



## Article

# Centering Women of Color: Chronic Vulvovaginal Pain (CVVP) Communication

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**Abstract:** Background: Black and white women describe their chronic vulvar pain (CVVP) symptoms differently, indicating a patient–provider communication deficit. This may contribute to the diagnostic delay commonly reported by patients with CVVP and/or pelvic pain. Methods: A pilot study demonstrated CVVP terminology differences between women of color and white women. The present study ( $N = 488$ ) includes a sample of predominantly cisgender women who identified their race/ethnicity as Black, Hispanic/Latinx, Native American/American Indian, and/or Asian. Participants reported how they describe their CVVP, their healthcare experiences, and characteristics of their diagnostic journey. Results: Descriptions of CVVP were not uniform. Instead, there was great variability in how women described their pain across racial/ethnic identities and pain contexts (e.g., sexual activity, menstrual product use, and pelvic exam). Some pain experiences and descriptors were associated with healthcare outcomes related to diagnostic delay. Conclusions: This study sheds light on the pain communication experiences of women of color with CVVP, an understudied population within the broader CVVP literature. By resisting white and non-white comparative methodologies, this study demonstrates the applicability of intersectionality principles to the study of CVVP and contributes to the existing literature regarding pain communication, race, and ethnicity.

**Keywords:** chronic vulvovaginal pain; pain communication; race; ethnicity; women's health; intersectionality



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## 1. Introduction

Chronic vulvovaginal pain (CVVP) refers to a group of conditions characterized by persistent pain that often defies explanation through typical mechanisms like physical trauma (Arnold et al. 2007; Lahaie et al. 2010) and that is distinct from the pain pathways of conditions like menopause. While prevalence estimates for some types of CVVP (e.g., vaginismus) are difficult to establish due to variations in definitions and study methodologies (McEvoy et al. 2021), research suggests that at least 7–8% of American women have or will develop chronic vulvar pain, a common type of CVVP, by age 40 (Harlow et al. 2014). This pain manifests during routine activities involving sitting for long periods, during sexual activities with and without vaginal penetration, while using menstrual products (e.g., tampons, menstrual cups), and during gynecological pelvic exams. CVVP can greatly reduce quality of life and can act as a substantial barrier for preventative healthcare, like routine pelvic exams for cancer screening (Macey et al. 2015).

Despite the prevalence of CVVP, people often report negative healthcare experiences and diagnostic delay when seeking treatment. For example, women with vulvodynia report an average time to diagnosis of 24 months from their initial visit, and consultations with up to 15 different physicians before starting any treatment (Ogden and Ward 1995; Buchan et al. 2007; Harlow et al. 2014). Many women do not seek treatment at all (Harlow and Stewart 2003), as they must also confront social barriers of treatment-seeking due to norms

surrounding gynecological pain (Kissling 1996; Rubinsky et al. 2018). Hintz and Scott (2020) also note the negative impact of persistent childhood messaging around both menstrual pain normalization and silencing that pain on women's ability to later communicate their symptoms, thus leading to diagnostic delay.

### 1.1. Bias in Pain Treatment

Diagnostic delay is a multifaceted issue for people managing CVVP, and attention to race and ethnicity as predictors of lower quality healthcare and poorer health outcomes provides additional insights into barriers faced by those seeking treatment for these chronic pain conditions (Carter et al. 2017). Of particular relevance to CVVP, studies on healthcare for pain show that medical professionals may evaluate and consequently treat white patients' pain differently than they do for Black patients (Hoffman et al. 2016). For example, studies conducted in hospital emergency departments have shown that both Black and Latinx patients presenting with long-bone fractures are only around half as likely as white patients to be offered opioid analgesia for pain management (Singhal et al. 2016; Todd et al. 2000; Romanelli et al. 2019). Racial disparities in pain treatment have been replicated in a number of other contexts, such as abdominal or tooth pain, and even in pediatric pain conditions (Lee et al. 2016; Shah et al. 2015; Goyal et al. 2015; Rasooly et al. 2014). These biases in assessment and care are associated with holding false beliefs, such as that Black people have thicker (e.g., tougher) skin than white people—a belief that was endorsed by between 22% and 42% of a sample of 222 medical students and residents (Hoffman et al. 2016).

A patient's gender is also a critical determinant of the quality of healthcare they will receive. In the context of a typical social interaction, people believe and expect that women will be more emotionally expressive than will men (Plant et al. 2000)—even though these stereotypes are not empirically supported (Weigard et al. 2021). Likewise, in the context of experiencing pain, social scripts stereotype women as both more sensitive to pain and more likely to openly express their pain than are men (Wesolowicz et al. 2018; Wandner et al. 2014). These gendered beliefs are endorsed by healthcare providers in various disciplines and can impact pain management decisions. This stereotype may lead providers to evaluate women's pain as low or less severe; in other words, if women are expressing their pain, that expression is interpreted as insubstantial because women are thought to express any of their feelings—regardless of severity.

### 1.2. Intersectional Dimensions of Healthcare Disparities

Intersectionality refers to an analytic lens developed by legal scholar Kimberlé Crenshaw that examines the interconnectedness of dominating social, legal, political, and other structures as well the effects of these interacting structures on individual lives (Crenshaw 1989, 1991). Crenshaw's work exists within a rich genealogy of Black feminist knowledge production developed both before and after her initial theorization of intersectionality, including work dedicated specifically to the ways in which Black women experience the U.S. healthcare system (for more information, see Roberts 1996; Washington 2006; Hill Collins 2009; The Combahee River Collective 2014). Healthcare disparities among Black women and other women of color are well documented in a wide variety of healthcare contexts, including diabetes and hypertension, breast cancer, HIV/AIDS, and maternal health (Britton et al. 2018a, 2018b; Ademuyiwa et al. 2011; Danforth 2013; Messer et al. 2013; Louis et al. 2015). Rates of CVVP diagnoses and treatment are no exception. For example, in a sample of women seeking treatment for chronic vulvar pain—the most common subtype of CVVP—formal diagnoses were given to 63% of white women, 50% of Hispanic/Latinx women, and 46% of Black women (Harlow and Stewart 2003). This 15-point discrepancy in chronic vulvar pain diagnoses may in part stem from poor patient–provider communication, which is often affected by the racial identities of both parties.

