

Objectives

To estimate the prevalence of unexplained chronic vulvar pain (burning or sharp knifelike pain or pain on contact) in an ethnically diverse population-based sample of women.

Methods

We used town census directories to identify 4915 women age 18 to 64 from 5 ethnically diverse Boston communities and asked them to complete a self-administered questionnaire pertaining to current and past chronic lower genital tract discomfort (response rate 68%). We calculated the cumulative incidence and 95% confidence intervals by demographic and reproductive characteristics.

Results

Approximately 16% of respondents reported histories of chronic burning, knifelike pain, or pain on contact that lasted for at least 3 months or longer, and nearly 7% were experiencing the problem at the time of the survey. Chronic vulvar pain on contact decreased with increasing age, but the cumulative incidence of chronic burning and knifelike pain was similar across all ages. Contrary to earlier clinical assessments, white and African American women reported similar lifetime prevalences. However, Hispanic women were 80% more likely to experience chronic vulvar pain than were white and African American women. Women with histories of chronic vulvar pain were 7 to 8 times more likely to report difficulty and great pain with their first tampon use than were women without such histories. Nearly 40% of women chose not to seek treatment, and of those who did, 60% saw 3 or more doctors, many of whom could not provide a diagnosis.

Conclusion

Chronic unexplained vulvar pain is a highly prevalent disorder that is often misdiagnosed. (*JAMWA*. 2003;58:82-88)

A Population-Based Assessment of Chronic Unexplained Vulvar Pain: Have We Underestimated the Prevalence of Vulvodynia?

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Vulvodynia is chronic vulvar pain in the absence of objective abnormalities such as infection or dermatoses. Dysesthetic vulvodynia (newly termed generalized vulvar dysesthesia) refers to episodic unprovoked stinging, burning, irritation, pain, or rawness anywhere on the vulva. Vulvar vestibulitis (newly termed localized vulvar dysesthesia) refers to pain consistently localized by point pressure mapping within the vulvar vestibule.¹

The pathophysiology of these conditions is largely unknown. Current theory suggests that localized vulvar dysesthesia represents neuro-inflammatory pain from nociceptors in the vulvar vestibule that have been sensitized by inflammation or trauma.² Generalized vulvar dysesthesia may represent neuropathic pain from damage to the pudendal nerve.³ Although the definitions of these conditions are still evolving, it is accepted that they are not explained by the diagnostic criteria for such known vulvar conditions as candidiasis, inflammatory vaginitis, sexually transmitted diseases, dermatoses, menopausal dyspareunia, or any pelvic pain disorder.

The magnitude of this problem in women in the general population is largely unknown. A recent pilot study found that 18% of a random sample of women in one Boston area community reported histories of chronic lower genital tract discomfort that lasted for 3 months or longer.⁴ In this report, we present estimates of the cumulative incidence of chronic lower genital tract symptoms in approximately 5000 women identified from a wide range of Boston area communities. Although we believe these estimates are closely related

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to the true incidence of generalized and localized vulvar dysesthesia, these terms cannot be applied without a complete medical history and physical examination to rule out other causes of genital discomfort. Thus, throughout this report, we use the term “chronic vulvar pain” in reference to women reporting chronic lower genital tract symptoms.

Methods

Population-Sampling Frame

The population-sampling frame described in this analysis is based on the first 14 months of a proposed 42-month screening period. This population-based cross-sectional sample of 5931 women between 18 and 64 years of age was selected from 3 ethnically diverse Boston neighborhoods, defined geographically by zip code, and 2 west suburban Boston communities. Massachusetts Town Books (annual publications that list residents by name, age, and address according to voter precincts) were used to identify all women in this age range with a verified address and telephone number. The sample was weighted according to the age distribution published in the 2000 US Census for each neighborhood and community. A 1-page, 2-sided, optically scannable questionnaire was mailed to each subject to assess current and past chronic vulvar pain as defined below.

