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Attributes and Barriers to Care of Pelvic Pain in University Women

Julie Mann, MPH*, Jonathan Shuster, PhD, and Nash Moawad, MD, MS

College of Public Health and Health Professions (Ms. Mann), Departments of Health Outcomes and Policy (Dr. Shuster), and Minimally Invasive Gynecologic Surgery, Department of Obstetrics and Gynecology, College of Medicine (Dr. Moawad), University of Florida, Gainesville, Florida

Abstract

Study Objective—To describe rates of pelvic pain in university women ages 18 and older and to explore the barriers to adequate health care for pelvic pain in this population.

Design—A cross-sectional study (Canadian Task Force classification II-2).

Setting—University of Florida, Gainesville, FL.

Patients—A total of 2000 female students at the University of Florida were randomly selected for participation.

Interventions—The 2000 sample members were sent a questionnaire to be completed online.

Measurements and Main Results—The online questionnaire was hosted through the REDCap electronic data capture tool hosted at the University of Florida. This questionnaire included demographic items, general health and health behavior questions, measures to assess different types of pelvic pain (e.g., dysmenorrhea; dyspareunia; urinary, bowel, and vulvar pain), items regarding barriers to care for pelvic pain problems, and quality of life measures. Data were exported to SAS software (SAS Institute Inc., Cary, NC) for analysis. Of the 2000 subjects who received the questionnaire invitation, 390 filled out the questionnaire, yielding a response rate of 19.5%. Respondents' ages ranged from 18 to 62 with a mean of 23 years. A total of 72.8% of respondents reported experiencing pelvic pain over the past 12 months. Dysmenorrhea was reported by nearly 80% of participants, over one third of participants noted deep dyspareunia, and a significant proportion of participants reported symptoms related to bowel movements. Vulvar symptoms, including superficial dyspareunia, were reported by 21.5% of participants. Most participants with pelvic pain (78.8%) have not received any diagnosis for their pain, whereas 73.6% reported not yet having visited a doctor. Significant barriers to receiving adequate medical care were reported, including difficulty with insurance coverage and physicians' lack of time and knowledge or interest in chronic pelvic pain conditions.

Conclusion—Pelvic pain in younger women is a critical public health issue experienced by a significant portion of the population. Significant awareness deficits and barriers to care exist.

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*Corresponding author: Julie Mann, MPH, College of Public Health and Health Professions, University of Florida, PO Box 100294, Gainesville, FL 32610. julie.m.mann@gmail.com.

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Careful study of the barriers to receiving adequate medical care reported by these women will allow researchers to describe how best to improve care for these syndromes.

Keywords

Barriers to care; Dyspareunia; Gynecology; Pelvic pain; University women

Chronic pelvic pain (CPP) refers to conditions involving nonmenstrual pain lasting 6 or more months and severe enough to cause functional disability or require medical or surgical management [1]. In primary care practices, 39% of patients report some type of pelvic pain [2]. CPP accounts for about 10% of referrals to gynecologists and is responsible for over 40% of gynecologic diagnostic laparoscopies [1]. CPP conditions are broadly classified into gynecologic and nongynecologic. Common nongynecologic causes of CPP include musculoskeletal, neurologic, gastrointestinal, and urologic etiologies as well as psychological factors [3].

Gynecologic CPP has been associated with a wide range of diagnoses. Severe dysmenorrhea can be linked to endometriosis [4–6], adenomyosis, and ovarian cysts [5,7]. Unrelenting insertional dyspareunia can be related to vulvodynia or myofascial pelvic floor pain syndrome [8], whereas deep dyspareunia often has its roots in endometriosis, adenomyosis, or, less likely, pelvic inflammatory disease [9]. Chronic pain with urination often stems from interstitial cystitis [10]. Other urologic causes of pelvic pain may include urolithiasis [11]. Bowel-related pain is linked in some cases to irritable bowel syndrome [12], functional constipation [13,14], diverticular disease [15–18], or, less commonly, inflammatory bowel disease or pelvic adhesive disease [19]. Some of these problems are more prevalent in the younger population, such as endometriosis, ovarian cysts, and irritable bowel syndrome.