Research consistently reports a positive association between racial concordance and patient–provider communication (Shen et al. 2018). Research also suggests that racial and

gender concordance holds particular importance for Black women. In the sexual healthcare context, Black women frequently express preferences for Black female doctors as a way to avoid expected bias or disrespect during the healthcare encounter (Townes et al. 2022). Importantly, language discordance as well as bias towards Spanish speakers also creates significant barriers to healthcare access (D’Anna et al. 2018; Betancourt et al. 2013). Patient–provider communication creates the foundation for the ongoing relationship, building a patient’s trust and a more accurate understanding on behalf of the provider (Benkert et al. 2006). Unfortunately, many report that their provider misunderstands their issue, promoting distrust (Sullivan 2020). When the language used (e.g., English) is the same for both parties, it seems that gender, race and ethnicity may guide the specific terminology used to describe—and thus understand—a patient’s experience with CVVP.

Communicating pain to one’s provider can be a vulnerable experience due to the subjectivity of pain and difficulties managing perceived or actual stigma in the patient–provider relationship. Relatedly, research also suggests that people select words based on the way they think their listener will receive the message (Hargie 2021; Deshields et al. 1995). This may be especially critical when seeking care for a genital or sexual problem. Black women are often met with the assumption that they are seeking care for a sexually transmitted disease, even in the context of a primary care appointment (Okoro et al. 2020; Gomez and Wapman 2017). Hypersexuality is also a commonly held stereotype of Black women, and studies have shown they are aware of the stereotype and purposefully act in ways to avoid being perceived as such (Ward et al. 2019; Jerald et al. 2017). Hispanic/Latinx women are similarly stereotyped as sexual risk-takers, and report being pressured into long-term birth control methods by biased providers (Gomez and Wapman 2017). Although little work exists documenting provider biases with Native American/American Indian or Asian American women, both groups are the subject of sexuality-based stereotypes (i.e., hypersexuality and submissive sexuality, respectively) that may impact how providers perceive these women’s needs (Merskin 2010; Le et al. 2020). Communicating CVVP symptoms may further complicate these interactions.

### 1.3. Race, Gender, and Pain Communication

Having navigated biases throughout their lifetimes, women of color may communicate their CVVP symptoms differently than white women to subvert or deviate from harmful stereotypical views. A study investigating pain communication among white and Black women with provoked vulvodynia found that descriptors differed by race: white women were more likely to use “burning” and “stinging” to describe their pain than were Black women (Brown et al. 2015). Although a seemingly trivial nuance, symptom descriptions greatly influence a provider’s diagnosis and proposed treatment (Rajabiyazdi et al. 2017; Lordon et al. 2020). “Burning” genital pain can be associated with sexually transmitted infections (Mayo Foundation for Medical Education and Research 2022); presenting in a clinic with “burning” pain may thus lead to misdiagnosis, especially in the context of racial biases. Because Black women are already assumed to be seeking care for sexually transmitted infections when they seek any form of healthcare (Okoro et al. 2020; Gomez and Wapman 2017), and are the target of hypersexual stereotypes (Ward et al. 2019; Jerald et al. 2017), these women—and other women of color who must also navigate harmful stereotypes—may avoid terminology that would further strengthen a provider’s erroneous presumptions. Racial and/or ethnic differences in symptom descriptions have the potential to greatly impact accurate and timely diagnosis, leaving many women to experience long-term chronic pain without help or resolution.

Few studies have investigated the confluence of race, gender, and pain in the study of CVVP, with particular regard to patient experiences. In fact, the majority of work investigating the journey to diagnosis and other healthcare-seeking contexts in the CVVP space feature the barriers faced by white women. While this work presents important research regarding the consistent dismissal of women’s pain (Shallcross et al. 2019; Buchan et al. 2007; Ogden and Ward 1995), critical race and Black feminist scholarship also demonstrates

that—like many spaces—healthcare is experienced differently depending on many factors, including race, gender, and ethnicity (Washington 2006; Gomez and Wapman 2017; Okoro et al. 2020). As a result, the specific experiences of women of color in the CVVP space require further investigation. In the present work, we contribute to this small but significant literature, reporting on the experiences and disparities of women of color living with CVVP. Below, we report findings from a preliminary study that informed the current study's research questions and methodology.

#### 1.4. Preliminary Data

In 2020, we conducted an IRB-approved exploratory online survey to gain more insights into CVVP experiences. We collected responses from 295 people who were experiencing vulvovaginal pain. Participants in this preliminary study were predominantly cisgender, heterosexual women in their mid-20s to mid-30s. They identified their race as white (68.8%), Native American/American Indian (10.5%), Asian (9.5%), Black (8.5%), and/or another race (3.7%); 12.9% of participants also identified their ethnicity as Hispanic/Latinx/Latina. Nearly 70% of this sample reported one or more chronic CVVP diagnoses (e.g., vulvodynia, provoked vestibulodynia, vaginismus, and dyspareunia). To capture pain communication experiences, participants indicated whether their pain in various contexts, including during sexual activity, menstrual product use, and pelvic exam/Pap smear, had a “burning”, “stinging”, “throbbing”, “aching”, and/or “stabbing” quality (terms adapted from Brown et al. 2015).

Due to the sample sizes of the various racial and ethnic groups described above, we conducted binary comparisons between white participants and participants of color to examine racial/ethnic differences in pain descriptions. Within all, participants of color were more likely to describe their pain as “throbbing” ( $r_s = 0.18\text{--}0.34$ ,  $p_s < 0.01$ ) and as “stinging” ( $r = 0.13\text{--}0.33$ ,  $p_s < 0.05$ ) than were white participants. Within only the sexual context, participants of color were less likely than white participants to describe their pain as “burning” ( $r = -0.13$ ,  $p < 0.05$ ). Finally, within the pelvic exam/Pap smear context, participants of color were less likely than white participants to describe their pain as “stabbing” ( $r = -0.21$ ,  $p < 0.001$ ). Although these were somewhat small effect sizes, these findings demonstrate the presence of differences in the communication of CVVP based on race/ethnicity. These findings were similar to those of Brown et al. (2015), who, in an earlier study on racial differences in pain communication, reported that Black women were more likely to use the term “throbbing” to describe their chronic vulvar pain, whereas white women were more likely to use the term “burning.” However, additional research investigating the specific experiences of women of color, rather than a homogenous grouping, was needed to further contextualize the binary differences observed in both this preliminary data as well as the Brown et al. study.

#### 1.5. Present Study

In the present study, we conducted an online survey to further investigate the impact of race and ethnicity on women's descriptions of their CVVP, focusing entirely on the experiences of women of color. We examined whether participants discuss their pain differently to providers versus friends and family and how this difference may affect diagnostic outcomes. Additionally, we examined racial/ethnic differences in pain descriptions and investigated the consistency of those descriptions across contexts. Gaining a racially conscious understanding of CVVP pain communication experiences is key for ensuring that millions of women continue to receive essential preventative care and treatment. Additionally, this study underscores the critical need for healthcare providers to recognize and validate diverse expressions of pain to enhance diagnostic accuracy, foster trust in patient-provider relationships, and ensure equitable health outcomes across different racial and ethnic groups.

