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An online survey of pelvic congestion support group members regarding comorbid symptoms and syndromes

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Abstract

Objectives: Patients with pelvic congestion syndrome (PCS) often report overlapping somatic symptoms and syndromes. The objective of this study was to explore the prevalence of co-existing symptoms and self-reported syndrome diagnoses among women with PCS and to inform future research hypotheses.

Methods: A brief online survey was offered to members of a PCS support group website. Responses were assessed for self-reported co-existing symptoms and formal diagnoses, including: chronic fatigue syndrome, fibromyalgia, postural tachycardia syndrome, irritable bowel syndrome, migraines, interstitial cystitis, and temporomandibular joint dysfunction.

Results: Of a total of 6000 members, there were 398 respondents; 232 (59%) had not yet been treated for PCS. Among these, the most prevalent co-existing symptoms were as follows: severe fatigue (72%), dizziness (63%), IBS symptoms (61%), brain fog (33%), migraines (49%), polyuria or dysuria (41%), excessive sweating (31%), TMJ pain (31%), and loose skin or lax joints (18%). These are much higher than reported for the general female population.

The most commonly self-reported comorbid syndrome diagnoses for the overall group of 398 were: irritable bowel syndrome (29%), fibromyalgia (13%), spinal nerve problems (18%), interstitial cystitis (10%), postural tachycardia syndrome (9%), hypertension (11%), chronic fatigue syndrome (10%), and Ehlers-Danlos syndrome (6%). Other than with hypertension, these rates are variably higher than in the general population.

Conclusion: Several self-reported co-existing symptoms and syndromes are more prevalent in members of a PCS support group relative to the reported prevalence in the general population. More formal investigation is warranted to evaluate this finding and to investigate potential etiologic links. Ehlers-Danlos Syndrome appears to be common in self identifying PCS women.

Keywords

pelvic congestion, dysautonomia, May-Thurner syndrome, Medical support groups, Social media survey

Introduction

Chronic pelvic pain (CPP) in women is a common medical problem that accounts for 39 billion dollars in annual direct and indirect health care costs in the United States.[1] It may also be more common in men than has been widely appreciated.[2] Studies have tried to differentiate CPP of unknown cause into different categories based on symptoms. CPP may be referred to as "myofascial pain" or "bladder pain syndrome" and has been reported to overlap with interstitial cystitis. [3–6]

Pelvic congestion syndrome (PCS) is an often-occult cause of CPP. PCS is defined as chronic noncyclic pelvic pain, of greater than 6 months duration, with worsening of pain during upright posture. [7,8] Also called pelvic venous insufficiency (PVI) now, it may be referred to as pelvic venous disease (PeVD), because of a new multi-specialty consensus.[9,10] It is often associated with dyspareunia and vulvodynia, as well as low back pain and hip pain.[8,11]

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Several reports have linked PCS/PeVD with dysuria.[12,13] It can also be associated with venous insufficiency in the lower extremities. Imaging findings may include enlargement and reflux in ovarian veins, compression of the left renal vein, and sometimes of the left common iliac vein, as well as varicosities in the ovarian and uterine venous plexuses.[7,8]

As early as 1949, Taylor described pelvic congestion syndrome patients as also having prominent severe fatigue, palpitations, and tachycardia, plus other non-gynecologic symptoms,[14] although the current literature does not include all of the somatic symptoms that Taylor did.[8,10] Informal observations from our clinical practice suggest that patients with PCS often report symptoms of other non-pelvic comorbid conditions. Moreover, after embolization and/or iliac vein stent placement for PCS, many in the authors' experience have reported significant improvement in symptoms not typically associated with pelvic venous disease. To estimate the prevalence of this overlap, we designed an internet-based survey to evaluate whether these somatic symptoms and syndromes occurred more commonly in the specific PCS patient population relative to the reported prevalence in the general population.

Methods

We identified an English language-specific internet support group site centered around pelvic congestion syndrome. The site is "closed," requiring administrator permission to join, but even so has approximately 6000 members. With the cooperation of the administrator of the Facebook Pelvic Congestion Syndrome Support Group, we designed a brief, anonymous, online survey that was presented to members of the PCS Support Group. Because no personal identifying information was collected, IRB approval was not required. The principles of the Declaration of Helsinki were followed.

Eligible participants were those who self-reported receiving a formal diagnosis of PCS by a treating physician. Using SurveyMonkey software, we asked a series of 18 general questions, including age (under 18 years, 18–24, 25–34, 35–44, 45–54, 55–64, and over 65), number of previous term pregnancies, prior diagnostic procedures for PCS, time to diagnosis, specific treatments, and the presence of specific symptoms and diagnoses. Each respondent was uniquely identified and numbered by the SurveyMonkey software so that only one questionnaire per respondent could be filed.

