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The Experience of Vulvodynia: A Qualitative Thematic Analysis of Women's Testimonies Using MAXQDA

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Abstract

Introduction: Vulvodynia is a chronic vulvar pain condition estimated to affect up to approximately 16% of women and is commonly associated with dyspareunia. Diagnosis is often challenging, and because its etiopathogenesis remains incompletely understood, identifying effective and timely treatment strategies can be difficult. The clinical presentation may be further complicated by comorbid conditions and associated psychological distress. The aim of this study was to identify the predominant themes and linguistic representations used by women to describe their lived experience of vulvodynia through qualitative textual analysis.

Methods: A total of 103 testimonies from women reporting a diagnosis of vulvodynia, aged 20–57 years, were analyzed. Qualitative data were examined according to the methodological framework proposed by Kuckartz and Rädiker (2019), using MAXQDA Analytics Pro 2022 (version 22.7.0).

Results: A coding system was developed to categorize relevant text segments, which were subsequently grouped into three thematic clusters: (1) physical pain, (2) psychological pain, and (3) psychosocial resources. Psychological pain emerged as the most prominent cluster. The analysis also identified recurrent linguistic representations through which women described their experience of vulvodynia, highlighting the substantial psychological and psychosocial burden associated with the condition.

Conclusions: These findings provide insight into the lived experience of women with vulvodynia and may contribute to a more comprehensive psychological assessment and clinical management of the condition.

Keywords: Chronic Pain; Psychological Distress; Qualitative Analysis; Vulvodynia; Women's Health.

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INTRODUCTION

Over the years, considerable challenges have emerged in accurately defining, describing, and classifying vulvar pain [1]. According to the International Society for the Study of Vulvovaginal Disease (ISSVD) [2], vulvodynia is a complex

chronic pain condition affecting the vulvar region, occurring in the absence of clinically identifiable abnormalities and characterized by persistent pain, often described as burning. Vulvar pain typically occurs in the absence of a clear identifiable cause or a clinically identifiable neurological disorder and persists for at least three months [3].

As a chronic pain condition, vulvodynia can substantially affect not only physical health but also psychological well-being, social functioning, intimate relationships, and self-perception [4].

Several studies have investigated the psychological and emotional experiences of women with vulvodynia, focusing on both the impact of the condition on quality of life and potential risk factors that, together with genetic and biological factors, may contribute to its onset [5,6].

Emotional factors represent an important component of the experience of vulvodynia and may provide relevant information about the psychological distress associated with living with the condition [7].

Previous studies have reported that approximately 35% of women with vulvodynia experience anxiety, whereas 18% experience depression. Anxiety in women with vulvodynia may be characterized by pain catastrophizing and hypervigilance and may involve fears related to death, hospitalization, loss of dignity, and other concerns [8].

Three main sources of distress have been identified in women with vulvodynia: (1) fear that pain may interfere with daily activities and prevent the achievement of personal goals, potentially leading to excessive attempts to control symptoms; (2) fear that pain may impair cognitive functioning, including attention, memory, and performance; and (3) fear that pain may threaten personal identity and negatively affect self-image [9].

In this context, depression may precede or follow the onset of vulvodynia. When depression precedes the condition, it may be associated with increased pain reactivity and reduced pain tolerance; when it develops after the onset of vulvodynia, chronic pain may contribute to depressive symptoms. Depression may also be accompanied by feelings of guilt, particularly when women question the reasons for the onset of their condition or attribute the pain to themselves. These experiences may contribute to feelings of shame, inadequacy, and low self-esteem [10].

Impact of Vulvodynia on Women's Quality of Life

Several studies have shown that vulvodynia can have significant consequences across multiple domains of women's lives:

Physical domain [11,12]: Vulvodynia may be associated with other conditions affecting different organs and anatomical regions, which can complicate and delay diagnosis because of overlapping symptoms. Frequently associated conditions include post-coital cystitis, interstitial cystitis, and urinary tract infections, which, like vulvodynia, may involve symptoms such as burning, vulvar or vaginal pain, pelvic pressure, and urinary frequency. Other associated conditions include chronic pelvic pain, endometriosis, irritable bowel syndrome, fibromyalgia, and chronic fatigue syndrome.