## 2. Materials and Method

### 2.1. Method

Participants ( $N = 665$ ) were recruited via the Internet. Standardized messages were posted to public social media platforms and forums (e.g., Twitter, Instagram, and Reddit), which were shared by other social media users. Posting on widely trafficked sites rather than only sexual health-related sites addressed some sampling bias, but the survey remained vulnerable to this bias as non-social media users were not reflected in the participant pool. All research procedures were reviewed by the Indiana University Bloomington Institutional Review Board (protocol #2004121027) and approved but deemed exempt. Eligibility criteria included being 18 to 55 years old, having no experience of (peri)menopause, and identifying as a race and/or ethnicity other than white non-Hispanic/Latinx. The final criterion was included to provide a more specific focus on people of color with CVVP. After ensuring data quality via attention check items, removal of responses from duplicate IP addresses, and analysis of reCAPTCHA test results, 488 participants were included in the final sample (see Table 1 for demographics).

**Table 1.** Participant Demographics.

	Percentage (N)
Gender	
Woman	99.8% (487)
Man	0.2% (1)
Transgender	
Yes	2.7% (13)
No	97.3% (475)
Sexual Orientation	
Straight	91.6% (447)
Bisexual	6.4% (31)
Pansexual	1.0% (5)
Gay/Lesbian	1.0% (5)
Race	
Arab or Middle Eastern	0.6% (3)
Pacific Islander	3.9% (19)
East Asian	5.9% (29)
Southeast Asian	7.2% (35)
White	6.8% (33)
Native American/American Indian	5.5% (27)
Black	70.3% (343)
Another identity not listed	0.2% (1)
Ethnicity–Hispanic/Latina	
Yes	27.3% (133)
No	72.7% (355)
Relationship Status	
Single and not dating anyone	4.3% (21)
Casually dating one or more people	11.9% (58)
In a committed romantic relationship	8.8% (43)
Engaged	1.8% (9)
Married	73.0% (356)
Another status not listed	0.2% (1)
Education Level	
Less than high school diploma	4.5% (22)
High school diploma	25.6% (125)
Vocational or technical school	20.5% (100)
Some college, no degree	30.5% (149)
Associate’s degree	8.6% (42)
Bachelor’s degree	10% (49)
Graduate or professional degree	0.2% (1)



Table 1. Cont.

	Percentage (N)
Age	$M = 32.7, SD = 4.5$
Chronic Vulvovaginal Pain Diagnosis (Formal) *	
None	17.2% (84)
Vulvodynia	62.9% (307)
Provoked Vestibulodynia (including vulvar vestibulitis syndrome)	11.9% (58)
Vaginismus	7.0% (34)
Dyspareunia (including “deep” dyspareunia, levator dyspareunia)	12.9% (63)
Chronic Pelvic Pain	20.9% (102)

\* For this item, participants were asked whether they had received a formal diagnosis of the listed conditions. Given current research on mis- and underdiagnosis of CVVP, participants were only removed if they indicated they had never experienced chronic vulvovaginal pain as to not prematurely remove participants who were trying to seek treatment or who had not sought treatment yet, thus accounting for the 17.2% of participants who reported no formal diagnosis.

## 2.2. Measures

### 2.2.1. Demographics

Participants reported demographics (e.g., age, gender, race and ethnicity) and whether they had been formally diagnosed with a CVVP condition (e.g., vulvodynia, vaginismus, provoked vestibulodynia, and dyspareunia). Participants could also report whether they suspected a diagnosis of a CVVP condition but did not yet have such a diagnosis, an important caveat as the existing research literature suggests significant diagnostic delays for people seeking care for CVVP symptoms.

### 2.2.2. Pain Communication

Participants completed the McGill Pain Questionnaire Short Form (SF-MPQ; [Melzack 1987](#)) in multiple versions. In its standard form, this measure includes an extensive list of pain descriptor terms meant to help physicians ask more specific questions about pain sensations when interviewing patients. Those descriptors included throbbing, shooting, stabbing, sharp, cramping, gnawing, hot-burning, aching, heavy, tender, splitting, tiring-exhausting, sickening, fearful, and punishing-cruel. Respondents rate each descriptor with regard to how severe that form or quality of pain has been on a scale from none (1) to severe (4). For example, they report whether they are experiencing no, mild, moderate, or severe “gnawing” pain. In the current study, participants completed the SF-MPQ first as it related to their vulvovaginal pain experience over the last six months. They completed six additional versions of the SF-MPQ to assess their vulvovaginal pain experience in various contexts: sexual activity with penetration, sexual activity without penetration, tampon use, contraceptive ring use, prolonged vulvar pressure (e.g., sitting for long periods and cycling), and during Pap smear/pelvic exam. Participants also reported whether they typically describe their pain differently to medical professionals, compared to when they describe their pain to a friend or family member (yes/no).

## 3. Results

### 3.1. Communication of CVVP Pain to Different Audiences

For all analyses below, we categorized participants by both their racial and ethnic identity in order to more specifically acknowledge the underrepresented identities of people who are both Black and Hispanic/Latinx. As a result, we compared five participant groups: Hispanic/Latinx non-Black; Black Hispanic/Latinx; Black non-Hispanic/Latinx; as well as Asian and Native American/American Indian, both of which were non-Hispanic/Latinx.

Due to small sample sizes, we did not include participants who identified their race as either Arab/Middle Eastern ( $n = 3$ ) or those who identified as another race not listed ( $n = 1$ ) in the following analyses. Of those who reported talking about their CVVP with both a healthcare professional and family/friends (73% of the total sample), 33% reported describing their CVVP differently depending on the audience. This includes 50% of

Hispanic/Latinx non-Black participants; 47% of Black Hispanic/Latinx participants; 42% of Asian participants; 28% of Black non-Hispanic/Latinx participants; and 13% of Native American/American Indian participants.

We conducted chi-square analyses to determine whether participants who communicate differently with medical professionals than close others also experience differences in whether or not they have received a diagnosis (if one was pursued) and whether they needed to see multiple medical professionals before a diagnosis was attained. There were no differences in whether participants had received a diagnosis ( $\chi^2[1] = 0.000$ ,  $p = 0.99$ ), but participants who differently describe their pain were more likely to have had to visit multiple medical professionals before attaining a diagnosis ( $\chi^2[1] = 29.41$ ,  $p < 0.001$ ).