Although available literature details CPP issues in some cohorts of adult women, it is also critical to assess the scope of these problems in younger populations because research suggests that young women are more likely to experience pelvic pain and to encounter significant barriers to care when seeking treatment [8,20–22]. Women who report symptom onset during adolescence commonly see longer diagnostic delays. Greene et al [23] reported that adolescents with pelvic pain waited on average 5.4 years before receiving a diagnosis, whereas women whose CPP began in adulthood waited only 1.9 years. These delays often stem from the vague nature of many CPP syndromes as well as the provision of inaccurate diagnoses [8,24], frequent switching of doctors and medications [25], and several surgical procedures performed for diagnostic and treatment purposes [26,27]. It is unclear whether endometriosis is a progressive disease and whether early interventions delay progression. In their study of rectovaginal endometriosis, Moawad et al [28] found that more aggressive surgical treatment (i.e., bowel resection and reanastomosis) was required more often in older patients, reflecting the possible progressive nature of endometriosis [28]. Unger and Laufer [29] showed the progression of endometriosis to a higher stage in a small case series of nonmedically managed adolescents.

The burden of CPP on individuals and the health care system necessitates examination to assess the true scope of this problem in younger women. Mathias et al [30] estimated an annual direct cost for CPP, including physician visits and out-of-pocket expenses for

patients, of \$2.8 billion in 1996, which reached nearly \$4 billion when adjusting for inflation. These staggering costs along with diagnostic delays create great burdens for society and individuals suffering from CPP. We aimed to describe and characterize rates of pelvic pain in university women ages 18 and older as well as to explore the barriers to receiving appropriate health care for pelvic pain in this unique, otherwise healthy, population.

Materials and Methods

We conducted a cross-sectional study designed to assess CPP in female students attending the University of Florida, Gainesville, FL. A random sample of 2000 female students aged 18 years and older was selected and e-mailed a fairly extensive questionnaire about various attributes of pelvic pain as well as perceived barriers to care. The random sample was compiled by the University's Office of Institutional Planning and Research. The Institutional Review Board of the University of Florida approved this study.

The questionnaire was created using the REDCap electronic data capture tool hosted at the University of Florida [31]. REDCap (available at <http://project-redcap.org/>) is a secure application used to build and manage complex online surveys. With REDCap, the questionnaire was built with specifically designed fields to capture desired types of responses, a function used to transmit the hyperlink for this questionnaire to participants via e-mail, and automated export procedures for the collected data. Participants consented to participation electronically once they followed the hyperlink to the online questionnaire.

The questionnaire included demographic items, general health and health behavior questions, measures to assess different types of pelvic pain (e.g., dysmenorrhea, dyspareunia, urinary, bowel, musculoskeletal, and vulvar), psychosocial factors, and items regarding barriers to care for pelvic pain problems. Some of these items were derived from the International Pelvic Pain Society's History and Physical Form. Health-related quality of life (HRQOL) questions from the Center for Disease Control and Preventions' HRQOL-14 Healthy Days Measure were included (2011). Branching logic was built into the survey to avoid redundancy and keep the subjects engaged, and to capture subject-specific information. For example, if participants note that they do not experience pelvic pain in the survey's initial questions, they are directed via branching logic past the items detailing pelvic pain and directly to general health questions. Three reminder e-mails were sent to subjects over 8 weeks to optimize response rates. Data were exported from REDCap into SAS statistical package (SAS Institute Inc., Cary, NC).

Statistical Methods

Quantitative and semiquantitative responses were compared by Satterthwaite corrected t tests. This allows us to compare the means between 2 groups even if the underlying variances are unequal. Because of the large sample sizes, where central limit theory applies, no distributional assumptions are made. General health is rated as excellent, very good, fair, or poor. Here the data are ordinal and analyzed by the Kruskal-Wallis test, also known as the Wilcoxon test, to compare the 2 groups. It needs to be noted that higher scores on the

Healthy Days Measures represent worse outcomes despite the name of the instrument. Two-sided p values $<.05$ are considered significant.

Although there is concern as to whether the survey responders are a generalizable sample, we did informally compare responders to the initial request for response (about 60% of the responding subjects) with those of the second request (about 40%). Their response distributions were quite similar.