Psychosexual domain [7]: Women with vulvodynia may experience profound feelings of loneliness, isolation, and lack of understanding from others. They may feel embarrassed when discussing their symptoms and may avoid seeking medical advice because of concerns that their pain will not be believed or that their symptoms will be attributed exclusively to psychological causes. These experiences may contribute to psychological distress, feelings of guilt, and reduced self-esteem. Vulvodynia can also substantially affect sexual functioning, as pain may inhibit sexual desire and arousal, resulting in reduced sexual responsiveness and satisfaction. This may lead to frustration with intimacy, negative body image, and, in some cases, negative genital self-image. Women may consequently experience fatigue, vulnerability, discouragement about the future, and, in the most severe cases, thoughts related to death.

Relational domain [3,13]: One of the most extensively studied relational aspects of vulvodynia concerns the relationship with the partner. Chronic illness can affect couples' functioning, and in vulvodynia these difficulties frequently involve sexual intimacy. Pain may limit sexual activity and, over time, contribute to avoidance or abstinence. Partner responses to women's genital pain may be broadly characterized as solicitous, negative, or facilitative. Solicitous responses involve care and affection, negative responses include hostility, whereas facilitative responses promote adaptive coping. Women's perceptions of negative partner responses have been associated with persistent pain, depressive symptoms, low mood, and sexual dissatisfaction, whereas more positive partner responses may be associated with more favorable outcomes.

Social domain [14]: Specialist consultations and pharmacological and non-pharmacological treatments for vulvodynia may impose a considerable financial burden on patients, particularly because vulvodynia is not currently recognized as a disabling condition by the Italian National Health Service (Servizio Sanitario Nazionale, SSN) and is not included in the Essential Levels of Care (Livelli Essenziali di Assistenza, LEA). In the absence of adequate healthcare coverage, treatment-related costs may be difficult to sustain and may contribute to feelings of isolation and frustration.

Vulvodynia can also substantially interfere with occupational functioning. Prolonged sitting may become difficult or intolerable, leading some women to reduce their working hours or leave employment. Women may also lose working days to attend medical appointments and receive treatment, particularly when specialist care is available only in other cities. Challenges are also evident within healthcare settings, where limited knowledge and training regarding vulvodynia, pain management, and symptom assessment may affect the quality of care provided. Evidence suggests that women with vulvodynia may feel insufficiently acknowledged within healthcare settings, partly because their pain is often perceived as "invisible."

These different domains share a common underlying feature: pain. An observational study conducted in Spain [15], using specific instruments to assess pain intensity, found that 29.6% of patients described their pain as "severe," 13.6% as "very severe," and 18.6% as "unbearable." These findings highlight the substantial burden of pain in the lives of women with vulvodynia. As persistent experience affects multiple situations and contexts, pain can negatively affect quality of life and is closely associated with anxiety, depression, low self-esteem, social withdrawal, and fear.

Pain assessment remains challenging because pain is inherently subjective and is shaped by individual perceptions as well as by its intensity and duration. Consequently, pain cannot be assessed entirely objectively: its evaluation depends both on the patient's ability to communicate her experience and on the clinician's ability to understand and interpret it [16].

Although no single instrument is considered the gold standard for the quantitative assessment of vulvar pain, several self-report measures are available. The Verbal Rating Scale (VRS) [9] consists of a list of verbal descriptors representing different levels of pain intensity, ranging from the absence of pain to severe pain. The Visual Analogue Scale (VAS) [9] consists of an approximately 10-cm line anchored by "*no pain*" and "*worst pain*," on which patients indicate the point corresponding to their perceived pain intensity at the time of assessment. The Behavior Rating Scale [9] presents a series of behaviors from which patients select those that best describe their condition and the extent to which pain interferes with daily activities. The Picture Scale [9] uses eight images depicting facial expressions corresponding to different levels of pain intensity, from which patients select the image that best represents their pain.

However, because these instruments have inherent limitations, more objective approaches to pain assessment have also been investigated. For example, the Neurometer® can be used to assess sensory thresholds in response to stimulation of the pudendal nerve in the vulvar and vestibular regions [17].