### 3.2. Pain Descriptions among Women of Color

We examined racial/ethnic differences in participants' pain descriptions and investigated the consistency of those descriptions across contexts. We focused our analysis on participants who reported "moderate" or "severe" pain for each individual descriptor they endorsed. For each of the six pain contexts—sexual activity with penetration, sexual activity without penetration, using menstrual products, inserting a contraceptive ring, undergoing a pelvic exam/Pap smear, and experiencing prolonged vulvar pressure—we observed racial and ethnic differences in descriptions of moderate-to-severe pain. No term emerged as the primary descriptor used by all identities in any context. Further, no term emerged as the primary descriptor used by any one identity across most or all contexts. Instead, results were characterized by high intra-group variance across contexts. We describe results by context below, and present frequencies by context for each race or ethnic group: see Table 2 for Black non-Hispanic/Latinx participants; Table 3 for Black Hispanic/Latinx participants; Table 4 for non-Black Hispanic/Latinx participants; Table 5 for Asian participants; and Table 6 for Native American/American Indian participants.

**Table 2.** Black, non-Hispanic/Latinx participants' reported types of pain by context.

	Pain Contexts					
	Sexual Activity with Penetration	Sexual Activity without Penetration	Using Tampons	Inserting Contraceptive Ring	Prolonged Vulvar Pressure	During Pelvic Exam/Pap Smear
<i>Descriptor terms</i>						
Throbbing	46%	30%	33%	29%	38%	36%
Shooting	30%	44%	24%	28%	30%	35%
Stabbing	43%	21%	41%	29%	37%	43%
Sharp	31%	41%	36%	23%	24%	45%
Cramping	36%	26%	40%	36%	40%	29%
Gnawing	29%	40%	35%	24%	29%	45%
Hot-burning	35%	33%	41%	29%	43%	27%
Aching	45%	35%	47%	33%	38%	24%
Heavy	45%	40%	33%	28%	39%	46%
Tender	33%	40%	33%	25%	34%	42%
Splitting	43%	33%	40%	32%	29%	30%
Tiring-exhausting	39%	36%	23%	29%	45%	37%
Sickening	31%	30%	41%	27%	35%	36%
Fearful	34%	35%	36%	35%	36%	26%
Punishing-cruel	44%	35%	18%	27%	41%	29%

**Table 3.** Black Hispanic/Latinx participants' reported types of pain by context.

	Pain Contexts					
	Sexual Activity with Penetration	Sexual Activity without Penetration	Using Tampons	Inserting Contraceptive Ring	Prolonged Vulvar Pressure	During Pelvic Exam/Pap Smear
<i>Descriptor terms</i>						
Throbbing	76%	36%	31%	61%	51%	50%
Shooting	45%	49%	51%	46%	31%	42%
Stabbing	39%	62%	37%	46%	39%	34%
Sharp	43%	36%	38%	42%	37%	58%
Cramping	32%	52%	51%	42%	31%	34%
Gnawing	49%	46%	57%	59%	29%	43%
Hot-burning	42%	41%	52%	49%	34%	40%
Aching	56%	50%	38%	48%	37%	46%
Heavy	43%	49%	51%	38%	56%	39%
Tender	62%	51%	27%	55%	40%	49%
Splitting	38%	37%	45%	31%	49%	31%
Tiring-exhausting	56%	40%	43%	36%	39%	36%
Sickening	63%	40%	59%	38%	36%	24%
Fearful	39%	64%	33%	46%	51%	30%
Punishing-cruel	53%	46%	42%	35%	33%	70%

**Table 4.** Hispanic/Latinx, non-Black participants' reported types of pain by context.

	Pain Contexts					
	Sexual Activity with Penetration	Sexual Activity without Penetration	Using Tampons	Inserting Contraceptive Ring	Prolonged Vulvar Pressure	During Pelvic Exam/Pap Smear
<i>Descriptor terms</i>						
Throbbing	42%	32%	31%	30%	26%	32%
Shooting	30%	36%	34%	36%	36%	36%
Stabbing	40%	45%	30%	54%	42%	56%
Sharp	40%	40%	36%	48%	42%	50%
Cramping	40%	42%	48%	48%	48%	38%
Gnawing	54%	40%	37%	52%	42%	36%
Hot-burning	44%	38%	40%	27%	40%	56%
Aching	44%	42%	40%	26%	30%	40%
Heavy	42%	40%	41%	48%	44%	36%
Tender	50%	36%	28%	30%	40%	44%
Splitting	38%	36%	42%	40%	38%	48%
Tiring-exhausting	40%	38%	38%	36%	42%	38%
Sickening	40%	30%	44%	54%	44%	28%
Fearful	40%	28%	30%	32%	34%	40%
Punishing-cruel	28%	38%	38%	32%	49%	30%