Results

Of the 2000 random female students who received the survey via e-mail, 390 completed the survey for a 19.5% response rate. The mean age of this sample was 23 years (range, 18–62 years; standard deviation [SD] = 6.45). The majority of the sample (78.6%) identified themselves as white, with 9.6% identifying themselves as black or African American. The mean age of respondents' first menstrual periods was 12.5 years (range, 9–16 years; SD = 1.37); 70.4% have used hormonal contraceptives beginning at a mean age of 17.9 years (range, 12–18 years, SD = 2.53) and using them for an average of 4.7 years (range, 0–30 years, SD = 4.34). Most respondents (90.1%) have never been pregnant, whereas 4.8% have been pregnant once and 5.1% have been pregnant 2 or more times; 9.6% of respondents reported ever having been diagnosed with a sexually transmitted infection. On average, per day, respondents reported consuming 1.25 cups of caffeine (range, 0–15; SD = 1.43), drinking .45 alcoholic drinks (range, 0–5; SD = .82), and smoking .11 cigarettes (range, 0–10; SD = .87).

Attributes of Pelvic Pain

A total of 284 respondents (72.8% of total responses) reported they have experienced some form of pelvic pain in the previous 12 months. Those reporting pelvic pain were significantly younger ($p = .020$), with a mean age of 23 years compared with 25 years in those without pelvic pain. Three respondents were of postmenopausal age, but this did not significantly impact the statistical analysis. Of the 284 women reporting pelvic pain, premenstrual pain was the most common complaint (reported by 185 [65.1%]); pain after menstruation was reported by 38 (13.4%), deep dyspareunia by 97 (34.2%), deep pelvic pain after intercourse by 30 (10.6%), bowel-related pain by 109 (38.4%), and vulvar pain by 61 women (21.5%). When considering only sexually active women (218), deep dyspareunia was reported by 44.5% and deep pelvic pain after intercourse by 13.8%.

Subjects reporting pelvic pain scored significantly worse on the CDC HRQOL-14 Healthy Days Measure in physical health ($p = .013$), mental health ($p = .0014$), limitation of activities ($p < .001$), the number of sad days per month ($p = .013$), poor sleep ($p = .0019$), and general health ($p = .0027$) (Table 1). When searching for possible contributors to pelvic pain, there were no statistically significant differences between the group who reported pelvic pain and the group who reported no pelvic pain in terms of cigarette or caffeine use, age of first period, or the prevalence of other illnesses. Interestingly, women with pelvic pain reported fewer years of hormonal contraceptive use ($p = .035$) (Table 2).

Treatment for Pelvic Pain

There seemed to be an issue with seeking or accessing medical care in this population. Relatively few women with pelvic pain reported receiving adequate care. Only 75 of 284 of women who experienced pelvic pain (26.4%) reported having seen a doctor, and nearly 80% of respondents lacked diagnoses for their pain. Of the women with identified conditions, 45 of 59 (76.3%) were diagnosed in less than 6 months, and around 5% of women received incorrect diagnoses before they finally received accurate diagnoses.

Most women reported never being prescribed any medication for their pelvic pain, whereas a small fraction (2.9%) has tried at least 3 different medications. Surgery was also uncommonly performed or offered, with only 7 respondents reporting diagnostic and/or therapeutic procedures, including colonoscopies, endoscopies, and excision of cysts and endometriosis.

Barriers to Adequate Health Care

When asked what the greatest barrier was to receiving optimal care for their pelvic pain issues, 16.4% of respondents noted difficulty with insurance coverage; 11.8% cited perceived lack of physicians' knowledge, training, or comfort managing their conditions; 9.6% noted perceived lack of physicians' empathy or interest in their conditions; and 10.7% stated that they had difficulties getting appointments with appropriate physicians. Although barriers to care are difficult to further assess quantitatively, respondents provided descriptions of the difficulties they faced in searching for diagnoses and solutions for their pelvic pain. The authors present a representative sample of these responses here, many of which were provided by respondents who had not seen doctors. One respondent said she was scared to discuss her pelvic pain problem with a medical professional, whereas another stated she was embarrassed to go to a doctor because she usually waited for her urinary symptoms to improve instead of addressing the problem. Another respondent said she had not yet visited a doctor because she had spent time "thinking pain was normal." One respondent, who reported having visited a doctor, felt her age was an issue, stating she "was young when it first started and it was difficult to talk about." Another respondent cited a lack of personal knowledge regarding pelvic pain and insufficient funds to seek help as her greatest barriers. One woman who reported having seen at least 3 doctors for her pain felt her greatest barrier was a lack of agreement between her and her physician. Although she felt stress contributed to her irritable bowel syndrome symptoms, her gastroenterologist did not, and she was uncomfortable with her doctor's suggestion to switch medications every few weeks to find something that worked.

