Social Listening: A Content Analysis of Social Media Discussions in Prader Willi Syndrome (PWS)

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Background

- Prader-Willi Syndrome (PWS) is a rare disease characterized by cognitive impairment, hypotonia, hyperphagia, obesity, and behavioral challenges.[1,2]
- Given its complexity, parents of children with PWS face heightened stress, mood disruption, and coping difficulties.[3]
- Given the rare nature of the disease, health research on PWS is difficult. Traditional research methods like surveys and clinical studies may not always capture the full scope of challenges faced by families.
- It is crucial to capture the real-world experiences, concerns, and unmet needs of patients and caregivers.
- Social media provides a powerful tool for understanding real-world experiences, concerns, and unmet needs within the PWS community

Objective

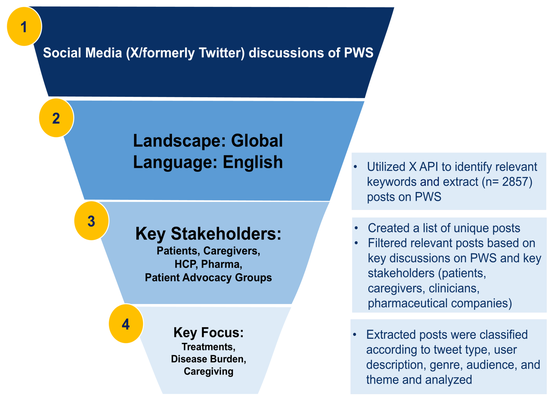
The study objective was to use a social listening approach to examine discussions surrounding PWS:

- To identify and understand the disease-related aspects experienced by PWS patients and caregivers.
- To understand the treatment discussion trends from multiple stakeholder perspectives.
- To examine the impact of PWS on different stakeholders.

Methods

- Publicly available posts (n=2,857) sent between October-December 2024 that matched keywords related to PWS were retrieved.
- Posts (n=1,663) that were unable to code or posted by bots were removed leading to the final count of n=1,194.
- Extracted posts were classified according to tweet type, user description, genre, audience, and theme.
- A random sample of 200 posts was analyzed to develop a coding framework and then applied to holdout data.
- Quantitative content analysis was conducted to identify themes.
- The analysis focused on understanding the extent of discussions vary between key stakeholders, including patient vs caregiver vs clinician vs pharmaceutical companies.

Methodology Scheme



- Utilized X API to identify relevant keywords and extract (n= 2857) posts on PWS
- Created a list of unique posts
- Filtered relevant posts based on key discussions on PWS and key stakeholders (patients, caregivers, clinicians, pharmaceutical companies)
- Extracted posts were classified according to tweet type, user description, genre, audience, and theme and analyzed

Limitations

- A majority of the posts (tweets) were junk posts or conversations that could not be coded, leading to invalid data.
- Most posts on X were uncategorized discussions or promotional, leading to a lack of disease and treatment-related insights on PWS.

References

1. Höybye C, Tauber M. Approach to the Patient With Prader-Willi Syndrome. J Clin Endocrinol Metab. 2022;107(6):1698-1705. doi:10.1210/clinem/dgac082
2. Yang L, Zhan GD, Ding JJ, et al. Psychiatric illness and intellectual disability in the Prader-Willi syndrome with different molecular defects--a meta analysis. PLoS One. 2013;8(8):e72640. Published 2013 Aug 14. doi:10.1371/journal.pone.0072640
3. van den Borne HW, van Hooren RH, van Gestel M, Rienmeijer P, Fryns JP, Curfs LM. Psychosocial problems, coping strategies, and the need for information of parents of children with Prader-Willi syndrome and Angelman syndrome. Patient Educ Couns. 1999;38(3):205-216. doi:10.1016/s0738-3991(99)00004-x

Results

Figure 1: Distribution of type of posts (tweets)