Our survey is based on 5931 questionnaires that were not returned as “undeliverable” after the initial mailing. After 2 separate mailings and 1 telephone follow-up, 805 surveys had not been returned and could not be confirmed to have reached the preidentified study subject. Because we could not confirm that these questionnaires were sent to eligible, or even existing, households, we did not consider them to have been eligible respondents. We also excluded as ineligible 211 surveys sent to households who, we learned after telephone follow-up, included non-English speaking residents. Thus, 4915 questionnaires were sent to study subjects we believe were eligible to complete the survey, and 3358 of them were returned (68.3%).

Measures of Chronic Vulvar Pain

The self-administered questionnaire was approved by the Brigham and Women’s Hospital Human Subject Review

Committee and was designed to assess current and past chronic lower genital tract symptoms consistent with generalized and localized vulvar dysesthesia. We based our survey on the symptoms reported by patients seen at a vulvovaginal specialty clinic in Boston and on symptoms reported by women treated by nationally recognized vulvar pain experts. The questionnaire asked about 4 types of lower genital tract discomfort that persisted for 3 months or longer, including: itching, burning, periodic knifelike or sharp pain, and excessive pain on contact to the genital area. For each symptom, we inquired about the age at first onset, the number of episodes experienced, whether women experienced symptoms continuously or intermittently, whether the symptom was provoked or spontaneous, whether the discomfort occurred during intercourse, and whether the discomfort limited or prevented sexual intercourse. In addition, we asked whether study subjects sought treatment for the problem, how many doctors were seen, and whether or not a diagnosis was ever conveyed.

We defined chronic vulvar pain as: a) burning in the genital area for 3 months or longer with or without chronic itching, b) knifelike or sharp pain in the genital area for 3 months or longer with or without burning or itching, or c) excessive pain on contact when inserting tampons, during sexual intercourse, or during pelvic examinations that lasted for 3 months or longer. These questions were reviewed by several national experts and represent the symptoms associated with this condition as outlined by the International Society for the Study of Vulvovaginal Diseases. Women with chronic genital itching that persisted for 3 months or longer and that was not accompanied by either burning or knifelike pain or pain on contact did not meet the criteria for chronic vulvar pain. It is more likely that, with itching alone, these women suffered from either *Candida* or some other pruritic vulvar condition.

Statistical Analysis

We calculated the age-specific cumulative incidence and 95% confidence intervals for any chronic vulvar pain type listed above and then stratified by excessive pain on contact versus other forms of chronic vulvar pain. The cumulative incidence was defined as the proportion (p) of

Hispanic women were at the greatest risk of unexplained chronic vulvar pain, and there was very little difference in risk between white and African American women.

Table 1. Age-Specific Cumulative Incidence of Unexplained Chronic Vulvar Pain in Women Age 18 to 64

