



# Sensory pain characteristics of vulvodynia and their association with nociceptive and neuropathic pain: an online survey pilot study

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## Abstract

**Objectives:** To evaluate self-reported sensory pain scores of women with generalized vulvodynia (GV) and provoked vestibulodynia (PVD), characterize pain phenotypes, and assess feasibility of using the Internet for recruitment and data collection among women with vulvodynia.

**Methods:** Descriptive online survey. Data collected using an online survey accessed via a link on the National Vulvodynia Association web site. Convenience sample, 60 women aged 18 to 45 years (mean =  $32.7 \pm 5.5$ ); 50 white, 2 black/African American, 4 Hispanic/Latino, and 4 Native American/Alaskan Native, diagnosed with vulvodynia, not in menopause. Pain assessment and medication modules from PAINReportIt.

**Results:** Women with GV ( $n = 35$ ) compared to PVD ( $n = 25$ ). Estimated mean pain sites ( $2.5 \pm 1.4$  vs  $2.2 \pm 1.0$ ,  $P = 0.31$ ), mean current pain ( $8.7 \pm 1.4$  vs  $5.5 \pm 4.0$ ,  $P = 0.0008$ ), worst pain ( $8.1 \pm 1.8$  vs  $6.1 \pm 3.6$ ,  $P = 0.02$ ), and least pain in the past 24 hours ( $4.4 \pm 1.8$  vs  $2.0 \pm 2.0$ ,  $P < 0.0001$ ). Average pain intensity ( $7.1 \pm 1.2$  vs  $4.6 \pm 2.9$ ,  $P = 0.0003$ ) on a scale of 0 to 10, mean number of neuropathic words ( $8.3 \pm 3.6$  vs  $7.7 \pm 5.0$ ), and mean number of nociceptive words ( $6.9 \pm 4$  vs  $7.5 \pm 4.4$ ). Nineteen (54%) women with GV compared to 9 (38%) with PVD were not satisfied with pain levels.

**Conclusion:** Women with GV reported severe pain, whereas those with PVD reported moderate to severe pain. Pain quality descriptors may aid a clinician's decisions about whether to prescribe adjuvant drugs vs opioids to women with vulvodynia.

**Keywords:** Vulvodynia, Dyspareunia, Pain measurement, Neuropathic and nociceptive pain

## 1. Introduction

Vulvodynia is "vulvar pain of at least 3-month duration without clear identifiable cause, which may have potentially associated factors."<sup>2</sup> There are 2 major subtypes of vulvodynia: generalized vulvodynia (GV) and provoked vestibulodynia (PVD). The pain of GV may affect the whole vulva as well as the inner thighs and perineum, and it may be spontaneous and/or provoked. Pain with PVD is confined to the vulvar vestibule and vaginal introitus.<sup>2</sup> It

may be provoked by sexual intercourse, tampon insertion, tight clothing, or sitting. Up to 7 million American women have this debilitating chronic pain syndrome. It is accompanied by dyspareunia (pain with vaginal penetration that renders sexual intercourse nearly impossible).<sup>16</sup> Also, women with vulvodynia experience relationship difficulties due to their inability to have sexual intercourse.<sup>1,4</sup> No treatment is consistently effective,<sup>15,37</sup> and only 25% of women diagnosed with vulvodynia attain

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remission.<sup>30</sup> Evidence suggests vulvodynia is a complex pain phenomenon with both neuropathic and nociceptive characteristics.<sup>14,22,33</sup> Few studies describe vulvodynia pain, and most are limited by lack of valid, reliable, and comprehensive pain measures. The development of effective pain treatment strategies has been impeded by lack of characterization of women's perceptions of their vulvodynia pain. Also, there is insufficient knowledge about the nature of the 2 subtypes. In this pilot study, we begin to address these gaps by presenting self-reported sensory pain scores and characterization of the pain phenotypes of 60 women diagnosed with either GV or PVD. The first aim of this study was to describe the sensory elements (location, intensity, quality, and pattern) and nociceptive and neuropathic components of GV and PVD pain. In other patient populations, the McGill Pain Questionnaire (MPQ) pain quality descriptors have been used to diagnose neuropathic pain.<sup>42,45</sup> Use of the pain quality descriptors in the characterization of GV and PVD may help guide development of appropriate and new treatments.

To inform a future large-scale national online study, our second aim was to determine the feasibility of using the Internet for recruitment and collection of data from women who have vulvodynia. We expected to recruit 50 women who would complete more than 90% of all questionnaire items.

## 2. Method

### 2.1. Design

An online survey pilot study was conducted over a 3-month period from November 2016 to January 2017. This study was approved by the University of Illinois at Chicago institutional review board.

