Voices of Vulvodynia: Qualitative Analysis of Patient Experiences on Reddit

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Abstract

Background: Although vulvodynia is a prevalent condition, diagnosis and effective treatment remain elusive. As a result, individuals with vulvodynia may turn to the internet for medical information and advice.

Objective: This study sought to evaluate content related to vulvodynia discussed on the popular internet forum Reddit. Unlike prior research on vulvodynia, this article 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. Threads were sorted from most to least popular and data from the top 70 posts from each subreddit was extracted and analyzed. Qualitative analysis was used to identify themes and assess attitudes towards shared experiences.

Results: At the time of analysis, the “r/vulvodynia” and “r/vestibulodynia” subreddits had 7,245 and 685 members, respectively. Of all posts analyzed, 45.7% had positive valence. Of all analyzed threads, the most commonly identified discussions centered around symptoms (28.9%), treatments (28.8%), followed by sexual experiences (16.0%), erasure/disbelief (15.3%), representation/media (6.1%), and humor (5.1%).

Conclusions: This is the first analysis of Reddit content related to vulvodynia. However, results are limited by the number of posts analyzed, an inability to access user demographics, and the study's cross-sectional nature. Findings reveal robust discussions on Reddit regarding vulvodynia. Analyzed content suggests that Reddit provides a unique forum for peer-to-peer caretaking in the form of advice, an outlet for frustration, and a means to find community through shared experiences.

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Keywords: sexual health; health literacy; vulvodynia; pelvic pain

Introduction

Vulvodynia is defined as vulvar pain lasting for at least three months without an identifiable cause, characterized by factors such as location of pain (e.g., localized or generalized), triggers (provoked, spontaneous, or mixed), onset (e.g., primary or secondary), and temporal nature (e.g., intermittent, constant, or delayed).[1] The most common subtype of vulvodynia is vestibulodynia, defined as pain isolated to the vulvar vestibule.[2] According to the International Society for the Study of Vulvovaginal Disease (ISSVD) guidelines, vulvodynia is characterized by persistent vulvar pain lasting at least three months with no identifiable cause, such as infection or dermatological infection.[2] The pain, often described as burning, stinging, irritation, or rawness, is triggered by activities that put pressure on the vulvar area, such as sexual intercourse, prolonged sitting, wearing tight clothing, biking, or horseback riding. There is also a notably high prevalence of concurrent lower urinary tract symptoms such as urinary urgency and frequency which can mimic urinary tract infections.[3]

Vulvodynia is prevalent, affecting approximately 16% of women in the United States.[4,5] However, the majority of people with vulvar pain remain undiagnosed and inadequately treated. Studies report that nearly 40% of people with chronic vulvar pain do not to seek treatment, and of those that do, 60% consult at least three physicians before receiving a diagnosis, if they receive one at all.[4] Factors contributing to this gap in care may include a lack of, on the part of medical providers, adequate medical education on vulvar anatomy and physiology, a longstanding history of medical dismissal of female pain, and shame and stigma surrounding female reproductive organs and sexuality.[6–8]

Since the advent of the internet, individuals have sought medical information, often before consulting healthcare professionals.[9,10] The trend is particularly noteworthy among those with understudied conditions such as vulvodynia and vestibulodynia. People with these conditions seek health information and peer support online. Reddit, a popular website with over 52 million daily users and 1.5 billion registered users, is a notable forum for those seeking medical information and peer support.[11] By design, Reddit facilitates open discussion across various topics, allowing for a global and substantive exchange of information that is not as readily facilitated on other platforms such as Instagram or Facebook.

For individuals with chronic diseases, peer support and community engagement on online platforms can be invaluable tool.[12] Online platforms have also been recognized as ways individuals with chronic diseases build social identity through group support.[13] These platforms not only provide a sense of community but also help individuals build social identities through shared experiences. Previous studies have shown that people turn to Reddit for information about chronic sexual dysfunctions, particularly erectile dysfunctions.[14,15] However, there has been no study examining the use of Reddit to obtain or share information on vulvodynia or vestibulodynia. While population-level data on patient experiences of vulvodynia exists, patient-centered studies that capture the experiences of individuals living with vulvodynia in their own words are rare.[16–18] This study seeks to qualitatively assess patient experiences of vulvodynia as discussed on Reddit, providing insights into current patient perspectives directly from those affected. By capturing these narratives, this study fills a gap in the existing literature and highlights the importance of understanding patient experiences beyond the clinical setting, which can inform more empathetic and effective healthcare strategies.

