

GASTROINTESTINAL ISSUES IN THE PWS COMMUNITY

February 2025



Prader-Willi syndrome (PWS) is a rare genetic disorder caused by the loss of function of specific genes on chromosome 15.¹ It is characterized by a constant feeling of hunger, leading to chronic overeating and obesity. Other symptoms can include poor muscle tone, poor growth and physical development, delayed motor development, and sleep disorders. Best managed by a team approach, various specialists can help manage symptoms of this complex disorder, reduce the risk of developing complications and improve the quality of life for those living with the condition.²

Formed in 1975, the Prader-Willi Syndrome Association | USA (PWSA | USA) unites parents, professionals, and concerned citizens to improve the lives of those with Prader-Willi syndrome. PWSA | USA supports the PWS community through shared experiences, research, education, advocacy, and assistance. As the only national PWS support organization, it has chapters in most states to help individuals with the syndrome and their families at every step.³

TREND Community is a community-powered data analytics company that turns the conversations of rare and chronic disease communities into actionable insights. This report explores discussions within social media communities focused on PWS, specifically addressing the topic of gastrointestinal (GI) issues. The goal is to amplify the voices of those living with this condition to shed light on their experiences to drive action and achieve improved outcomes.

DATA SOURCES

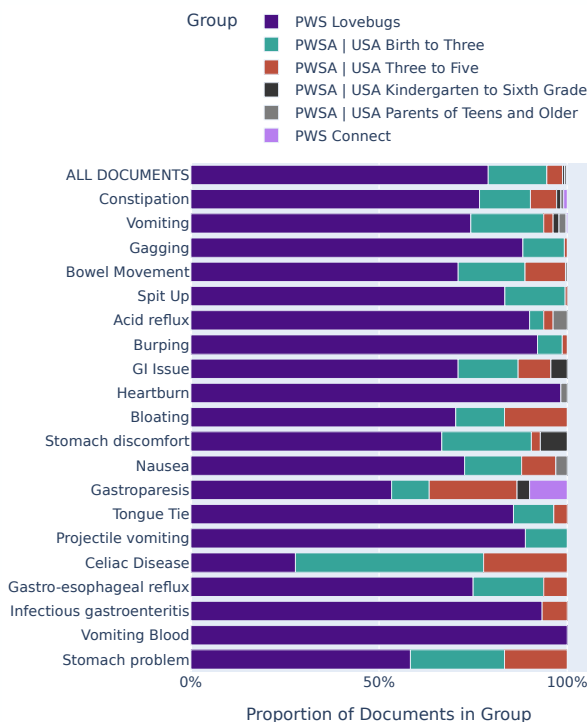
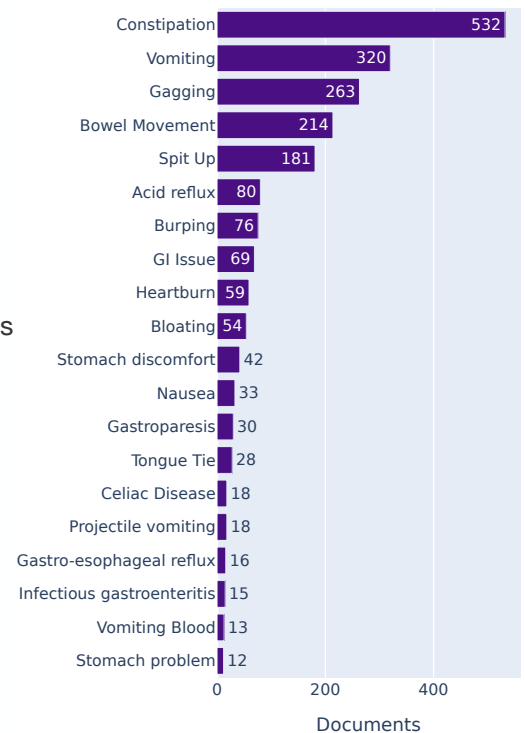
GROUPS*: PWS Lovebugs (Facebook group); PWSA | USA Facebook groups: Birth to Three, Three to Five, Kindergarten to Sixth Grade, Parents of Teens and Older; PWS Connect (discord server)

POSTS ANALYZED:	COMMENTS ANALYZED:	AVERAGE ENGAGEMENT:	TIME RANGE:
24,775	226,535	9.1 comments per post	2012 – 2025

*Note: The PWS Lovebugs group constitutes the majority (79%) of the data used in this analysis.

GASTROINTESTINAL TRACT FINDINGS

- TREND’s analytics engine, Krystie™, was utilized to recognize mentions of clinical findings related to the GI tract.
- Overall, 1,976 documents (0.79%) from the data sources mentioned a GI tract clinical finding.
- The twenty most frequent such concepts are shown on the right. ‘Constipation’, ‘Vomiting’, and ‘Gagging’ were the most common.
- ‘Bowel Movement’ and ‘Spit Up’ round out the top five, after which there is a pretty steep drop off.
- The most frequently mentioned condition, ‘Gastroparesis’, was only mentioned in 30 documents.



- The figure on the left shows the proportional breakdown of which groups the documents mentioning each GI Tract finding were found in, as well as the baseline distribution of all documents for reference. (Using the groups as a proxy for age, it’s worth mentioning that PWS Lovebugs is for caregivers of children 0-2 with PWS. PWS Connect is for all ages.)
- ‘Gastroparesis’ and ‘Celiac Disease’ are represented less in the youngest groups (age 0-3) than the baseline, whereas ‘Gagging’, ‘Spit Up’, and ‘Burping’, ‘Projectile vomiting’, and ‘Vomiting Blood’ are almost exclusively present in the youngest groups.