### 2.2. Sample

A convenience sample of women with self-identified diagnosis of GV or PVD meeting the following criteria were eligible to participate: (1) between 18 and 45 years of age; (2) not pregnant; (3) not in menopause; and (4) able to read English. To deter women without vulvodynia from participating, interested participants were asked the following bogus screening question<sup>21</sup>: "What happens when your vulvodynia flares up?"; possible responses included: I get a rash on my arms and legs, I get short of breath, I get bad diarrhea, all of the above, or none of the above. Eligible, potential participants were screened for exclusionary conditions: endometriosis, untreated vaginal/cervical infections, pain from pelvic inflammatory disease, vulvar skin diseases/vulvar conditions causing pain, vulvar cancer/precancer, neurological problems causing pelvic pain such as pudendal nerve entrapment or herpetic neuralgia, ovarian cysts, fibroids, painful scar tissue, pain from a previous genital injury, or pain from a cut/tear to the genitals that occurred during childbirth/an operation. Of the 121 women screened, 87 were eligible (64%). Sixty of these (50%) completed the study; 18 did not. The average age of the 60 participants was  $32.7 \pm 5.5$  years, and they self-identified as white ( $n = 50$ ), black/African American ( $n = 2$ ), Hispanic/Latino ( $n = 4$ ), or Native American/Alaska Native ( $n = 4$ ). Demographic characteristics are in **Table 1**.

### 2.3. Procedures

Potential participants found the survey link on the National Vulvodynia Association web site at NVA.org. The study purpose and procedures were explained in writing, and

**Table 1**  
Patient characteristics by vulvodynia subtype.

| Variable          | Category                       | Total (n = 60) | Generalized vulvodynia (n = 35) | Provoked vestibulodynia (n = 25) | P*    |
|-------------------|--------------------------------|----------------|---------------------------------|----------------------------------|-------|
|                   |                                | Mean (SD)      | Mean (SD)                       | Mean (SD)                        |       |
| Age               |                                | 32.7 (5.5)     | 34.3 (4.6)                      | 30.4 (5.9)                       | 0.007 |
| Marital status    | Single                         | 7 (12%)        | 1 (3%)                          | 6 (24%)                          | 0.012 |
|                   | Married/partnered              | 53 (88%)       | 34 (97%)                        | 19 (76%)                         |       |
| Race              | White                          | 50 (83%)       | 28 (80%)                        | 22 (88%)                         | 0.101 |
|                   | Black/African American         | 2 (3%)         | 0 (0%)                          | 2 (8%)                           |       |
|                   | Native American/Alaska Native  | 4 (7%)         | 4 (11%)                         | 0 (0%)                           |       |
|                   | Hispanic                       | 4 (7%)         | 3 (9%)                          | 1 (4%)                           |       |
| Income            | <40k                           | 16 (27%)       | 10 (29%)                        | 6 (24%)                          | 0.249 |
|                   | 40–50k                         | 20 (33%)       | 14 (40%)                        | 6 (24%)                          |       |
|                   | 50k+                           | 24 (40%)       | 11 (31%)                        | 13 (52%)                         |       |
| Education         | <HS, HS, and vocational school | 18 (30%)       | 10 (29%)                        | 8 (32%)                          | 0.079 |
|                   | Associates/some college        | 19 (32%)       | 15 (43%)                        | 4 (16%)                          |       |
|                   | Bachelor's degree              | 13 (22%)       | 7 (20%)                         | 6 (24%)                          |       |
|                   | Graduate or professional       | 10 (17%)       | 3 (9%)                          | 7 (28%)                          |       |
| Employment status | Unemployed                     | 22 (37%)       | 16 (46%)                        | 6 (24%)                          | 0.024 |
|                   | Employed (part or full time)   | 31 (52%)       | 18 (51%)                        | 13 (52%)                         |       |
|                   | Student                        | 7 (12%)        | 1 (3%)                          | 6 (24%)                          |       |

\*Results from  $\chi^2$  or Fisher exact test where applicable. HS, high school.

eligibility questions were completed. After screening for eligibility, online written informed consent was obtained. Participants who completed the study received a code to access a \$30 gift card from an online retailer.

## 2.4. Instruments

Instruments used to measure the sensory pain experience of study participants were from the pain assessment and medication modules from *PAINReportIt* (Nursing Consultant LLC, Seattle, WA).<sup>18,41,43</sup> *PAINReportIt* is a computerized version of the 1970 MPQ,<sup>26</sup> which is a multidimensional measure of pain intensity, location, quality, and pattern. The equivalence of the paper MPQ and *PAINReportIt* has been demonstrated.<sup>18</sup> It has been validated in many pain patient groups including those with vulvodynia.<sup>8,25,44,45,48</sup> The survey took approximately 20 minutes to complete.

In *PAINReportIt*, participants mark the locations of their pain on a body outline; the number of pain sites is considered a location measure and is used to calculate the multidimensionality of a patient's pain. We modified the coding of pain locations for the vulvodynia population. Two expert women's health practitioners (urogynecologist and certified nurse midwife) determined the specific pain sites relevant to vulvodynia pain using the body outline image, establishing content validity for the location index.<sup>26</sup> A maximum of 14 pain sites were identified. The interrater agreement rate across all body sites between separate coders ranged from 67% to 100%, and 12 of the body site kappa statistics showed moderate (0.41) or better agreement (for all 14 sites, kappa ranged from 0.12 to 1.0).<sup>20</sup> Interrater reliability for the count of the number of pain sites was excellent (intraclass correlation coefficient = 0.956,  $P < 0.0001$ ). We derived the total number of vulvodynia pain sites per person based on consensus coding between the 2 raters, when disagreements were evident.