	Population at Risk, n	All Cases, % (95% CI)	Burning or Knifelike Pain,* % (95% CI)	Pain on Contact, [†] % (95% CI)	Symptoms Limited or Prevented Intercourse, % (95% CI)
All women	3358	15.6 (14.4, 16.8)	3.3 (3.0, 3.6)	12.4 (11.8, 13.0)	9.8 (9.3, 10.3)
Age at first onset					
<25	3358	6.8 (6.4, 7.2)	1.1 (0.9, 1.3)	5.7 (5.3, 6.1)	4.7 (4.3, 5.1)
25-34	3080	5.0 (4.6, 5.4)	1.2 (1.0, 1.4)	3.8 (3.5, 4.1)	3.2 (2.9, 3.5)
35-44	2264	3.4 (3.0, 3.8)	0.8 (0.6, 1.0)	2.6 (2.3, 2.9)	1.7 (1.4, 2.0)
45-54	1316	3.6 (3.1, 4.1)	0.8 (0.6-1.0)	2.8 (2.3, 3.3)	2.1 (1.7, 2.5)
55-64	491	3.9 (3.0, 4.8)	1.4 (0.9-1.9)	2.4 (1.7, 3.1)	1.6 (1.0, 2.2)
No history of pelvic disorder [‡]	2615	13.7 (13.0, 14.4)	2.9 (2.6, 3.2)	10.8 (10.2, 11.4)	8.7 (8.1, 9.3)
Age at first onset					
<25	2615	6.6 (6.1, 7.1)	1.2 (1.0, 1.4)	5.4 (5.0, 5.8)	4.6 (4.2, 5.0)
25-34	2348	4.1 (3.7, 4.5)	1.0 (0.8, 1.2)	3.1 (2.7, 3.5)	2.6 (2.3, 2.9)
35-44	1613	2.7 (2.3, 3.1)	0.5 (0.3, 0.7)	2.2 (1.8, 2.6)	1.2 (0.9, 1.5)
45-54	878	4.1 (3.4, 4.8)	1.0 (0.7, 1.3)	3.1 (2.5, 3.7)	2.4 (1.9, 2.9)
55-64	333	3.6 (2.6, 4.6)	1.2 (0.6, 1.8)	2.4 (1.6, 3.2)	1.8 (1.1, 2.5)

*Self-reported burning or knifelike pain that persisted for 3 months or longer with or without the presence of chronic genital itching.

[†]Self-reported excessive pain on contact on insertion of tampon, during sexual intercourse, or during pelvic examination that persisted for 3 months or longer with or without burning, itching, or knifelike pain.

[‡]Excludes women with self-reported histories of endometriosis, uterine fibroids, and polycystic ovarian syndrome.

women who developed chronic vulvar symptoms at any time between 18 and 64 years of age.⁵ The age-specific cumulative incidence was based on the following age at first onset categories: younger than 25, 25 to 34, 35 to 44, 45 to 54, and 55 to 64. Women were considered “at risk” for developing first onset of symptoms during a particular age interval only if their current age was within or older than the specific age interval assessed. For example, a 37-year-old woman was considered “at risk” for first onset of vulvar symptoms for the age categories younger than 25, 25 to 34, and 35 to 44. The 95% confidence interval was defined based on a χ^2 distribution with the standard error of the proportion estimated as the square root of $[p - (1-p)]/n$.⁶ We further characterized differences in the cumulative incidence by race, education, age at first menarche, self-reported pain, and difficulty with first use of tampons and statistically assessed these differences based on multivariate adjusted odds ratios and 95% confidence intervals.

Results

We compared the age distribution and geographical location of those Massachusetts Town Book subjects who did and did not complete the survey. Those who completed the survey were slightly older (16% of participants were younger than 30 compared to 20% of nonparticipants, and 26% of

participants were 50 or older compared to 22% of nonparticipants). Although women in the 3 Boston neighborhoods accounted for 73% of our original sample, they made up only 67% of those who completed the survey, whereas women in the 2 suburban communities accounted for 27% of our original sample, but made up 33% of those who completed the survey. Given that chronic vulvar pain occurs more commonly in younger women and that our population of participants was somewhat older than nonparticipants were, we may have underestimated the true incidence. The prevalence of chronic vulvar pain was similar across the 5 neighborhoods/communities. Thus, it is likely that the greater proportion of suburban women among respondents had little effect on our estimates of the cumulative incidence.