**Table 5.** Asian participants’ reported types of pain by context.

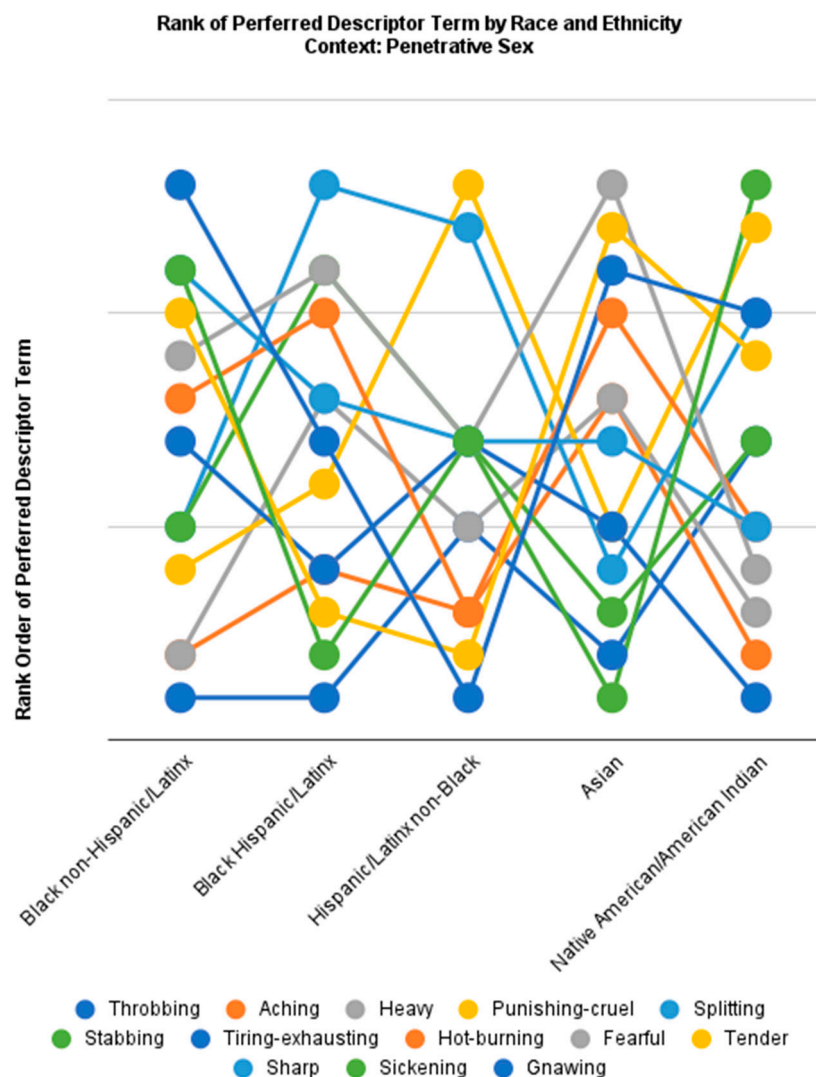
	Pain Contexts					
	Sexual Activity with Penetration	Sexual Activity without Penetration	Using Tampons	Inserting Contraceptive Ring	Prolonged Vulvar Pressure	During Pelvic Exam/Pap Smear
<i>Descriptor terms</i>						
Throbbing	72%	38%	70%	56%	56%	39%
Shooting	16%	51%	34%	37%	34%	53%
Stabbing	60%	35%	38%	35%	53%	32%
Sharp	44%	62%	37%	63%	40%	81%
Cramping	35%	32%	29%	16%	11%	36%
Gnawing	34%	10%	53%	55%	80%	56%
Hot-burning	38%	54%	35%	19%	11%	31%
Aching	41%	56%	18%	39%	40%	59%
Heavy	41%	37%	57%	56%	37%	53%
Tender	20%	16%	50%	36%	79%	15%
Splitting	59%	32%	37%	55%	13%	59%
Tiring-exhausting	57%	41%	34%	39%	53%	59%
Sickening	76%	9%	35%	17%	59%	39%
Fearful	18%	35%	37%	52%	53%	61%
Punishing-cruel	57%	14%	39%	19%	61%	28%

**Table 6.** Native American/ American Indian participants’ reported types of pain by context.

	Pain Contexts					
	Sexual Activity with Penetration	Sexual Activity without Penetration	Using Tampons	Inserting Contraceptive Ring	Prolonged Vulvar Pressure	During Pelvic Exam/Pap Smear
<i>Descriptor terms</i>						
Throbbing	48%	15%	15%	15%	30%	26%
Shooting	30%	18%	48%	30%	33%	30%
Stabbing	48%	27%	30%	30%	18%	26%
Sharp	52%	37%	26%	37%	26%	37%
Cramping	48%	30%	41%	33%	33%	37%
Gnawing	41%	22%	30%	30%	44%	30%
Hot-burning	52%	22%	30%	44%	33%	26%
Aching	67%	37%	44%	30%	22%	41%
Heavy	59%	33%	23%	58%	30%	18%
Tender	44%	15%	18%	44%	33%	26%
Splitting	41%	15%	41%	30%	11%	37%
Tiring-exhausting	78%	30%	11%	26%	18%	22%
Sickening	15%	18%	63%	33%	52%	18%
Fearful	56%	26%	26%	30%	41%	33%
Punishing-cruel	30%	22%	30%	22%	22%	30%

### 3.3. Pain during Sexual Activity Involving Penetration

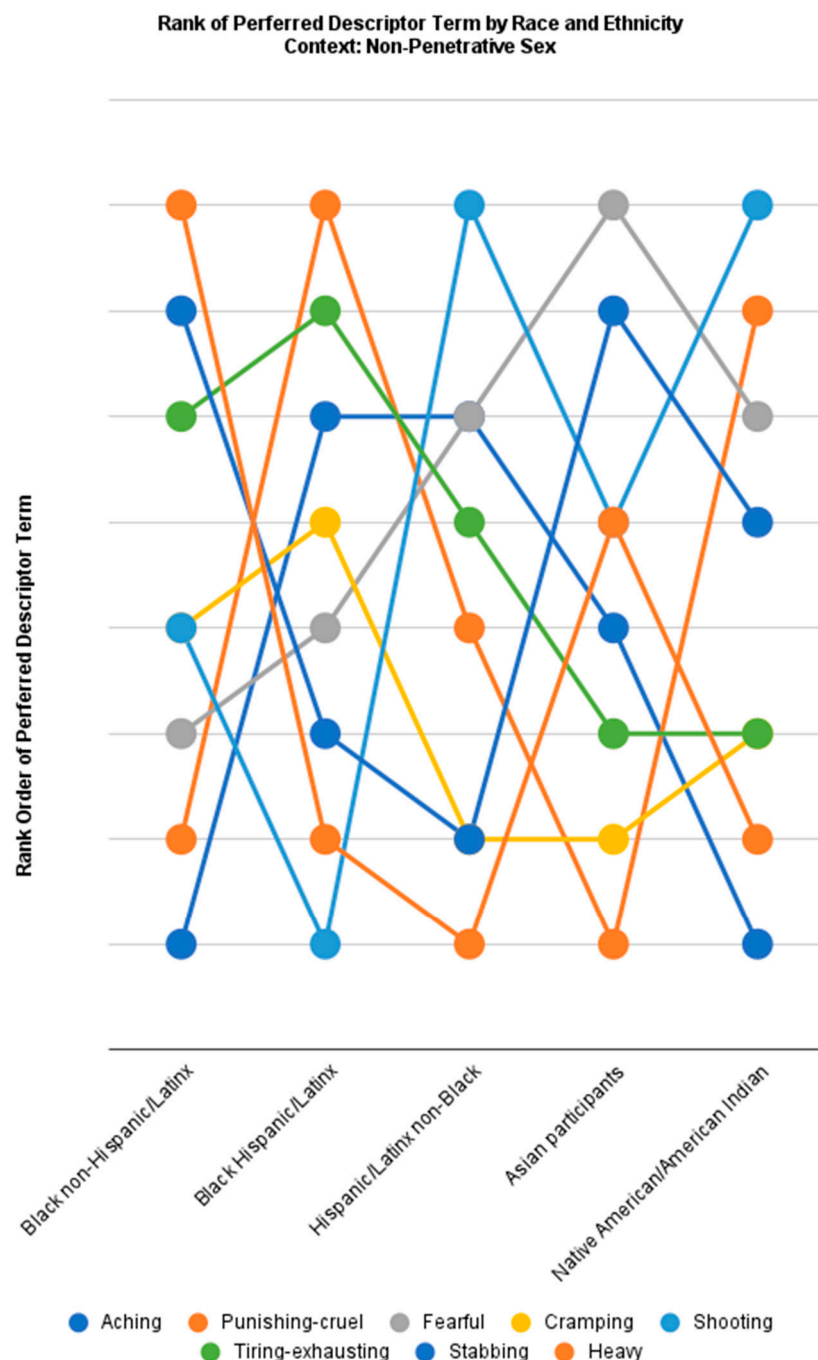
Most Black Hispanic/Latinx participants (76%) and Asian participants (74%)—and many Black non-Hispanic/Latinx participants (46%)—described their moderate-to-severe sexual pain with penetration as “throbbing.” However, throbbing was not a primary descriptor of sexual pain for Native American/American Indian or Hispanic/Latinx non-Black participants. Instead, most Native American/American Indian participants reported “tiring/exhausting” sexual pain (78%), and many Hispanic/Latinx non-Black participants reported “gnawing” sexual pain (54%). In addition to “throbbing” pain, most Asian participants also described their sexual pain as “sickening” (74%), while many Black non-Hispanic/Latinx participants also described their sexual pain as “heavy” (46%). See Figure 1 for frequencies ranked by descriptor term preference.