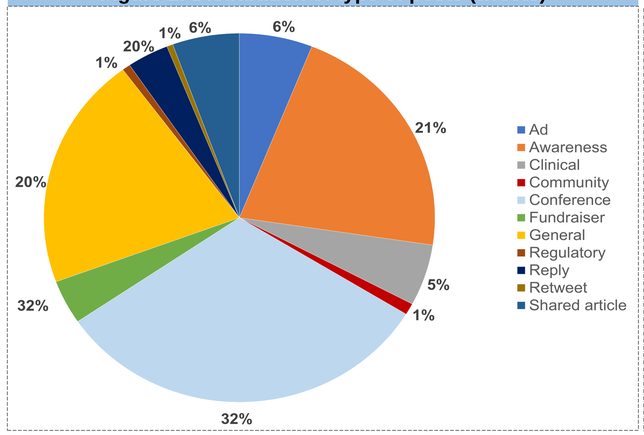


Figure 2: Type of people posting

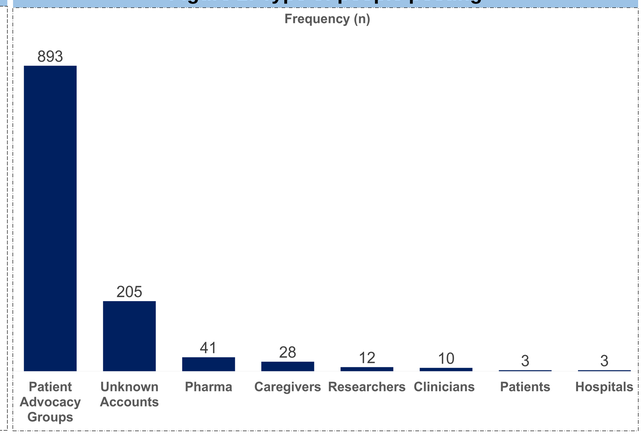


Table 1: Thematic frequency analysis of discussions on PWS

Themes	Subtheme	n (%)
Access-related Discussions	Access related discussions	8 (0.7%)
Caregiving	Having a child with PWS	25 (2.1%)
	Sharing PWS diagnosis	6 (0.5%)
	Caregiving experience	27 (2.3%)
	Perceptions about caregiving	5 (0.4%)
	Caregiving resources	36 (3.0%)
Disease-related Discussions	Living with PWS	13 (1.1%)
	Nutrition	2 (0.2%)
	Symptom management	2 (0.2%)
Disease Challenges	Endocrine issues	2 (0.2%)
	Hyperphagia	10 (0.8%)
	Risk of blood clots	5 (0.4%)
	Sleep apnea	3 (0.3%)
	Mental health	25 (2.1%)
	Unmet needs	6 (0.5%)
	Orthopedic challenges	5 (0.4%)
Clinical Trials and Research	Treatment pipeline	31 (2.6%)
	Research	53 (4.4%)
Treatments	Treatments	89 (7.5%)
Social Challenges	Social challenges	33 (2.8%)
Support	Community support	33 (2.8%)
Promotion	Fundraising	73 (6.1%)
	PWS awareness	315 (26.4%)
	Conferences/Ads	348 (29.1%)
Other	Schaaf-Yang syndrome	39 (3.3%)
Total		1194 (100.0%)

Detailed list of current treatments and treatment pipeline		
Current treatments and pipeline	**n (%)**	**Themes of the post**
Sex hormone/growth hormone treatment	38 (43%)	• Most discussed therapy option for hypogonadism by clinicians and patient advocacy groups • Clinicians posted about a hormone-therapy-based OTBB3Trial, coordinated by PedCRIN
Vagus nerve stimulation	20 (22.5%)	• Clinicians and patient advocacy groups mentioned VNS for managing behaviors/reducing disruptive behaviors
Noninvasive peripheral ultrasound, Transcranial magnetic stimulation, Bright light therapy	10 (11.2%)	• Posted by clinicians and patient advocacy group as therapies for managing PWS symptoms
Tesomet by Saniona	7 (7.9%)	• Posted by advocacy groups, announces orphan drug designation for hypothalamic obesity
DCCR by Soleno Therapeutics	4 (4.4%)	• Posted by Soleno Therapeutics announcing the initiation of Phase III clinical trial of DCCR in PWS
Carbetocin by Acadia Pharmaceuticals	4 (4.4%)	• Posted by an advocacy group mentioning Phase III (12-week) efficacy and safety study of Carbetocin nasal spray in approximately 170 children aged 5-30 years
CSTI 500 by ConSynance Therapeutics	1 (1.1%)	• Posted by an advocacy group mentioning that FDA has granted Rare Pediatric Disease Designation to CSTI-500 for treating PWS
ARD-101 by Aardvark Therapeutics	1 (1.1%)	• Posted by an advocacy group mentioning treatment pipeline in PWS
NNZ-2591 by Neuren Pharmaceuticals	1 (1.1%)	• Posted by Neuren Pharmaceuticals and included a trial recruitment announcement
LV-101 by Levo Therapeutics	1 (1.1%)	• Posted by an advocacy group mentioning the clinical trial results on LV-101 for Prader-Willi Syndrome
Pitolisant by Harmony Biosciences	1 (1.1%)	• Harmony Biosciences announced a Phase III study of Pitolisant for children and adults with PWS who struggle with daytime sleepiness

