GENERAL GYNECOLOGY

Prevalence of symptoms consistent with a diagnosis of vulvodynia: population-based estimates from 2 geographic regions

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OBJECTIVE: We used validated sensitive and specific questions associated with clinically confirmed diagnoses of unexplained vulvar pain (vulvodynia) to compare the cumulative incidence of vulvar pain and prevalence of care-seeking behavior in Boston metropolitan area (BMA) and in Minneapolis/Saint Paul metropolitan area (MSP) from 2001 through 2005 using census-based data, and 2010 through 2012, using outpatient community-clinic data, respectively.

STUDY DESIGN: We received self-administered questionnaires from 5440 women in BMA and 13,681 in MSP, 18-40 years of age, describing their history of vulvar burning or pain on contact that persisted >3 months that limited/prevented intercourse.

RESULTS: By age 40 years, 7-8% in BMA and MSP reported vulvar pain consistent with vulvodynia. Women of Hispanic origin compared to whites were 1.4 times more likely to develop vulvar pain symptoms (95% confidence interval, 1.1—1.8). Many women in MSP (48%) and BMA (30%) never sought treatment, and >50% who sought care with known health care access received no diagnosis.

CONCLUSION: Using identical screening methods, we report high prevalence of vulvar pain in 2 geographic regions, and that access to health care does not increase the likelihood of seeking care for chronic vulvar pain.

Key words: ethnic groups, health services accessibility, prevalence, vulvodynia

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We[1] and others[2-4] have shown that vulvodynia (chronic vulvar pain in the absence of objective abnormalities, eg, infection or dermatoses) is highly prevalent with lifetime estimates ranging from 10-28% among reproductive-aged women in the general population. Our previous assessment of vulvodynia cumulative incidence in the Boston metropolitan area (BMA) was conducted in women systematically sampled from census-based directories. All ethnicities we sampled were affected, with a somewhat greater occurrence among Hispanic women. Furthermore, the cumulative incidence decreased with increasing age, with nearly half of all women affected choosing not to seek treatment.[1]

We have also recently shown that questions asked of women in the general population pertaining to undiagnosed pain on contact that limited or prevented intercourse have good sensitivity and specificity compared to a clinically confirmed diagnosis of vulvodynia.[5] Thus, in the absence of a clinical examination, investigators now have the capability to use a few questions to reasonably screen for the proportion of women in the general population who may possibly have vulvodynia. This is particularly important given that so many women choose not to seek treatment[1,6] and therefore can only be identified through population screening methods.

Using data from a new sample of women in the Minneapolis/Saint Paul metropolitan area (MSP), in conjunction with our previously reported sample from the BMA, we have the opportunity to extend our previous estimates of vulvodynia occurrence. Our data allow for a comparison of vulvodynia cumulative incidence from a census-based population sample (BMA), and a sample derived from the administrative database of women who were seen for any reason at one of several outpatient community clinics within a defined geographic region (MSP). In addition to cumulative incidence comparisons, we also assess care-seeking behavior between those with and without known access to health care resources. We believe these findings provide the best estimates of the magnitude of this debilitating condition in the general population given that similar diagnostic screening occurred across 2 geographic regions. Our findings also shed light on the associated stigma that prevents women from seeking care even when access to health care resources is available.

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MATERIALS AND METHODS

This study was approved by the human subjects research committees at the Brigham and Women's Hospital in Boston, the University of Minnesota, and Fairview Health Services in the greater Minneapolis and St. Paul area of Minnesota.

Population-sampling frame, BMA

Details pertaining to the source of subjects within this sampling frame have previously been described.[1] At the time of this earlier publication, we were still screening and recruiting women through this sampling frame. We now have completed this screening study and present a larger sample than previously reported. Although the BMA sample included women 18-64 years of age, we restricted the sample in this analysis to women 18-40 years of age for comparability between BMA and MSP. Thus, the BMA sample included 9878 women between 18-40 years of age from 3 ethnically diverse Boston-area neighborhoods and 2 west suburban communities surveyed from January 2001 through September 2005. Massachusetts Town Books (annual publications that list residents by name, age, and address according to voter precincts) served as the source population for our sample, which was restricted to households in which we could confirm an address and telephone number. The sample was weighted according to the 2000 Census age distribution within each of the 5 geographic areas.