Perceived Health Status

We found a striking difference in this random sample between the group who reported being sexually active and those who reported not being sexually active regardless of pelvic pain symptoms. Subjects who are sexually active reported lower scores on physical health, mental health, and the number of worried days (Table 3). Among the students who reported pelvic pain, those who were sexually active (overall 76%) perceived their physical health and mental health to be worse ($p < .001$ and $p = .040$, respectively) than women who were not sexually active (Table 4).

Among the sexually active population in this study, women who reported pelvic pain perceived worse physical health ($p = .0037$) and mental health ($p = .0095$) and felt that these issues limited their usual activities more ($p = .0013$). They also reported more sad days per month ($p = .023$) and less rest or sleep ($p < .001$). However, this group did not perceive that their pain affected their day-to-day activities any more than did subjects not reporting pelvic pain ($p = .42$) (Table 5).

Among subjects without pelvic pain in the last 12 months, there was no difference in their perception of their physical health linked to whether they were sexually active or not. However, women without pelvic pain who were sexually active perceived their mental health to be worse ($p = .036$) (Table 6). Overall, pelvic pain was associated with more problems in sexually active subjects than in those who are not sexually active (Tables 5 and 7). Interestingly, even in women without pelvic pain, those who were sexually active reported lower perceived mental health scores (Table 6).

Discussion

The results of this study suggest that pelvic pain, including pain with menstruation, intercourse, and bowel movements, is a significant problem for younger women. Pelvic pain does not appear to be associated with any of the demographic factors explored in this study; however, women experiencing pelvic pain perceived worse physical and mental health than women without pelvic pain. Moreover, being sexually active was linked with lower mental health scores regardless of pain status.

It is impossible to ensure accurate identification of the prevalence of pelvic pain in this population. It is likely that this sample overrepresents women with pelvic pain because our response rate of 19.5% might have included more women who self-selected and felt the subject matter appealed to them because of their pain. It is not clear what the prevalence of pelvic pain is in subjects who chose not to respond to the survey. Additionally, many women may see this as a sensitive subject about which they prefer not to share information with researchers. Furthermore, the nature of symptoms can be confusing for women with or without diagnoses because many pelvic pain problems can have asymptomatic periods, can vary in severity, and can present overlapping symptoms; several pelvic pain conditions can also coexist [24–27].

Our study shows a lack of access to optimal health care for pelvic pain. Potential barriers to care included incompatibility with health care providers, finance and insurance issues, and a lack of understanding of these diseases or a lack of confidence in the need to seek help. It is also likely that the lack of patients' awareness of pelvic health and the availability of effective and specialized care for such problems may be contributing to patients' hesitation to seek care, particularly in their early reproductive years. This informational gap highlights the need for education and awareness to reach this population with accurate information regarding pelvic pain. Future research should explore associations between subtypes of pelvic pain and barriers to care because women with different symptoms may encounter different obstacles.

In particular, university women may have a difficult time receiving adequate care because they are away from their primary care providers and families, and many of them are still covered under their parents' health insurance, which may not provide adequate coverage if care is provided by out-of-network physicians. These issues may contribute to the greater diagnostic delays for adolescents (5.4 years as compared with 1.9 years for older adult women) observed by Greene et al [23], which may lead to the chronicity of pelvic pain and may render treatment more difficult [28]. It should be noted that although the respondents in this study attend university, higher education does not appear to protect women with pelvic pain from receiving delayed or inadequate care. Women with less education may fare even worse.

Finally, quality of life poses a major problem for women with pelvic pain because this cohort reported lower scores for perceived physical and mental health status. This is consistent with the findings of Mathias et al [30] that women with pelvic pain had lower general health scores and more mood disturbances. Interestingly, Mathias et al also found that women with endometriosis reported the most distress relating to pain and its interference with daily activities. In future research, separating women by symptom type might yield similarly meaningful results. The interaction among pelvic pain conditions, sexuality, and perceived mental and physical health status in this study of university women is also enlightening. It will be valuable to examine the effect of treatment of pelvic pain on sexuality and quality of life measures in future research.

This study benefited from the use of REDCap software allowing for a highly organized and precise measurement tool. Additionally, the automated data collection and export process ensured accuracy and minimized transcription errors. The content of the questionnaire was compiled from extensive research and widely used, validated measurement tools, such as the CDC's HRQOL-14 Healthy Days Measure [32] and questionnaires on vulvodynia [33]. When validated surveys could not be found, items were drawn from the International Pelvic Pain Society's Pelvic Pain Assessment form, which was compiled in 2008 based on a collaborative process with the International Pelvic Pain Society's Board of Directors and clinician members. The questionnaire captured both quantitative and qualitative information from respondents. Unlike studies focused on patients presenting with pelvic pain, this sample was collected randomly from a cohort of average healthy women through the University of Florida's Office of Institutional Planning and Research, which allowed for the comparison of women with and without pelvic pain.

