The Emotional Impact of Hyperphagia: Insights from the Prader-Willi Syndrome Community

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Aims

Hyperphagia is a well-known yet poorly understood symptom of Prader-Willi syndrome (PWS), making it difficult for individuals and caregivers to communicate their experiences with clinicians and support networks. Social media platforms offer valuable access to real-world, patient-generated health data (PGHD). This study aimed to analyze the sentiment and emotional terms of hyperphagia-related conversations within PWS-focused online communities, with the goal of identifying key emotional burdens and informing better clinical communication and psychological support strategies for those living with or caring for someone with PWS.

Methods

TREND analyzed 257,970 posts and comments (from March 2012 to September 2024) sourced from five PWSA USA Facebook groups and various Reddit communities. Using natural language processing and statistical methods, we identified hyperphagia-related language through semantic search and cosine similarity and clustered them into seven meaningful categories. Sentiment analysis was applied at the paragraph level, and a proprietary span recognition model extracted emotional terms, which were then categorized into six primary emotions. Standardized Pointwise Mutual Information Squared (PMI^2) was used to measure associations between hyperphagia categories and the six primary emotions across the dataset.

Results

Figure 1: Sentiment By Hyperphagia Categories (n=number of paragraphs)
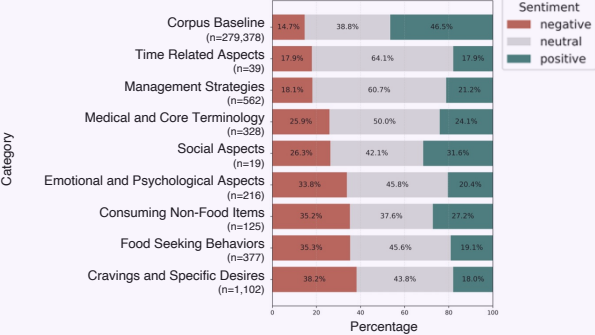
Hyperphagia-related posts had more negative sentiment than the dataset baseline, especially around *cravings and specific desires* (38.2%), *food-seeking behaviors* (35.3%), *eating non-food items* (35.2%), and *emotional and psychological aspects* (33.8%). These findings reflect the community's strong negative sentiment toward these aspects of hyperphagia.

Figure 2: Primary Emotions Across Hyperphagia-related Categories and Baseline (n=number of emotions)
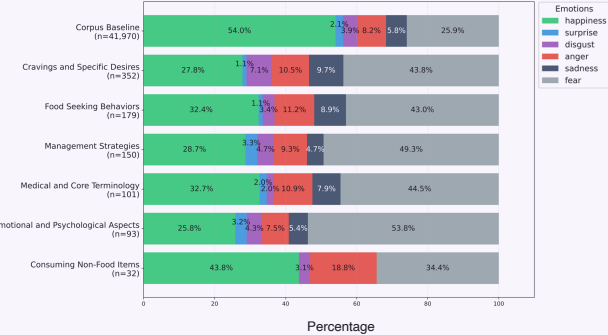
Emotion analysis showed that paragraphs containing *emotional and psychological aspects* or *cravings and specific desires* of hyperphagia had the fewest mentions of happiness terms and the most negative emotion terms like fear and anger. Although *consuming non-food* items also showed high negative sentiment, its emotional profile was similar to the baseline, likely due to a small sample size (n=32).

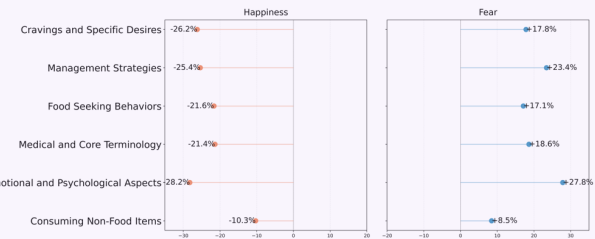### Figure 3: Emotion Deviation from Corpus Baseline (%): Happiness and Fear

Figure 3 highlights the percentage deviation from the corpus baseline for happiness and fear within each hyperphagia-related category. Compared to the baseline, hyperphagia-related categories contained more fear terms and fewer happiness terms, especially in *emotional and psychological* aspects, management strategies, and cravings and specific desires.