Methods

To evaluate Reddit forum content related to vulvodynia, the subreddit pages “r/vulvodynia” and “r/vestibulodynia” were selected for analysis in May 2023.[19,20] The “r/vestibulodynia” subreddit was included to provide a more comprehensive understanding of patient experiences, as vestibulodynia is a specific form of vulvodynia. For each subreddit, threads were sorted from most popular to least popular by selecting the “top” thread feature over “all time.” A thread becomes a “top” thread based on the number of upvotes, comments, and overall engagement it receives from others in the Reddit community. We reviewed the top 70 threads from each subreddit, as these were deemed most representative of user interactions and information-seeking behavior.

The study was deemed exempt by the Institutional Review Boards of the University of California San Diego and Johns Hopkins Institutional Review Boards due to the use of publicly available information. Qualitative data from the top 70 threads in “r/vestibulodynia” and the top 70 threads in “r/vulvodynia” subreddits were extracted into an Excel spreadsheet (Version 16.82, Microsoft Corporation, Redmond, WA). Six team members (SP, EM, KS, MC, AP, JM) independently assessed all 140 threads, employing a thematic analysis approach. One team member (AG) reviewed and compared the individual assessments. Codes were revised as necessary based on commonly identified themes, following established qualitative analysis procedures.[21]

Additionally, threads were evaluated for positive/negative attitudes. “Positive” attitudes included expressions of optimism, relief, or joy; references to cures; and observational or light humor. “Negative” attitudes encompassed expressions of frustration, despair, fear, isolation; mentions of pain, pessimism, exhaustion, or unresolved symptoms; and dark humor with elements of bitterness or the macabre/morbid. Any discrepancies in themes and attitudes based on individual coding were identified by AG and resolved by group consensus. Examples of included threads included in the analysis are provided in Table 1. This methodological approach allows for a nuanced understanding of patient experiences and attitudes towards vulvodynia as discussed in online forums, contributing valuable insights into patient perspectives and community interactions.

Results

At the time of analysis, the “r/vulvodynia” and “r/vestibulodynia” subreddits had a combined total of 7,930 members (7,245 and 685 members, respectively). Of the 140 analyzed threads, 50 (35.7%) were seeking information or advice. The other 90 threads (63.4%,) comprised peer support discussions, sharing personal experiences related to vulvodynia, including treatments, symptoms, mental health struggles, and advice exchange with other members of the subreddit.