This study was limited by the inherent reporting bias associated with this cross-sectional study design. The response rate of 19.5% was low and might reflect a bias toward responses from women with pelvic pain issues. There were also few pain-free controls for the comparison of lifestyle factors and quality of life ratings. Future research can aim to reach larger, more comprehensive samples of women to ensure less reporting bias. Additionally, symptoms and diagnoses were self-reported and retrospective in nature, which limits the accuracy of the data collected. On the other hand, this study design is credited by the large, homogenous sample of educated young women and the anonymous electronic survey that avoided personal data collection on such a sensitive topic. We believe that this has allowed

the survey to capture more candid responses and enlightening qualitative data that would have been challenging otherwise.

In conclusion, the issue of pelvic pain is a pressing one for young women. Efforts can be made toward reaching optimal care for these women with a focus on providing useful information and increasing awareness about pelvic pain symptoms, disorders, and the available diagnostic and treatment options. Along with expanded research initiatives, this will hopefully contribute to greater quality of life for women suffering from chronic pelvic pain.

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References

- Howard FM. Chronic pelvic pain. *Obstet Gynecol.* 2003; 101:594–611. [PubMed: 12636968]
- Jamieson DJ, Steege JF. The prevalence of dysmenorrhea, dyspareunia, pelvic pain, and irritable bowel syndrome in primary care practices. *Obstet Gynecol.* 1996; 87:55–58. [PubMed: 8532266]
- Cambitzi J. Chronic pelvic pain: causes, mechanisms and effects. *Nurs Stand.* 2011; 25:35–38. [PubMed: 21329169]
- Harel Z. Dysmenorrhea in adolescents and young adults: etiology and management. *J Pediatr Adolesc Gynecol.* 2006; 19:363–371. [PubMed: 17174824]
- French L. Dysmenorrhea in adolescents: diagnosis and treatment. *Paediatr Drugs.* 2008; 10:1–7. [PubMed: 18162003]
- Mannix LK. Menstrual-related pain conditions: dysmenorrhea and migraine. *J Womens Health (Larchmt).* 2008; 17:879–891. [PubMed: 18537489]
- Coco AS. Primary dysmenorrhea. *Am Fam Physician.* 1999; 60:489–496. [PubMed: 10465224]
- Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Am Med Womens Assoc.* 2003; 58:82–88. [PubMed: 12744420]
- Ferrero S, Ragni N, Remorgida V. Deep dyspareunia: causes, treatments, and results. *Curr Opin Obstet Gynecol.* 2008; 20:394–399. [PubMed: 18660692]
- Shin JH, Howard FM. Management of chronic pelvic pain. *Curr Pain Headache Rep.* 2011; 15:377–385. [PubMed: 21556711]
- Vercellini P, Somigliana E, Viganò P, Abbiati A, Barbara G, Fedele L. Chronic pelvic pain in women: etiology, pathogenesis and diagnostic approach. *Gynecol Endocrinol.* 2009; 25:149–158. [PubMed: 19347704]
- Hungin AP, Chang L, Locke GR, Dennis EH, Barghout V. Irritable bowel syndrome in the United States: prevalence, symptom patterns and impact. *Aliment Pharmacol Ther.* 2005; 21:1365–1375. [PubMed: 15932367]
- Modesto WO, Bahamondes L. Relationship between chronic pelvic pain and functional constipation in women of reproductive age. *J Reprod Med.* 2011; 56:425–430. [PubMed: 22010528]
- Bharucha AE, Wald A, Enck P, Rao S. Functional anorectal disorders. *Gastroenterology.* 2006; 130:1510–1518. [PubMed: 16678564]
- Simpson J, Neal KR, Scholefield JH, Spiller RC. Patterns of pain in diverticular disease and the influence of acute diverticulitis. *Eur J Gastroenterol Hepatol.* 2003; 15:1005–1010. [PubMed: 12923374]
- Humes DJ, Simpson J, Neal KR, Scholefield JH, Spiller RC. Psychological and colonic factors in painful diverticulosis. *Br J Surg.* 2008; 95:195–198. [PubMed: 17939130]