Pain intensity was assessed by asking participants to assign a number to their current pain, and their worst and least pain in the past 24 hours, using a scale of 0 (no pain) to 10 (pain as bad as it could be) as well as compared with their worst headache, toothache, and stomachache.<sup>47</sup> The mean of these items constituted the pain intensity scale, which has established acceptable concurrent ( $r = 0.80\text{--}0.89$ )<sup>28,39</sup> and construct<sup>10,19</sup> validity, and reliability and sensitivity.<sup>6,11,19,39</sup>

Participants reported their vulvodynia pain quality by selecting from among 78 pain quality descriptors, divided into 20 pain quality categories, containing words that represent a range of intensity. Endorsed descriptors were coded using 3 methods summarizing different constructs. Melzack's original method of summing the number of endorsed words was used to create the following scales: (1) sensory (PRI-S, 42 words); (2) affective (PRI-A, 14 words); (3) evaluative (PRI-E, 5 words); (4) miscellaneous (PRI-M, 17 words); and (5) a total score (PRI-T, 78 words).<sup>26</sup> Test-retest reliability for all 4 subscales (0.31–0.82)<sup>44</sup> and construct validity ( $r = 0.53\text{--}0.89$ )<sup>25</sup> have been established with high internal consistency ( $\alpha = 0.92$ ) in a PVD sample.<sup>7</sup>

The number of words chosen (NWC) shows how many of the 20 groups of pain quality categories are represented, 1 word is chosen from each group (1–20), which enables understanding of the quality of the vulvodynia pain without intensity being a factor. For the pain quality descriptors, test-retest reliability (0.62–0.7),<sup>26,44</sup> construct validity ( $r = 0.89$ ),<sup>25,26</sup> and stability (70.3%)<sup>26</sup> have been

demonstrated. There is substantial documentation that neuropathic and nociceptive pain may be differentiated using the pain quality descriptors from the MPQ.<sup>3,5,9,23,24,26,27,31,32,38,42,45</sup> Others have demonstrated 81% sensitivity to neuropathic and 59% sensitivity to nociceptive pain with the MPQ.<sup>44</sup> Measures were scored by counting the number of neuropathic (0–28) and nociceptive words (0–26) chosen by each participant.<sup>12,34</sup>

The temporal pain pattern represents how pain changes over time and helps determine the optimal timing for the administration of pain medications and therapies. Temporal pain pattern scores were calculated by having participants select from 3 pain patterns each comprised of 3 descriptors: continuous (continuous, steady, or constant); intermittent (rhythmic, periodic, or intermittent); and transient (brief, momentary, or transient).<sup>45,46</sup> Each pain pattern was assigned a numeric value: 3 for continuous, 2 for intermittent, and 1 for transient. We calculated a total pain pattern score by summing the values of the 3 pain patterns. A total pain pattern score ranging from 0 (no pain pattern descriptors selected) to 6 (at least 1 descriptor selected for each pain pattern) was derived. Reliability and validity of the pain patterns have been established.<sup>29</sup>

The Composite Pain Index (CPI) was developed to denote the multidimensionality of participants' pain using a single score, ranging from 0 to 100. It is calculated by converting the number of pain sites, pain intensity (current, least, and worst), PRI-T, and pain pattern scores to proportional scores and then averaging them.<sup>46</sup> The CPI has been shown to have adequate internal consistency for the 4 pain measures (Cronbach's  $\alpha = 0.71$  for baseline data and 0.69 at posttest). Test-retest reliability over 3 to 4 weeks was 0.52 in a sample of outpatients with cancer.<sup>46</sup>

Within the *PAINReportIt* medication module, participants chose from lists of analgesic medications used to reduce pain. Analgesic categories were: nonopioid (eg, nonsteroidal anti-inflammatories, acetaminophen, and aspirin); adjuvants (eg, antidepressants and membrane stabilizers); and opioids. The number of medications used in each category was summed. Participants provided demographic information including age, race, and education.

## 2.5. Statistical analysis

Data were exported from the *PAINReportIt* structured query language database into Microsoft Excel and imported into SAS 9.4 for statistical analyses. Descriptive statistics (means, variability measures, frequencies, and percentages) and inferential tests (the independent  $t$  test,  $\chi^2$  test, Fisher exact test, and Pearson correlation coefficients) were used to examine the relationships between variables and the vulvodynia subtypes (GV or PVD). We did not undertake multivariable analyses controlling for confounding because this was a feasibility pilot study with a small sample size. Statistical significance was set at an  $\alpha$  level  $P < 0.05$ .

## 3. Results

### 3.1. Feasibility of recruitment

Of the 121 women screened, 34 did not meet eligibility criteria: 11 skipped all screening questions, 18 had 1 or more exclusionary criteria, and 5 failed the bogus screening question. Of the 87 women deemed eligible (64%), 60

completed the study (77%), and 27 did not start the survey (23%), 9 of whom did not consent. Thus, we exceeded our goal of 50 completed surveys.

Although we attempted to prevent women without vulvodynia from participating by having them respond to the bogus screening question, we acknowledge that it was still possible to guess correctly and be admitted to the study. Another limitation is that the same woman may have entered the study more than once using different email addresses.

### 3.2. Completion of study measures and missing data

All questionnaires were completed by the 60 participants. Four women (7%) did not mark their pain locations on the body outline, and thus the CPI could not be calculated on those 4 participants. One woman did not report current, least, and worst pain in the past 24 hours, or average pain

intensity (API). All other study measures were completed in their entirety. Overall, there was less than 1% missing data.