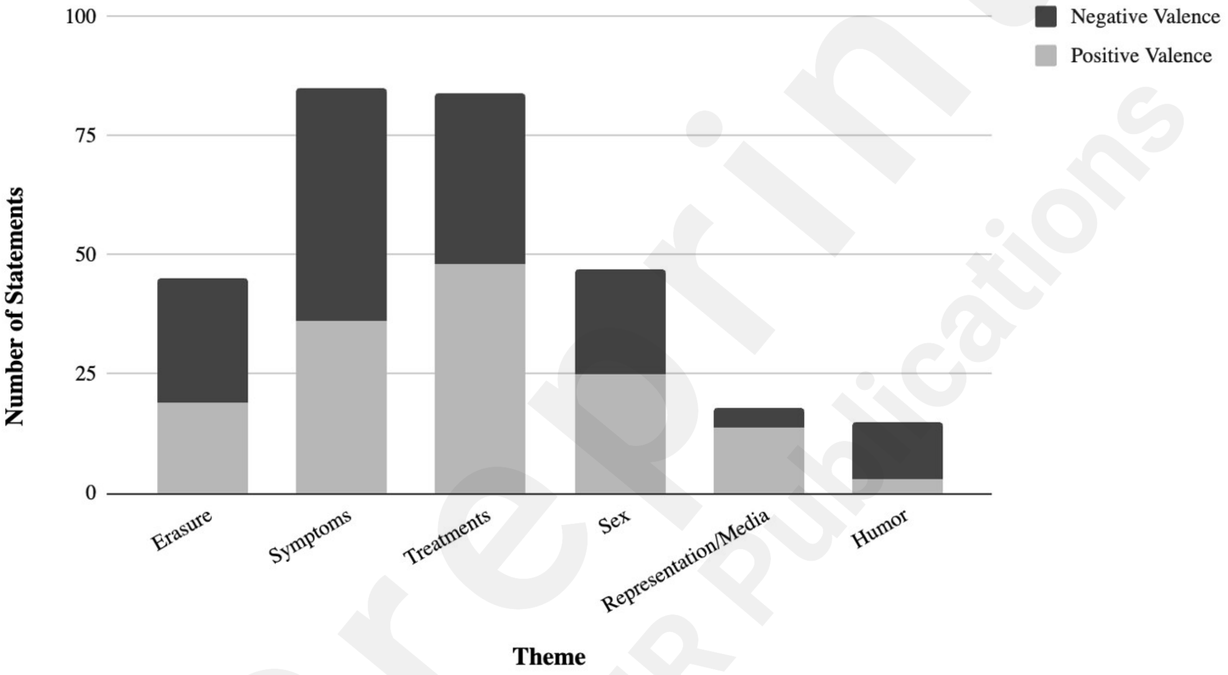
Six core themes emerged from the qualitative analysis: 1) a subjective sense of erasure of the lived experience of those with the condition and/or disbelief by those experiencing the condition; 2) difficulty managing symptoms; 3) the condition’s impact on sexuality and sexual experiences; 4) representation and/or media; 5) humor as a coping technique or a response to the condition; 6) treatments sought or tried. The most discussed themes were symptoms (28.9%) and treatments (28.8%), followed by sexual experiences (16.0%), erasure/disbelief (15.3%), representation/media (6.1%), and humor (5.1%). There were positive attitudes in 45.7% of all analyzed threads. The core themes of treatments (57.1%), sexual experiences (53.2%), and representation (77.8%) had the highest proportions of positive attitudes in analyzed threads. The themes of erasure (58.3%), symptoms (57.6%), and disbelief (57.1%) had the highest proportions of negative attitude threads. The distribution of positive and negative attitudes across themes is illustrated in Figure 1.

Table 1. Example positive and negative valence statements.

	Positive	**Negative**
Description:	*The theme of the user’s post is what any given person would interpret as a positive experience.*	*The theme of the user’s post is what any given person would interpret as a negative experience.*
Examples:	“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.”	“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.”
	“These were unbelievable, soft and breathable, non-chafing, benign, the [underwear] REALLY helped me feel better. “	“Do you ever just want to send your vagina into space?”
	“I know vulvar pain is terrible, like the worst thing to ever happen to a Vulva owner but we have to find at least a touch of humor in it to keep sane right?”	“I'm on tinder and open to dating, but at the same time I'm just so scared of exposing myself to men and having to deal with the thought of having an "unavailable" vagina.”
	“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)”	“Does anyone have any advice on this how to release these trigger points ? - lidocaine only helps to some extent temporarily”
	“I know I just posted but I forgot to add in the book by a few well known doctors that specialize in pelvic pain.	“Then [I] was told by my doctor to accept the pain and that it will be there forever.”

	It’s called when sex hurts: understanding and healing pelvic pain.”	
	“With a hefty amount of lube (game changer), relaxation and slow pace, inserting the toy is completely painless, I got to a point I can just slide it in effortlessly with no pain.”	“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”

Figure 1. Positive vs. negative valence by theme.