**Figure 1.** Frequencies ranked by descriptor term preference (Includes only terms that at least 50% of one racial/ethnic group endorsed—as a result, the terms “cramping” and “shooting” were removed from this figure) in the penetrative sex context.

### 3.4. Pain during Sexual Activity without Penetration

Pain descriptors for sexual activity without penetration did not align with the most common descriptors used for penetrative sexual activity. Further, no racial or ethnic subgroup agreed on primary pain descriptors. Most Black Hispanic/Latinx participants (64%) described their moderate-to-severe pain from non-penetrative sex as “fearful”, while many Black non-Hispanic/Latinx participants (44%) described it as “shooting” and many Hispanic/Latinx non-Black participants (45%) described it as “stabbing.” Most Asian participants reported “sharp” non-penetrative sexual pain, while Native American/American Indian participants were equally likely to have described this pain as “sharp” or as “aching” (37%). See Figure 2 for frequencies ranked by descriptor term preference.



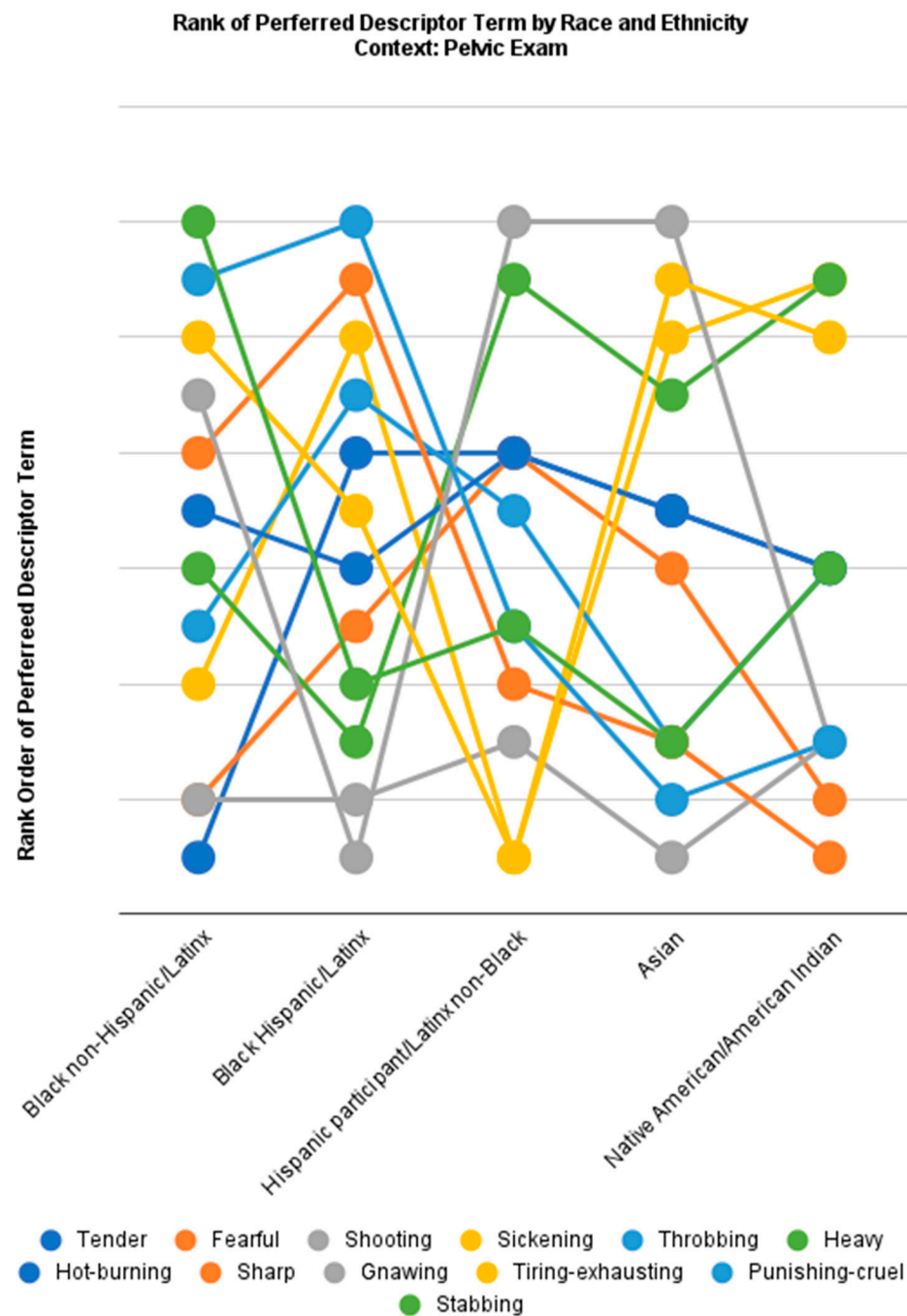
**Figure 2.** Frequencies ranked by descriptor term preference (Includes only terms that at least 50% of one racial/ethnic group endorsed—as a result, the terms “hot/burning”, “splitting”, “gnawing”, “tender”, “sickening”, and “throbbing” were removed from this figure) in the non-penetrative sex context.