### 3.3. Univariate results

#### 3.3.1. Vulvodynia pain location

Women reported pain sites on a full body outline without specific genitalia locations. This lack of specificity prevented us from differentiating vulvodynia pain location by the subtype on the body outline. The areas we coded and the proportion who endorsed them were: women ( $n = 50$ , 89%) who drew a mark where they approximated the vulva to be, then upper thighs ( $n = 35$ , 63%), coccyx ( $n = 35$ , 63%), pelvis ( $n = 30$ , 54%), sacral iliac joint ( $n = 30$ , 54%), and sacrum ( $n = 27$ , 48%). Only 4 women marked nonvulvodynia sites (2%) that included the head and wrist ( $n = 1$ ), neck, shoulders, upper back ( $n = 1$ ), and mid back ( $n = 2$ ).

**Table 2**

**Descriptive statistics for the pain measures.**

| Variable                                                        | Category                                      | Total (n = 60) |      | Generalized (n = 35) |      | Provoked (n = 25) |      | P      |
|-----------------------------------------------------------------|-----------------------------------------------|----------------|------|----------------------|------|-------------------|------|--------|
|                                                                 |                                               | Mean           | SD   | Mean                 | SD   | Mean              | SD   |        |
| Average # of pain sites*                                        |                                               | 2.4            | 1.3  | 2.5                  | 1.4  | 2.2               | 1.0  | 0.3179 |
| Pain intensity (0–10 possible)†                                 | Current pain                                  | 7.4            | 3.2  | 8.7                  | 1.4  | 5.5               | 4.0  | 0.0008 |
|                                                                 | Worst pain in last 24 h                       | 7.3            | 2.8  | 8.1                  | 1.8  | 6.1               | 3.6  | 0.0163 |
|                                                                 | Least pain in last 24 h                       | 3.4            | 2.3  | 4.4                  | 1.8  | 2.0               | 2.1  | <.0001 |
|                                                                 | Average Pain Intensity (API)                  | 6.1            | 2.4  | 7.1                  | 1.2  | 4.6               | 2.9  | 0.0003 |
|                                                                 | Worst ever toothache                          | 4.7            | 1.6  | 4.9                  | 1.5  | 4.5               | 1.7  | 0.3303 |
|                                                                 | Worst ever headache                           | 5.2            | 2.0  | 5.3                  | 1.9  | 5.2               | 2.1  | 0.9277 |
|                                                                 | Worst ever stomachache                        | 4.9            | 2.2  | 4.4                  | 2.2  | 5.6               | 2.0  | 0.0368 |
| Pain goal (0–10 possible)                                       | Optimal goal for pain level                   | 3.3            | 2.5  | 4.1                  | 2.3  | 2.2               | 2.5  | 0.0049 |
|                                                                 | Tolerable pain level                          | 4.0            | 1.8  | 4.5                  | 1.4  | 3.3               | 2.1  | 0.0157 |
| Pain Rating Index (PRI)                                         | PRI-S: sensory (0–42 possible)                | 19.4           | 8.1  | 19.7                 | 7.1  | 18.9              | 9.5  | 0.7087 |
|                                                                 | PRI-A: affective (0–14 possible)              | 6.2            | 3.5  | 7.1                  | 3.1  | 4.9               | 3.7  | 0.0154 |
|                                                                 | PRI-E: evaluative (0–5 possible)              | 3.2            | 1.9  | 3.3                  | 1.9  | 3.1               | 1.8  | 0.7238 |
|                                                                 | PRI-M: miscellaneous (0–17 possible)          | 8.9            | 4.9  | 9.4                  | 4.8  | 8.1               | 5.0  | 0.3300 |
|                                                                 | PRI-T: total (0–78 possible)                  | 37.6           | 15.5 | 39.4                 | 14.0 | 35.0              | 17.4 | 0.2791 |
| Pain Words                                                      | # of words chosen (0–20 possible)             | 11.2           | 3.7  | 11.6                 | 3.0  | 10.5              | 4.5  | 0.3028 |
|                                                                 | # of neuropathic words (0–26 possible)        | 8.1            | 4.2  | 8.3                  | 3.6  | 7.7               | 5.0  | 0.6146 |
|                                                                 | # of nociceptive words (0–28 possible)        | 7.2            | 4.2  | 6.9                  | 4.0  | 7.5               | 4.4  | 0.6096 |
| CPI (0–100)*                                                    | Composite Pain Index                          | 50.8           | 16.8 | 56.0                 | 12.6 | 42.7              | 19.6 | 0.0080 |
| Variable                                                        | Category                                      | Total (n = 60) |      | Generalized (n = 35) |      | Provoked (n = 25) |      | P      |
|                                                                 |                                               | n (%)‡         |      | n (%)‡               |      | n (%)‡            |      |        |
| Average Pain Intensity (API)†                                   | No Pain (API = 0)                             | 2 (3%)         |      | 0 (0%)               |      | 2 (8%)            |      | 0.0002 |
|                                                                 | Mild Pain (API >0 and ≤3)                     | 10 (17%)       |      | 1 (3%)               |      | 9 (38%)           |      |        |
|                                                                 | Moderate Pain (API >3 and ≤6)                 | 5 (8%)         |      | 3 (9%)               |      | 2 (8%)            |      |        |
|                                                                 | Severe Pain (API > 6)                         | 42 (70%)       |      | 31 (89%)             |      | 11 (46%)          |      |        |
| Pain Expectation                                                | Worse than expected (0)                       | 32 (53%)       |      | 24 (69%)             |      | 8 (32%)           |      | 0.008  |
|                                                                 | Same as expected (2)                          | 24 (40%)       |      | 9 (26%)              |      | 15 (60%)          |      |        |
|                                                                 | Not bad as expected (1)                       | 3 (5%)         |      | 2 (6%)               |      | 1 (4%)            |      |        |
|                                                                 | No answer                                     | 1 (2%)         |      | 0 (0%)               |      | 1 (4%)            |      |        |
| No. of hours in last 24 that pain was less than tolerable level | 0–6 h                                         | 8 (13%)        |      | 2 (6%)               |      | 6 (24%)           |      | 0.0004 |
|                                                                 | 7–12 h                                        | 20 (33%)       |      | 17 (49%)             |      | 3 (12%)           |      |        |
|                                                                 | 13–18 h                                       | 23 (38%)       |      | 15 (43%)             |      | 8 (32%)           |      |        |
|                                                                 | 19–24 h                                       | 8 (13%)        |      | 1 (3%)               |      | 7 (28%)           |      |        |
|                                                                 | No answer                                     | 1 (2%)         |      | 0 (0%)               |      | 1 (4%)            |      |        |
| Pain Pattern                                                    | Continuous                                    | 45 (75%)       |      | 32 (91%)             |      | 13 (52%)          |      | 0.0005 |
|                                                                 | Intermittent                                  | 40 (67%)       |      | 24 (69%)             |      | 16 (64%)          |      | 0.7111 |
|                                                                 | Transient                                     | 46 (78%)       |      | 30 (86%)             |      | 16 (64%)          |      | 0.0499 |
|                                                                 | Total pattern score (0–6 possible), mean (SD) | 4.4 (1.9)      |      | 5.0 (1.5)            |      | 3.5 (2.1)         |      | 0.0021 |