Discussion

Gaps in healthcare delivery often drive individuals to seek information and support on the internet. Studies indicate that many people consult online sources for medical advice before seeing a healthcare professional.[9] Reddit offers a supportive platform where individuals can anonymously share experiences and access suggestions from peers about treatments and coping strategies. This fosters validation, empowerment, and peer support, which may explain the prevalence of positive valence posts. Reddit’s discussion-based communities, or subreddits, differ from platforms like Twitter and Instagram by facilitating ongoing conversations rather than static posts. This dynamic nature encourages active participation, making Reddit a valuable hub for information sharing. Given the complex and often misunderstood nature of vulvodynia, Reddit offers a rich source of qualitative data that provides insights into patients' lived experiences. Analysis of Reddit threads revealed six common themes. Findings for each theme are discussed below, with representative quotes shared to illustrate these themes.

Erasure and Disbelief

A published study exploring the experience of women with vulvodynia in the UK found that healthcare professionals often dismiss patients' expressions of concern or lack knowledge about the condition.[22] The high percentage of posts mentioning erasure and disbelief (15.3%) underscores the healthcare system's inadequate support for vulvodynia patients, which may explain the prevalence of negative valence posts (58.3%). One subreddit member asked, "What's the least helpful thing you've heard from a doctor?" spurring broader conversations about shared experiences and coping strategies. Another individual described the difficulty of navigating a medical world that does not acknowledge the existence and experiences of vulvodynia: "I know what I want and what I need for myself. I don't need someone to try to downplay the constant pain I'm feeling." Erasure seemed consistent and prevalent: "being your own medical advocate is the most exhausting job I've ever had and will ever have." These experiences highlight the persistent marginalization and disbelief that individuals with vulvodynia face, necessitating their role as advocates for themselves and the broader vulvodynia community. Patients shared disappointment regarding conversations with doctors: "A doctor today asked me if I tried using lube," revealing a gap in understanding and empathy about vulvodynia's etiology and treatment. This underscores the critical need for improved medical education and patient-centered care in addressing vulvodynia.

Symptoms

Symptoms were the most prevalent theme (28.9%), with many threads emphasizing the impact of physical health challenges on daily lives. Posts discussing symptoms predominantly had a negative valence (57.7%), reflecting on the disruptive nature of physical discomfort. It is essential to acknowledge, however, that participants posting in these threads may not all be diagnosed with vulvodynia; platforms are used for open discussion about personal experiences and empathetic support. Despite this limitation, there were parallels between what user-reported symptoms and clinical diagnostic criteria for vulvodynia. Currently, there is no exclusive classification for vulvodynia; rather, a diagnosis is characterized by the description of pain.[1,2,15]

Reddit users described experiences of burning pain, pain with tampon insertion, pain during sexual intercourse, and irritation from clothing. Some symptoms mentioned, such as swollen tissue with tampon insertion, pain with urination, and pelvic floor tightness, do not align with established diagnostic criteria, suggesting current diagnostic tools may not capture the full range of experiences.[2]

Vulvodynia can interfere with daily functioning, as one user noted: “When I ride my bike my vestibule hurts.” Others find it challenging to stay active due to pain and seek advice from others, asking, “If anyone ever feels this pain after going to the gym?” The pervasive pain of vulvodynia extends beyond physical discomfort: “Prior to dealing with vulvodynia I was never someone who spent more than $5 on a pair of underwear.” Pain was the most discussed symptom (46.8% of analyzed threads), emphasizing the debilitating impact of vulvar pain on health and quality as well as the need for a multi-disciplinary approach to treatment that involves a team of well-educated specialists in chronic pain.[24] The heterogeneity of pain associated with vulvodynia underscores the need for further research to better understand its etiology and develop more effective treatment strategies.

In addition to pain, the subreddit threads delved into anger, frustration, anxiety, depression, and even trauma, highlighting the connection between mental health and chronic pain. One user stated that "not enough people talk about how chronic pain makes depression so much worse," reflecting literature findings that link chronic pain with unremitting anxiety and depression. In the US, it is estimated that 4.9% of US adults live with chronic pain, and 23.9% of individuals with chronic pain experience unremitting anxiety and depression.[25] Comprehensive care for vulvodynia must consider both physical and mental health to improve overall patient well-being.