From a qualitative perspective, pain can also be assessed using questionnaires that consider its impact on quality of life. One example is the McGill Pain Questionnaire (MPQ) [9], a verbal pain assessment instrument comprising descriptors commonly used by patients to characterize their symptoms. These descriptors are grouped into three dimensions: (1) *sensory*, (2) *affective*, and (3) *evaluative*. The questionnaire also includes the VRS and a body diagram that allows patients to indicate the location of their pain.

To the best of our knowledge, however, no linguistic study has specifically examined the words used in the testimonies of women with vulvodynia to describe their lived experience of the condition. The aim of this study is to explore and characterize women's lived experiences of vulvodynia by analyzing their narrative testimonies, with the objective of identifying recurrent patterns of physical pain, psychological distress, and coping resources through a structured qualitative coding process.

METHODS

Study Design

A qualitative descriptive study incorporating quantitative content counts was conducted to explore women's narratives of vulvodynia.

The analysis of the language used in the testimonies of women with vulvodynia represents an important and relatively underexplored area of research in understanding this complex condition. Vulvodynia, characterized by chronic and persistent vulvar pain without a clearly identifiable cause, can substantially affect the quality of life of affected women. Although several studies have investigated the physical, psychological, sexual, and social dimensions of vulvodynia, comparatively less attention has been paid to the language women use to describe and communicate their lived experience of the condition.

Examining thematic patterns of patients' narratives may provide a more comprehensive understanding of how women perceive, interpret, and communicate their symptoms and their emotional experience of vulvodynia.

A qualitative analysis of these testimonies may therefore contribute to identifying recurrent themes and patterns in women's accounts, complementing existing evidence on the clinical and psychosocial impact of the condition.

Participants

The study included a total of 103 Italian women reporting a diagnosis of vulvodynia, with no predefined age restrictions. Participants' ages ranged from 20 to 57 years.

Materials and Data Collection

Multiple methods were used to collect data for the study. First, an ad hoc questionnaire was developed using Google Forms. The questionnaire combined closed-ended items for quantitative data with open-ended questions designed to capture women's emotional and subjective experiences.

The subsequent sections focused on participants' testimonies and explored the following areas:

I. age;
II. diagnostic delay;
III. emotional reaction to receiving a diagnosis of vulvodynia;
IV. ability to communicate vulvodynia-related distress;
V. changes in daily life resulting from pain symptoms;
VI. positive, negative, or catastrophic perceptions of personal identity and the future;
VII. the extent to which the condition affects sexual activity and the ways in which this occurs;
VIII. treatments received;
IX. emotional state;
X. suicidal risk;
XI. financial burden associated with the condition and limited specialist knowledge;
XII. sleep disturbances;
XIII. seeking support from other women experiencing the same condition;
XIV. description of physical pain.

An additional data collection approach involved identifying spontaneously published testimonies on online sources, including blogs and social media platforms. These accounts provided further insight into women's lived experiences of vulvodynia, including the functional and dysfunctional coping strategies they adopted, their perceptions of pain, and their ability or difficulty in living with the condition.

Procedure and Ethics

Data collection was conducted over approximately two months, between January and February 2023. The questionnaire was distributed via Instagram, primarily through the involvement of two accounts dedicated to raising awareness and disseminating information about vulvodynia and related conditions: "*ohmiseriaccia*" and "*chiara.lapelvi*". Additional testimonies were identified through an individual manual search of websites, including *vulvodinia.online*, *cistite.info*, and *puntogyn*, as well as social media platforms such as Instagram and Facebook. These included pages specifically dedicated to vulvodynia, such as *Comitato Vulvodinia e Neuropatia del Pudendo*. Further testimonies were obtained from recorded television interviews, including *Le Iene* (Mediaset) and *Tonica* (Rai).

The questionnaire included an introductory section describing the purpose of the study and requesting informed consent. Electronic informed consent was obtained before participation in the questionnaire. The study was conducted in accordance with principles of anonymity and privacy, and all collected data were used exclusively for research purposes. Additional material consisted of testimonies already available in public online sources; no additional identifying information was collected from these sources.