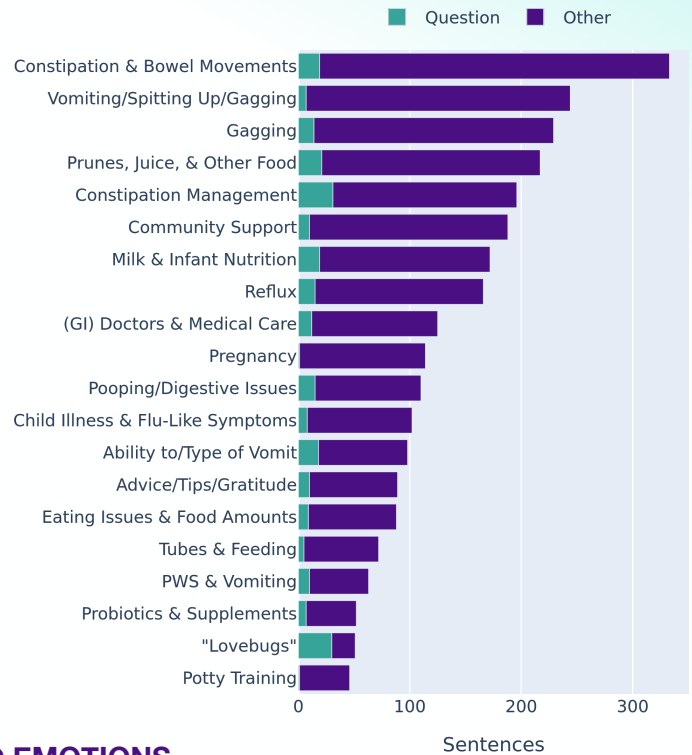
¹U.S. Department of Health and Human Services. (n.d.-a). Prader-willi syndrome (PWS). Eunice Kennedy Shriver National Institute of Child Health and Human Development.

² Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/prader-willi-syndrome/symptoms-causes/syc-20355997>

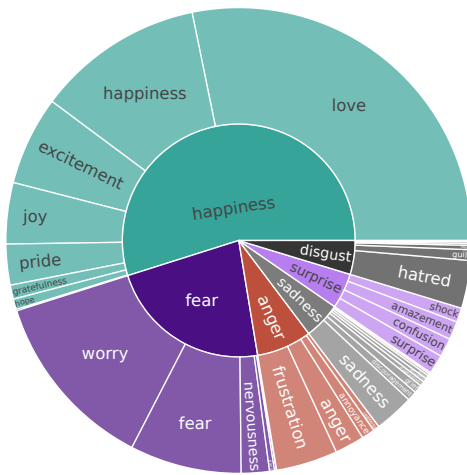
³Prader-willi syndrome association USA - supporting families. USA. (2024, June 5). <https://www.pwsausa.org/>

TOPIC ANALYSIS

- The paragraphs that mention a GI tract clinical finding were examined for further analysis.
- The twenty most common topics are shown as well as the breakdown of how many questions were asked.
- After three topics relating to GI issues specifically (constipation, vomiting, and gagging), the next most discussed topic is **'Prunes, Juice, & Other Food'**, displaying that users often discuss the impact of food on GI health and food remedies for constipation.
- The presence of **'(GI) Doctors & Medical Care'** in the top 10 topics suggests caregivers take the GI issues seriously and seek medical advice/attention.
- The majority of sentences where users refer to infants with PWS as "Lovebugs" are questions. **'Constipation Management'** also has a disproportionate amount of questions, suggesting caregivers often seek advice about how to handle constipation.



GASTROINTESTINAL TRACT CLINICAL FINDINGS AND EMOTIONS



Baseline



GI Tract Finding Paragraphs

- The distribution of emotion words found within paragraphs that mention a GI tract finding is shown on the left, along with the baseline distribution across the whole dataset for reference.
- The proportion of **fear** emotions is far higher, and that of **happiness** emotions is far lower, in paragraphs that mention a GI tract finding than in the baseline.
- Non-clinical language associated with fear mentions includes **"gj tube"**, **"ng tube"**, **"mask"**, **"nursing"**, **"surgeon" / "surgery"**, **"sleep study"**, and **"low tone"**.**

**Term frequency – Inverse document frequency (TF-IDF) was used to identify the non-clinical language associated with fear.

CONCLUSION

The gastrointestinal issue discussed most frequently in these online PWS communities is constipation. The breakdown of mentions reveal this is a concern across age groups. Also, topic analysis shows that caregivers often discuss management techniques, including prunes and juice. Moreover, these caregivers are asking many questions specifically about how to manage constipation. Specific conditions, e.g., gastroparesis and celiac disease, are mentioned far less frequently than GI issue symptoms, and are mentioned proportionally less in the groups for younger children (0-3).

Topic analysis of the paragraphs that mention a GI tract finding also revealed that caregivers often discuss doctors and medical care alongside GI issues. Examining the emotion words used in the context of GI issue mentions reveals an association with fear. Some of the language that separates those fear mentions from the rest of the GI issue discussion suggests the fear relates, in part, to feeding tubes, surgery, sleep studies, and low muscle tone.