Approximately 16% of women in our study reported histories of chronic burning, knifelike or sharp pain, or pain on contact that lasted for 3 months or longer at some point during their lifetimes (Table 1). Seven percent of these women were experiencing the problem at the time of the survey. Approximately 80% of the cumulative incidence was attributed to extreme pain on contact. The cumulative incidence was highest before age 25, decreased through age 44, and then remained fairly constant through age 64. Women who experienced chronic burning or knifelike pain

Table 2. Cumulative Incidence of Unexplained Vulvar Pain by Race, Education, Age at Menarche, and Difficulty With First Tampon Use

	Population at Risk	All Cases				Cases With Symptoms that Limited or Prevented Intercourse			
		No.	%	OR*	95% CI [†]	No.	%	OR*	95% CI [†]
Race									
African American	494	80	16.2	1.1	0.9, 1.5	44	8.9	0.9	0.7, 1.4
White	2171	320	14.4	1.0		215	9.9	1.0	
Hispanic	154	35	22.7	1.8	1.1, 2.7	20	13.0	1.5	0.9, 2.6
Asian	99	11	11.1	0.7	0.4, 1.4	5	5.1	0.5	0.2, 1.3
Other nonwhite	440	86	19.5	1.4	1.1, 1.9	46	10.5	1.1	0.8, 1.6
Education									
High school	404	56	13.4	0.9	0.6, 1.2	28	6.9	0.7	0.4, 1.1
Voc-tech	643	121	18.8	1.3	1.0, 1.6	75	11.7	1.2	0.9, 1.7
College graduate	1238	181	14.6	1.0		124	10.0	1.0	
Graduate school	991	157	15.8	1.1	0.9, 1.4	99	10.0	1.0	0.8, 1.4
Not stated	82	10	12.2	4	4.9
Age at menarche									
10	240	50	21.4	1.2	0.9, 1.7	31	12.9	1.2	0.8, 1.9
11	487	75	16.0	1.0	0.8, 1.4	44	9.0	1.0	0.7, 1.4
12-13	1863	288	15.5	1.0		179	9.6	1.0	
14	432	62	15.5	1.0	0.7, 1.3	40	9.3	1.0	0.7, 1.5
15	336	50	16.7	1.0	0.7, 1.3	36	10.7	1.1	0.7, 1.6
Difficulty with first tampon use									
Little/no pain	2006	219	10.9	1.0		136	6.8	1.0	
Some/minimal pain	871	189	21.7	2.2	1.8, 2.7	120	13.8	2.2	1.7, 2.9
Difficulty/great pain	144	69	47.9	7.4	5.2, 10.6	49	34.0	8.4	5.6, 12.6
Never used	305	42	13.8	1.2	0.8, 1.8	21	6.9	1.1	0.6, 1.8

*Odds ratio adjusted for all variables in the table using unconditional logistic regression.
[†]Empty cells indicate reference group.

with or without genital itching did so across all age-specific time points equally, whereas chronic pain on contact with or without other vulvar symptoms became less prevalent with increasing age. An important diagnostic assessment is whether the symptoms limit or prevent sexual intercourse. When we restricted the population of women with histories of chronic vulvar pain to those who reported limitations in normal sexual relations, we observed an overall cumulative incidence of 10% with a similar age at onset distribution as that observed for all women experiencing excessive pain on contact.

We were also unable to determine what proportion of the cumulative incidence may have been due to women confusing their symptoms with those commonly related to such pelvic disorders as endometriosis, polycystic ovaries, or leiomyomata. When we restricted the population to women who reported no history of any of these conditions at any point during their lifetimes, we still found an overall chronic

vulvar pain cumulative incidence of 14% with a similar age-specific and vulvar type distribution as that observed in all women.

Hispanic women were at the greatest risk of unexplained chronic vulvar pain (Table 2), and there was very little difference in risk between white and African American women. A substantial number of women could not classify themselves into 1 of the 4 broad race/ethnicity categories. We therefore assumed that they were likely to be of mixed ethnicity, and we classified them as “other nonwhite” subjects. Consistent with this assumption, their cumulative incidence fell between that of Hispanic women and those of African American or white women. These findings remained consistent even when stratified by type of vulvar pain (chronic burning, knifelike pain, or pain on contact, data not shown). There was very little difference in risk by educational status or age at menarche after multivariate adjustment. Women who reported difficulty and great pain with