17. Zondervan KT, Yudkin PL, Vessey MP, Dawes MG, Barlow DH, Kennedy SH. Prevalence and incidence of chronic pelvic pain in primary care: evidence from a national general practice database. *Br J Obstet Gynaecol.* 1999; 106:1149–1155. [PubMed: 10549959]
18. Stollman N, Raskin JB. Diverticular disease of the colon. *Lancet.* 2004; 363:631–639. [PubMed: 14987890]
19. Liakakos T, Thomakos N, Fine PM, Dervenis C, Young RL. Peritoneal adhesions: etiology, pathophysiology, and clinical significance. Recent advances in prevention and management. *Dig Surg.* 2001; 18:260–273. [PubMed: 11528133]
20. Pitts MK, Ferris JA, Shelley JM, Richters J. Prevalence and correlates of three types of pelvic pain in a nationally representative sample of Australian women. *Med J Aust.* 2008; 189:138–143. [PubMed: 18673099]
21. Danielsson I, Sjöberg I, Stenlund H, Wikman M. Dyspareunia in women is common, particularly in younger women. Pain history and the women's age provide valuable clues for diagnosis. *Lakartidningen.* 2003; 100:2128–2132. [PubMed: 12841108]
22. Berglund AL, Nigaard L, Rylander E. Vulvar pain, sexual behavior and genital infections in a young population: a pilot study. *Acta Obstet Gynecol Scand.* 2002; 81:738–742. [PubMed: 12174158]
23. Greene R, Stratton P, Cleary SD, Ballweg ML, Sinaii N. Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril.* 2009; 91:32–39. [PubMed: 18367178]
24. Hulisz D. The burden of illness of irritable bowel syndrome: current challenges and hope for the future. *J Manag Care Pharm.* 2004; 10:299–309. [PubMed: 15298528]
25. Petersen CD, Giraldi A. Should physiotherapy be part of a multidisciplinary treatment for women with chronic pelvic pain? *Int J Clin Pract.* 2008; 62:174–175. [PubMed: 18199272]
26. Lamvu G, Tu F, As-Sanie S, Zolnoun D, Steege JF. The role of laparoscopy in the diagnosis and treatment of conditions associated with chronic pelvic pain. *Obstet Gynecol Clin North Am.* 2004; 31:619–630. [PubMed: 15450323]
27. Williams RE, Hartmann KE, Steege JF. Documenting the current definitions of chronic pelvic pain: implications for research. *Obstet Gynecol.* 2004; 103:686–691. [PubMed: 15051560]
28. Moawad NS, Guido R, Ramanathan R, Mansuria S, Lee T. Comparison of laparoscopic anterior discoid resection and laparoscopic low anterior resection of deep infiltrating rectosigmoid endometriosis. *JSLs.* 2011; 15:331–338. [PubMed: 21985719]
29. Unger CA, Laufer MR. Progression of endometriosis in non-medically managed adolescents: a case series. *J Pediatr Adolesc Gynecol.* 2011; 24:e21–e23. [PubMed: 21126894]
30. Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. *Obstet Gynecol.* 1996; 87:321–327. [PubMed: 8598948]
31. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009; 42:377–381. [PubMed: 18929686]
32. Centers for Disease Control and Prevention. *Measuring Healthy Days.* Atlanta, GA: G.C.; 2000.
33. Harlow BL, Vazquez G, MacLehose RF, Erickson DJ, Oakes JM, Duval SJ. Self-reported vulvar pain characteristics and their association with clinically confirmed vestibulodynia. *J Womens Health (Larchmt).* 2009; 18:1333–1340. [PubMed: 19743906]

Table 1Quality of life^{a,b}

Variable	Never pain Mean (SD [n])	Ever pain Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health ("not good" in past 30 days)	2.91 (2.59 [70])	3.99 (4.94 [274])	-1.08 (-1.93 to -0.23)	.013
Mental health ("not good" in past 30 days)	5.16 (4.8 [70])	7.50 (7.26 [274])	-2.34 (-3.77 to -0.92)	.0014
Poor health limited activities (past 30 days)	2.48 (2.8 [71])	4.17 (5.72 [274])	-1.69 (-2.63 to -0.75)	<.001
Pain limited activities (past 30 days)	2.13 (3.8 [71])	2.71 (4.5 [273])	-0.58 (-1.62 to 0.46)	.27
Sad days (past 30 days)	4.19 (4.48 [69])	5.89 (6.82 [269])	-1.70 (-3.05 to -0.36)	.013
Worried days (past 30 days)	8.04 (7.77 [69])	9.36 (8.83 [269])	-1.31 (-3.45 to 0.83)	.23
Sleep (not enough over past 30 days)	9.2 (7.03 [69])	12.36 (8.65 [269])	-3.16 (-5.13 to -1.18)	.0019
Energy (enough energy over past 30 days)	15.99 (8.41 [69])	14.24 (8.69 [268])	1.75 (-0.52 to 4.01)	.13
General health (%)				
Excellent	33/72 (46)	80/276 (29)		.0027 (significant difference for "excellent")
Very good	36/72 (50)	164/276 (59)		
Fair	3/72 (4)	30/276 (11)		
Poor	0	2/276 (1)		