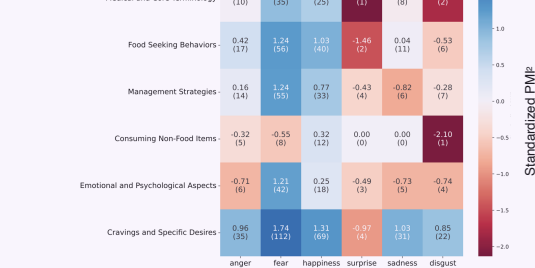### Figure 4: Standardized PMI^2 and (Co-occurrence Counts) Between Categories and Emotions

Figure 4 presents a heat map using standard PMI^2 scores to illustrate the strength of association between hyperphagia-related categories and the primary emotions. A positive score indicates that a given category and emotion co-occur more frequently than expected by chance, while a negative score suggests they co-occur less frequently than expected; larger absolute values reflect stronger associations. Cells with low co-occurrence counts should be interpreted cautiously, as they may not reliably represent broader trends. The result shows that the fear is associated across most categories, highlighting the emotional impact of hyperphagia.

Conclusions

Our findings underscore that hyperphagia discussions within the PWS community are often emotionally charged, with a strong presence of negative sentiment and fear-related language. This suggests that hyperphagia carries not only physical and behavioral challenges but also a significant psychological burden. These insights highlight the importance of developing supportive resources tailored to the emotional needs of the community members, which can empower individuals with PWS and their caregivers as well as assist clinicians in addressing hyperphagia more effectively.

Future Findings

Future research will explore temporal patterns in emotional expression around hyperphagia-related events, such as diagnosis, treatment changes, or life transitions. Expanding the analysis to include more diverse social platforms and international communities may also reveal cultural differences in the emotional burden and support needs. Additionally, future findings can inform the development of tools that help clinicians better understand and address the psychosocial aspects of PWS care.

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Introduction: Patient perspectives are vital to understanding the impact of a disease, and disease-focused social media groups provide a rich source of patient-generated health data (PGHD). Hyperphagia is a common but poorly understood symptom of Prader-Willi syndrome (PWS). Consequently, community members often face challenges in discussing it with their clinicians and family members. The aim of this study is to examine the sentiment and emotions associated with hyperphagia-related discussions by analyzing PGHD from social media.

Methods: This analysis used natural language processing and other statistical techniques to analyze 257,970 posts and comments shared (3/2012-9/2024) from five PWSA USA Facebook groups and multiple reddit groups mentioning "Prader-Willi Syndrome". Semantic search and cosine similarity was used to identify phrases similar to predefined hyperphagia seed terms and clustering. Sentiment analysis classified the sentiment of each paragraph. Next, a proprietary span recognition model was used to extract emotional terms. The emotional terms were mapped into six primary emotions. Standardized Pointwise Mutual Information (PMI²) measured the association between hyperphagia-related categories and these primary emotions.

Results: Hyperphagia related phrases were extracted and clustered into seven meaningful categories: *Cravings and Specific Desires*, *Management Strategies*, *Food Seeking Behaviors*, *Medical and Core Terminology*, *Emotional and Psychological Aspects*, *Consuming Non-Food Items*, *Time-Related Aspects*, and *Social Aspects*. Paragraphs containing these phrases had a higher proportion of negative sentiment compared to the overall negativity of 14.7% across the dataset. Notably, 38.2% and 33.8% of paragraphs containing *Cravings and Specific Desires* and *Emotional and Psychological Aspects* had negative sentiment. Paragraphs with these two categories also showed the lowest proportion of happiness-related terms and highest proportion of negative emotional terms (e.g., fear, anger, disgust), with fear being notably prevalent (comprising 53.8% of emotional terms in *Emotional and Psychological Aspects* and 43.8% in *Cravings and Specific Desires*, versus 25.9% of all emotional terms dataset-wide). Additionally, Standardized PMI² scores indicate that fear demonstrated strong associations and frequent co-occurrence across most categories.

Conclusions: These findings highlight the frequent negative sentiment and use of negative emotional terms in the hyperphagia-related discussions within the PWS community. This suggests the need to better understand and address the emotional and psychological impact of hyperphagia on individuals with PWS to help healthcare professionals better support PWS patients and their caregivers, ultimately improving health care outcomes.