

Original Article

Attributes and Barriers to Care of Pelvic Pain in University Women

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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. 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. *Journal of Minimally Invasive Gynecology* (2013) 20, 811–818 © 2013 AAGL. All rights reserved.

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

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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

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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.

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