Montali *et al. BMC Psychology* (2025) 13:260
https://doi.org/10.1186/s40359-024-02318-z

BMC Psychology

RESEARCH **Open Access**

Aggravating and protective factors in patients' experiences of vulvodynia: a qualitative study with Italian women

Lorenzo Montali[1*], Chiara Bernareggi[1] and Valeria Crispiatico[1]

Abstract

Background Vulvodynia, a chronic pain condition affecting 15% of women aged 18–70, significantly impacts daily life and sexual functioning, contributing to self-perception issues, depression, and anxiety. This study aims to explore Italian womens' experiences, recognizing the influence of cultural background on their perceptions of chronic pain and sexual problems. Additionally, this research explores the role of family support and autoeroticism in managing vulvodynia.

Methods A total of 35 interviews were conducted with women diagnosed with vulvodynia. The transcripts of these interviews were then subjected to reflexive thematic analysis.

Results The analysis identified four themes: A Disabling pain; Aggravating factors: lack of support and delegitimization; Protective factors: experiences of sexual agency and relational support; Identity in reconstruction: an incomplete woman.

Discussion This study confirmed a lack of medical knowledge, hindering accurate diagnosis and treatment. Women's unmet expectations of family support amplified their sense of abandonment. Two factors reduced the burden of the disease. First, women were able to find alternatives to penetrative sex, gaining more confidence in themselves and their sexuality. Second, they developed empowering relationships in online patient groups where they were able to access valuable information and receive emotional support. This study underscores the necessity of multidisciplinary care for women with vulvodynia, addressing their various needs.

Conclusions Psychological interventions involving partners and families can mitigate women's delegitimization, and treatments centered on autoeroticism can promote women's overall well-being.

Keywords Vulvodynia, Women's experience, Thematic analysis, Italy

---

*Correspondence:
Lorenzo Montali
lorenzo.montali@unimib.it
[1]Department of Psychology, University of Milano-Bicocca, Piazza dell'Ateneo Nuovo 1, Milan 20126, Italy

Introduction

Vulvodynia is a chronic pain of the vulva [1] that affects 15% of women between the ages of 18 and 70 [2]. The condition is clinically characterized by a constellation of symptoms, including irritation, swelling, itching, redness, burning, and, most notably, pain, which may manifest as “pinpricks” or “electric shocks” [3]. Pain may be localized to specific areas, such as the vestibule or clitoris, or may affect the entire vulva [4]. In some cases, women may experience both localized and generalized pain [1, 5]. As reported by women who have had past symptoms of vulvodynia, the average duration of pain is 12.4 years [6], and although it generally decreases gradually over the years, complete resolution remains rare [7].

The etiology of vulvodynia remains elusive, although several hypotheses have been proposed. These include but are not limited to nociceptor neuroproliferation, pelvic floor dysfunction, and estrogen-related hormonal changes [8]. Genetic polymorphisms in myelin basic protein and an excess of mast cells, which are immune cells of the myeloid lineage in the vaginal area, have been identified as potential contributing factors [9, 10]. Moreover, various psychological factors may contribute to the maintenance of vulvodynia [11]. These include depression and anxiety, a possible history of childhood sexual and physical abuse [12], fear of pain, pain avoidance [13], and catastrophizing behavior [11].

Vulvodynia has a detrimental effect on the possibility of engaging in penetrative sexual intercourse, which can exacerbate symptoms [6]. Moreover, some women report an impact on numerous aspects of their lives [14], affecting their ability to perform daily activities such as walking, getting out of bed, sleeping, working or studying, wearing tight clothing, washing, and sitting [15]. These difficulties could result in a psychological impact that is far more significant than the physical pain itself [16, 11]. Consequently, illness is associated with a number of psychological symptoms, including anxiety, fear, and depression, as well as lowered self-esteem and a negative self-image [11].

In light of the profound impact that vulvodynia can have on women, it is crucial to gain insight into the factors that may either facilitate or impede the management of the disease. These factors pertain to both the health and social support women require and the utilization of sexual practices that may enable them to attain pleasure while concurrently reducing pain. The subsequent two sections will address the literature on these issues.

The challenge of receiving medical and social support

Considering the women’s difficulties, a challenging question concerns the support women receive for managing their illness, both medically and socioemotionally.

With respect to medical aspects, vulvodynia was only recently recognized as a disease in the latest revision of the International Classification of Diseases (ICD-11), and it is known that women encounter significant challenges in obtaining a diagnosis from different healthcare systems [15, 17]. Women define the diagnostic path via metaphors such as ‘journey,’ ‘battle,’ and ‘struggle,’ highlighting the problematic and complex nature and the lack of precise direction [15]. Despite the recent identification of descriptors for vulvodynia [18], the absence of a specific diagnostic tool and the lack of knowledge on the part of physicians make the diagnosis of vulvodynia challenging [19, 20]. Furthermore, the difficulty of making a diagnosis on the basis of the patient’s reported pain led doctors to adopt an explicit attitude of minimization, hypothesizing that the woman was exaggerating or that the symptoms were not real [21]. Consequently, women may feel ‘misunderstood’ [19] and turn to private care, which is perceived as more time-efficient and hospitable than the public sector [17]. Additionally, vulvodynia is a costly condition to treat [22] because of the necessity of accessing specialist gynecologists, medication, consultation with specialist physiotherapists [23], and creams containing lidocaine, an anesthetic, or gabapentin, used to treat neuropathic pain [3]. These difficulties may be further compounded in Italy, where the National Health Service has not formally recognized vulvodynia as a disease because the relevant legislation has not yet been revised to reflect the latest developments in medical knowledge regarding this condition. A recent survey indicated that approximately 45% of women experienced persistent pain for a period of between one and five years before receiving an accurate diagnosis [24]. Furthermore, they are required to bear the financial burden of their treatment, as the National Health Service does not cover treatment costs.

With respect to socioemotional support, women describe it as the most crucial factor in coping with vulvar pain [25], as it enhances well-being and functioning, including sexual functioning [26]. Women have reported feeling understood when they share their thoughts and feelings about vulvar pain, breaking down the wall of loneliness [26]. However, it is important to note that partners are often the only individuals who are aware of the extent to which pain affects them [27], and their ability to provide adequate support is not always sufficient [28]. Moreover, the disclosure of this condition to family members or friends can act as a significant impediment due to the shame experienced by the individuals [15]. A considerable number of women have indicated that they experience feelings of frustration, embarrassment, and discomfort when confronted with the necessity of disclosing and acknowledging their sexual health concerns [29]. This phenomenon can be attributed to the social taboo surrounding issues about female genitalia and sexual activity [16]. Some women also reported feeling blamed and shamed by their social network for not engaging in sexual activity [27]. Such stigmatization has led to isolation and failure to seek support for symptoms [25, 30]. Nevertheless, the situation in Italy may differ, given that Italian family culture emphasizes emotional closeness and solidarity among members [31, 32]. Conversely, the traditionalist nature of Italian culture with respect to sexuality may impede women's ability to discuss their issues in this domain. Therefore, this study aims to investigate the role of family members in providing social and emotional support for women's needs.

Sexual impairment and autoeroticism

Vulvodynia is perceived as an obstacle to the establishment and maintenance of relationships [33] because of the impairment in the sexual sphere, which makes it challenging to live in a happy relationship over time [34]. This concern is linked to two issues that characterize sexual socialization.

First, the widespread social expectation that women must assume a submissive position to facilitate the pleasure of their male partners [35]. According to this view, men are characterized by an innate, spontaneous sexual desire [36], which women must satisfy. Research on women with vulvodynia highlights the belief that men 'need' to have sex because it is 'the only thing they truly want' from a woman [19]. Women prioritized their partners' needs over their own need for 'pain-free sexual acts' [16]. Consequently, women with vulvodynia may experience feelings of inadequacy, which can increase their sense of guilt and uselessness [16]. This perception engenders a sense of difference in comparison with other women, who are perceived as capable, eager, and sexually active [16]. Women may feel incompetent and excluded from the community of heterosexual women compared to them [21].

