



The experience of pain severity and pain interference in vulvodynia patients: The role of cognitive-behavioural factors, psychological distress and fatigue



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ABSTRACT

Objective: Vulvodynia is a chronic pain condition characterised by severe pain affecting the vulva. Biopsychosocial models have revealed the importance of illness perceptions, cognitive-behavioural variables and psychological distress in explaining the experience of pain and disability across several conditions. These factors have never been collectively examined in vulvodynia. We predicted that distress, fatigue, illness perceptions, and cognitive-behavioural factors would be associated with pain severity and interference among women with vulvodynia.

Methods: This online cross-sectional study recruited 335 vulvodynia patients from an Italian charity association (Vulvodiniapuntoinfo.com), who completed pain severity and interference measures in addition to the Hospital Anxiety and Depression scale, Revised Illness Perception Questionnaire, Chalder Fatigue Questionnaire, Cognitive-Behavioural Symptom Questionnaire and a demographic questionnaire.

Results: Hierarchical regression models controlling for demographic and illness characteristics, revealed that lower treatment control beliefs, greater illness identity, catastrophizing and psychological distress, were significant predictors of pain severity, explaining 35% of the variance. A second adjusted hierarchical regression model revealed that low treatment-control, higher fatigue, distress, and avoidance/resting behaviours were significant predictors of pain interference, explaining 48% of the variance.

Conclusion: Distress, illness perceptions, fatigue, and cognitive-behavioural factors are associated with pain severity and interference in patients with vulvodynia, highlighting the importance of adopting a biopsychosocial approach in this setting. Future research should examine these factors over time to inform the development of future tailored interventions to help support women better manage vulvodynia.

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1. Introduction

Vulvodynia is a chronic pain condition characterised by severe vulvar pain lasting >3 months, referred to as burning and cutting (knife-like) pain. The prevalence of vulvodynia is 15–18% [1] with an elusive aetiology [2]. According to the International Society for the Study of Vulvovaginal disease (ISSVD) [2], vulvodynia can be classified as generalised (involving the whole general area), localised in one area such as the Vestibule (Vestibulodynia) or mixed (localised and generalised). This can be further divided by how the pain arises, either spontaneous, provoked (i.e. triggered by a stimulus such as sexual intercourse) or mixed (spontaneous and provoked).

Similar to patients with neuropathic pain conditions, women with vulvodynia present with allodynia and hyperalgesia [3], therefore dyspareunia and pain occur during normal daily activities. Whilst the aetiology is still unclear, conceivable factors include abnormal inflammatory response in the vestibule and an increased number and superficialization of pain fibers [4,5] due to genetic polymorphisms associated with functional alterations to IL-1 β and TNF- α [6], as well as the presence of recurrent infections due to an altered distribution of mannose-binding lectin [7].

Since women with vulvodynia are faced with severe long-term pain, it is not surprising that it poses multiple challenges for their psychological health. However, there is limited research examining psychological factors associated with vulvodynia. The lack of research might be partly explained by the fact that vulvodynia is still conceptualised in a dualistic fashion: either as a psychogenic sexual condition or a biomedical condition. Whilst there is increasing recognition regarding the contribution of psychosocial and behavioural factors in several chronic pain conditions

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[8,9], a biopsychosocial approach to understanding vulvodynia has not been widely considered.

Within vulvodynia, studies have mostly focused on the prevalence of depression and anxiety in this population. The prevalence of psychological distress in women with vulvodynia has revealed inconsistent findings, with studies suggesting more anxiety and depression compared to healthy women [10,11], and some suggesting no differences [12]. The only study to our knowledge investigating the relation between pain and distress [13] suggests an association between depression and the severity of vulvodynia.

Importantly, whilst recent advances in other conditions such as chronic lower back pain has identified the importance of catastrophizing, fear and hypervigilance in the aetiology of pain and its maintenance [14,15,16], these factors have not been examined in women with vulvodynia and only once among Vestibulodynia women [17]. According to the fear-avoidance model, pain-catastrophizing leads to fear of pain, resulting in the use of maladaptive coping strategies such as avoidance of activities which may cause pain. Long-term avoidance, however results in deconditioning and lower mood, all factors lowering the threshold at which subsequent pain will be experienced, thus contributing to pain chronicity and exacerbation of catastrophic thoughts. Among Vestibulodynia women, the only study conducted in this domain [17] found that catastrophizing, anxiety, fear of pain, and hypervigilance collectively explained 15% of variance in intercourse pain, but that only pain-catastrophizing contributed unique variance to this outcome. This suggests that whilst pain-catastrophizing is important, other factors might play a role.

