

What's TRENDing: Emotional and Behavioral Patterns and PWS

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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 digital 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 emotional and behavioral patterns. 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

PWSA | USA FACEBOOK GROUPS: *Three to Five, Kindergarten to Sixth Grade, Parents of Teens and Older*
POSTS & COMMENTS ANALYZED: 1,897/11,704
TIME RANGE: 2022-2024

Overall Emotion Profile in PWS Caregiver Discussions



Figure 1. Emotion Wheel

TREND used its proprietary approach to identify the emotional words in all documents and categorized them by using Paul Eckman's six primary emotions of happiness, fear, anger, sadness, disgust, and surprise.

Figure 1 reveals that **happiness** emerges as the largest primary emotion, with **love** as the most prominent sub-category. **Fear** is the second most prevalent primary emotion, with **worry** as its main sub-category.

Happiness and **worry (under fear)** predominantly reflect parental emotions and their expression of support or concerns about their children. There is a more balanced mix of **anger-related terms** shared by both parents and children, with substantial examples of emotional regulation challenges for children. **Sadness** terms are mostly from parents, with only a few instances of children expressing this emotion.

As children's emotions are often reflected through behavior, the analysis was expanded to include behavioral contextual words (such as 'behavior issue', 'skin picking'). Environment keywords ('school', 'hospital', 'kitchen', etc) were extracted to help find connections between the environment and emotion regulation issues. Additional analysis on these topics can be found on the next page.

*"I'm **concerned** that the schoolwork might be too demanding for my daughter's current abilities."*

*"I get **worried** every time my son becomes upset about not having his snack."*

*"I would say it's **frustration** caused by being unable to communicate her thoughts."*

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/svc-20355997>

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



"What's helpful for us is practicing what to do instead for the known triggers. We practice when she isn't upset. She knows to use certain phrases to express her frustration and squeezes her hands/stress balls versus hitting."

"My daughter started picking her nose at 4 & now picks until it bleeds."

The analysis of support group discussions for families of children with PWS reveals notable emotional and behavioral patterns that are central to the challenges faced by both children and their caregivers. Emotional regulation difficulties, particularly around fear, anger, and sadness, are prevalent in the PWS community. These emotions are often tied to specific behavioral challenges, including aggression, tantrums, and self-injurious behaviors. Parents' discussions suggest that changes in routine or unmet expectations can be challenging for their children, and they express concern and frustration regarding these behaviors, they also share strategies that have been helpful, such as behavior therapy and coping techniques to manage frustration. And while statistically significant associations between emotions, behaviors, and environmental factors could not be made, the many mentions of school-related topics are quite prevalent and should be studied further. Overall, this report provides insights into how parents discuss emotional experiences, behavioral patterns, and environmental factors in children with PWS through support group discussions, highlighting the need for tailored interventions and support strategies.