The second issue relates to the coital imperative, according to which sex corresponds to penetration of the vagina by the penis [37]. The sexual act is considered natural because of the combination of male and female genitalia [37], which makes sex "easy and natural" [15]. Women with vulvodynia tend to perceive coitus as the sole "real", and normal form of sex [16]. Consequently, some women believe that remaining single is the best alternative to avoid responding sexually to anyone and, thus, to ignore the problem [16, 37]. In other cases, women continue to engage in penetrative sexual acts, despite the pain and physical-emotional consequences, to maintain their status as a desirable woman or caring heterosexual partner [16]. Nevertheless, recent evidence has shown that women with chronic pelvic pain can experience sexual pleasure [38]. Indeed, autoeroticism, i.e., the practice of stimulating oneself sexually [39] in the absence of an external stimulus coming directly or indirectly from another person, and its most common practice, masturbation, which can also occur with a partner, are more pleasurable than partner vulvar stimulation or penetrative sex and are more likely to lead to orgasm. Women who experience sexual pleasure through autoeroticism exhibit lower levels of pain, anxiety, and catastrophic behavior than those who have not experienced vulvar pleasure [38]. However, the societal expectations regarding sexual behavior differ for men and women and are based on socially constructed scripts [40]. Women are subjected to harsher and more negative judgments than men when engaging in the same sexual behaviors, such as masturbation [41], and their sexual freedom is often more limited. Therefore, women neglect other potentially pain-free sexual activities [27]. In the European context, Italy is the country with the highest degree of machismo, which places a significant emphasis on the importance of sexual intercourse and discourages masturbation. However, sexual attitudes are changing, albeit at a slower pace than they are in other societies in Europe and the West [40]. The role attributed to masturbation in a traditional sexual context, such as the Italian context, is an interesting topic to explore because of the combination of these cultural factors.

Study aims

This study has two aims. The first is to explore women's experiences of vulvodynia in the Italian context, as we are unaware of any study conducted in this country. Shallcross and colleagues [20] suggest that further research is needed, as women's experiences with vulvodynia are understudied and that the characteristics of the context may have an impact on this experience. The Italian context is characterized by the fact that vulvodynia is still not recognized medically. This could contribute to the delegitimization of these women and increase their burden, as they have to bear the costs of illness and treatment themselves.

The second aim is to explore the importance of family social support and the role of autoeroticism in the management of this condition, two dimensions that have been explored to a limited extent in previous studies. The family may serve as a relevant resource for protection and solidarity, which could positively impact these women's support needs. Furthermore, given the impact that vulvodynia has on the sexual sphere, autoeroticism could function as a coping resource from a perspective that extends beyond the coital imperative.

Methods

This study employed a qualitative description approach [42]. This methodology was chosen to facilitate participants' expression and in-depth exploration and description of their experiences, including perceived exacerbating and protective factors. To this end, studies adopting this methodology, such as our own, recruit purposive sampling to obtain information-rich cases and use open-ended data collection instruments, as exemplified by the interviews in our study. The interviews permit participants to present their experiences in as much depth and details as possible. Similarly, in descriptive qualitative studies, there is no preselection of variables to study, nor is there any a priori commitment to any one theoretical view of a target phenomenon (Sandelowski, 2000). Indeed, as much as any description is inevitably interpretive, the purpose is to remain as close as possible to the data and the surface of words and events [42]. Consequently, in our study, the data analysis followed an inductive model. This entails the gradual conceptualization of the data as the familiarity and knowledge of the views expressed by participants and their language increase. The focus is on the semantic level, where the analysis explores meaning at the more surface, explicit, or manifest level [43].

Recruitment and participants

After obtaining permission from the Facebook page administrators, we published a post on the self-help page 'Unite for Vestibulitis'. The post presented the study's aims and methodology and described the participation requirements. This Facebook page, which has been active since 2010 and is followed by more than 5,000 women, aims to provide information, help, and emotional support to those affected by the condition. Despite the page's name, this online group includes women with vulvodynia, vestibulodynia, and mixed forms [4]. All women included in this study had a diagnosis of vulvodynia, which was confirmed during the semi-structured interview.

The participants were selected on the basis of four inclusion criteria: a diagnosis of provoked or unprovoked vulvodynia by a gynecologist, experiencing symptoms for at least one year, an adequate ability to speak and comprehend Italian to understand the purpose of the research and participate in the interviews, and being between 18 and 50 years of age. This age group was selected because the literature indicates that women of childbearing age are more commonly affected by vulvodynia [6]. Although the number of menopausal women with vulvodynia is also increasing [2], it was decided not to include those in their 50s, as the typical problems and sexual difficulties of menopausal women may overlap with those of women with vulvodynia. The exclusion criteria were as follows: vulvar pain caused by a diagnosis other than vulvodynia, such as infectious causes (candidiasis, bacterial vaginosis), inflammatory forms (lichen sclerosis, contact dermatitis), neoplastic causes (Paget's disease, squamous cell carcinoma) and neurological forms (pudendal nerve entrapment, spinal nerve compression); absence of a well-defined diagnosis provided by a gynecologist; and age < 18 years.

Thirty-five participants were recruited, a number that was deemed sufficient to present a comprehensive narrative [44]. The participant characteristics are presented in Table 1. Twenty-three women had a Master's degree, and twelve had a high school diploma. Twenty-three participants were employed at the time of the interview. Thirty-one were in a romantic relationship, of which one woman was in a same-sex relationship, and four were single. The participants signed a consent form for data protection and anonymity as requested by the Ethics Committee of the University of Milano-Bicocca, which approved the research. Our participants did not receive any compensation.

Data collection

The semi-structured qualitative interviews, which lasted an average of two hours, were conducted in Italian via similar online platforms (Skype and Google Meet).

The interview guide was pilot-tested with two participants to check for clarification of any ambiguous questions and to provide feedback on the procedures and methods used. In this study, the pilot helped identify repetitive questions and the appropriateness of the procedure used during the research [45]. The final version of the interview guide (available as supplementary material) is structured according to five subobjectives on the basis of the relevant literature. The first set of questions aimed to explore the pathway to diagnosis (e.g., 'How would you describe your experience from when you first noticed the symptoms until you were diagnosed with vulvodynia?'). A second set of questions explored the relationships with medical staff and the treatment received (e.g., 'What aspects of your care did you feel were adequately addressed?'). This part was followed by some questions exploring the area of social relationships and support (e.g., 'How would you describe the support you have received from your family in dealing with vulvodynia?'). Other questions have explored couple and individual sexuality (e.g., 'How has vulvodynia affected your sexual relationships?'). The final questions explored self-perception and identity (e.g., 'Has your view of yourself changed since you received the diagnosis?'). Sociodemographic information was collected at the end of the interview.

In addition to the primary questions, follow-up questions were asked depending on the interview's course and the narrative's richness. Given the topic's sensitivity,

Table 1 Demographic characteristics of participants

Characteristic			
Age (%)			
	18–20	10	(28.58%)
	20–30	9	(25.70%)
	30–40	10	(28.58%)
	40–50	6	(17.14%)
Duration of pain/ onset of pain (years)		7.46	[8.50]
Educational Level (%)			
	Bachelor's/Master's degree	23	(65.71%)
	High School Diploma	12	(34.29%)
Employment Status (%)			
	Full-time/part-time	23	(65.7%)
	Student	12	(34.29%)
Living condition (%)			
	With family/friends/partner	33	(94.28%)
	Alone	2	(5.72%)
Relationship status (%)			
	Partner	31	(88.57%)
	Single	4	(11.43%)

Note: values are presented as n (%) or as mean [standard deviation]

the interviewer also used nondirective interventions: encouragement, expressions of interest, summarizing the answer to seek confirmation, pausing, and asking for more detail. These strategies encouraged the respondents to continue and deepen their stories.

The interviews were conducted by one of the authors (CB), a woman with a Master's degree in psychology trained in qualitative interviewing, who did not know any participants. All the interviews were transcribed, and the participants were asked to review the transcripts for accuracy.

Data analysis

An inductive thematic analysis was conducted via Braun and Clarke's six-phase model [43, 44], which was applied from a critical realist perspective. This perspective views language as a tool for constructing social realities influenced by cultural, linguistic, and social factors that operate within the material world [46]. One rationale for adopting this perspective is that it recognizes the impact of the socio-cultural context, in this instance the Italian context, on how participants experience their illness. This context provides the conditions within which agency can be exercised [47]. The second reason for adopting a critical realist stance is that it acknowledges the importance of examining participants' discursive choices (in terms of contents and modes of expression), as they constitute the way in which humans interpret and construct meanings, thereby developing shared versions of reality [48].