Treatments

Treatment-related discussions comprised 28.8% of the analyzed threads, revealing the range of difficulties individuals face in managing chronic health conditions. Participants exchanged information about various treatment modalities, sharing insights into effectiveness, side effects, and accessibility. A higher proportion of posts (57.1%) had a positive valence when discussing treatments, suggesting that individuals often shared experiences of treatments that found effective. Four of the five most mentioned treatments in the Reddit threads aligned with guidelines by American College of Obstetricians and Gynecologists (ACOG), American Urological Association (AUA), and ISSVD. Current guidelines from the mentioned organizations provide a framework for healthcare professionals to approach treating vulvodynia. Because the validity of online sources cannot be confirmed, it is crucial to understand which treatments — as considered by those who use them — are currently employed by individuals with vulvodynia to manage symptoms.

Physical therapy and vaginal creams were the top two treatment modalities discussed, each comprising 18.5% of the total discussed treatments. While physical therapy has been shown to have long-term success in the treatment of vulvodynia, vaginal creams such as baclofen and amitriptyline, though effective, are still considered novel remedies.[26–28] Surgery (13.0%) and stopping oral contraception pills (OCPs) (9.2%) were also commonly discussed. Although controversial, AUA and ACOG recommend discontinuing hormonal contraceptive treatments, as they may worsen symptoms. The literature on this topic is divided, with some evidence linking long-term OCP use to vestibulitis and other studies refuting this connection.[29,30] It is clear, then, that much uncertainty regarding risk factors for vulvodynia remains, which only compounds the current education gap in understanding of vulvodynia.

Surgery, such as vestibulectomy or neuromodulation, is considered for cases where conservative methods fail.[1,23] Procedures such as vestibulectomy or neuromodulation aim to alleviate pain by removing affected tissue or modifying nerve signals. One user asked, “Does anyone in the US who has had this surgery [vestibulectomy] have any idea what it costs before any insurance payments? I have no idea what to do,” highlighting the need for support and information. he vast discrepancy in treatment success underscores the need for congruence among guidelines from prominent medical organizations. Ensuring consistency in guidelines can help reduce inequitable treatment and provide a uniform resource for clinicians and patients.

Another notable hurdle for patients with vulvodynia is the vast discrepancy in treatment success. Ensuring congruence among guidelines for conditions like vulvodynia, which are poorly understood, is crucial for providing consistent and effective care. While the majority of guidelines from the AUA, ACOG, and ISSVD align, there are details that differ between the three. All three guidelines advocate for a multidisciplinary approach encompassing various treatments such as medications, physical therapies, and behavioral interventions for managing vulvodynia. While all recommend pelvic floor physical therapy and cognitive behavioral therapy, there are minor differences between these organizations. For example, ACOG emphasizes vulvar hygiene, whereas the AUA highlights the discontinuation of estrogen-containing hormonal contraceptives. As an international organization, ISSVD expands on more holistic approaches such as acupuncture, hypnotherapy, and homeopathic treatments alongside medications and topicals.

Discrepancies in the guidelines only complicate care for providers already navigating serious time constraints. Given the difficulties associated with finding adequate treatment options, as shared by Reddit users, the authors recommend that prominent medical organizations align their guidelines to reduce the inequitable treatment of individuals with vulvodynia and promote a uniform resource for clinicians and patients alike.

Sexuality and Sexual Experiences

It is not surprising that sexual experiences also emerged as a prevalent theme in these subreddit threads, given that vulvodynia directly affects individuals' intimate lives and can significantly impact their sexual well-being.[31] One user shared that “my pain makes me confused about my sexuality,” demonstrating complexities associated with the connection between experiences of pain and desire, pleasure, and sexual experiences more generally. Within the subreddit threads, the distribution of 53.1% positive and 46.8% negative valence within this theme is supported by the wide range of experiences discussed. Some users detailed the frustrations and challenges of finding an understanding partner: “So many men didn’t want me because I couldn’t have sex.” Others shared stories of supportive partners who recognized difficulties associated with vulvodynia and accommodated an individual’s needs. Further research is needed to understand how vulvodynia impacts relationships and sexuality. Qualitative interviewing is one way to center the voices of individuals within the community and hear about experiences in the words of those who live them.