Data Analysis

Microsoft Excel was used for the analysis of quantitative data, whereas qualitative data were analyzed using MAXQDA Analytics Pro 2022 (Release 22.7.0) [18] and word clouds.

MAXQDA is a software package for qualitative data analysis that provides functions such as code development, memo writing, and variable definition, enabling the systematic management and analysis of qualitative research data [19]. The methodological framework underlying the software is based on case-oriented quantification, as described by Max Weber [20]. Within this approach, qualitative analysis aims to classify and, where appropriate, quantify qualitative data, with the case serving as the primary unit of analysis. A case may refer to an individual participant but may also represent an action, situation, or other unit of analysis.

MAXQDA enabled the analysis to be conducted at multiple levels. The qualitative analysis followed a multilevel coding procedure: first, *in-vivo coding* was applied to preserve the participants' original linguistic expressions; subsequently, these in-vivo codes were subjected to *interpretive (axial) coding,* through which the research team grouped

the content into three higher-order thematic clusters (physical pain, psychological pain, resources). The word lists reported in the Results section represent the distribution of in-vivo codes within each interpretive cluster.

RESULTS

The data obtained from the collected testimonies were analyzed to identify the most frequently reported themes. A total of 103 testimonies from women with vulvodynia were included in the analysis. Of these women, 63% had also received a diagnosis of pelvic floor hypertonicity and/or pudendal neuropathy.

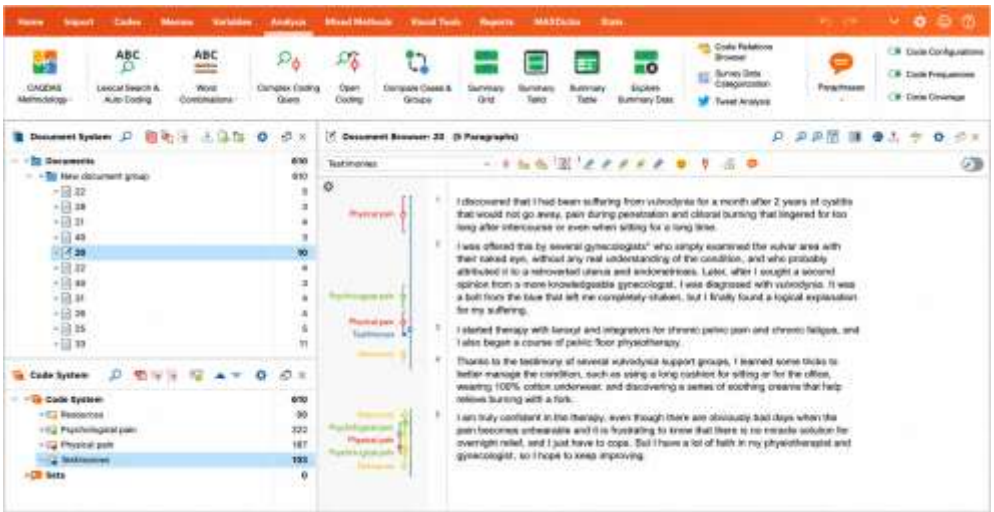
Regarding age distribution, most women were aged between 22 and 23 years, with another notable age group comprising women aged between 29 and 32 years. Although women over the age of 40 represented a considerably smaller proportion of the sample (8%), their presence indicates that vulvodynia also affects women at later stages of life. This finding is consistent with studies suggesting that vulvodynia may have a later onset or may recur in association with triggering conditions such as menopause.

Testimonies were collected from different sources. Most data were obtained through the questionnaire distributed via social media, followed by the manual identification of testimonies and comments posted by women on social media platforms. No data were collected through face-to-face methods. Online communication emerged as the primary context in which women shared their experiences of vulvodynia, allowing them to connect anonymously with others living with the same condition and to describe its disabling impact and the associated emotional distress.

Analysis of the Prevalent Themes

To conduct an in-depth analysis of the 103 testimonies collected, within a corpus of more than 4,000 words, MAXQDA was used as the primary tool for qualitative data analysis (Figure 1). The software enabled the systematic examination of each paragraph and the identification of relevant aspects and nuances of women's experiences. During the analytical process, a coding system was developed to represent different aspects of the condition and dimensions of women's lived experiences. These codes were used to systematically organize, categorize, and analyze the collected data, thereby allowing the identification of the predominant themes.