In the first phase of familiarization with the data [44], two authors (LM and CB) read all the interviews and identified concepts and linguistic expressions relevant to the research aims. The authors documented their observations and ideas in a systematic manner, which served as the foundation for subsequent analytical steps.

To develop a shared perspective on the data via the logic of collaborative data analysis [49], two authors (LM and CB) selected the three most extended interviews and carried out inductive initial coding via NVivo software (phase 2). Each identified code was selected to correspond to a feature of the data that the analyst deemed significant. The code name was chosen to reflect the respondents' linguistic expression as closely as possible. In a series of meetings, the authors compared codes, discussed differences, and arrived at a common overall approach to coding [50]. The purpose was not to obtain an objective reading of the data but to promote deep engagement with them and a situated, reflexive interpretation [51]. This result was achieved through productive discussions among the coders, which encouraged them to explain and deepen their perspectives and reflections on the interviews. This approach places significant value on the subjectivity of coders as a resource for analysis [52]. With this logic, coding is an open, iterative process, and codes can change throughout the analysis process "to better capture the researcher's developing conceptualization of the data" [52, p. 848].

On the basis of this coordinated and cumulative approach, two authors (LM, CB) individually coded all the other interviews, compared their analysis in further meetings in which the third author (VC) participated in discussions to resolve discrepancies, and finally agreed on a final list of codes and more meaningful quotes for each code (phase 3). The next step (phase 4) was to organize the codes into themes, which was facilitated by graphic maps of themes and subthemes. Four main themes were identified after several rounds of revisions and a final review of their internal homogeneity and mutual heterogeneity. Once the names and definitions of the themes were finalized (Phase 5), further selection of the illustrative extracts was performed to produce the report (Phase 6). This systematic approach to the analysis established an audit trail from the transcripts of raw data through the final interpretation. The results are reported according to the consolidated criteria for reporting qualitative research (COREQ) checklist [53].

Results

The analysis identified four themes representing the most salient aspects of how participants experienced vulvodynia (Table 2).

A disabling pain

This theme presents women's accounts of their experiences with vulvodynia, with a focus on the main symptom of pain and its effects on various aspects of their lives. The pain, often described as "needles in the flesh," is "a constant presence" and the first indication of the condition.

The impact on daily activities

The pain's highly debilitating nature obstructs daily activities, making them "more difficult, exhausting, and challenging to manage" (P31). The interviewees' narratives highlight the difficulty, and sometimes impossibility, of carrying out essential activities. One interviewee stated, "It's like being paralyzed in life. Because it crystallizes your life a little bit. This thing affects everything, right?" (P25).

The participants indicated that their sense of self-determination was eroding, which in turn diminished women's capacity to determine present and future events. This can result in a loss of agency and a sense of powerlessness, as illustrated by the following quote: "You put the things you want to do in a drawer. I couldn't do what I wanted" (P22). The participants reported that their autonomy was eroding, mainly as a result of the profound limitations imposed by pain. Furthermore, they observed that their internal resources could no longer sustain their functioning.

Effects on sexuality

The condition had a significant effect on sexuality, affecting both the frequency of sexual activity and the associated psycho-emotional experience. Pain during penetration causes "extreme anxiety every time I understand that I should have sex, an anxiety that eats me

Table 2 Main themes and subthemes

Main theme	Subthemes	Examples
A disabling pain	Impact on daily activities	*It's like being paralyzed in life. Because it's like it crystallizes your life a little bit. This thing affects everything, right?*
	Effects on sexuality	*The extreme anxiety every time I understand that I should have sex, an anxiety that eats me alive.*
	Impact on psychological well-being	*When I feel well, my day is calm. Conversely, if I wake up feeling shitty, I'll have a shitty day, and maybe I'll lash out at everyone.*
Aggravating factors: experiences of lack of support and delegitimization	Lack of acceptance from health professionals	*During a visit to the gynecologist for a pap test, I informed her of my condition, vulvodynia, and requested that she be gentle with the speculum. Nevertheless, her maneuvers made me cry from the pain. She asked, 'But really, is it possible that you can't relax?'*
	Delegitimization in the context of social relationships	*They made me feel like I was overreacting, I was the problem. They have always told me I was overdoing it.*
Protective factors: experiences of sexual agency and relational support	The discovery of a new sexual practice	*It's easier because I know where I feel pain and pleasure at that moment, so I can also adapt to what I feel*
	Listening and socioemotional support	*I tend to become demoralized and feel down.' On the other hand, my partner is an optimist who always sees the glass as half full. This is beneficial because he encourages me to have hope that things can improve, even when I am feeling discouraged.*
Identity in reconstruction: An incomplete woman	A betraying body	*My subconscious began to think that the worst thing was that I had no control over myself.*
	Devaluation of self as woman and mother	*My illness has taken something away from me, which is my maternal aspect, the caring and the ability to care for others, which is very much a part of me. In addition, it left me with a lesser sense of competence, of having less value.*
	The discovery of new characteristics of the self	*Although I may feel weak, cry, or throw myself down, I have never given up. I have endured difficult things, and it has become natural for me to endure things that people my age don't even think possible.*

alive" (P32), leading to decreased libido, reduced concentration, and the inability to enjoy sexual activity fully.

Some interviewees reduced the number of sexual encounters or abstained from sex altogether because of these negative experiences. In other cases, however, women "sacrificed" their physical and psychological well-being to satisfy their partner's sexual desires. This behavior allowed them to avoid guilt and inadequacy in sexual intimacy. For example, one interviewee stated, "I feel sorry because I feel guilty about it because I know that our sex life sucks" (P26).

In these cases, individuals may experience sexuality as a duty to their partner in order "to maintain a sense of normality in our intimate relationship" (P6). This can lead to intimacy feeling "planned and rigid" rather than a moment of freedom and exploration of pleasure. As one participant stated, "The biggest blow is when it comes to intercourse because there are good days and bad days, so I have to plan it" (P4).

Impact on psychological well-being

Most respondents reported that vulvodynia had a significant effect on their psychological health and stability, as well as their mood. This included depression, anxiety, panic attacks, negative thoughts, and paranoia. The respondents also described unpredictable and fluctuating moods characterized by sadness and despair. For example, one respondent stated, "When I feel well, my day is calm. Conversely, if I wake up feeling shitty, I'll have a shitty day, and maybe I'll lash out at everyone" (P11).

For some participants, these symptoms led to extreme choices. Sometimes, individuals may forgo having a partner to avoid constant relational suffering. For example, one participant argued, "I wanted to be single, so I would not have to answer anyone" (P33). In other cases, suicidal ideation was apparent; for example, one participant stated, "I thought about ending my life, that I didn't want to live with the pain anymore" (P23).

Aggravating factors: experiences of lack of support and delegitimization

This theme encompasses the participants' discourses on the factors that have increased the difficulties they have experienced due to their vulvodynia. These factors were identified in their interactions with healthcare professionals, family members, and friends and exacerbated their sense of isolation in dealing with the condition.

Lack of acceptance from health professionals

Several respondents reported negative experiences when interacting with health professionals due to their limited knowledge and inability to deal with women's pain during the visit:

> *During a visit to the gynecologist for a pap test, I informed her of my condition, vulvodynia, and requested that she be gentle with the speculum. Nevertheless, her maneuvers made me cry from the pain. She asked in a rather brusque manner, 'But really, is it possible that you can't relax?' (P21).*

In this case, the patient's distress was treated as a mere inconvenience and attributed to her own volition without acknowledging its involuntary nature and connection to her illness.

More generally, lack of acceptance was related to a series of encounters with health professionals who were described as "arrogant" and "rude," unable to reassure patients, "cold and distant", "not empathetic", and therefore unwilling to listen to patients:

*I thought, 'Doctor, why don't you listen to me, listen to my symptoms, and listen to what I'm saying?' The reason for their disbelief was simply that they did not listen to me. This treatment caused me to lose confidence in the health worker*s (P17).

