

Identifying Mental Health Challenges Experienced by Caregivers in Rare Disease Communities: A Social Media Analysis

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INTRODUCTION

To understand the unique challenges associated with caregivers for individuals living with rare diseases, it is imperative to actively listen to and interpret their experiences. It has been shown that these caregivers are at risk for negative mental health consequences.^{1,8} However, many investigations target individual rare diseases; as a result, the mental health challenges shared by caregivers across diseases are not fully understood. In this exploratory study, we aimed to identify mental health challenges and the factors that might elicit them across multiple communities of caregivers for individuals living with rare diseases.

METHODS

Krystie, TREND's custom analytics engine, leverages a variety of natural language processing techniques to identify prevalent terms, concepts, and topics from social media sources. Here, we analyzed mental health-related conversations across 10 private Facebook communities (Fig. 1) intended for caregivers in rare disease. First, we ran TREND's mental health classifier to tag posts/comments discussing mental health (Fig. 2). We then used a topic modeling approach to understand themes across diseases (Fig. 3). Finally, we parsed topics by conversational frequency (Fig. 4).

RESULTS

FIGURE 1. MONTHLY SOCIAL MEDIA POSTS BY COMMUNITY

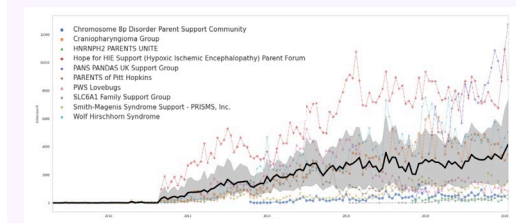
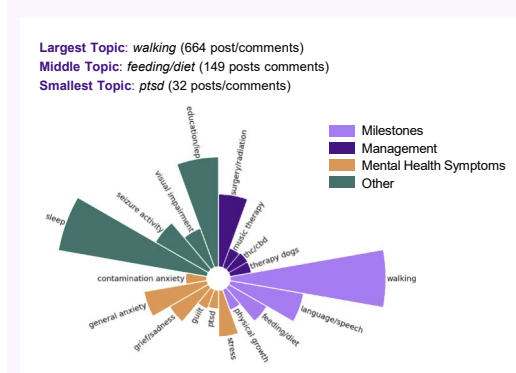


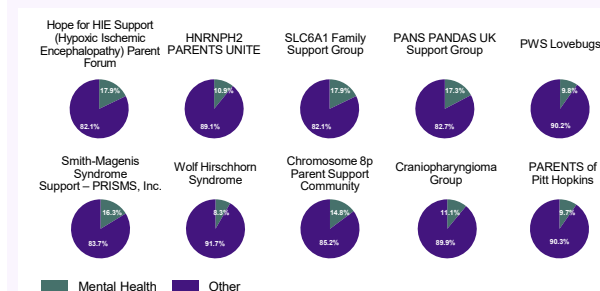
Figure shows the monthly total social media posts of each group over time. Conversations included more than **2 million posts/comments** over more than **14 years** of data across **10 rare disease caregiver communities** (mean [SD], 9.0 [3.7] years). The average group size was 204,927 posts/comments. The black line shows the average monthly total, and the gray shaded band is the 95% CI.

FIGURE 3. RECENT TOPICS ACROSS RARE COMMUNITIES



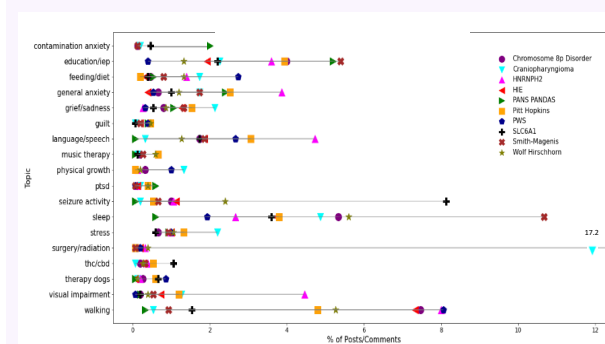
To understand the most prevalent conversational themes in mental health conversations, we conducted topic modeling on the most recent 1500 posts/comments in each community (15,000 total; required the most recent 1.6 years [SD: 1.7 years] on average). Figure shows the topics across all groups. Topics are colored by overarching category (top right). The largest, middle, and smallest topic sizes are noted for reference (top left).

