 minutes	3 (12.5)
15 minutes to 1 hour	4 (16.7)
1 to 2 hours	10 (41.7)
2 to 4 hours	5 (20.8)
More than 4 hours	2 (8.3)
COVID-19 use changes	n (%)
Did not change	8 (33)
Decreased	2 (8.3)
Increased	15 (58)

length of the "Big Five Personality Survey" when combined with sections 1-3. The survey did not evaluate for the classification of PH of the child such as congenital heart disease or bronchopulmonary dysplasia, which may provide a deeper understanding for other comorbidities of the child and complexity of care needs. Finally, the survey was completed during the COVID-19 pandemic. This limited the number of PCGs present with the child because of visitation restrictions. While the survey attempted to assess how the caregiver or parent's involvement has changed because of the pandemic, it can be difficult to fully interpret how the pandemic has affected social media use in this population.

## RESULTS

Twenty-four PCGs completed the survey. Eighteen of the surveys had all 4 sections completed, and 6 surveys only had the first 3 sections completed.

### Section 1: Demographic Data

Among respondents, the mean age of the child receiving PH care was 7 years with a range of 6 months to 16 years. Twenty-three of the respondents were

mothers, and 1 respondent was a grandmother. The average number of household members among all 24 respondents was 4 persons, and most children had a mean of 2 caregivers.

### Section 2: PH

Of the 24 responses, children had been diagnosed with PH for a mean of 5.5 years (range 3 months to 15 years.) Children had an average of at least 1 hospitalization in the preceding year (range 0-5, standard deviation 1.25.) Children were taking 0 to 5 medications to treat PH, mean 2 medications, standard deviation 1.27.

### Section 3: Social Media Use

Social media platform use is summarized in Table 1. Respondents were asked about the type of support platforms they used. Seventy percent (17 of 24 responses) of the respondents reported using social media as a support resource. Of this 17, 12 respondents reported using social media alone as a resource, and 5 respondents reported using both social media and support groups as a resource. Twenty percent (5 of 24 responses) of the respondents denied using either support groups or social media as a support resource. Three respondents reported support groups alone as their support resource. The use of particular social media platforms including Facebook, Twitter, YouTube, LinkedIn, Instagram, Snapchat, and Reddit was assessed. Fifty percent of the participants (12 of 24 responses) marked use of 2 to 5 platforms. Three respondents marked "other" and reported using TikTok.

PCGs reported finding social media groups through the search function of the social media platforms and recommendations from their health care team and other PCGs. A free-text area was provided for respondents to write how they feel when participating in social media groups. PCGs reported feeling overwhelmed, connected, discouraged, depressed, supported, seen, and good. They also said involvement was helpful and useful. One respondent stated that involvement provided "guidance in decision-making and information gathering from those with actual experience [with the disease]." Another stated they are

**Table 2.** Big Five Personality Survey Data (N = 18)<sup>a</sup>

	Mean	Standard deviation
Extroversion	17.0	8.4
Agreeableness	31.9	4.9
Conscientiousness	27.2	6.2
Neuroticism	19.3	7.4
Openness to experience	26.7	5.1

<sup>a</sup>Scores can range from 0 to 40 on each dimension.

"always able to find a resource or answer to a question from those with real-life experience." Another free-text area was provided to assess how involvement in social media groups may help others. Responses included gathering learning tips from others, getting support and encouragement, and helping others to know they are not alone. In addition to social media, PCGs were also asked about other support resources they rely on. Family and friends were reported as a support resource by 15 of 24 respondents (62.5%). Other support resources included the Pulmonary Hypertension Association, counseling, and the PCG's faith community.

### Section 4: "Big Five Personality Survey"

Of the 24 respondents, only 18 respondents completed the "Big 5 Personality Survey." From these responses, scores for extroversion, agreeableness, conscientiousness, neuroticism, and openness to experience were calculated. Table 2 provides an overview of the mean and standard deviation for the "Big Five Personality" scores for this group of respondents.

## DISCUSSION

The primary objectives of this study were to (1) determine what resources PCGs use for support of the child's illness, (2) determine common social media platforms used by this population, and (3) understand how social media platforms are perceived by PCGs. All objectives were met for this study, though this study does raise several questions for future investigation.