- Majority of the posts were predominantly directed towards the awareness of PWS, fundraising for PWS, or discussions on conferences/research meetings for PWS. (Figure 1) Additionally, notable focus areas include treatments in PWS, caregiving resources, and clinical trials/ upcoming research in PWS. (Table 1)
- Discussions featured clinical trials in PWS, namely TEMPO (Phase 3) trial, NNZ2591 (Phase 2) trial by Neuren Pharmaceuticals, trial for DCCR by Soleno Therapeutics, RAD011 trial by Radius Health, OTTB3 trial by PedCRIN, COMPASS study by Acadia pharmaceuticals, Pitolisant trial by Harmony Biosciences, and LV101 trial by CARE-PWS.

Table 2: List of clinical trials in PWS

Detailed list of current clinical trials	
Clinical trials and related research	**Description of Trial**
TEMPO Clinical Trial by Harmony Biosciences	• Phase 3 trial of Pitolisant for excessive sleepiness in patients with PWS.
NNZ-2591 Clinical Trial by Neuren Pharmaceuticals	• Phase 2 clinical trial of NNZ-2591 for reducing neuroinflammation and stimulate growth of dendrites that form synapses.
VNS4PWS Clinical Trial by FPWR	• Phase 3 trial for patients with PWS ages 10-40 who experience disruptive behaviors and temper outbursts.
OTBB3 Clinical Trial by University Hospital, Toulouse	• Phase 3 trial of intranasal oxytocin for the main symptoms of PWS like difficulties with sucking and swallowing.
COMPASS Study by Acadia Pharmaceuticals	• Phase 3 Study of Carbetocin (ACP-101) for the Treatment of Hyperphagia in PWS.
Global PWS Registry by FPWR	• Global registry for sleep disorders, seizures, and psychiatric issues in PWS.
PWS-CLIC Studytrax Database by FPWR	• Shared database to document clinical aspects of the disease.

Disease-related discussions among stakeholders

Clinicians

- Clinicians shared posts to raise awareness about PWS, highlighting its association with feeding difficulties and intellectual or social challenges.
- Other disease-related challenges included Hyperphagia (persistent hunger) and increased risk of blood clots among individuals with PWS.

Patient advocacy groups

- Posts from advocacy groups such as the Foundation of Prader-Willi Research revolved around the disease burden of PWS and raising awareness.
- Posts were focused on topics like recognizing the signs and symptoms in PWS (risk of blood clots, mental health challenges, orthopedic challenges, bladder dysfunction).

Caregiving-related discussions among stakeholders

Caregivers

- Caregivers voiced concerns about the disease burden of PWS but often shared a positive outlook on raising a child with the condition, including motivational stories.
- Posts on caregiving highlighted helpful resources focused on care strategies, coping mechanisms, support systems, and recognizing mental health challenges in the child.

Figure 3: Word Cloud from PWS posts (tweets)

Opportunities, Learnings, and Application

- Given the rarity of PWS and limited patient data, our study revealed key unfiltered insights on the disease burden of PWS, treatment pipeline, and unmet needs from a diverse perspective.
- The data also shed light on the clinical engagement as well as the role of peer support in PWS.
- These insights can be utilized to raise PWS awareness, understand disease burden, and understand conversations beyond formal clinical settings and across geographies.