\* Total  $n = 56$  due to 4 missing data for average number of pain sites and API due to blank body images.

† Total  $n = 59$  due to 1 missing data for current pain, worst and least pain in last 24 hours, and API.

‡ Column percentages shown, results from  $\chi^2$  or Fishers Exact test where applicable. Due to rounding column percentages may not add up to 100%.

### 3.3.2. Intensity

Pain scores for the total sample and the 2 vulvodynia subtypes are in **Table 2**. Among women with GV, none had an API score of 0. Mild pain (API >0 and ≤3/10) was reported by 1 woman (3%), and moderate pain (API >3 and ≤6/10) was reported by 3 women (9%). Severe pain (API >6 and ≤10/10) was reported by 31 women (89%). The MPQ includes a single item aimed at measuring a person's satisfaction in living with their level of chronic pain.<sup>26</sup> The majority (54%) of women were not satisfied with their level of pain, 11 women (31%) were unsure whether they were satisfied or not satisfied, and 5 women (14%) were satisfied with their level of pain.

Among those women with PVD, 2 had an API of 0 (8%). Nine women (38%) reported mild pain (API >0 and ≤3/10). Two women (8%) reported moderate pain (API >3 and ≤6/10). Eleven women (46%) reported severe pain (API >6 and ≤10/10). Nine women (38%) were not satisfied with their level of pain, thirteen women (54%) were unsure whether they were satisfied or not satisfied, and 2 women (8%) were satisfied with their level of pain.

### 3.3.3. Quality

**Table 2** also shows descriptive pain quality scores for the total sample and the 2 vulvodynia subtypes. Women with GV had PRI-T scores ranging from 7 to 64 (mean 39.4 ± 14.0). The mean

**Table 3**

**Frequency of selected McGill pain quality descriptors chosen by ≥40% of women by the vulvodynia subtype.**

| Descriptors  | Total<br>(n = 60) |    | Generalized<br>(n = 35) |    | Provoked<br>(n = 25) |    |
|--------------|-------------------|----|-------------------------|----|----------------------|----|
|              | n                 | %  | n                       | %  | n                    | %  |
| Burning*     | 52                | 87 | 34                      | 97 | 18                   | 72 |
| Itchy*       | 43                | 72 | 28                      | 80 | 15                   | 60 |
| Hot*         | 41                | 68 | 29                      | 83 | 12                   | 48 |
| Stabbing*    | 41                | 68 | 25                      | 71 | 16                   | 64 |
| Aching*      | 39                | 65 | 24                      | 69 | 15                   | 60 |
| Tight*       | 35                | 58 | 21                      | 60 | 14                   | 56 |
| Stinging*    | 34                | 57 | 19                      | 54 | 15                   | 60 |
| Tingling*    | 30                | 50 | 18                      | 51 | 12                   | 48 |
| Pricking*    | 25                | 42 | 14                      | 40 | 11                   | 44 |
| Heavy†       | 36                | 60 | 25                      | 71 | 11                   | 44 |
| Pressing†    | 36                | 60 | 24                      | 69 | 12                   | 48 |
| Crushing†    | 34                | 57 | 24                      | 69 | 10                   | 40 |
| Sharp†       | 34                | 57 | 19                      | 54 | 15                   | 60 |
| Hurting†     | 33                | 55 | 20                      | 57 | 13                   | 52 |
| Squeezing†   | 31                | 52 | 18                      | 51 | 13                   | 52 |
| Tearing†     | 28                | 47 | 17                      | 49 | 11                   | 44 |
| Annoying‡    | 38                | 63 | 22                      | 63 | 16                   | 64 |
| Dreadful‡    | 37                | 62 | 24                      | 69 | 13                   | 52 |
| Killing‡     | 36                | 60 | 26                      | 74 | 10                   | 40 |
| Terrifying‡  | 29                | 48 | 21                      | 60 | 8                    | 32 |
| Vicious‡     | 29                | 48 | 20                      | 57 | 9                    | 36 |
| Troublesome‡ | 27                | 45 | 16                      | 46 | 11                   | 44 |
| Torturing‡   | 27                | 45 | 18                      | 51 | 9                    | 36 |
| Unbearable‡  | 26                | 43 | 17                      | 49 | 9                    | 36 |