FIGURE 2. MENTAL HEALTH CONVERSATIONS PER COMMUNITY



We used our mental health classifier to isolate all conversations discussing mental health. Figure shows the percentage of mental health conversations by community (mean [SD], 13.4% [3.8%]).

FIGURE 4. RECENT TOPICS BY RARE COMMUNITY



Although we were interested in understanding the most recent topics across communities, we also wanted to illustrate the relative contribution of each community to individual topics. Figure shows the percentage of posts/comments by community in each topic.

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CONCLUSIONS

Our aim was to characterize caregiver mental health challenges shared across 10 social media communities dedicated to caregivers for individuals living with rare diseases.

- Across the 10 communities evaluated in this study, the average number of posts/comments has doubled over 10 years.
- Approximately 10% to 16% of all community conversations were related to mental health.
- Shared topics across communities included conversations about specific mental health symptoms (e.g., *guilt, ptsd, anxiety, stress*) as well various milestones (e.g., *walking, language, growth*), management approaches (e.g., *therapy dogs, thc/cbd*), and other events (e.g., *seizure activity, education/IEPs*).
- We observed that certain conversation topics among the groups were weighted on specific rare communities (e.g., *surgery/radiation* in Craniopharyngioma Group, *sleep* in Smith-Magenis Syndrome Support, and *seizure activity* in SLC6A1).

FUTURE DIRECTION

Future work ought to further elucidate the relationship between the specific mental health symptoms (e.g., *stress, anxiety*) and external factors (e.g., *milestones, seizure activity*) highlighted in this analysis. With continued investigation, we can better inform mental health professionals, clinicians, and caregivers alike regarding mental health risk factors.

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Figure 4. Recent Topics by Rare Community as a Table. Values are listed as percentages.

Topic by Community	Chromosome 8p Disorder	Craniopharyngioma	HNRNP2	Hypoxic-Ischemic Encephalopathy	PANS/PANDAS	Pitt Hopkins Syndrome	Prader Willi Syndrome PWS	SLC6A1 Epilepsy	Smith-Magenis Syndrome	Wolf Hirshhorn Syndrome
Contamination Anxiety	0.13	0.2	0	0	2	0	0	0.47	0.13	0
Education/IEP	4	2.27	3.6	1.93	5.2	3.93	0.4	2.2	5.4	1.33
Feeding/Diet	0.47	1.73	1.4	0.33	0.53	0.2	2.73	0.4	0.8	1.33
General Anxiety	0.67	1.73	3.87	0.4	2.4	2.53	0.53	1	1.73	1.2
Grief/Sadness	0.8	2.13	0.27	1.27	1.07	1.53	0.33	0.53	1.33	0.87
Guilt	0.47	0.07	0	0.2	0.4	0.47	0.4	0.07	0.2	0.47
Language/Speech	1.73	0.33	4.73	1.87	0.07	3.07	2.67	1.73	1.87	1.27
Music Therapy	0.2	0.13	0.67	0	0.67	0.67	0	0.13	0.27	0.6
Physical Growth	0.33	1.33	0.13	0.07	0	0.07	1	0	0	0.2
PTSD	0.13	0.2	0.13	0.13	0.6	0.4	0.06	0	0.07	0.4
Seizure Activity	1	0.2	1.07	1.13	0.07	0.53	0	8.13	0.67	2.4
Sleep	5.33	4.87	2.67	3.73	0.6	3.8	1.93	3.6	10.67	5.6
Stress	0.67	2.2	1	1	0.93	1.33	1	0.6	0.93	1.07
Surgery/Radiation	0.13	17.27	0.33	0.2	0.13	0.07	0.2	0	0.07	0.4
THC/CBD	0.2	0.07	0.4	0.27	0	0.53	0	1.07	0.33	0.27
Therapy dogs	0.27	0.13	0.2	0.07	0.07	0.6	0.87	0.67	0	0.13
Visual Impairment	0.2	1.27	4.47	0.73	0.2	1.2	0.07	0.2	0.53	0.4
Walking	7.47	0.53	8	7.3	0.33	4.8	8.07	1.53	0.93	5.27