The quoted passage illustrates how negative experiences can lead to a general distrust of the health system, contributing to the patient's overall sense of abandonment. Patients' negative experiences have driven them to seek answers to their illnesses independently. For this reason, the participants described their search for diagnostic and therapeutic solutions as a "lonely and challenging journey." As one participant stated, "I had to do everything by myself" (P8) to signify that she had to persevere and find specialized medical centers and professionals on her own.

Delegitimization in the context of social relationships

The delegitimization of the patient's symptoms by the network of family and friends takes different forms.

First, it manifested itself in the minimization of the patient's pain, which was attributed to her tendency to exaggerate: "They made me feel like I was overreacting, I was the problem. They have always told me I was overdoing it" (P9). The women reported that this lack of understanding of the illness often led to them being labeled "crazy" and "not normal."

Second, delegitimization was evident in the failure to recognize the chronic nature of vulvodynia. The condition is often considered temporary and treatable, leading to surprise when patients have not yet resolved it. For example, one woman reported that her ex-husband still asks her every week "if she is still sick" (P24). In long-standing relationships, such as those with partners or ex-partners, this lack of understanding could prove particularly challenging, as patients made numerous attempts to involve them in the vicissitudes of the illness.

Third, delegitimization manifested itself in a refusal to maintain the relationship once the patient had explained the nature of her illness, with behaviors of rejection and repulsion. For example, a woman reported that a person she went out with, “When I tried to talk to him about it, he made this gesture of disgust and pulled away” (P30).

Patients' experiences with delegitimization have harmed their relationships with friends and partners, resulting in a reduced network of relationships. This has contributed to a sense of loneliness in facing the disease because “the biggest impact on your life is feeling very lonely” (P27). The negative impact has also extended to the family sphere, where high expectations are typically held. The women in the study commonly described their family of origin as “disappointing,” “passive,” “absent,” or “null,” except for financial and economic support:

I wished my father had sat with me at the computer to search for doctors and symptoms. It would have been helpful to have someone, like my mum or dad, sit beside me and say, ‘I'm here, I ‘ll help you.’ Unfortunately, I never received any phone calls or information. I expected a parent to provide that kind of support, but it didn't happen (P5).

In Italy, where the family is highly valued and considered a source of protection and support, the woman felt abandoned when her expectations of receiving help in managing her illness were not met.

Protective factors: experiences of sexual agency and relational support

This theme presents the respondents' views on the experiences and factors that helped alleviate the burden of the disease and protected them from a significant deterioration in their quality of life.

The discovery of a new sexual practice

The participants reported finding it beneficial to explore alternatives to penetrative sex, such as engaging in foreplay, using sex toys, and practicing tantric sex. As one participant stated, “vulvodynia may increase creativity” (P7). These innovations allowed them to approach intimacy with their partner in a more relaxed way and to achieve more satisfying and less painful levels of pleasure. One participant explained, “You can find other forms, other things, other ways, and alternative methods that can be implemented. Additionally, pleasure doesn't have to be sexualized, and it doesn't have to come from the sexual act” (P22).

In particular, the participants described various methods of self-stimulation that pleasured without the pain typically associated with sexual activity. For example, one participant reported, “I have never been able to masturbate with my fingers because it always hurts at the end. Therefore, I have always masturbated by rubbing without inserting anything” (P28). In contrast, one participant reported, “I can't stand any rubbing on the clitoris. So now I apply pressure on the outside, and there's no problem” (P5). The observed variability indicates that autoeroticism is not a singular activity but a diverse range of practices that may undergo changes over time and are subject to varying perceptions regarding their practicality or level of discomfort.

Practicing autoeroticism has provided a new perspective on sexual intimacy and an increased ability to achieve pleasure because it provided a greater sense of control that participants experienced in a variety of aspects. Some individuals found that they were better able to identify the parts of their bodies that provide pleasure without pain through masturbation. For example, one interviewee stated, “It's easier because I know where I feel pain and pleasure at that moment, so I can also adapt to what I feel” (P17). In other cases, greater control was associated with the perception that this sexual practice developed their ability to listen to their body and respect its needs: “If I do it alone, it's not a problem because I follow my own pace” (P30). For some participants, greater control was achieved because masturbation allowed them to discover their body and identify inappropriate and painful sexual practices, as well as those that gave them pleasure. One participant stated, “I used my small vibrator, which I knew had tolerable power because I'm not afraid of hurting myself. Doing it manually is a bit of a stumbling block for me because I experience discomfort, which limits me” (P20). Finally, in other situations, participants have used masturbation to achieve better control over their condition, that is, monitoring the progression of their condition to detect signs of improvement. For example, one participant stated, “Masturbation helped me understand how my situation was changing. Up to a certain point, I couldn't feel contractions, and I couldn't orgasm. When the hypertonicity healed, I could orgasm again, and I had noticed this because of masturbation” (P11).

The knowledge and sense of control gained through autoeroticism were, in some cases, beneficial to the couple's relationship, as one interviewee explained: “This is a topic that I discussed with my physiotherapist during our last session. It could be a helpful first step toward resuming life as a couple. Starting alone may be useful to feel comfortable and avoid further trauma” (P6).

In these cases, this improved self-awareness had a positive effect on a couple's sexuality because women could share with their partners the practices they have identified as best for themselves. For example, a woman explained that she learned to use a vibrator for autoeroticism in a way that gave her pleasure and then taught her partner.

> *Initially, I tried to endure everything, but eventually, I realized that self-stimulation was the only feasible choice for me. I gave very clear instructions to my last partner about the double dildo. I insert the wider part into my partner, and I move on top of it. However, you have to explain these things and to explain them, you must know them (P19).*

Another beneficial effect of masturbation was that it could change the partner's perception of the woman with vulvodynia as unable to feel pleasure, encouraging more conscious sexual practice.

> *Autoeroticism has also been a resource for me. My boyfriend previously believed that I could not experience pleasure, but after seeing me use a sex toy, he realized that this was not the case. As a result, he was able to improve his own ability to bring me to orgasm without the toy (P32).*

Overall, this practice resulted in an increase in self-confidence and the exploration of previously unchartered aspects of their sexuality, described by one participant as "those sensations that were no longer present" (P18).

Listening and socioemotional support

The respondents reported positive experiences with individuals who provided appropriate support by actively listening and offering understanding. They emphasized the importance of health professionals who demonstrated this attitude, as it helped them feel cared for as a person rather than just in terms of their illness. As one respondent stated, "After visiting several hospitals, I eventually arrived at XY, a private hospital. I was impressed with their well-rounded approach to my care. They asked me many questions, thoroughly considering my situation" (P4).

The participants stressed the significance of healthcare providers' expertise in the relevant condition. However, they also argued that possessing knowledge alone is insufficient without a respectful attitude toward welcoming the patient, which demonstrates a genuine interest in their well-being. In this respect, the online vulvodynia forum was the context in which participants perceived to be most listened to, as the forum's members helped patients feel understood and accepted rather than judged as "crazy" and reassured about the "normality" of their condition.

A second important factor was the emotional support of some doctors, who "showed closeness and a human touch" (P20). Additionally, emotional support from a partner was mentioned, with one participant stating:

> *I tend to become demoralized and feel down.' On the other hand, my partner is an optimist who always sees the glass as half full. This is beneficial because he encourages me to hope that things can improve, even when I am discouraged (P25).*

Our data confirm that emotional support can assist these women in transitioning from feelings of powerlessness, passivity, mistrust, and discouragement to a state of hope and increased confidence in the future.

With respect to the feeling of loneliness described in the previous theme, participation in online forums with other patients was found to be a significant protective factor. These social communities are considered "secure environments" for obtaining pertinent information about the disease and establishing strong connections on the basis of practical and emotional support. Moreover, these communities enabled patients to communicate freely about their condition, "breakdown the wall of loneliness" and "find support that would otherwise be impossible" (P31). This was possible because they could relate to other women who shared their condition and had been through similar situations.

Identity in reconstruction: an incomplete woman

This theme encompasses the respondents' discourses on the redefinition of their identity following the diagnosis. The diagnosis and the challenges associated with living with the pain resulted in a negative and self-deprecating shift in their identity, although some women also mentioned some positive changes.

A body that betrays

The relationship with the body has suffered a crisis, particularly in the area of sexual activity. The sexual act was perceived as an "enemy" causing deep suffering rather than being associated with positive aspects such as sexual pleasure or procreation.