Representation and Media

The low percentage of posts discussing representation and media (6.1%) highlights the invisibility of vulvodynia to the general public. Of the posts discussing media and representation, 77.8% of posts that mentioned the media and representation had a positive valence. The prevalence of positivity in such posts underscores the urgent need for increased awareness and support for those living with chronic vulvar pain from both medical professionals and the general public. One user shared that “watching these videos [about vulvodynia] made me feel less alone and also less of a personal ginny pig." In this way, media may represent a unique avenue for individuals with vulvodynia to find support and recognition of their experience. Healthcare providers should be aware of the power of representation and its ability to act as a grounding force for some people experiencing vulvodynia. For others, media can be a reminder of the difficulties associated with pain, sexuality, and daily functioning: "One minute I'm enjoying a TV show or a movie on Netflix. Next thing I know, a sex scene pops up and I am extremely uncomfortable." Overall, media representation plays a dual role, offering both solace and discomfort, which highlights the complex needs of individuals with vulvodynia.

Humor

Humor is well recognized as an adaptive tool for coping with stressful situations. For individuals with chronic pain, in particular, humor has been shown to reduce pain intensity and decrease disruptions to quality of life.[32] Explicit humor therapy, in which individuals engage with materials they find entertaining, is associated with decreased pain and feelings of loneliness.[33] In this way, humor represents a nonpharmacological approach for addressing and even ameliorating pain. Humorous interpersonal interactions have been noted as a method for individuals with chronic pain to engage with one another, find community, and even improve clinical outcomes.[34] Members of the vulvodynia community on Reddit creatively constructed the reality of their experience through memes and intra-thread conversations. For example, one user rhetorically asked of the subreddit, "Do you ever just want to send your vagina into space?" perhaps highlighting the extent to which symptoms can interfere with daily living and how separation of body and mind could be a relief. Another user created a meme entitled "Pants are of the devil" in which they describe the process of getting dressed during a flare of vulvodynia (Figure 2). For members of the vulvodynia Reddit community, the role of humor was summarized well by a user who posted "…we have to find at least a touch of humor in it to keep sane right? At least 12 doctors, nurses and 2 friends have seen my junk since I began experiencing pain.” Humor therefore represents a unique approach for managing experiences of vulvodynia, and it is one means by which members of the Reddit community express themselves, engage with each other, and find relief.

Figure 2. Example meme: “Pants are of the devil.”

Limitations

A notable limitation of this study is the lack of access to user demographics due to the anonymous nature of Reddit. As a result, we were unable to interpret the possible effects of factors including race, age, health literacy, socioeconomic status, location, transportation, and access to healthcare which may have impacted the experiences mentioned by each user. Along with this, it is impossible to know if users do indeed meet diagnostic criteria for vulvodynia. However, although we cannot determine whether a user received an official diagnosis, they were driven to the platform for specific reasons. As a cross-sectional study, these results are only representative of the time in which data was collected.

Conclusion

This article seeks to better understand patient experiences of vulvodynia by evaluating online discussions on Reddit. The analyzed content revealed that Reddit serves as a vital platform sharing struggles, frustrations, symptoms, and personal experiences. It fosters peer-to-peer support, enabling users to find community and healthcare-related information. This research highlights the importance of accurate information as well as the need for informed, coordinated, sensitive, and accessible care. The robust Reddit conversations provide anecdotal evidence of the need for healthcare providers to be trained on the management of vulvodynia, ensuring that patients do not need to navigate multiple visits to obtain an accurate diagnosis and receive timely care. The existence of Reddit communities "r/vulvodynia" and "r/vestibulodynia" underscores the value of community-based support and suggests that healthcare providers can better serve patients by centering the patient perspective. This study contributes to the existing literature by centering the voices of patients, offering insights directly from those affected by vulvodynia or who are experiencing vulvodynia-like symptoms.

Conflicts of Interest

The authors report no conflicts of interest and have no funding to disclose.

Abbreviations

ISSVD: International Society for the Study of Vulvovaginal Disease
ACOG: American College of Obstetricians and Gynecologists
AUA: American Urological Association
OCPs: Oral contraceptive pills

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