Figure 1. MAXQDA Analysis Screen.



The analysis was conducted through the following stages:

Phase 1: Data Preparation

All segments were imported into MAXQDA and prepared for analysis. The testimonies were checked for completeness and to ensure that they did not contain personally identifiable information.

Phase 2: Code Development

A coding framework was developed to represent potentially relevant themes, concepts, and categories emerging from the testimonies. Codes included concepts such as "*pain*," "*impact on quality of life*," "*coping strategies*," and "emotional experience." Each code was clearly defined to ensure consistency throughout the analytical process.

Phase 3: Data Coding

Each testimony was carefully examined, and relevant codes were assigned to text segments addressing the identified themes. For example, segments describing physical pain were assigned the corresponding "*pain*" code. This coding procedure was systematically applied.

Phase 4: Analysis of Coded Segments and Codes

After coding was completed, MAXQDA functions were used to explore the coded segments and their associated codes. Reports, graphs, and tables were generated to identify the themes occurring most frequently across the testimonies.

Phase 5: Grouping and Categorization

Similar codes were grouped into broader thematic categories to provide a clearer representation of the emerging themes. For example, codes describing physical symptoms and experiences were grouped within the broader category of "*physical pain*."

Phase 6: Creation of Code Memos

Throughout the analytical process, MAXQDA code memos were used to document reflections and interpretations concerning the data and emerging themes. These memos provided a systematic record of observations made during the analysis.

Phase 7: Iterative Review

The data, codes, and thematic categories were iteratively reviewed and refined as the analysis progressed, allowing adjustments to be made in response to patterns emerging from the data.

Phase 8: Presentation of Results

Finally, the predominant themes identified through the analysis of the testimonies were summarized and presented, together with representative quotations supporting the interpretation of the findings.

This multi-stage analytical process enabled an in-depth exploration of women's experiences of vulvodynia and the systematic identification of the most relevant themes emerging from their testimonies.

To provide an immediate visual representation of the key concepts identified in the testimonies, word clouds were generated (Figure 2). In these visual representations, the size of each word reflects its frequency of occurrence within the analyzed data.

Figure 2. Overall Word Cloud of the Coded Testimonies.

Note: *Font size indicates the number of times each theme was identified, with larger text representing more frequent occurrences.*

Three main thematic clusters were subsequently identified:

I. physical pain;
II. psychological pain;
III. psychosocial resources.

Cluster 1 – Physical Pain

In this section, all codes related to physical pain were analyzed. The table presents the themes related to physical pain that occurred most frequently across women's experiences (Figures 3 and 4).

Figure 3. Frequency of Codes Related to Physical Pain.

Pain	186
Burning	56
Burning sensations	18
Itching	10
Chronic	9
Constantly	5
Sexual	17
Pins and needles	9
Fire	2
Flames	2
Discomfort	12
Sitting	29
Painful intercourse	80
Electric shocks	7
Vagina	20
Abdomen	2
Viscera	3
Chronic	9
Pelvic	40

***Physical Pain Codes**: Physical pain: redness, burning, persistence, fatigue, chronicity, pain, penetration, tight clothing, remaining seated, dyspareunia, irritation, cystitis, candidiasis, itching, cuts, pins and needles, disabling, crushing, impossibility, excruciating, treatment, fear, jeans, underwear, roller coaster, hell, sexual intercourse, atrocious, electric shocks, dryness, burning sensation, discomfort, constant, vulva, bladder, lower abdomen, agonizing, thighs, blood, buttocks, orifice, flames, vagina, unbearable, tingling, suffering, knives, body, terrible, sharp blade, laceration, and heat.*

Figure 4. Word Cloud of Physical Pain.

***Note**: Font size indicates the number of times each theme was identified, with larger text representing more frequent occurrences.*

Pain emerged as the predominant theme (occurring 186 times) and was also implicitly conveyed through other terms used by the women. In particular, expressions such as "burning," "redness," "pins and needles," and "itching" describe the painful sensations associated with the condition.

