

Voices of Vulvodynia: Qualitative Analysis of Patient Experiences on Reddit

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Background

- ❖ The International Society for the Study of Vulvovaginal Disease (ISSVD) guidelines characterize vulvodynia as chronic vulvar pain lasting at least three months with no identifiable cause.¹
- ❖ Despite its prevalence, diagnosing and treating vulvodynia can be challenging, leading many to seek medical information online.^{2,3}

Objective

- ❖ This study sought to evaluate content related to vulvodynia discussed on the internet forum Reddit. This study uniquely captures the experiences of individuals with vulvodynia told in their own words.

Methods

- ❖ The subreddits “r/vulvodynia” and “r/ vestibulodynia” were selected for analysis in May 2023. The top 70 posts from each subreddit was extracted and analyzed. Qualitative analysis was used to identify themes and assess attitudes towards shared experiences (Table 1).

	Positive	Negative
Description:	<i>The theme of the user's post is what any given person would interpret as a positive experience.</i>	<i>The theme of the user's post is what any given person would interpret as a negative experience.</i>
Examples:	<p>“After 8 YEARS of pain, no other symptoms... I finally found a doctor that listened to me, took me seriously, and was willing to try some things out.”</p> <p>“Reddit has helped me so much on my journey to find relief (if nothing else, just a massive sense of support from others who understand)”</p>	<p>“A doctor telling you that you have vulvodynia and putting you on an antidepressant or anticonvulsant to numb your pain is like putting a bandaid on a stab wound.”</p> <p>“I dont know what to do, i am so confused, i want to live normally, i want to have husband and have kids, please help me”</p>

Table 1. Example positive and negative valence statements.

Results

- ❖ The “r/vulvodynia” and “r/ vestibulodynia” subreddits had 7,245 and 685 members. Of posts analyzed, 45.7% had positive valence.
- ❖ Fifty threads (35.7%) were **seeking information or advice**.
- ❖ Six common themes were identified- **symptoms** (28.9%), **treatments** (28.8%), **sexual experiences** (16.0%), **erasure/ disbelief** (15.3%), **representation/media** (6.1%), and **humor** (5.1%).
- ❖ **Pain** was the most discussed symptom (46.8% of analyzed threads).
- ❖ Distribution of positive and negative valence by theme is shown in Figure 1.

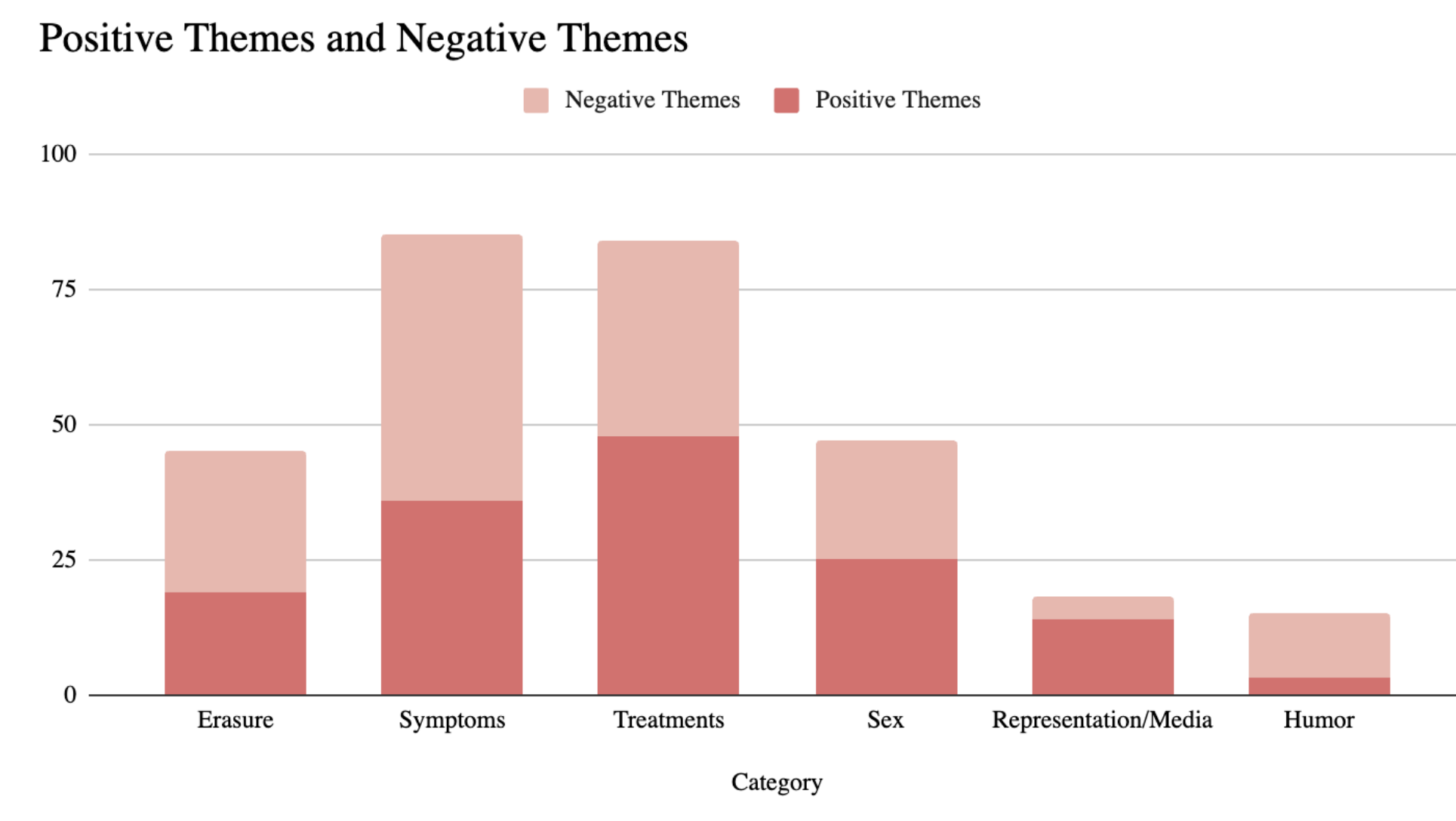


Figure 1. Positive vs. negative valence by theme.

Key Takeaways

- ❖ Vulvodynia symptoms significantly disrupt daily life and mental health.
- ❖ There is no exclusive classification for vulvodynia; rather, diagnosis is characterized by the description of pain.^{1,4,5}
- ❖ Management challenges persist due to varying treatment guidelines from the AUA, ACOG, and ISSVD.
- ❖ Online groups provide emotional support that may help individuals navigate both chronic pain and its mental health impacts.

References

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