

November 2024

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.³ 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 various aspects of pain, including low pain sensitivity. 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.

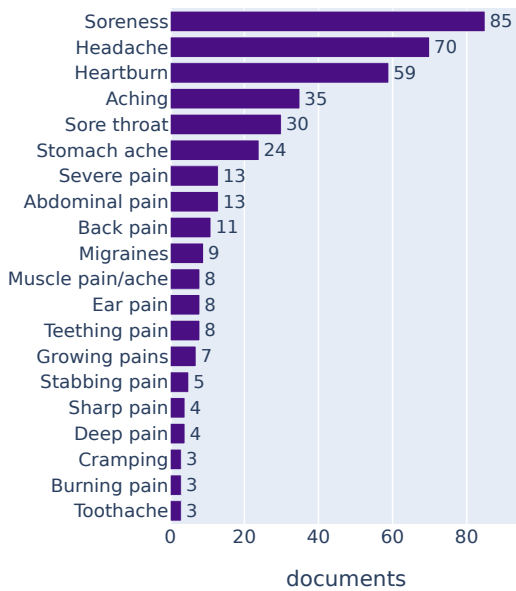
DATA SOURCES

FACEBOOK GROUPS: PWS Lovebugs, PWSA | USA Birth to Three, PWSA | USA Three to Five, PWSA | USA Kindergarten to Sixth Grade, PWSA | USA Parents of Teens and Older

POSTS & COMMENTS ANALYZED: 24,504/226,333

TIME RANGE: 2022-2024

PAIN TYPES



PAIN TYPES

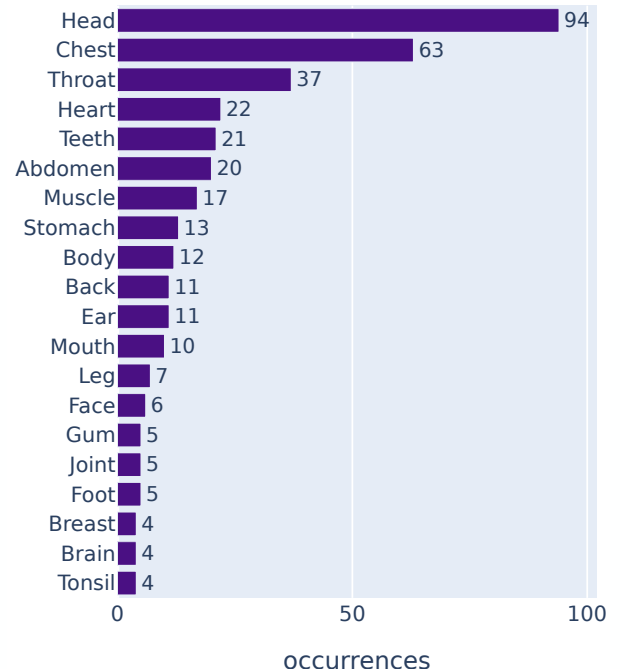
TREND's analytics engine, Krystie™, recognizes mentions of clinical concepts and links them to a knowledge base of medical terminology. Here, relationships are identified between the concepts to isolate mentions of any type of pain. Some types of pain are associated with a specific body part while others are more general. The following are the most mentioned types of 'Pain': Soreness, 'Headache', and 'Heartburn'. The next most common topics are: 'Aching', 'Sore throat', and 'Stomach ache.' Throughout the data set, the following adjectives were used to describe the pain: severe, stabbing, sharp, deep, and burning.

It should be noted that pain itself was excluded because it is much more prevalent, occurring in 1,222 documents.

PAIN LOCATIONS

The 20 most frequently occurring body parts associated with pain are shown to the right. 'Head' was by far the most specific body part mentioned throughout the PWS conversations about pain. 'Chest' was the second most common body part followed by 'Throat'. 'Heart', 'Teeth', 'Abdomen', and 'Muscle' round out the top 7 most frequently mentioned body parts connected to pain. It appears that the lower extremities are less frequently impacted by pain than upper body parts.

PAIN LOCATIONS



"There are so many types of pain to deal with: Internal organ pain, tooth ache pain, throbbing pain when dropping something on your toe, pain from extreme cold, and sharp pain from needles and they all use different receptors in the nervous system."

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.

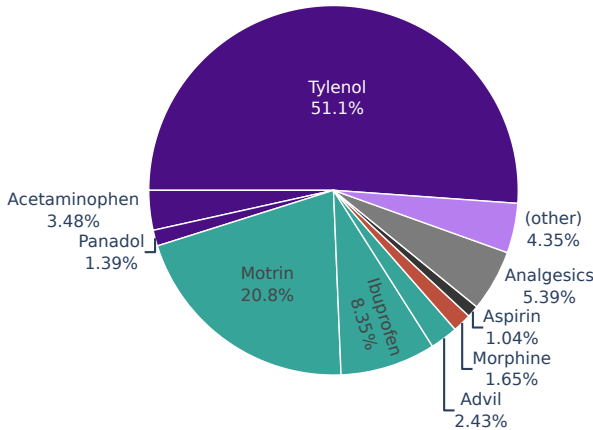
²Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/prader-willi-syndrome/symptoms-causes/syc-20355997>