\* Neuropathic words.

† Nociceptive words.

‡ Other words (affective and evaluative).

NWC was 11.6 ± 3.0 with 6.9 ± 4.0 of these being neuropathic pain quality descriptors. Women with PVD had PRI-T scores that ranged from 0 to 58 (mean 35.0 ± 17.4). The mean NWC was 11.2 ± 3.7; they selected 7.2 ± 4.2 neuropathic pain quality descriptors (**Table 2**). The frequency of sensory (nociceptive or neuropathic), affective, and evaluative pain quality descriptors chosen by at least 40% of women by the vulvodynia subtype for the total sample is in **Table 3**; Supplemental Digital Content 1, Table (available at <http://links.lww.com/PR9/A39>) shows all pain quality descriptors chosen by the total sample (n = 60).

### 3.3.4. Temporal pain patterns

Pain pattern scores for the total sample and the 2 vulvodynia subtypes are in **Table 2**. A large majority of 35 women with GV (91%) reported their pain pattern as continuous and selected the pain pattern descriptors continuous, steady, or constant. Thirty women (86%) reported their pain pattern as rhythmic and selected the pain pattern descriptors rhythmic, periodic, or intermittent. Twenty-four women (69%) reported their pain pattern as transient and selected the pain pattern descriptors brief, momentary, or transient. Their total mean pain pattern score was 5.0 ± 1.5. Thirteen women (52%) with PVD reported their pain pattern as continuous and selected the pain pattern descriptors continuous, steady, or constant. Sixteen women (64%) reported their pain pattern as rhythmic and selected the pain pattern descriptors rhythmic, periodic, or intermittent. Sixteen women (64%) reported their pain pattern as transient and selected the pain pattern descriptors brief, momentary, or transient. Their total mean pain pattern score was 3.5 ± 2.1 (**Table 2**).

### 3.3.5. Composite Pain Index

Mean CPI scores for the total sample and 2 vulvodynia subtypes are in **Table 2**. Scores for women with GV and PVD were significantly different. Women with GV had a CPI score range between 14.0 and 76.9 with a mean of 56.0 ± 12.6. Women with PVD had a CPI score range between 5.5 and 66.0 with a mean CPI score of 42.7 ± 19.6.

### 3.3.6. Analgesics

For the total sample, 2 women (3.3%) did not report their medication use. For nonopioid analgesics in the total sample, women reported using a range of 0 to 8 medications (mean = 2.5 ± 1.9). Thirty-three women with GV (97%) reported using a range of 0 to 8 (mean 2.8 ± 1.9) nonopioid analgesics, and 17 women with PVD (71%) reported using a range between 0 and 6 (mean 2.0 ± 2.0) nonopioid medications.

For adjuvant analgesics in the total sample, women reported using a range of 0 to 5 (mean 1.8 ± 1.2) medications. Twenty-eight women with GV (82%) reported using a range of 0 to 5 (mean 1.9 ± 1.4) adjuvant analgesics, and 21 women with PVD (88%) reported using a range of 0 to 4 (mean 2 ± 1.1) adjuvant analgesics.

For opioid analgesics in the total sample, women reported using a range of 0 to 4 (mean 1.1 ± 1.1) medications. Twenty-seven women with GV (80%) reported using a range of 0 to 3 (mean 1.4 ± 1.0) opioid analgesics, and 10 women with PVD (42%) reported using a range of 0 to 4 (mean 0.8 ± 1.2) opioid analgesics.

## 3.4. Bivariate results

Women with GV compared to women with PVD were more likely to have pelvic pain sites (71% vs 36%;  $\chi^2(1, 56) = 6.39, P = 0.0115$ ) and

upper thigh pain sites (82% vs 45%;  $\chi^2(1, 56) = 8.3, P = 0.0039$ ). The correlation between API and the number of pain sites was moderate and highly significant (Pearson's  $r = 0.41, P < 0.0016$ ); therefore, as the number of pain sites increased, the API increased.