Of potential importance is the role of illness perceptions in response to symptoms. However, to date, illness perceptions among women with vulvodynia have not been evaluated. According to the Common-Sense Model of illness representations (CSM), illness perceptions refer to cognitions that individuals have surrounding an illness or symptom(s) (in the current study perceptions surrounding vulvodynia), which then guide individuals' coping behaviours to manage and control their conditions [18]. Illness perceptions consist of the following dimensions: (1) *identity* (Beliefs concerning the illness label and symptoms attributed to the condition); (2) *cause* (beliefs about causes of the illness); (3) *timeline* (the perceived duration of the illness, cyclical, acute or chronic); (4) *consequences* (beliefs about the effects of the illness), (5) *control/cure* (beliefs regarding the controllability/curability of the illness); (6) *coherence* (understanding of the illness). To date, there is robust evidence demonstrating the importance of examining illness perceptions in relation to health outcomes across several conditions [19,20]. For instance, among orofacial pain patients and osteoarthritis patients [21,22], negative illness perceptions at baseline were predictive of higher pain-related disability after 6 months and 6 years respectively, suggesting these could be worth exploring in vulvodynia.

Biopsychosocial models have been shown to explain variability in symptoms across a range of conditions [23,24]. For example, Multiple Sclerosis (MS) fatigue [23], is associated with that negative cognitions in responses to fatigue symptoms can lead to negative emotions, which in turn manifest themselves in maladaptive behaviours, such as all-or-nothing (over-exertion followed by excessive rest) and avoidance behaviours, creating a vicious cycle ultimately exacerbating and maintaining fatigue. Within acute and chronic pain conditions fear-avoidance beliefs and distress is associated with greater disability [25]. Furthermore, behavioural avoidance has been associated with greater distress and disability among those with chronic pain [26]. Despite promising findings elsewhere no studies have explored these factors in relation to pain in vulvodynia patients.

Collectively, the lack of vulvodynia research requires an urgent need for expansion to give an insight into the contributions of psychological and behavioural factors in women's experience of pain. Furthermore, given the success of tailored psychological interventions on other chronic conditions [27,28], it is of paramount importance to investigate the contributions of these factors which will help inform the future

development of interventions designed to help support women manage their pain.

The overarching objective of this study was to evaluate a biopsychosocial approach in women with vulvodynia, examining factors associated with the variability of pain severity and interference. Given the findings of past studies investigating the role of psychological and behavioural factors in other long-term conditions we tested the following hypotheses:

1. Psychological distress, as measured by depression and anxiety symptoms, and fatigue would be associated with greater pain severity and interference.
2. Negative illness perceptions, higher levels of catastrophizing, fear-avoidance, damage beliefs, symptoms-focusing, embarrassment-avoidance and greater use of all-or-nothing behaviour and avoidance/resting behaviours would all be associated with greater levels of pain severity and inference.

2. Method

2.1. Study design and procedure

This study employed an online cross-sectional design. The primary outcome variables were self-reported pain severity and pain interference. Participants completed these and other questionnaires (described below) online, using Bristol online Survey (BOS). The study received approval by King's College London committee in June 2016.

2.2. Participants

Vulvodynia patients were recruited through media announcements from Vulvoduniapuntoinfo.com, an Italian non-profit organization on vulvodynia. Participants were considered eligible providing the following: 1) presence of vulvodynia diagnosis from a health professional (all subtypes of vulvodynia were eligible), 2) participants were still suffering from the condition, 3) participants were over 18, 4) participants were fluent in Italian. No upper age limit was set as vulvodynia can affect women of any age (1). Participants with a comorbid condition were considered eligible. Participants were considered ineligible if the following were present: lack of a vulvodynia diagnosis from a health professional (2) participants were diagnosed with vulvodynia in the past but fully recovered, (3) pregnant, (4) insufficient fluency in Italian (5) being under 18.

3. Materials

3.1. Questionnaires measures - dependent variables

3.1.1. Pain severity (primary outcome)

Participants' pain severity was assessed through a Numeric Pain Rating Scale (NPRS) consisting of four questions measuring the severity of the pain experienced [29]. Each of the following items was rated on a scale where 0 is "no pain" and 10 is "extremely intense pain (*How intense is your pain right now?; How intense was your pain on average last week?; How distressing is your pain right now?; How distressing was your pain on average last week?*). The questionnaire was back-translated. Internal reliability was high ($\alpha = 0.93$).

3.1.2. Pain interference (primary outcome)

The Brief-Pain Inventory (interference scale) was used to measure participants' pain interference [30]. This scale measures the extent pain interferes with the following aspects of one's life over the course of the past week: general activity, mood, normal work, relationships with people, sleep, enjoyment of life. For each of these domains, a person is asked to choose the rate the degree pain has interfered on a scale from 0 to 10, where 0 is "does not interfere" and 10 is "completely

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