### 3.5. Pain While Inserting a Contraceptive Ring

Again, no subgroups shared a common primary descriptor for this context. Most Asian participants (63%) reported “sharp” pain with contraceptive ring insertion, while most Black Hispanic/Latinx participants (61%) reported “throbbing” pain with insertion. Hispanic/Latinx non-Black participants were equally likely to describe this pain as either “sickening” or “stabbing” (54%), while many Native American/American Indian participants (48%) reported “heavy” pain. Last, Black non-Hispanic/Latinx participants primarily reported “cramping” (36%) pain in this context.

### 3.6. Pain during Pelvic Exam

Primary descriptor terms varied by subgroup. Most Asian participants (81%) reported “sharp” pain during pelvic exams/Pap smears. Most Black Hispanic/Latinx participants (70%) reported “punishing/cruel” pain during pelvic exams/Pap smears. Most Hispanic/Latinx non-Black participants (56%) reported either “hot/burning” or “stabbing” pain here, while Black non-Hispanic/Latinx participants reported either “sharp” or “heavy” pain (46%). Finally, “aching” pain was most common for Native American/American Indian participants (41%). See Figure 3 for frequencies ranked by descriptor term preference.



**Figure 3.** Frequencies ranked by descriptor term preference (Includes only terms that at least 50% of one racial/ethnic group endorsed—as a result, the terms “aching”, “cramping”, and “splitting” were removed from this figure) in the pelvic exam context.

### 3.7. Pain during Menstrual Product Use

Most Black Hispanic/Latinx participants (61%) reported moderate-to-severe “sharp” pain from menstrual products. Most Asian participants (56%) reported “fearful” or “aching” pain in this context, while Black non-Hispanic/Latinx participants reported both “sharp” pain and “stabbing” pain as their primary descriptors (39%). Hispanic/Latinx non-Black participants reported “sickening” and “heavy” pain (both 38%); Native American/American Indian participants most often reported “aching” pain (33%).

### 3.8. Pain with Prolonged Vulvar Pressure

Most Native American/American Indian participants (67%) reported moderate-to-severe “sickening” vulvar pressure pain. Most Hispanic/Latinx non-Black participants (58%) also reported “sickening” pain from vulvar pressure, as well as “stabbing” pain (58%) in this context. Most Asian participants described their vulvar pressure pain as either “gnawing” or “tender” (both 79%); most Black Hispanic/Latinx participants described this pain as “heavy” (68%); and most Black non-Hispanic/Latinx participants described this pain as “tiring/exhausting” (60%).

## 4. Discussion

In this study, we examined racial and ethnic group differences in how people report their chronic vulvovaginal pain across six contexts. We found that around one-third of the sample communicates about their CVVP differently with healthcare professionals than with close others, and this differential communication was associated with having to utilize more healthcare resources before reaching a diagnosis. While our preliminary data suggested that people of color are likely to describe their pain differently than are white participants—and may subsequently experience disparate treatment journeys—our findings in the present study spotlighted substantial variation in pain descriptions by racial/ethnic group and context.

Our findings provide further contextualization for the issue of patient–provider communication for women of color. Of those who have talked about their CVVP with others, one-third reported describing their symptoms differently depending on the audience—and specifically when the audience is a medical professional. Furthermore, doing so appears to lengthen the journey to diagnosis and increases the resources one needs to obtain treatment for their pain. Our study does not provide enough context to definitively state that this shift in symptom description by audience is a strategy to avoid provider bias. For example, it may also reflect language-based problems in patient–provider communication given the robust research literature citing language discordance as a major healthcare barrier for Spanish-speaking patients. However, considering the sizable minority of patients who reported this behavior and the existing research literature regarding women of color’s experience of perceived stigma and coercion when seeking gynecological care, this line of inquiry should be investigated further.

The racial differences we observed in both the preliminary study and the present study illustrate the importance of a more holistic approach to patients’ communication about their pain symptoms and conditions. The broad range of ways participants often described their CVVP symptoms suggests that current understandings of specific qualities of pain and diagnostic criteria for vulvovaginal conditions may not serve all patients equally. The issue of tying diagnoses to specific pain descriptor terms is especially important in the context of chronic *vulvar* pain—the most common subtype of chronic vulvovaginal pain—as historically published guidelines direct clinicians to look for “burning” pain as a key indicator for diagnosis (Moyal-Barracco and Lynch 2004; Bergeron et al. 2001). Our preliminary data indicated that participants of color were particularly less likely to describe their sexual pain as “burning”, perhaps as a response to sexual stereotypes held about women of color (Ward et al. 2019; Jerald et al. 2017). Instead, these data suggested that women of color more often describe their pain as “throbbing”, consistent with an earlier study on racial differences in pain descriptor terms among women with provoked



vulvodynia (Brown et al. 2015). Furthermore, the present study suggests significant and persistent between- and within-group variations in pain descriptor terms, with “burning” rarely arising as a popular term except in the pelvic exam/Pap smear context for 56% of Hispanic/Latinx non-Black participants.

Because genital burning pain is also associated with various STIs, women—particularly Black and Hispanic/Latinx women—could have a specific aversion to using this term when describing their pain in order to avoid any provider biases regarding their perceived STI risk. “Burning” may have been less frequently used by participants of color as a protective strategy regarding provider biases. In a broad reproductive and sexual health context, Gomez and Wapman (2017) suggest that young Black and Latina women report feeling pressured into long-term contraceptives regardless of their actual sexual behaviors or healthcare preferences. Thorpe et al. (2022) also report Black women’s difficulties in discussing sexual pain with their providers, in part due to concerns about being perceived as hypersexual or “sexually loose” (p. 1536).

Some of the reported pain descriptor terms also suggest complex dynamics between pain severity and context that deserve additional qualitative investigation. For example, the terms “tiring/exhausting” and “sickening” were reported by large proportions of Native American/American Indian and Asian participants in the pain during penetrative sex context, possibly indicating poor relationship communication like feelings of obligation to participate in painful sex, a problem reported in qualitative work on CVVP (Braksmajer 2017). Pain descriptor terms that arose in the pelvic exam/Pap smear context may also point towards additional elements of the patient–provider relationship that may affect screening access (Nolan et al. 2014). Here, 70% of participants who identified as both Black and Hispanic/Latinx reported pelvic exam pain using the “punishing/cruel” descriptor term. Navigating these types of procedures while also managing chronic pain can be difficult, especially if one’s provider has limited experience with modifying the procedure for chronic pain or if the provider dismisses the patient’s pain altogether. Relatedly, Hispanic/Latinx non-Black participants also used the term “stabbing” to describe their pain during this context; here again, the agency of the provider may be contributing to the pain descriptor choice where the participant felt “stabbed” by the speculum or that the pain felt during this procedure was “punishing” and “cruel”. These interpretations should be explored further through qualitative methodologies to better understand the subjective and multifaceted nature of pain.