Correlations between the sensory pain variables are in **Table 4**. There were multiple strong positive and significant correlations among the sensory pain variables. The PRI-S and PRI-A positively correlate ( $P < 0.001$ ). The PRI-S, PRI-A, and PRI-T also positively correlate with the NWC ( $P < 0.001$ ) and for the number of words, associated with neuropathic and nociceptive pain ( $P < 0.001$ ).

The mean current pain score was significantly higher for women with GV than for women with PVD ( $t_{27} = 3.8, P = 0.0008$ ). The mean least pain score was significantly higher for women with GV than for women with PVD ( $t_{57} = 4.6, P < 0.0001$ ). The mean worst pain score was significantly higher for women with GV than for women with PVD ( $t_{31} = 2.5, P = 0.0163$ ). Although women with both subtypes of vulvodynia reported significantly different vulvodynia pain intensity, reported pain intensities for worst toothache ( $t_{57} = 0.98, P = 0.33$ ) and worst headache ( $t_{57} = 0.09, P = 0.92$ ) did not differ. However, their pain intensities did differ significantly for worst stomachache ( $t_{57} = -2.1, P = 0.0368$ ). The mean pain pattern temporal score was significantly higher for women with GV than for women with PVD ( $t_{58} = 3.2, P = 0.002$ ). Women with GV had significantly higher constant, continuous, or steady pain ( $\chi^2(1, 60) = 12.09, P = 0.0005$ ) as well as momentary, transient, or brief pain ( $\chi^2(1, 60) = 3.84, P = 0.05$ ) than for women with PVD, but did not differ significantly in their reports of intermittent, periodic, or rhythmic pain ( $\chi^2(1, 60) = 0.13, P = 0.71$ ).

#### 4. Discussion

This pilot project was designed to obtain recruitment feasibility, participants completing all measures, missing data, and parameter

estimates for variables of interest. It provides initial subtype comparisons of pain intensity, location, quality, and pattern. The women with GV and PVD were experiencing moderate to severe current and worst pain intensities. It is notable that the mean pain scores did not appear to be a function of response bias because mean common pain intensities for worst toothache and worst headache did not differ by the vulvodynia subtype; pain intensity for worst stomachache did differ, but this could be a spurious finding and needs to be assessed in a larger sample.

An important limitation of our study is that data were not collected on the date of the participant's last menstrual period nor did we inquire whether their vulvodynia pain was cyclic relative to the menstrual cycle. These variables may have affected reported pain parameters and should be included in future studies on vulvodynia. Also, although a diagnosis of endometriosis was an exclusionary criterion, there is an interval of 7 to 8 years between symptom onset and diagnosis.<sup>13</sup> Therefore, some study participants may have had undiagnosed endometriosis, which may have potentiated their pain in addition to vulvodynia.

We identified an importation limitation of the body outline pain location tool (ie, the lack of genitalia to more specifically identify the location of genital pain). As a result, we are developing an additional module for PAINReportIt that will feature a drawing of the external female genitalia. This more detailed anatomical drawing will allow women with vulvodynia to select all areas of genital pain, allowing for further differentiation between the symptoms of GV and PVD. Regardless of the subtype, women reported severe pain in the vulva in addition to several other body sites. The higher the API, the more pain sites women with both types of vulvodynia reported. Although women with GV reported more sites than women with PVD, the difference was not significant. In the future, a difference may be found if women are able to draw all pain sites on a drawing of the external

**Table 4**  
Correlations among sensory pain variables in women with vulvodynia.

| Variables               | 1      | 2      | 3     | 4      | 5     | 6      | 7      | 8     | 9     | 10    | 11    | 12    | 13    | 14    | 15    |
|-------------------------|--------|--------|-------|--------|-------|--------|--------|-------|-------|-------|-------|-------|-------|-------|-------|
| 1. Pain now             |        |        |       |        |       |        |        |       |       |       |       |       |       |       |       |
| 2. Pain least           | 0.64*  |        |       |        |       |        |        |       |       |       |       |       |       |       |       |
| 3. Pain worst           | 0.63*  | 0.58*  |       |        |       |        |        |       |       |       |       |       |       |       |       |
| 4. API                  | 0.90*  | 0.83*  | 0.86* |        |       |        |        |       |       |       |       |       |       |       |       |
| 5. Worst toothache      | 0.28†  | 0.29†  | 0.47* | 0.40‡  |       |        |        |       |       |       |       |       |       |       |       |
| 6. Worst headache       | -0.25  | -0.03  | -0.05 | -0.14  | 0.56* |        |        |       |       |       |       |       |       |       |       |
| 7. Worst stomachache    | -0.28† | -0.31† | -0.12 | -0.27† | 0.26† | 0.40‡  |        |       |       |       |       |       |       |       |       |
| 8. PRI-S§               | 0.27†  | 0.12   | 0.25  | 0.25   | 0.2   | -0.23  | 0.14   |       |       |       |       |       |       |       |       |
| 9. PRI-A                | 0.55*  | 0.42‡  | 0.38‡ | 0.53*  | 0.02  | -0.29† | -0.02  | 0.70* |       |       |       |       |       |       |       |
| 10. PRI-E¶              | 0.12   | 0.13   | 0.34‡ | 0.23   | 0.29† | 0.14   | -0.18  | 0.25  | 0.21  |       |       |       |       |       |       |
| 11. PRI-M#              | 0.43*  | 0.15   | 0.26† | 0.34‡  | 0     | -0.42* | -0.04  | 0.74* | 0.73* | 0.05  |       |       |       |       |       |
| 12. PRI-T**             | 0.42*  | 0.22   | 0.35‡ | 0.39‡  | 0.14  | -0.30† | 0.03   | 0.95* | 0.85* | 0.32† | 0.87* |       |       |       |       |
| 13. No. of words chosen | 0.41‡  | 0.29†  | 0.41‡ | 0.44*  | 0.22  | -0.23  | 0.01   | 0.88* | 0.85* | 0.47* | 0.79* | 0.92* |       |       |       |
| 14. Neuropathic words   | 0.46*  | 0.25   | 0.49* | 0.48*  | 0.26† | -0.28† | -0.03  | 0.91* | 0.71* | 0.45* | 0.83* | 0.92* | 0.82* |       |       |
| 15. Nociceptive words   | 0.23   | 0.14   | 0.25  | 0.24   | 0.2   | -0.15  | 0.22   | 0.92* | 0.63* | 0.36‡ | 0.78* | 0.88* | 0.80* | 0.73* |       |
| 16. Pain pattern        | 0.66*  | 0.46*  | 0.58* | 0.67*  | 0.08  | -0.39‡ | -0.29† | 0.58* | 0.63* | 0.37‡ | 0.55* | 0.64* | 0.63* | 0.68* | 0.42* |