Furthermore, the participants expressed a sense of alienation from their own bodies, which had become a "crazy" object, leaving them feeling powerless: "My subconscious began to think that the worst thing was that I had no control over my body" (P8).

Devaluation of self as woman and mother

Illness can lead to a devaluation of oneself as a woman and mother, resulting in self-representation as an "incomplete" or "half" woman. The participants perceived the limitations caused by the illness as a loss of an essential part of themselves. For example, one participant stated, "I perceived myself as much less valuable, a person of no value" (P21). This impact of the illness is also vividly expressed through the metaphor of the clock, which highlights the self-image of a "nonfunctioning" woman.

"When I talk to my partner, I have always described myself as a broken clock, missing the most important part of its mechanism" (P13).

Additionally, self-image as a mother is negatively impacted, and women feel "too fragile to care for someone else," as the burden of illness limits the skills associated with the maternal role, both in the accounts of those who are not yet mothers and those who are:

> *My illness has taken something away from me, which is my maternal aspect, the caring and the ability to care for others, which is very much a part of me. In addition, it left me with a lesser sense of competence, of having less value (P35).*

For participants who were already mothers, the impact of vulvodynia on mood and daily fatigue led to a sense of guilt toward their children. For example, one participant wondered if they would ever be a "normal" mother: "I get angry easily; I don't feel like playing with them. However, they need it now. In addition, I don't want them to remember mummy not doing anything with them" (P28).

The discovery of new aspects of self

Despite their negative self-perception, some respondents also identified positive impacts of vulvodynia on their identity. Specifically, they mentioned that vulvodynia helped them develop traits such as "tenacity" or "strength" that they were previously unaware of or did not believe they possessed, making them more resilient in the face of the illness. One participant clarified, "Although I may feel weak, cry, or throw myself down, I have never given up. I have endured difficult things, and it has become natural for me to endure things that people of my age do not even think possible" (P9).

Similarly, some participants explained that their "illness had completely revolutionized their view of problems" (P3). It enabled them to distinguish what is relevant to their lives and understand the real issues to focus on and worry about. It is a skill that gave them an advantage over other women who do not have vulvodynia, at least in this regard. Overall, some patients were able to reinterpret their journey with chronic illness in terms of opportunities after discovering these aspects of themselves.

Discussion

This research aimed to explore the experiences of Italian women with vulvodynia, thus providing voice and visibility to patients living in a socio-health context that has not yet been qualitatively investigated; a second aim was to explore issues such as social support from family and partner, and autoeroticism in the management of the disease.

The initial theme underscores the repercussions of pain on all dimensions of the subjects' everydays lives. This symptom is characterized by its intensity, persistence, and unpredictability, which imposes considerable constraints on their capacity to engage in future-oriented planning, thereby corroborating the conclusions of preceding studies [14]. The fear of pain experienced by participants had a significant adverse effect on their sexual relationships. This confirms Kaler's [21] observation of a 'terror' associated with the sexual act. The gravity of this matter is so considerable that some respondents have contemplated the termination of their relationship as a means of circumventing the necessity for sexual accountability, as also reported in the study by Myrtveit-Stensrud and colleagues [27]. In certain instances, the coital imperative gave rise to feelings of guilt and perceptions of inadequacy, leading to the "planning" of sexual activity, which was divorced from any dimension of possible pleasure. This transition of sexual activity into a requisite undertaking was accompanied by the establishment of designated days for this sexual act, to avoid acute phases of the disorder. To our knowledge, this account of the strict planning of sexual intercourse differs from that of other studies that have investigated this aspect [15, 20, 54]. Therefore, the experiences of women with regard to sexual health were significantly shaped by compelling social discourses that encourage them to act in a demure manner, to objectify their bodies, and to subvert their own needs in order to meet the needs of others [55]. These findings contribute to the growing body of evidence supporting the concept of sexual care work, which encompasses the sexual activities that women engage in to fulfill the sexual obligations they perceive to be inherent in intimate relationships [56] among women with sexual difficulties, particularly those related to vulvodynia. The concept of sexual care work, which is closely associated with a feminine ethic of care and self-sacrifice, can be viewed through the lens of the 'third shift' of labor that women are expected to perform as part of their domestic responsibilities [56].

The participants commonly reported experiencing negative impacts on their mental health and stability as a direct consequence of vulvodynia. These impacts included depression, anxiety, panic attacks, negative thoughts, paranoia, unpredictable moods, sadness, and discouragement. These findings are consistent with those of previous studies [57]. As with other studies, some participants reported that vulvodynia led to self-harm and suicidal thoughts [58].

The second theme identified the aggravating factors in the illness experience. These factors concern the lack of acceptance and delegitimization experienced by patients in their relationships. The lack of acceptance was primarily attributable to the inadequate preparation of medical practitioners, which resulted in delays in establishing a diagnosis or identifying an appropriate treatment for the condition. A further issue pertains to the perceived relational incompetence of some doctors [19, 54, 59, 60]. This has resulted in feelings of abandonment, frustration with the medical care system, and subsequent negative emotional experiences among these women [59]. These results indicate the persistent underestimation of the problem, as demonstrated by Italian legislation, which does not recognize the disease. The lack of recognition by the National Health Service can be a source of denial by health professionals, who may attribute the condition to psychological factors in their patients. However, it is essential to note that these results are consistent with those found internationally, even in countries with healthcare systems different then Italy [61, 54, 59]. Therefore, developing innovative methods to increase awareness of this issue and provide new training resources for healthcare professionals is crucial.

In the patients' relational context, the study identified two main issues: first, the invalidation of the illness, which downplays the severity of the painful symptoms and questions its physical origin, attributing it to a psychological condition [28], and second, a lack of comprehension and acknowledgment of the patient's emotional needs and daily support requirements [33]. The abovementioned factors presented a significant challenge to the participants, impeding their ability to feel heard and understood. This, in turn, resulted in a pervasive sense of social exclusion, which was particularly detrimental for patients engaged in reconstructing their self-identities [62]. According to Connor and colleagues [54], most women reported that their families played a minimal or absent role, apart from providing financial support for medical expenses. Although this support is beneficial in alleviating the financial burden of the condition, it fails to address the patient's need for emotional support and understanding from their families. This can result in a perception that the pain experienced is not taken seriously, which may lead to feelings of isolation and invisibility [54, 60]. It is also crucial to acknowledge that the challenges encountered in accessing psycho-emotional support and understanding within the family context may be associated with a more pervasive issue, namely the difficulty in discussing health matters, particularly sexual health concerns, within the family. This may be particularly relevant in the Italian context, where family members are often less formally educated than their children, particularly with regard to sexual health [63]. In conclusion, our study indicates that even in a context such as Italy, which is characterized by the importance placed on protective and supportive family ties, establishing close relationships and providing assistance on issues related to sexuality can still be challenging owing to traditional cultural norms that may restrict familial assistance in matters of a sexual nature.