Cluster 2 – Psychological Pain

In the second cluster, codes related to psychological pain were grouped and analyzed. The table presents the themes related to psychological pain that occurred most frequently across women's testimonies (Figures 5 and 6).

Figure 5. Themes Related to Psychological Pain.

Psychol*	31
Depression	15
Feeling down	3
Mental	8
Rigidity	2
Fear	26
Shame	2
Ill	2
Guilt	8
Frightened/Scared	7
Anxiety	6
Worry	4
Anger	6
Despair	9
Fatigue	13
Death/End it all	3
Unrecognized	4
Not understood	7
Therapy	49
Chronic	9
Pregnancy	6
Lack of treatment	90
Normal	28
Wrong	2
Woman	12
Crying	8
Useless	9
Loneliness	3
Isolation	2
Alone	29
Family	11

Psychological pain codes: *loneliness, fighting, dependence, burden, dissatisfaction, disappointment, depression, superficiality, guilt, lack of understanding, destabilization, suffering, feeling down, frustration, limitation, traumatic disorder, imbalance, trauma, anxiety, fear, incompleteness, difficulty, partner, courage, sadness, despair, stress, humiliation, anger, disabling, debilitating, discouraging, insecurity, fragility, future, dreams, gaslighting, disorientation, terror, awareness, blame, loss of self-esteem, feeling wrong or broken, nervousness, demoralization, hatred, death, ordeal, hell, crying, anguish, panic attacks, fear of going crazy, survival, patience, agony, suicide, distrust, fatigue, nightmares, screaming, help, fear, tragedy, and prison.*

Figure 6. Word Cloud of Psychological Pain.

Note: *Font size indicates the number of times each theme was identified, with larger text representing more frequent occurrences.*

The Word Cloud clearly highlights the coexistence of the concepts of "*life*" and "*pain*," two markedly different themes that nevertheless coexist in women's descriptions of their lived experience of vulvodynia.

Among the most frequently recurring factors associated with psychological pain were lack of treatment, loneliness, frustration, and fear.

Cluster 3 – Psychosocial Resources

In the third cluster, codes related to psychosocial resources were grouped and analyzed. The table presents the themes related to psychosocial resources that occurred most frequently across women's testimonies (Figures 7 and 8).

Figure 7. Themes Related to Resources.

Hope	13
Support	3
Support	8
Sharing experiences	5
Other women	14
Voice	3
Group	6
Strength	14
Energy	4
Assistance	3
Web	12
Forum	10
Trust	4
Sport	4
Information	4
Recognition (of disease-related rights)	7

***Resources Codes**: testimonies, peers, trust, luck, stable relationship, internet, network, healthcare co-payment, television program, social media, groups, recovery, supporting, recognition, help, forums, Facebook, web, hope, family, dissemination, Instagram, friends, financial resources, awareness-raising, partner, commitment, energy, money, living, other women, solution, helping, advice, sharing, resilience, support, assistance, psychologists.*

Figure 8. Word Cloud of Psychosocial Resources.

***Note**: Font size indicates the number of times each theme was identified, with larger text representing more frequent occurrences.*

Comparison of the three clusters

When considering the three clusters, pain emerged as the most prominent theme, closely associated with the recurring concepts of "*fear*" and "*life.*"

Across all clusters, pain emerged as the predominant theme. Although the term primarily evokes physical pain and is therefore associated with expressions such as "*burning*" and "*itching*," the psychological dimension of pain also clearly emerged from the women's descriptions of their experience of vulvodynia. Indeed, a greater number of coded segments were assigned to the Psychological Pain cluster. Across the 103 testimonies, 222 segments reflected negative psychological experiences associated with the condition, including feelings of "*frustration*," "*fear*," and "*loneliness.*"