A self-administered questionnaire to assess a history of vulvar pain (see vulvar pain classification below) was mailed to each woman, and after 2 mailings and 1 telephone follow-up assessment, 67.2% completed the questionnaire. Response varied by <10% across communities and age categories. After further restricting the respondents to those with complete screening data, 5440 (55.1% of the target sampled population) were included in these analyses.

Population-sampling frame, MSP

Our sampling frame in MSP included women between 18-40 years of age who were seen for any reason in any outpatient clinic that was part of a large health care network that caters to approximately 27% of the MSP population. We randomly sampled 25,754 women seen in any of these clinics within the past 2 years that were within a 70-mile radius of the University of Minnesota from March 2010 through December 2011.

Women sampled were mailed a letter describing the study and a self-administered questionnaire to assess the same history of vulvar pain as that queried among women in the BMA. After 3 mailings, 13,681 women (53.1%) returned a completed questionnaire that included all key questions needed for this analysis. Participants represented all geographic areas of the MSP region.

Classifying vulvar pain and assessing care-seeking behavior

The initial development of the self-administered screening questionnaire, which was given to both samples of women, has been previously described.[1] In brief, we assessed a vulvar pain history for each woman on criterion used to classify a history consistent with vulvodynia. These criteria are consistent with the International Society for the Study of Vulvovaginal Disorders (ISSVD) initiative to develop consistent diagnostic criteria for vulvodynia.[7] Women surveyed in both BMA and MSP were asked about their history of vulvar burning or pain on contact that persisted for a period of ≥3 months. Self-reported age at first onset of vulvar pain was obtained and used to estimate age-specific cumulative incidence (see statistical approach below). We further queried whether the discomfort was continuous, intermittent, provoked, or spontaneous. In addition, we determined whether the pain and discomfort occurred only during intercourse or at other times as well, and whether it limited or prevented women from having intercourse. Although all of these questions were asked of women sampled from both BMA and MSP, we previously reported that women reporting pain on contact for a period of ≥3 months that limited or prevented intercourse was associated with 83% sensitivity and 94% specificity for meeting a true diagnosis of vulvodynia based on the gold standard of a clinical examination to rule out other known causes of vulvar pain.[5]

Statistical methods

We created a retrospective cohort of all women sampled who completed the self-administered screening questionnaire and then assessed the age at first onset of vulvar pain categorized as <20, 20-24, 25-29, 30-34, and 35-40 years. We also stratified the cumulative incidence by the following self-reported race/ethnicity categories: white, African American, Hispanic, or of other racial backgrounds. Calculating age-specific cumulative incidence of vulvar pain required us to account for censoring since a woman's history stopped at the time they completed the survey. Cumulative incidence was estimated using life table methods[8] and confidence intervals (CIs) were obtained by bootstrapping. Kaplan-Meier product-limit survival analyses were used to illustrate differences in cumulative incidence by age across ethnic groups and the 2 geographic regions.

We then restricted the analyses to women who met our classification for symptoms consistent with vulvodynia to assess geographic differences in care-seeking behavior and by primary (always having had pain on contact) vs secondary (having had a pain-free period of intercourse prior to the onset of vulvar pain symptoms) onset of vulvodynia. We estimated what proportion of women sought treatment, how many different clinicians were seen to address their vulvar pain, and whether they were able to receive a diagnosis (either correct or incorrect based on the respondent's self-report). Separate logistic models were used to determine the adjusted proportion of women who sought treatment, and whether or not a diagnosis was obtained, adjusted for the women's age at the time of the survey, race, and the length of time they had experienced vulvodynia-like symptoms. Multinomial models were used to estimate the proportion of women with vulvodynia who saw 1-2, 2-3, or ≥4 clinicians to address their vulvar pain. We examined differences in these proportions between