The third theme emphasized the protective factors contributing to reducing the disease burden. First, some women explored alternative forms of sexual expression, including the use of sex toys and tantric sex. The data presented in this study differ from those reported by Gates and Galask [57] and Arnold et al. [64]. In the aforementioned studies, women who engaged in autoeroticism expressed concerns about damaging their sensitive vaginal area. Additionally, the findings of Connor and colleagues [54] diverge from the current study's results. In their study, several respondents expressed disinterest or discomfort in using alternatives to vaginal intercourse because they felt that the natural end goal of sexual intimacy was vaginal intercourse. This is the first study to investigate this issue through in-depth interviews, allowing us to gain insight into how this practice can be beneficial during counseling and intervention practices. Indeed, the participants in our study highlighted how the practice of autoeroticism facilitated control over one's body, thereby enhancing women's capacity to discern what is pleasurable and what is painful or uncomfortable. Autoeroticism engenders knowledge and control over the sexual act, fostering an awareness that a certain rhythm, speed, and mode can still elicit pleasure. This develops the ability to listen to one's body and reduces anxiety about sex. It is of the utmost importance that the entire multidisciplinary team not only promotes autoeroticism as a practice that improves knowledge of one's own body and reduces anxiety, as shown by a recent study on women with chronic vulvar pain conditions [38] but is also aware that it is not a practice suitable for everyone. Instead, this approach may result in the utilization of diverse modalities, tools, and practices for each woman. In alignment with the recommendations put forth by Danielsen and colleagues [55], the therapeutic approach should be grounded in a distinct process that is capable of fostering positive sentiments of embodiment. This process involves a transition from self-objectification and bodily shame towards an appreciation of the body as a subject, accompanied by a greater sense of comfort and confidence in one's physical being. Moreover, therapy should facilitate the development of heightened awareness of internal feelings and bodily states, encouraging an inward focus and fostering trust and value for bodily cues. Additionally, therapists should facilitate the development of sex-positive beliefs and behaviors, This process involves fostering a healthy curiosity regarding one's own body and sexuality,ultivating comfort with and a sense of entitlement to sexual feelings of desire and pleasure, and establishing the capacity to discern and assert sexual boundaries and needs. Therefore, therapists should be cognizant of these different aspects to facilitate women's awareness and control and to provide them with a comprehensive explanation. Finally, it is of the utmost importance that the partner is aware that a woman with vulvodynia can also experience pleasure, as indicated by some participants. In line with a previous study [54], the present findings reinforce the recommendation to provide couples' treatment. Encouraging the male partner's involvement in treatment can be pivotal in promoting a more profound understanding of this medical condition and reducing delegitimization. Additionally, it can facilitate a shift in the perception that intercourse is the epitome of vaginal sex, a notion that is socially constructed and narrow in its scope. This evidence is rucial, as it can assist clinicians in managing vulvodynia by providing targeted interventions, personalized advice, and strategies.

Even though our interviewees displayed greater proclivity toward exploring other sexual practices, the coital imperative remained a salient issue [54], as expressed in the first theme. This ambivalent attitude toward masturbation can be attributed to changes in cultural representations and public discourse on these issues in the Italian context [65]. On the one hand, Italian culture continues to exhibit a high degree of conservatism regarding sexual matters [66]. However, recent evidence has shown that among women, especially young women, there has been a shift toward a lifestyle more oriented toward pleasure-seeking and sexual activity [67].

Another protective factor was the development of positive relationships with health professionals and patients. It is of the utmost importance to establish a robust therapeutic alliance with the patient when confronting sexual health challenges in this context. This alliance should be founded upon empathy, trust, and collaborative decision-making [55]. The participants reported that certain healthcare professionals provided hope and reassurance due to their capacity to listen and empathize. This emphasizes the importance of physicians avoiding objectifying their patients, such as perceiving their bodies as objects to be fixed. It is crucial to acknowledge and welcome patients' subjectivity, including the emotional impact of their illness and their need to be heard [59, 68]. Furthermore, our participants also found that attending an online forum dedicated to this condition was beneficial. The usefulness of knowledge-sharing online communities for vulvodynia has already emerged from the study by Young & Miller [69]. Our study provides additional evidence to the existing literature, demonstrating that participants in these groups had access to a non-judgmental space where they could engage with others experiencing a similar condition. Our findings indicate that having someone to talk to who is facing a comparable situation is crucial for these women [60]. This allowed these women to find credible answers to their needs for information and emotional support, reduced their loneliness, and enabled them to make some positive sense of their stories. This finding is consistent with research conducted on arious chronic conditions [70, 71], as well as with social support theory in the context of chronic illness [72]. Indeed, individuals with chronic conditions may seek support from a specific subset of their broader social network or even explore additional sources of support within the digital domain from other individuals who share similar experiences [73].

The fourth theme explores how vulvodynia impacts the identity of participants. Chronic health conditions are frequently associated with a sense of biographical disruption [74] and reconstruction [75]. In our study, this reconstruction was associated mainly with a sense of loss, leading these women to define themselves as incomplete [54]. Indeed, participants associated their experience of the condition with a predominantly negative view of themselves, feeling like a 'half-woman', and a sense of betrayal by their bodies. Similarly, in other studies, women have defined themselves as 'nonfunctional' because they perceive their body as a 'mad object' over which they have lost some or all control [21]. Our study revealed that negative self-perceptions were based on the inability to have pain-free sex, which made the participants feel less feminine. Additionally, their physical and psychological discomfort limited their ability to carry out caring tasks, which caused fear of not fulfilling their maternal role. These factors have a significant emotional impact and increase feelings of guilt [33]. Within this general framework, some participants identified elements of positive change. They discovered new aspects of their identities which in turn enabled them to onfront the constant challenges associated with their condition and to set new priorities in their lives, as already observed in other chronic diseases [76]. This element is innovative compared with previous studies, which have focused exclusively on the negative impact of the disease. This finding illustrates the importance of healthcare professionals recognizing and embracing their clients' full range of subjective experiences , including the potential for positive outcomes associated with the disease. A multidimensional approach, based on empathy and acceptance as powerful therapeutic tools and including psychological therapy, may offer valuable help in the clinical setting [77, 78].

In conclusion, the patients' challenges highlight the importance of greater awareness among health professionals and society. The results also underscored the longstanding unmet needs in managing vulvodynia [61], including the necessity for enhanced medical training to facilitate early diagnosis of affected women and for advanced policy reforms to guarantee that these women can be offered multidisciplinary treatments, including access to physiotherapists and psychologists. Health professionals should improve sexual health by promoting sexual pleasure rather than sexual function [54], as this can open up opportunities for couples to develop new ways of being sexual together [27]. In addition, psychological support and intervention for the couple and family would be helpful in favor of more profound knowledge of this medical issue and reducing delegitimization.

Limitations and future developments

This research is subject to certain limitations that may prove beneficial to address in future studies. This study focused on the 18–50-year-old age group, as the literature has shown that women of childbearing age are more likely to experience vulvodynia [6]. Exploring the experiences of menopausal women would also be interesting. Some studies have shown that vulvodynia is increasingly common in this age group [2]. This could lead to a more articulated understanding of the experiences of women with vulvodynia and facilitate comparisons of conditions across different age groups. Additionally, it may be worthwhile to include patients with symptoms of vulvodynia in research, even if they have not yet received a formal diagnosis. Studies have shown that women may discover this diagnostic label independently, often online, as some health professionals struggle to assign their symptoms to a coherent nosographic framework [79]. Exploring these individual patient paths is important for understanding the dynamics and possible risk dimensions for patients who rely on nonspecialist sources that may offer unqualified help. It is also crucial to consider the potential for selection bias, given the methodology's subjective nature and the nonrandom selection of participants [80].

Conclusions

The present study aimed to investigate the illness experience of women with vulvodynia in the Italian context, with a particular focus on the role of family support and autoeroticism in the management of the condition and its associated consequences.

The findings suggest that patients' experiences are influenced by multiple exacerbating factors, including the delegitimization of women at the health and social levels, as well as the dearth of emotional support they receive within the family.

Two facilitating factors in the management of the illness were identified. At the level of sexual practice, the use of autoeroticism was found to facilitate pleasurable sexuality and a better relationship with the body, even within the context of a romantic partnership. With regard to relational support, it was found that participation in online patient groups that function as communities of practice can satisfy patients' informational and social needs.

Furthermore, despite the detrimental impact of vulvodynia on the identity of women afflicted by it, the study revealed that a subset of participants was able to discern elements of positive transformation. These findings thus provide researchers and healthcare professionals with a more nuanced comprehension of the intricacies of patients' experiences and underscore the necessity for multidisciplinary interventions that enhance sexual well-being by prioritizing sexual pleasure over sexual function. Concurrently, they underscore the imperative for enhanced societal awareness and support to assist these women in navigating the challenges of the disease.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40359-024-02318-z.

Supplementary Material 1

Acknowledgements
Not Applicable.

Author contributions

LM: Conceptualization, Methodology, Formal analysis, Supervision, Funding acquisition, Writing – original draft, Writing – review & editing. CB: Conceptualization, Investigation, Data curation, Formal analysis, Writing – original draft., Writing – review & editing. VC: Formal analysis, Writing – original draft, Writing – review & editing.

Funding
The author(s) declare that financial support was received for the research, authorship, and/or publication of this article. This study received financial support from the ATE - University of Milano-Bicocca Fund ID project 56927 "Aggravating and protective factors in patients' experiences of vulvodynia: A qualitative study with Italian women".