Many questions were included about the common symptoms associated with PCS, including pelvic heaviness, pelvic pain when upright, low back pain, hip pain, pain during or after sex, vaginal or vulvar pain, and heavy, painful legs. The specific wording used to identify symptoms associated with other somatic syndromes was: "frequent or painful urination," "severe chronic tiredness, limiting activity," "dizziness, passing out, heart flutters," "excessive sweating," "migraine headaches," "jaw disorders," "brain fog," "abdominal bloating," and "excessive gas." Participants were also asked whether they had been diagnosed by a physician with any of the following conditions: irritable bowel syndrome, endometriosis, vaginal infections, fibromyalgia, spinal nerve problems, interstitial cystitis, postural tachycardia syndrome, hypertension, chronic fatigue syndrome, Ehlers-Danlos syndrome, systemic lupus, Sjogren syndrome, and diabetes.

To compare the prevalence of symptoms and conditions in the PCS group respondents with the general population, we identified estimates of prevalence from published epidemiologic studies.

Not all respondents answered every question; skipped questions were counted as negative responses. For the prevalence of symptoms, we included only those who had not undergone treatment (since asking treated patients to recall original symptom severity introduces recall bias). For the prevalence of formally diagnosed overlapping conditions, we report the responses from the entire sample.

Results

Three hundred ninety-eight women responded to the survey. The median age category was 35–44 years, with one participant under 18 and none over 64 years. Sixty-one (15%) were nulliparous, and 16%, 37%, and 32% had one, two, or three or more pregnancies, respectively. The majority (64%) of respondents received a PCS diagnosis with imaging, while 20% received a PCS diagnosis at surgery. While 10% of respondents received a diagnosis of PCS immediately, 29% remained undiagnosed for 1– years, 27% remained undiagnosed for 2–5 years, 20% remained undiagnosed for 5–10 years, and 13% remained undiagnosed for over 10 years. Regarding the level of awareness of primary doctors or primary gynecologists about PCS, 39% of respondents indicated that their primary physicians either did not mention PCS, or claimed that the condition does not exist. Overall, 19% of respondents indicated that they were diagnosed by their primary physician and referred for treatment. The majority of respondents (232/398, 59%) had been diagnosed with PCS but not treated. Of the remainder, 24% had been treated with ovarian or pelvic embolization, 4% had stents placed (with or without embolization), and 2% had undergone open or laparoscopic surgery to ligate or reposition pelvic veins. Hysterectomy with or without oophorectomy had been performed in 6%. Six percent had been treated with physical therapy or non-Western methods alone. Twenty three percent of respondents had received a diagnosis of endometriosis in the past.

Of the 398 female respondents, 232 reported diagnoses of PCS that remained untreated. In those who had not been treated for PCS, the most prevalent symptoms referable to

Table 1. Prevalence of other medical diagnoses reported by $n = 398$ survey respondents from PCS support group (95% C.I.) compared to estimates of condition prevalence in general female population.

Diagnosed syndrome or condition	General female population %*	Formally diagnosed in PCS responders, %
POTS	1% (est.)[15,28]	9 ±3
Irritable bowel syndrome	9.4%[16]	29 ±4
Chronic fatigue	1.4%%[29,41]	7±2
Ehlers-Danlos	0.02%[17]	6 ±2
Interstitial cystitis	7.5%[16]	10 ±3
Fibromyalgia	11.8%[16,42]	13 ±4
Endometriosis	10%[43]	23 ±44

ovarian and pelvic varices were: pelvic pain when upright (84%), back pain (80%), pain during or after sex (66%), vaginal or vulvar pain (60%), heavy menses (53%), and leg swelling or painful leg veins (42%). A further 17% reported bulging veins in the vulva or buttocks.

In this same group of 232 untreated respondents, the most prevalent symptoms not directly referable to ovarian and pelvic varices were: severe chronic tiredness limiting activity (72%), dizziness or passing out (63%), IBS type symptoms (61%), brain fog (33%), frequent or painful urination (41%), migraines (49%), excessive sweating (31%), and jaw problems/TMJpain (31%). Eighteen percent of respondents said that they had loose skin or laxity of joints. These are much more common than in the general female populatiuon.