Table 3. Self-Reported Health Care Seeking Characteristics of Women With Chronic Vulvar Pain, by Race, %

	All Cases (n=525)	Limited Intercourse (n=330)	White (n=313)	African American (n=80)	Hispanic (n=35)	Asian American (n=11)	Other Nonwhite (n=86)
Sought treatment							
Never	39.6	30.9	40.3	43.8	28.6	36.4	38.4
Yes	54.1	64.2	56.2	48.8	51.4	54.6	52.3
Not stated	6.3	4.9	3.5	7.5	20.0	9.1	9.3
Clinicians seen*							
1 or 2	37.0	34.9	34.7	33.3	33.3	66.7	46.7
3 or 4	28.2	29.2	27.8	33.3	27.8	16.7	26.7
5 or more	28.8	30.7	31.8	25.6	38.9	16.7	17.8
Not stated	6.0	5.2	5.7	7.7	0	0	8.9
Diagnosis obtained*							
No	39.1	35.8	36.9	53.9	50.0	33.3	31.1
Yes	60.9	64.2	63.1	46.2	50.0	66.7	68.9

*Among women who sought treatment only.

Table 4. Diagnoses Women With Chronic Vulvar Pain Reported Receiving From Physicians*

Diagnosis	All Cases, n (%)	Cases with Symptoms Limiting Intercourse, n (%)
Infection [†]	60 (34.7)	49 (36.0)
Pelvic disorder [‡]	51 (29.5)	38 (27.9)
Skin disorder [§]	17 (9.8)	14 (10.3)
Hormonal problem	8 (4.6)	5 (3.7)
Mental health disorder [¶]	2 (1.2)	1 (0.7)
Dietary factors ^{¶¶}	2 (1.2)	1 (0.7)
Chronic vulvar pain ^{**}	16 (9.2)	15 (11.0)
Other ^{††}	17 (9.8)	13 (9.6)

*284 of 525 women with symptoms sought treatment, and 173 reported a diagnosis. 212 of 330 women with symptoms that prevented or limited sexual intercourse sought treatment, and 136 reported a diagnosis.

[†]Recurrent vaginal or pelvic infections with or without yeast.

[‡]Ovarian or uterine cysts, structural abnormalities; endometriosis; pelvic area cancer; kidney infection; vaginal birth trauma.

[§]Lichen sclerosus; nonspecified dermatological problem; psoriasis.

^{||}Ovulatory pain; tamoxifen use; menopausal symptoms; vaginal dryness; reaction to oral contraceptives.

[¶]Sleep deprivation; stress; tension.

^{¶¶}Lack of vitamins; nonspecified diet related.

^{**}Vulvodynia; pain during exam; vestibulitis; vaginismus; vaginal atrophy; vaginosis; vulvar pain disorder.

^{††}Sexual inactivity

their first use of tampons were 7 times more likely to report chronic vulvar pain than were women who experienced little or no difficulty and pain. Women who chose never to use tampons were at no greater or lesser risk of chronic vulvar

pain than were women whose first tampon use resulted in little difficulty or pain. All of the findings in Table 2 remained unchanged when we restricted the cases to women whose symptoms limited or prevented intercourse.

Only 54% of women who reported histories of unexplained chronic vulvar pain sought treatment, and even when the symptoms limited intercourse, only 64% sought treatment. More than 60% of those who sought treatment saw 3 or more clinicians, and more than 30% of women whose pain limited intercourse sought care from 5 or more doctors. Although many women who sought treatment saw several different physicians, about 61% succeeded in obtaining diagnoses. The findings in Table 3 were only slightly attenuated when restricted to cases with symptoms that limited or prevented intercourse. In addition, very little difference was noted when stratified by race.

One-third of the diagnoses reported were vaginal or pelvic infections, and the next most common diagnoses were pelvic disorders of unknown origin (Table 4). Only 9% of these women were diagnosed with chronic vulvar pain.