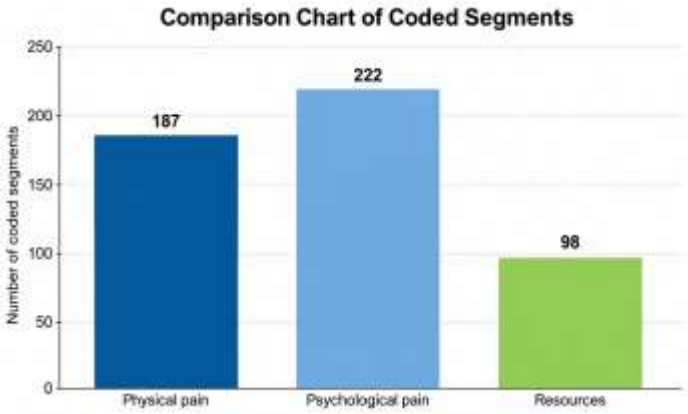
Attention should be paid to the highly sensitive theme of suicide, as six testimonies contained statements suggestive of possible suicide risk. These accounts conveyed wishes not to wake up, thoughts of ending one's life, and descriptions of death as a possible escape from unbearable suffering.

In contrast, eight statements conveyed a more positive perspective and included terms such as "*hope*," "*trust*," and "*treatment.*" Two testimonies specifically described recovery, using expressions such as "*happy ending*" and "*there is a solution.*"

Figure 9. MAXQDA, Cluster Codes Comparison.

Code	Segments coded across all documents
Physical pain	187
Resources	98
Psychological pain	222
Testimonials	103

Figure 10. MAXQDA, Comparison Chart.



The qualitative analysis showed that both physical and psychological pain represented central dimensions of women's experiences of vulvodynia. Psychological Pain was the most frequently coded category, with 222 coded segments, followed by Physical Pain, with 187 coded segments.

These findings highlight the substantial burden of persistent pain on women with vulvodynia. Physical pain can markedly interfere with quality of life by limiting everyday activities and contributing to ongoing suffering. Psychological pain, in turn, reflects the profound emotional impact of the condition, including experiences of anxiety, depression, and stress associated with chronic pain.

At the same time, the substantial presence of the Resources cluster, comprising 98 coded segments, is noteworthy. This finding suggests that women with vulvodynia actively seek resources and support to cope with the condition. These may include treatment, healthcare, social support, and information regarding the management of vulvodynia. The search for such resources may reflect women's efforts to cope with the condition and improve their quality of life despite the difficulties they experience.

Overall, the findings highlight the considerable burden of both physical and psychological pain in the lived experience of vulvodynia, while also indicating that women actively seek resources, support, and opportunities to share their experiences as strategies for coping with the condition.

The qualitative analysis identified several recurring needs and concerns across the study sample. These findings may inform timely psychological support and interventions aimed at helping women manage the condition and maintain quality of life.

The following needs emerged:

Psychological intervention: 21 women reported a need for psychological intervention;

Understanding: approximately 20 women expressed a need to feel understood, with many reporting experiences of misunderstanding and loneliness;

Healthcare professionals' expertise: approximately 63 testimonies highlighted a perceived lack of expertise among healthcare professionals in recognizing and treating vulvodynia. This perceived lack of expertise was also associated with diagnostic delays and inappropriate treatments, which may contribute to symptom persistence and worsening;

Recognition of the condition: approximately 18 women expressed the need for vulvodynia to be formally recognized by the Italian National Health Service, allowing treatment costs to be covered by the healthcare system. Several women reported feeling abandoned by public institutions because they were required to personally bear the substantial costs associated with treatment and care;

Treatment: approximately 42 women used the term "treatment," predominantly with a hopeful connotation and in relation to the desire to find a "definitive treatment."

DISCUSSION

The aim of this study was to explore and characterize women's lived experiences of vulvodynia by analyzing their narrative testimonies, with the objective of identifying recurrent patterns of physical pain, psychological distress, and coping resources through a structured qualitative coding process.

The findings of this study highlight the multidimensional burden of vulvodynia, showing that women's experiences are shaped by an interplay of physical pain, psychological distress, and the active search for psychosocial resources.