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.

^bHigher numbers correspond with worse outcomes.

Table 2

Lifestyle factors and health behaviors

Variable	Never pain Mean (SD [n])	Ever Pain Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Age	25.4 (8.88 [74])	22.8 (5.29 [284])	2.55 (0.41–4.7)	.020
Caffeine (cups per day)	1.51 (2.16 [73])	1.19 (1.17 [281])	0.33 (–0.19 to 0.85)	.21
Cigarettes per day	0.12 (0.62 [73])	0.11 (0.94 [281])	0.0094 (–0.17 to 0.19)	.92
Alcohol (drinks per day)	0.48 (0.96 [73])	0.44 (0.78 [281])	0.034 (–0.21 to 0.28)	.78
Age of first menarche	12.7 (1.54 [73])	12.4 (1.3 [280])	0.26 (–0.13 to 0.65)	.18
Exercise (days per week)	3.39 (1.06 [72])	3.09 (1.05 [280])	0.3 (0.027–0.58)	.032
Age of starting hormonal contraception	18.3 (2.88 [54])	17.8 (2.45 [192])	0.44 (–0.41 to 1.3)	.31
Duration of hormonal contraception	6.19 (5.93 [53])	4.34 (3.74 [191])	1.85 (0.13–3.56)	.035
Anxiety/age	26.4 (14.7 [8])	16.7 (6.07 [31])	9.73 (–2.62 to 22.1)	.11
Depression/age	22 (12.48 [8])	18.53 (5.86 [30])	3.47 (–7.04 to 14)	.47
Migraines/age	18 (9.39 [10])	16.52 (4.64 [42])	1.48 (–5.33 to 8.28)	.64

p<.05 (2 sided) is considered significant.

Table 3Quality of life by sexual activity^{a,b}

Variable	Not sexually active Mean (SD [n])	Sexually active Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health	2.55 (2 [82])	4.32 (5.05 [265])	-1.59 (-2.34 to -0.84)	<.001
Mental health	5.55 (5.31 [83])	7.46 (7.24 [264])	-1.9 (-3.35 to -0.46)	.010
Poor health/activities	3.10 (4.39 [83])	4.02 (5.51 [265])	-0.92 (-2.08 to 0.24)	.12
Pain/activities	2.12 (1.6 [83])	2.73 (4.9 [264])	-0.61 (-1.30 to 0.08)	.081
Sad days	4.58 (4.62 [80])	5.83 (6.88 [259])	-1.26 (-2.58 to 0.07)	.063
Worried days	7.56 (7.08 [80])	9.54 (9 [259])	-1.97 (-3.89 to -0.06)	.043
Sleep	12.51 (8.27 [80])	11.46 (8.47 [259])	1.06 (-1.05 to 3.16)	.33
Energy	14.8 (8.21 [79])	14.6 (8.81 [259])	0.19 (-1.93 to 2.32)	.86

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.^bHigher numbers correspond with worse outcomes.

Table 4Quality of life by sexual activity in patients with pelvic pain^{a,b}

Variable	Not sexually active mean (SD [n])	Sexually active Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health	2.48 (2 [65])	4.46 (5.47 [209])	-1.99 (-2.88 to -1.1)	<.001
Mental health	6.11 (5.67 [65])	7.93 (7.65 [209])	-1.83 (-3.56 to -0.09)	.040
Poor health/activities	3.39 (4.85 [65])	4.41 (5.95 [209])	-1.03 (-2.47 to 0.42)	.16
Pain/activities	2.26 (1.66 [65])	2.85 (5.07 [208])	-0.59 (-1.39 to 0.22)	.15
Sad days	4.81 (4.94 [64])	6.23 (7.29 [205])	-1.42 (-3.00 to 0.17)	.079
Worried days	7.70 (7.13 [64])	9.79 (9.27 [205])	-1.82 (-4 to 0.36)	.10
Sleep	12.61 (8.40 [64])	12.3 (8.75 [205])	0.33 (-2.082 to 2.74)	.79
Energy	14 (7.99 [63])	14.3 (8.91 [205])	-0.31 (-2.66 to 2.03)	.79

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.^bHigher numbers correspond with worse outcomes.