Discussion

Clinicians and researchers have long relied on a single survey of women seen in a gynecological practice for the standard estimate of the prevalence of vulvar vestibulitis.⁷ In that survey of 210 patients, 40 women (19%) fulfilled the definition of clinical vestibulitis. Another study in Britain reported a 1% to 3% prevalence among 150 consecutive new female patients attending a walk-in genitourinary clinic.⁸ We could not determine the true incidence of unexplained

chronic vulvar pain that met the specific diagnostic criteria for generalized or localized vulvar dysesthesia. However, by restricting symptoms to those that limited or prevented sexual intercourse and by restricting the population to women with no lifetime histories of any pelvic disorders (such as endometriosis, leiomyomata, or polycystic ovarian syndrome), we can conservatively estimate that at least 9% of women will experience a condition likely to meet vulvodynia criteria at some point. We can further conservatively estimate that approximately 5% of women will experience this condition before age 25. Given that these figures are likely to underestimate the true incidence, they bring to the forefront a highly prevalent condition that is associated with substantial disability.

The age-specific incidence of these disorders is largely unknown. However, clinical series that have focused on women with localized dysesthesia (vestibulitis) suggest that it is predominantly seen in women under age 35.^{9,11} Because women of reproductive age are more likely to seek gynecological care, one might expect to see a higher proportion of cases in a younger population. Although we observed the highest cumulative incidence in women younger than 25, this was specific to those who reported chronic vulvar pain on contact provoked by sexual touch, insertion of a tampon, or pelvic examination. But even within this subgroup, we still conservatively estimated that about 2% experienced this type of chronic vulvar pain on contact even after age 55. However, we do not know to what extent vulvar pain on contact during the perimenopausal years could be due to estrogen-related dyspareunia in this population.

Approximately 35% of our population-based sample were nonwhite women, which allowed us to make one of the most accurate assessments of this condition by race. Unexplained vulvar pain was similar among white and African American women, and Hispanic women were 80% more likely than white women to have experienced chronic vulvar pain. Clinical series suggest that this condition is predominantly seen in white women.¹⁰⁻¹² Although nonwhite women are less likely to seek health care in general, particularly for stigmatizing gynecological ailments,¹³ our findings showed very little racial difference in the proportion of women who sought treatment. Our finding

of no consistent differences in educational status between women with and without chronic vulvar pain is consistent with that of one study among women suffering from dyspareunia and no-pain controls¹⁴ and that of another of women with chronic pelvic pain and chronic vulvar pain.¹⁵

In an earlier study,⁴ we observed a 2.4-fold risk of chronic vulvar pain in women who reported difficulty and pain with first tampon use relative to women who reported no pain or difficulty, and a 7- to 8-fold risk in this study. We found similar distributions of women who never used tampons in those with and without histories of chronic vulvar pain in this study, as we did in the earlier one. We know that women with chronic vulvar pain have higher levels of inflammatory cytokines such as interleukin-1 and TNF alpha, but do not necessarily have visible erythema.¹⁶ It is important to determine if these immunological markers are present even earlier than puberty in those who go on to develop this condition.

A recent clinical review multiplied the number of specialists by the average number of vulvodynia patients seen by each specialist to estimate that 200 000 women in the United States are affected by vulvodynia.¹⁷ If, in fact, our lifetime cumulative incidence estimate of 16% is anywhere near the true prevalence in women 18 to 64 years of age, then approximately 14 million US women may experience this problem during their lifetimes,¹⁸ and at least 30% will suffer without seeking medical care. Fortunately, the National Institutes of Health has allocated funds to begin research into the etiology of and treatment for this condition. Recognizing the magnitude of the problem will bring a better understanding of possible etiological pathways that, we hope, will lead to suitable prevention strategies.

If, in fact, our lifetime cumulative incidence estimate is anywhere near the true prevalence, then approximately 14 million US women may experience this problem in their lifetimes.

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