Across participants' accounts, physical pain emerged as a pervasive and intrusive element of daily life, frequently articulated through vivid sensory images and metaphors that conveyed its intensity, quality, and chronic nature. This finding aligns with theoretical work showing that standardized pain measures, although essential in clinical settings, do not fully capture the complexity of real-life pain experiences. As demonstrated by Pukall et al. [21], reducing the sensory component of pain alone is often insufficient to restore sexual functioning or overall well-being, highlighting the importance of emotional, cognitive, and interpersonal factors such as catastrophizing, hypervigilance, and fear of pain. Within this framework, the metaphorical and embodied descriptions provided by women are not merely stylistic devices but cognitive tools that express dimensions of suffering that visual scales fail to detect — including anticipatory fear, loss of control, daily intrusiveness, and relational impact. Consistent with the "vicious cycle" model of vulvar pain, metaphorical language can complement numerical ratings by providing a more nuanced representation of subjective experience, illuminating the broader consequences of pain on daily functioning and sexuality.

As expected, the psychological dimension of pain was even more prominent, with a higher number of coded segments reflecting fear, frustration, loneliness, and—in a small but clinically important subset—expressions suggestive of suicidal ideation. This underscores the importance of conceptualizing vulvodynia as a multidimensional pain

condition with substantial emotional and existential implications. This interpretation aligns with literature on chronic pain and vulvodynia showing that pain is not merely a sensory event but is shaped by emotional and cognitive processes [1-6]. The fear-anxiety-avoidance cycle describes how painful sensations may be interpreted catastrophically, leading to hypervigilance, avoidance, and progressive restriction of daily activities. This mechanism appears particularly relevant for women with vulvodynia, who may experience heightened anxiety when the cause of pain is uncertain or not immediately identifiable [7-12]. Psychological difficulties, including anxiety and depressive symptoms, have also been documented in women with vulvodynia [22]. Within this framework, our findings suggest that emotional and cognitive factors are important components of the subjective experience of vulvar pain, supporting multidisciplinary approaches that address these dimensions in addition to pain itself [23,25].

At the same time, the distinct Psychosocial Resources cluster indicates that women actively mobilize coping strategies, seek peer support, and engage with online communities to manage the condition. Frequent references to treatment, information-seeking, and social support suggest that participants were active agents navigating a healthcare landscape they often perceived as fragmented or inconsistent. Many testimonies described limited clinical expertise, diagnostic delays, and the need for formal recognition of vulvodynia within the national health system. This pattern is consistent with ethnographic literature on vulvar pain describing medical nomadism, short-term therapeutic alliances marked by misunderstanding, and mistrust toward healthcare professionals [24]. In this context, online forums may become important sources of information and emotional support. These findings highlight the value of competent, integrated care pathways that address both the clinical and psychosocial dimensions of vulvodynia.

Strengths and Limitations

This study examined a relatively large corpus of first-person accounts and combined in-vivo coding with an iterative thematic categorization process. However, the findings should be interpreted in light of the self-selected and predominantly online nature of the sample, the heterogeneity of data sources, the absence of face-to-face diagnostic verification, and the possible overrepresentation of women who were digitally engaged or motivated to share their experiences. In addition, code frequencies describe the analyzed text and should not be interpreted as prevalence estimates. Publicly available narratives may also differ in depth and context from responses collected directly through the study questionnaire.

CONCLUSIONS

The qualitative analysis of women's testimonies identified recurrent physical, psychological, and psychosocial dimensions of the lived experience of vulvodynia. The findings provide insight into women's perceptions of pain, the coping resources they mobilize, their communication with healthcare professionals, and the relational challenges associated with the condition. Narrative analysis may therefore complement conventional symptom assessment by capturing dimensions of suffering and support needs that are not easily represented by numerical measures alone.

Integrating linguistic, psychological, and clinical perspectives may support more individualized care and more effective communication between women with vulvodynia and healthcare professionals. Future interdisciplinary research should further examine these themes in clinically characterized and more diverse samples and evaluate how psychosocial support can be incorporated into comprehensive care pathways for this complex chronic pain condition.

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Ethics and Informed Consent Statement: The questionnaire included an introductory section explaining the purpose of the study and an informed-consent procedure; informed consent was obtained before participation. Data were handled anonymously and used exclusively for research purposes. Additional material consisted of testimonies already publicly available on websites, social media platforms, and recorded television interviews, as described in the Methods section.

Data Availability Statement: The source material comprised questionnaire responses and publicly available testimonies as described in the Methods section. Because the questionnaire responses contain sensitive personal narratives, the full analytic dataset is not reproduced in this article.

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