Data availability

The dataset supporting the conclusions of this article will be made available by the authors upon reasonable request.

Declarations

Ethics approval and consent to participate

This study has been conducted in accordance with the ethical standards set forth in the Declaration of Helsinki. Ethical approval for this study was obtained from the University of Milano-Bicocca Ethics Committee (RM-2021-697). All participants provided informed written consent.

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests.

Received: 25 September 2024 / Accepted: 23 December 2024

References

1. Pukall CF, Goldstein AT, Bergeron S, Foster D, Stein A, Kellogg-Spadt S, Bachmann G. Vulvodynia: definition, prevalence, impact, and pathophysiological factors. J Sex Med. 2016;13(3):291–304.
2. Graziottin A, Murina F. Vulvodinia: Strategie Di Diagnosi E cura. Milano: Springer- Verlag Italia; 2011.

3. Shah M, Hoffstetter S. Vulvodynia. Obstet Gynecol Clin. 2014;41:453–.
4. Bornstein J, Goldstein AT, Stockdale CK, Bergeron S, Pukall C, Zolnoun D, Coady D. Consensus Terminology and classification of Persistent Vulvar Pain and Vulvodynia. J Sex Med. 2015;13(4):607–12.
5. Schlaeger JM, Patil CL, Steffen AD, Pauls HA, Roach KL, Thornton PD, Hartmann D, Kobak WH, Yao Y, Suarez ML, Hughes TL, Wilkie DJ. (2019). Sensory pain characteristics of vulvodynia and their association with nociceptive and neuropathic pain: an online survey pilot study. Pain Rep, 4(2), e713.
6. Reed BD, Harlow SD, Sen A, Legocki LJ, Edwards M, Arato M, Haefner HK. Am J Obstet Gynecol. 2012;206(2):171–9.
7. Chauhan SP, Berghella V, Sanderson M, Magann EF, Morrison JC. American College of Obstetricians and gynecologists practice bulletins: an overview. Am J Obstet Gynecol. 2006;194(6):1564–72.
8. Pukall CF. Primary and secondary provoked vestibulodynia: a review of overlapping and distinct factors. Sex Med Reviews. 2016;4(1):36–44.
9. Babula O, Danielsson I, Sjoberg I, Ledger WL, Witkin S. Altered distribution of mannose-binding lectin alleles at exon I codon 54 in women with vulvar vestibulitis syndrome. Am J Obstet Gynecol. 2004;191(3):762–6.
10. Tonc E, Omwanda GK, Tovar KA, Golden XME, Chatterjea D. Immune mechanisms in vulvodynia: key roles for mast cells and fibroblasts. Front Cell Infect Microbiol. 2023;13:1215380.
11. Chisari C, Monajemi MB, Scott W, Moss-Morris R, McCracken LM. Psychosocial factors associated with pain and sexual function in women with Vulvodynia: a systematic review. Eur J Pain. 2021;25(1):39–50.
12. Corsini-Munt S, Bergeron S, Rosen NO, Beaulieu N, Steben M. A dyadic perspective on Childhood Maltreatment for Women with provoked Vestibulodynia and their partners: associations with Pain and sexual and psychosocial functioning. J Sex Res. 2017;54(3):308–18.
13. Dewitte M, Meulders A. Fear learning in Genital Pain: toward a Biopsychosocial, ecologically valid research and treatment model. J Sex Res. 2023;60(6):768–85.
14. Zolnoun D, Bair E, Essick G, Gracely R, Goyal V, Maixner W. Reliability and reproducibility of novel methodology for assessment of pressure pain sensitivity in pelvis. J Pain. 2012;13(9):910–20.
15. Shallcross R, Dickson JM, Nunns D, Mackenzie C, Kiemle G. Women's subjective experiences of living with Vulvodynia: a systematic review and Meta-ethnography. Arch Sex Behav. 2018;47:577–95.
16. Ayling K, Ussher JM. If sex hurts, am I still a woman? The subjective experience of Vulvodynia in hetero-sexual women. Arch Sex Behav. 2008;37:294–304.
17. Templeman L, Eberhardt J, Ling J. Exploring the health care experiences of women diagnosed with vulvodynia. J Sex Med. 2023;20(1):97–106.
18. Bornstein J, Preti M, Simon JA, As-Sanie S, Stockdale CK, Stein A, Parish SJ, Radici G, Vieira-Baptista P, Pukall C, Moyal-Barracco M, Goldstein A. & International Society for the Study of Vulvovaginal Disease (ISSVD), the International Society for the Study of Women's Sexual Health (ISSWSH), and the International Pelvic Pain Society (IPPS) (2019). Descriptors of Vulvodynia: a Multisocietal Definition Consensus (International Society for the Study of Vulvovaginal Disease, the International Society for the Study of Women Sexual Health, and the International Pelvic Pain Society). J Lower Genit Tract Dis, 23(2), 161–3.
19. Marriott C, Thompson AR. Managing threats to femininity: personal and interpersonal experience of living with vulval pain. Psychol Health. 2007;23(2):243–58.
20. Shallcross R, Dickson JM, Nunns D, Taylor K, Kiemle G. Women's experiences of Vulvodynia: an interpretative phenomenological analysis of the Journey toward diagnosis. Arch Sex Behav. 2019;48:961–74.
21. Kaler A. Unreal women: sex, gender, identity and the lived experience of Vulvar Pain. Feminist Rev. 2006;82(1):50–75.
22. Niedenfuehr J, Edwards M, King LM. A scoping review: the psychosocial barriers that exist for people with vulvodynia. J Sex Med. 2023;20(6):833–58.
23. Leusink P, Kaptheijns A, Laan E, van Boven K, Lagro-Janssen A. Comorbidities among women with Vulvovaginal complaints in Family Practice. J Sex Med. 2016;13(2):220–5.
24. Graziottin A, Murina F, Gambini D, Taraborrelli S, Gardella B, Campo M, VuNet Study Group. Vulvar pain: the revealing scenario of leading comorbidities in 1183 cases. Eur J Obstet Gynecol Reproductive Biology. 2020;252:50–5.
25. Gordon AS, Panahian-Jand M, McComb F, Melegari C, Sharp S. Characteristics of women with Vulvar Pain disorders: responses to a web-based survey. J Sex Marital Therapy. 2003;29:45–58.
26. Rosen NO, Bois K, Mayrand MH, Vannier S, Bergeron S. Observed and Perceived Disclosure and Empathy are Associated with Better Relationship Adjustment and Quality of life in couples coping with Vulvodynia. Arch Sex Behav. 2016;45:1945–56.
27. Myrtveit-Stensrud L, Haugstad GK, Rème SE, Schaller SL, Groven KS. It's all my fault: a qualitative study of how heterosexual couples experience living with vulvodynia. Acta Obstet Gynecol Scand. 2023;102(10):1378–89.
28. Rosen NO, Bergeron S, Lambert B, Steben M. Provoked Vestibulodynia: mediators of the associations between Partner responses, Pain, and sexual satisfaction. Arch Sex Behav. 2013;42:129–41.
29. Munday P, Buchan A, Ravenhill G, Wiggs A, Brooks F. A qualitative study of women with vulvodynia: II. Response to a multidisciplinary approach to management. J Reprod Med. 2007;52(1):19–22.
30. Buchan A, Munday P, Ravenhill G, Wiggs A, Brooks F. A qualitative study of women with vulvodynia: I. The journey into treatment. J Reprod Med. 2007;52(1):15–8.
31. Putnick DL, Bornstein MH, Lansford JE, Chang L, Deater-Deckard K, Di Giunta L, Bombi AS. Agreement in mother and father acceptance-rejection, warmth, and hostility/rejection/neglect of children across nine countries. Cross-Cultural Res. 2012;46(3):191–223.
32. Pivetti M, Montali L, Simonetti G. The discourse around usefulness, morality, risk and trust: a focus group study on prenatal genetic testing. Prenat Diagn. 2012;32(12):1205–11.
33. Ponte M, Klemperer E, Sahay A, Chren M. Effects of Vulvodynia on quality of life. J Am Acad Dermatol. 2008;60(1):70–6.
34. McNulty JK, Wenner CA, Fisher TD. Longitudinal associations among relationship satisfaction, sexual satisfaction, and frequency of sex in early marriage. Arch Sex Behav. 2015;45:85–97.
35. Du Plessis R. A discourse analysis of male sexuality in the magazine Intimacy. Afr J Prim Health Care Family Med. 2015;7(1):e1–7.
36. Vitellone N.`Condoms and the Making of Testosterone Man: A Cultural Analysis of the Male Sex Drive in AIDS Research on Safer Heterosex'. Men and Masculinities, 2000;3(2).
37. McPhillips K, Braun V, Gavey N. Defining (Hetero)sex: how imperative is the coital imperative? Women's Stud Int Forum. 2001;24(2):229–40.
38. Mautz TT, Mulroy ME, Krapf JM, Goldstein AT, Pukall CF. Pleasure despite pain: associations between experiences of vulvar pleasure, vulvar pain, and sexual function in patients with chronic vulvar pain conditions. Sex Med. 2023;11(4):qfad047.
39. Corona, G., Ricca, V., Boddi, V., Bandini, E., Lotti, F., Fisher, A. D., … & Maggi, M. (2010). Autoeroticism, mental health, and organic disturbances in patients with erectile dysfunction. The journal of sexual medicine, 7(1_Part_1), 182–191.
40. Minello A, Caltabiano M, Dalla-Zuanna G, Vignoli D. Catching up! The sexual behaviour and opinions of Italian students (2000–2017). Genus. 2020;76(1):16.
41. Zaikman Y, Marks MJ. Promoting theory-based perspectives in sexual double standard research. Sex Roles. 2017;76(7):407–20.
42. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40.
43. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3(2):77–101.
44. Braun V, Clarke V. Thematic analysis. American Psychological Association; 2012.
45. Shakir M, Rahman A. Conducting pilot study in a qualitative Inquiry: learning some useful lessons. J Posit School Psychol. 2022;6(10):1620–4.
46. Willig C. Constructivism and 'The Real World': Can they coexist? QMiP Bulletin> 2016;(21).
47. Wiltshire G. A case for critical realism in the pursuit of interdisciplinarity and impact. Qualitative Res Sport Exerc Health. 2018;10(5):525–42.
48. Sims-Schouten W, Riley SC, Willig C. Critical realism in discourse analysis: a presentation of a systematic method of analysis using women's talk of motherhood, childcare and female employment as an example. Theory Psychol. 2007;17(1):101–24.
49. Cornish F, Gillespie A, Zittoun T. Collaborative analysis of qualitative data. In: Flick U, editor. The SAGE Handbook of Qualitative Data Analysis. New York: SAGE; 2013. pp. 79–93.
50. Coates WC, Jordan J, Clarke SO. (2021). A practical guide for conducting qualitative research in medical education: part 2—coding and thematic analysis. AEM Educ Train, 5(4), e10645.
51. Braun V, Clarke V, Weate P. Using thematic analysis in sport and exercise research. In: Smith B, Sparkes AC, editors. Routledge handbook of qualitative research in sport and exercise. New York, NY: Routledge; 2016. pp. 191–205.

52. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. In: Liamputtong P, editor. Handbook of Research Methods in Health Social Sciences. Singapore: Springer; 2019.
53. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health care: J Int Soc Qual Health Care. 2007;19(6):349–57.
54. Connor JJ, Robinson B, Wieling E. Vulvar pain: a phenomenological study of couples in search of effective diagnosis and treatment. Fam Process. 2008;47(2):139–55.
55. Danielsen KG, Kaarbø MB, Groven KS, Helgesen ALO, Haugstad GK, Wojniusz S. Towards improved sexual health among women with provoked vestibulodynia: experiences from a somatocognitive therapy approach. Eur J Physiotherapy. 2024;26(1):51–61.
56. Braksmajer A. That's kind of one of our jobs: sexual activity as a form of care work among women with sexual difficulties. Arch Sex Behav. 2017;46(7):2085–95.
57. Gates EA, Galask RP. Psychological and sexual functioning in women with vulvar vestibulitis. J Psychosom Obstet Gynecol. 2001;22(4):221–8.
58. Major J, Brackenbury F, Gibbon K, Tomson N. (2016) The impact of vulval disease on patients' quality of life. J Community Nurs, 30(2).
59. Connor JJ, Brix CM, Trudeau-Hern S. The diagnosis of provoked vestibulodynia: steps and roadblocks in a long journey. Sex Relatsh Therapy. 2013;28(4):324–35.
60. Lountzi AZ, Durand H. Help-seeking experiences and intimate partner support in vulvodynia: a qualitative exploration. Women's Health. 2024;20:17455057241241866.
61. Toeima E, Nieto J. Junior doctors' understanding of vulval pain/Vulvodynia: a qualitative survey. Arch Gynecol Obstet. 2011;283:101–4.
62. Dickson A, Knussen C, Flowers P. Stigma and the delegitimation experience: an interpretative phenomenological analysis of people living with chronic fatigue syndrome. Psychol Health. 2007;22:851–67.
63. Cardoso D, Scarcelli CM. Breaking the silence: young people, sex information and the internet in Italy and Portugal. In: Scarcelli CM, Chronaki D, De Vuyst S, Villanueva S, Baselga, editors. Gender and sexuality in the European media. Routledge; 2021. pp. 41–57.
64. Arnold LD, Bachmann GA, Kelly S. Vulvodynia: characteristics and associations with co-morbidities and Quality of Life. Obstet Gynecol. 2006;107(3):617–24.
65. Todesco L, Camoletto RF. Tackling the relationship between pornography's consumption and female sexual scripts: does masturbation play an activating role? Int Rev Sociol. 2021;31(3):554–76.
66. Bertone C, Camoletto F, R., Torrioni PM. Sessualità femminile, tra nuovi desideri e nuovi confini. Polis. 2011;25(3):363–92.
67. Dalla Zuanna G, Vignoli D. Tra piacere e fedeltà. I millenials Italiani E Il Sesso. Bologna: Il Mulino; 2021.
68. Svenaeus F. The phenomenology of objectification in and through Medical Practice and Technology Development. J Med Philosophy: Forum Bioeth Philos Med. 2023;48:2, 141–50.
69. Young AL, Miller AD. This Girl is on Fire Sensemaking in an Online Health Community for Vulvodynia. In Proceedings of the 2019 CHI conference on human factors in computing systems. 2019;1–13.
70. Willis E, Royne MB. Online Health communities and Chronic Disease Self-Management. Health Commun. 2017;32(3):269–78.
71. Montali L, Zulato E, Frigerio A, Frangi E, Camussi E. Mirroring, monitoring, modelling, belonging, and distancing: psychosocial processes in an online support group of breast cancer patients. J Community Psychol. 2022;50(2):992–1007.
72. Frohlich DO. The social support model for people with chronic health conditions: a proposal for future research. Social Theory Health. 2014;12:218–34.
73. Di Mattei, V. E., Taranto, P., Perego, G., Caneva, M., Parma, M., Fontana, E., … & Montali, L. (2024). Illness experience and (unmet) needs of women with Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH): a qualitative analysis of an online forum. Psychology & Health, 1–23.
74. Bury M. Chronic illness as biographical disruption. Sociol Health Illn. 1982;4:167–82.
75. Larun L, Malterud K. Identity and coping experience in chronic fatigue syndrome: a synthesis of qualitative studies. Patient Educ Couns. 2007;69:20–8.
76. Helgeson VS, Zajdel M. Adjusting to chronic health conditions. Ann Rev Psychol. 2017;68:545–71.
77. LePage K, Selk A. What do patients want? A needs Assessment of Vulvodynia patients attending a Vulvar diseases Clinic. Sex Med. 2016;4(4):242–8.
78. Backman H, Widenbrant M, Bohm-Starke N, Dahlof LG. Combined physical and psychosexual therapy for provoked vestibulodynia-an evaluation of a multidisciplinary treatment model. J Sex Res. 2008;45(4):378–85.
79. Chisari C, Chilcot J. The experience of pain severity and pain interference in vulvodynia patients: the role of cognitive-behavioural factors, psychological distress and fatigue. J Psychosom Res. 2016;93:83–9.
80. Florczak KL. Best available evidence or truth for the moment: Bias in Research. Nurs Sci Q. 2022;35(1):20–4.

Publisher's note