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

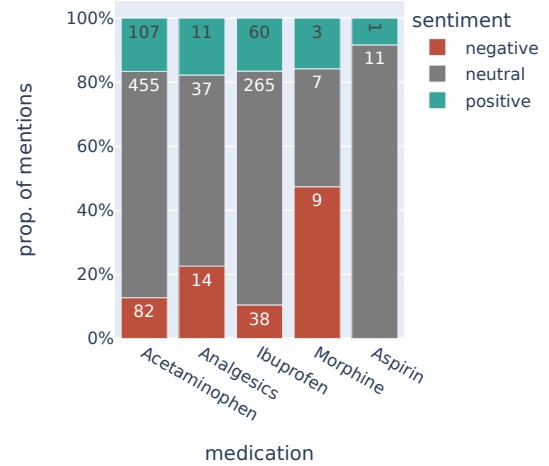
PAIN MEDICATIONS

In terms of pain medications (analgesics), ‘Tylenol’ accounts for more than half (51.1%) of pain medication mentions while the combined generic ‘Acetaminophen’ and brand name medications (‘Tylenol’ and ‘Panadol’) make up almost 56%. Nonsteroidal anti-inflammatory drugs (NSAIDs), including ‘Ibuprofen’, ‘Motrin’, and ‘Advil’, are mentioned almost 32% of the time. The distribution of these is shown below in the pie chart. Medications with fewer than 10 mentions were combined into the ‘Other’ category. In exploring the sentiment towards these medications (as seen below in the bar chart), there is not much difference in the proportion of positive mentions among ‘Acetaminophen’, ‘Analgesics’, and ‘Ibuprofen’. The difference mainly lies in the proportion of negative mentions, with generic ‘Analgesics’ having the highest proportion and ‘Advil’ the lowest. The sample sizes for ‘Morphine’ and ‘Aspirin’ are too small to draw any conclusions.

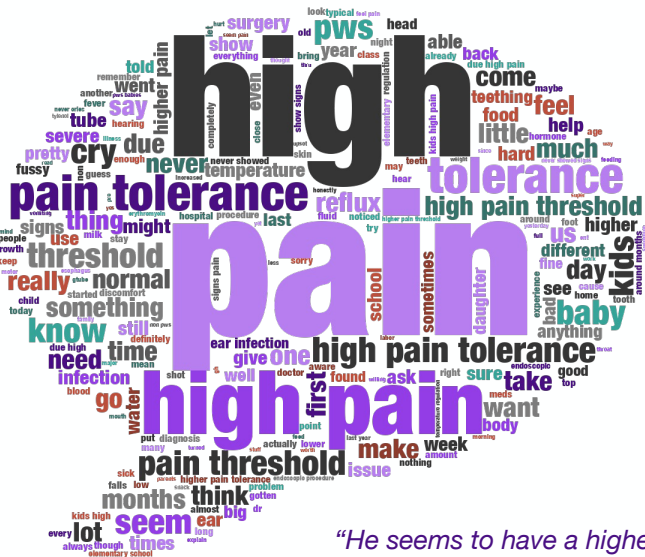
PAIN MEDICATIONS



SENTIMENTS



LACK OF PAIN SENSITIVITY



LACK OF PAIN SENSITIVITY

Upon analyzing discussions about pain tolerance and sensitivity, there are frequent phrases such as: ‘high(er) pain tolerance’, ‘high(er) pain threshold’, ‘can’t feel pain easily’, and ‘don’t feel pain in a normal way’. The larger words and phrases found in the word cloud to the left indicate a higher occurrence.

Due to high pain tolerance and issues with temperature regulation, children with PWS may not show typical symptoms of illness, making diagnosis challenging. Parents of these children stress the importance of trusting their instincts and seeking medical attention even for minor health concerns. Parents recommend watching for subtle cues, like fussiness or unusual behavior, as these may signal underlying health issues. Many parents also use tools like pulse oximeters for monitoring, as signs like warm extremities or strong urine odor can indicate illness rather than a fever.

Because children with PWS might not display standard signs of pain or discomfort, medical issues may go undetected, potentially leading to delays in treatment and escalating to life-threatening situations.

“He seems to have a higher pain tolerance since it does not bother him when he bumps his head. He just keeps going.”

“Something seems minor in a typical kid needs to be taken seriously in one with PWS.”

CONCLUSION

This analysis of common pain types and affected body parts in individuals with PWS highlights sore throats, headaches, heartburn, teething, sore muscles, and abdominal pain as key areas of concern. Among pain medications, Tylenol (Acetaminophen) emerged as the most frequently used, with Ibuprofen also frequently mentioned. Feedback about these medications lean slightly more positive, suggesting that most parents find them beneficial. However, sentiment around general analgesics was mixed, indicating a need for further study into their effectiveness for PWS-related pain. Future research could explore the effectiveness of specific medications for different types of pain or body areas, as patients may experience varying responses.

Additionally, the awareness of reduced pain sensitivity in individuals with PWS underscores the need for vigilant and proactive medical advocacy. These insights also point to the importance of educating healthcare providers and supporting parental advocacy. Urgent care guidelines and tools for parents could be valuable and well received. Providing guidance on creating individualized education plans (IEPs) and risk management plans that address unique PWS needs—such as dietary restrictions, pain tolerance, and temperature regulation—also would be valuable for families navigating educational and caregiving settings.