Providers should be aware of both the range in terminology that patients use to describe their pain as well as specific strategies women use to combat perceived racism or other biases from providers regarding their sexual health. Findings from the present study further underscore this need, demonstrating a proliferation of pain descriptions used rather than clear descriptive patterns tightly bound to racial or ethnic identity. Furthermore, given the findings regarding race bias in pain perception among medical students and residents by Hoffman et al. (2016), as well as existing work on gendered stereotypes regarding women’s pain expression in general, provider-education efforts need to prioritize reductions in implicit racial and gender pain bias overall before targeting the issue of pain descriptor usage.

As Brown et al. (2015) reported, Black and white women may describe their CVVP symptoms in qualitatively different ways. Additional research analyzing CVVP from an intersectional perspective argues that Black and Hispanic/Latinx patients could be screened out of care due to biases from providers due to norms surrounding which gynecological problems are frequently tied to women of color (and not white women) via stereotyping (Labuski 2017). In this work, Labuski describes an interaction with a gynecological resident who claimed that “‘Vulvar pain is white. [And] [p]elvic pain is black’”, a disturbing statement that suggests the normalization of sorting medical diagnoses into disparate racial categories (p. 160).

Importantly, the decision in the present study to focus entirely on the experiences of women of color also reflects a methodological turn away from comparative works that



posit whiteness as a control group against which to measure the experiences of people of color. Whitfield et al. (2008) argue that this type of between-group analysis fails to recognize the vast diversity within racially and ethnically minoritized groups, creating a singular “ethnic umbrella” that results in “important distinctions within each group [being] lost” (p. 302). Taking up the mantle of Black feminist work that calls out depictions of Black life as monolithic, the present study’s focus on distinct groups of women of color and the subsequent reporting of vast diversity both within and between participant racial/ethnic groups regarding their pain communication for CVVP symptoms points both towards the utility in avoiding white and non-white comparative methodological schema. Additionally, the findings from the present study point towards the potential inefficacy of terminology-dependent diagnostic strategies for CVVP conditions. Instead, training in cross-cultural communication for medical professionals—rather than clinical guidelines that may misrepresent pain communication experiences of diverse CVVP patients—should be pursued to improve provider interactions with racial and ethnic groups different from their own (Park et al. 2006) as well as patients of a different gender than themselves.

Our findings thus emphasize the need for person-centered medicine, including focused attention to individual experiences of pain and personal concerns. Working to reduce pressure that patients feel to “correctly” describe their symptoms without fear of being seen negatively will help those patients effectively utilize healthcare resources and improve their quality of life. The threat of being perceived as incompetent regarding one’s own body—a powerful concept developed by McMillan Cottom (2019) in her essay “Dying to Be Competent”—acts as a powerful organizing force in how people, particularly multiply marginalized people, experience healthcare. This pressure also impacts women with CVVP in a unique way—in an exploration of their own experiences seeking care for vulvodynia, Hintz and Scott (2020) note that social taboos discouraging open communication around genital pain meant that they had little practice to articulate their concerns to providers as they were constantly using euphemisms or avoidance techniques among friends and family. Provider awareness of these taboos may also help reduce perceptions of incompetence if patients struggle with describing their symptoms given the influence of social norms.

### *Strengths and Limitations*

A major strength of this study lies in the racial diversity of our sample—much of the literature on chronic vulvovaginal pain conditions like vulvodynia and vaginismus are either predominantly or entirely focused on white women. To address this gap in the literature, the present study excluded any participant who identified as non-Hispanic/Latinx in an effort to analyze the CVVP experiences of women of color without comparing their experiences to those of white women. Because of this, we were also able to conduct a more nuanced analysis of CVVP experiences across race and ethnicity, particularly with regard to the experiences of Black Hispanic/Latinx/Latinx and non-Black Hispanic/Latinx women.

We also employed a highly successful recruitment strategy yielding a robust sample size ( $N = 488$ ) even when excluding white, non-Hispanic/Latinx participants. This outcome reflects broader interests in research on CVVP, and particularly projects dedicated to examining racial differences in CVVP experiences. Our results will contribute to the literature on CVVP and racial disparities in healthcare and provide a starting point for practical changes that can be quickly implemented.

In terms of limitations, we rely exclusively on self-report data, which suffers from bias due to inaccurate memory. However, we do believe that patients possess special expertise when it comes to evaluating their own bodies and pain. We also failed to collect data on other forms of reproductive or sexual healthcare procedures beyond the pelvic exam that may be affected by anticipated and actual pain, namely insertion and removal procedures associated with the IUD. Future researchers should consider including non-subjective data such as appointment dates for tracking time to diagnosis and should expand their scope to better understand the extent to which actual or anticipated vulvovaginal pain affects other critical forms of healthcare. It is also notable that while our work

focused entirely on people of color and allowed for a nuanced exploration of Black and Hispanic/Latinx women's experiences, our small sample sizes of Asian women and Native American/American Indian women did not allow for a similarly nuanced exploration of these diverse ethnic and racial groups. Finally, our analysis focused entirely on cisgender women, and predominantly on heterosexual women. Although our sample included 13 transgender participants, they were not included in analyses due to low statistical power; relatedly, only 41 participants reported a sexual identity other than heterosexual, prohibiting comparison testing. Given the consistent focus on these groups in other CVVP research, future work on the dimensions of gender and sexuality in investigations of the CVVP journey to diagnosis should strive for greater representation of LGBTQ+ experiences.

## 5. Conclusions

Chronic vulvovaginal pain affects 11 million or more people in the U.S. but is characterized by substantial diagnostic delay before treatment. Existing research suggests that this is especially emphasized in women of color—particularly those who identify as Black or Hispanic/Latinx—although many racial and ethnic groups remain underrepresented in the literature. Our data suggest that one contributor to this disparity lies in patient–provider communication, as demonstrated by our findings with Asian, Black, Hispanic/Latinx (including participants who identified as both Black and Hispanic/Latinx), and Native American/American Indian participants. In particular, the ways in which CVVP symptoms were described differed by patient race. Addressing the effects of racism on a systemic level is needed, but our findings point to a more quickly amenable point of intervention in the form of communication competency education for providers, including insight into why patients choose to frame their symptoms in certain ways to avoid racial bias and/or stereotyping as well as broader observations regarding the proliferation of terms used by women to describe their CVVP symptoms.

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**Informed Consent Statement:** Informed consent was obtained from all subjects involved in this study.

**Data Availability Statement:** The data presented in this study are available via Open ICPSR (DOI: openicpsr-183665).

**Conflicts of Interest:** The authors declare no conflicts of interest.

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