Table 5Quality of life in sexually active cohorts^{a,b}

Variable	Never pain Mean (SD [n])	Ever pain Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health	2.93 (2.7 [56])	4.46 (5.47 [209])	-1.54 (-2.57 to -0.51)	.0037
Mental health	5.66 (5.07 [55])	7.93 (7.65 [209])	-2.28 (-3.99 to -0.57)	.0095
Poor health/activities	2.54 (3.02 [56])	4.41 (5.95 [209])	-1.88 (-3.01 to -0.74)	.0013
Pain/activities	2.3 (4.23 [56])	2.85 (5.07 [208])	-0.54 (-1.86 to 0.78)	.42
Sad days	4.32 (4.83 [54])	6.23 (7.29 [205])	-1.92 (-3.56 to -0.27)	.023
Worried days	8.57 (7.93 [54])	9.79 (9.27 [205])	-1.22 (-3.72 to 1.28)	.34
Sleep	8.32 (6.48 [54])	12.28 (8.75 [205])	-3.97 (-6.09 to -1.84)	<.001
Energy	15.7 (8.44 [54])	14.3 (8.91 [205])	1.34 (-1.26 to 3.93)	.31

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.^bHigher numbers correspond with worse outcomes.

Table 6Quality of life by sexual activity in patients without pelvic pain^{a,b}

Variable	Not sexually active Mean (SD [n])	Sexually active Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health	2.86 (2.18 [14])	2.93 (2.7 [56])	-0.071 (-1.49 to 1.34)	.92
Mental health	3.33 (3.16 [15])	5.66 (5.07 [55])	-2.32 (-4.48 to -0.17)	.036
Poor health/activities	2.27 (1.83 [15])	2.54 (3.02 [56])	-0.27 (-1.53 to 0.99)	.67
Pain/activities	1.47 (1.06 [15])	2.3 (4.23 [56])	-0.84 (-2.09 to 0.42)	.19
Sad days	3.73 (3.01 [15])	4.32 (4.83 [54])	-0.58 (-2.65 to 1.48)	.57
Worried days	6.13 (7.09 [15])	8.57 (7.93 [54])	-2.44 (-6.82 to 1.94)	.26
Sleep	12.4 (8.19 [15])	8.32 (6.48 [54])	4.09 (-0.71 to 8.88)	.091
Energy	17.2 (8.45 [15])	15.65 (8.44 [54])	1.55 (-3.55 to 6.66)	.54

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.^bHigher numbers correspond with worse outcomes.

Table 7Quality of life in non-sexually active cohorts^{a,b}

Variable	Never pain Mean (SD [n])	Ever pain Mean (SD [n])	Difference (95% CI)	p value (2 sided)
Physical health	2.86 (2.18 [14])	2.48 (2 [65])	0.38 (-0.95 to 1.71)	.56
Mental health	3.33 (3.16 [15])	6.11 (5.67 [65])	-2.77 (-4.95 to -0.6)	.014
Poor health/activities	2.27 (1.83 [15])	3.39 (4.85 [65])	-1.12 (-2.65 to 0.41)	.15
Pain/activities	1.47 (1.06 [15])	2.26 (1.66 [65])	-0.8 (-1.49 to -0.097)	.027
Sad days	3.73 (3.01 [15])	4.81 (4.94 [64])	-1.08 (-3.1 to 0.94)	.29
Worried days	6.13 (7.09 [15])	7.97 (7.13 [64])	-1.84 (-6.07 to 2.4)	.38
Sleep	12.4 (8.19 [15])	12.6 (8.4 [64])	-0.21 (-5.11 to 4.7)	.93
Energy	17.2 (8.45 [15])	14 (7.99 [63])	3.2 (-1.8 to 8.2)	.20

CI = confidence interval.

p<.05 (2 sided) is considered significant.

^aCenters for Disease Control and Prevention HRQOL-14 Healthy Days Measure.^bHigher numbers correspond with worse outcomes.