\*  $P < 0.001$ .

†  $P < 0.05$ .

‡  $P < 0.01$ .

§ Pain Rating Index-sensory.

|| Pain Rating Index-affective.

¶ Pain Rating Index-evaluative.

# Pain Rating Index-miscellaneous.

\*\* Pain Rating Index-total.

API, average pain intensity.

genitalia. Upper thigh and pelvic pain was reported by more than 50% of women with GV vs PVD.

The MPQ pain quality descriptors have been used to determine the presence of neuropathic and nociceptive pain in diabetic peripheral neuropathy, lung cancer, sickle cell disease, and other chronic pain conditions.<sup>3,24,26,27,35,38,40,42,45</sup> Dargie et al.<sup>7</sup> recently performed a preliminary investigation of 4 measures used to assess neuropathic pain in women with PVD, the Leeds Assessment of Neuropathic Pain and Symptoms (S-LANSS), the Neuropathic Pain Symptoms Inventory, and the Pain Quality Assessment Scale. They concluded that these 4 instruments produced inconsistent findings and that more exploration into pain mechanisms of PVD were needed.<sup>7</sup> However, Dargie et al. did not explore the MPQ's 78 pain quality descriptors for their ability to discern between neuropathic and nociceptive pain. Our study is not only the first to examine the use of the MPQ pain quality descriptors for determining the presence of neuropathic and nociceptive pain in women with vulvodynia but also in GV as well as PVD.

In this small sample of women with GV and PVD, we successfully used the MPQ pain quality descriptors to assess for the presence of neuropathic and nociceptive pain and summed the number of nociceptive and neuropathic words chosen to create subscale scores.<sup>3,12,24,40,42,45</sup> We found that both women with GV and those with PVD selected neuropathic and nociceptive pain quality descriptors, which may suggest the presence of both types of pain.

Study limitations are that our sample size is small and, although appropriate for a pilot study, did not allow us to control for potential confounders when comparing pain results between the 2 vulvodynia subtypes. Also, as a convenience sample, women were self-selected for enrollment and so it is difficult to generalize their experiences to the entire vulvodynia population. Similarly, a larger number of women with GV than with PVD participated, which may be due to the fact that they had severe and constant pain and were more motivated to participate in a survey. In other words, our sample does not match the proportions expected for the diagnostic subtypes (GV, 20% and PVD, 80%).<sup>2</sup> Also, the sample included few Hispanic, African-American, or other minority women, which limits the transferability of our findings.

We successfully recruited 60 women who self-reported a diagnosis of vulvodynia and completed the study, which is greater than our goal of 50. However, it is possible that women who deceptively self-reported a diagnosis of vulvodynia answered the bogus screening question correctly and entered the study, or women with or without vulvodynia may have participated multiple times to receive more than 1 online gift card, as we did not check computer IP addresses.

## 5. Conclusion

Our findings of the sensory pain characteristics of women with vulvodynia are novel. They add to the growing body of evidence, suggesting that women with vulvodynia are also experiencing neuropathic pain. We also found that it was feasible to perform an online survey; however, we cannot assess if the range of pain experiences was represented or if only those with severe pain were represented. This pilot study needs to be replicated with a larger nationwide sample of women with vulvodynia in an attempt to ensure a representative sample. Further exploration of the use of the MPQ pain quality descriptors in women with GV and PVD is needed to provide a more in-depth interpretation of the subscales and how these might relate to determining optimal drug treatment regimens for women with vulvodynia. Also, future

randomized controlled trials to determine efficacy of adjuvant drugs and nonaddictive therapies such as acupuncture<sup>36</sup> and physical therapy<sup>17</sup> should be performed because despite women with GV and PVD reporting using multiple pain medications including opioids, their pain is not controlled.

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## Appendix A. Supplemental digital content

Supplemental digital content associated with this article can be found online at <http://links.lww.com/PR9/A39>.

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