### Support Resources

Pediatric PH is a heterogeneous disease with significant morbidity and mortality. The etiology of disease can vary greatly

and carry with it quality of life challenges due to the burden of illness. In their study evaluating the impact of PH on quality of life on children diagnosed with the disease and their caregivers, Mullen et al<sup>9</sup> reported that parents of children diagnosed with PH encountered more stressful events than published norms of parents of children diagnosed with cancer. Parents in Mullen et al's study<sup>9</sup> reported using coping strategies more often than a normative sample, and parental stress correlated inversely with the quality of life of the child.

The data in this survey illustrates the reliance of PCGs on social media as a support resource. While some PCGs reported that involvement can be overwhelming and discouraging, the majority of respondents indicated that involvement was a source of support and encouragement. PCGs appreciated hearing advice from peers who were also dealing with the real-life manifestations of the disease and learning advice to make things easier. Twenty percent of participants noted they do not use social media as a support resource, but later noted they felt supported and less alone when participating in social media groups. This suggests that some participants may experience a lack of recognition or an unwillingness to name social media as an actual support resource.

### Social Media Platform Use

Facebook was reported as the primary social media platform used among respondents. This platform as well as most of the others listed in the survey allows participants to actively participate in discussion, read current and historical postings, and show support for discussion through *liking* a particular posting. Participants in this survey were not asked whether they actively participate



through conversations with others or approach social media more passively by reading conversations rather than directly contributing. This would be helpful to understand in future studies, to better characterize the PCG's role in support forums and understand optimal methods of providing supports: passive vs active.

The COVID-19 pandemic also affected the use of social media platforms with over half of participants stating their use increased. This finding was expected given that in addition to social posts, social media is often used as a source of current events and news information. Furthermore, the combination of social isolation, and lack of entertainment during quarantine or lockdown periods through the COVID-19 pandemic, was a likely impetus for more people to scroll through social media. Even during isolating moments, through an internet connection, social media could offer a quick connection to the outside world.

### Perception of Social Media Platforms

This study highlights how PCGs feel when participating in social media platforms. PCGs noted the importance of hearing information from others going through a similar experience. Nicholl et al<sup>10</sup> discuss how parents in their study felt empowered when engaging in social media, and their engagement allowed them to better understand their child's condition. Their study also highlighted the importance for health care teams to understand what information PCGs seek in these platforms, which may be areas of missed opportunities for discussion and education.

### Personality Assessments

The "Big Five Personality Survey" was included in this study to better understand the types of personalities who may be more inclined to participate in social media groups. Kircaburun et al<sup>8</sup> conducted a similar study seeking to understand the correlation between social media use and the Big Five personality traits among college-aged students. They discovered that differences in social media use were tied to differences in personality traits. For example, persons scoring highest in agreeableness

may be more likely to maintain relationships found on social media and seek information and education. Persons scoring highest in extroversion may use social media as a task management tool and may exhibit more self-disclosure. Conscientious individuals may feel more gratified maintaining relationships on social media.

Among respondents, the 3 highest-scoring personality traits were agreeableness (31.9), conscientiousness (27.2), and openness to experiences (26.7). These were scored out of 40, thus a higher score may suggest a stronger personality trait.<sup>8</sup> However, interpretation of the results must be done with caution. The results could indicate an unintentional but inherent selection bias as persons with these traits may be more amenable to completing the research survey in its entirety. Unfortunately, the small sample size limits application to the general PH PCG community.

For the PCGs who completed the survey, the mean extroversion score was below the overall mean among the 5 personality traits. It is unclear if this suggests that those who are not extroverts can use social media for support or that everyone uses social media. The mean agreeableness score was highest among the 5 personality traits. As noted above, this may be a reflection of an inherent selection bias given that more agreeable people may agree to participate in the survey when asked.

An additional limitation to this study is the lack of socioeconomic context for the survey. It would be helpful to also understand demographics and socioeconomic differences among those involved and if these pose barriers to using social media (for example, age of user, access to internet, access to computing devices, literacy, language).

### CONCLUSION

This is the first study that seeks to understand social media's role as a support resource and its impact on PCGs of children diagnosed with PH. It offers insight as to why PCGs may use social media platforms and emphasizes its significant role as a support resource for these families. With the rising rates of social media use over the last decade, it

remains evident that this resource will continue to be used by PCGs. Health care teams should work to understand the impact of social media use by PCGs and explore opportunities for education on topics PCGs may be wanting more information about. The role of social media as a resource should be promoted with efforts to promote health education and virtual support options.

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