Among the entire group of 398, the most commonly self-reported formally diagnosed gynecological comorbid condition was endometriosis (23%). Non-gynecological comorbid conditions included: irritable bowel syndrome (29%), fibromyalgia (13%), spinal nerve problems (18%), interstitial cystitis (10%), POTS (9%), hypertension (11%), chronic fatigue syndrome (10%), and Ehlers-Danlos syndrome (6%). These are more commonly prevalent in the PCS group respondents than in the general population [Tables 1 and 2]. Ehlers-Danlose syndrome is excessively common in this group. Autoimmune conditions, including Lupus, scleroderma, Sjogren's syndrome, and rheumatoid arthritis, had been diagnosed in 6% of respondents.

Discussion

The main findings of this study are that symptoms suggestive of overlapping comorbid syndromes are common in self-reporting women with diagnosed PCS and that the prevalence of several comorbid medical diagnoses is also higher than in the general population. Among the untreated respondents, the most commonly reported symptoms suggestive of overlapping comorbid syndromes were severe chronic tiredness that limited activities (72%), dizziness (63%), irritable bowel symptoms (61%), and frequent or painful urination (41%). The most common self-reported comorbid diagnoses in the overall PCS diagnosed group were irritable bowel syndrome, endometriosis, fibromyalgia, interstitial cystitis, POTS, and CFS. These findings support what was described in detail by Taylor in a series in 1949.[14] Back and hip pain are known to be related to PCS and venogenic pain may cause hip pain that responds to embolization.[11]

What might the survey results tell us about the pathophysiology of the related conditions? It is known that CFS, POTS, TMJ, migraines, fibromyalgia, IBS, and interstitial cystitis are heavily inter-linked.[6,15–26] Ehlers-Danlos syndrome is linked with most of these disorders and early development of varicose veins is a known consequence of the connective tissue laxity in that condition.[27] Although drawn from subjects motivated to join a PCS support group and to answer a survey, prevalence of diagnoses other than PCS was remarkably high—up to 10 times more for the dysautonomia of hyperhidrosis than estimates for the general population.[15–18,28–32]

We know that PCS patients present with damaged, blocked, or abnormally dilated veins. This suggests a possible intrinsic venous abnormality, although with no generally agreed-upon etiology. Taylor proposed an intrinsic venous abnormality and noted fibrosis in veins and adnexae.[14]

PCS is an orthostatic syndrome, in that symptoms are strongly associated with upright posture and symptoms are improved after a night of sleep. Several of the other comorbid conditions self-reported by responders with PCS in this survey also share a strong link to orthostatic intolerance (POTS, fainting, profound fatigue, dysuria, fibromyalgia, and headache). An attractive hypothesis to explain the comorbid factors is that connective tissue laxity in vessel walls predisposes individuals to increased venous pooling in dependent vessels, and reduced return of blood to the heart, thereby contributing to orthostatic intolerance[15,17,24–26,28] and in fact a recent study showed an increased prevalence of pelvic vein abnormalities in patients with the postural tachycardia syndrome.[33] Joint laxity has also been linked to "myofascial pelvic pain."[34] In all, results of this internet survey are most

Table 2. Prevalence of other symptoms reported by n = 232 untreated survey responders from PCS support group (95% C.I.) compared to estimates of condition prevalence in general female population.

Symptom	General female population %[a]	Symptoms in PCS responders, %
Dizziness, passing out, and heart flutters	1% (est.)[15,28]	63 ±6
Severe chronic tiredness limiting activity	21–33%[41]	72 ±6
Irritable bowel symptoms	9.4%[16]	61 ±6
Loose skin or "double- jointedness"	0.02%[17]	18 ±5
Frequent or painful urination	7.5%[16]	41 ±6
Migraines	20.7%[30]	49 ±6
Jaw problems	5–33%[18]	31 ±6
Excessive sweating	2.8–4.8%[a 31,43]	31 ±6

The frequency brain fog was 33%, but no data exists for the incidence of brain fog in a general female population.
[a]Unless thought to be equal in men and women.

supportive of Taylor's 1949 description of the "congestion-fibrosis syndrome."

Although 398 respondents participated in this survey, several methodological limitations are important to acknowledge. First, it is unclear whether individuals who participate in online support groups represent a different subgroup from the general population of those with PCS/PeVD, or from those who seek treatment. Second, the survey relies on self-reported medical conditions by members of the disease group being studied and there was no independent confirmation through chart review. Third, there are known biases in information from volunteers, who may differ from an overall population.[35–37] Possibly, the presence of chronic pain leads to central sensitization such that minor pain generators result in minimal or no distress to unsensitized individuals result in significant symptoms in sensitized ones.[38] This phenomenon might account for the significantly higher percentage of additional symptoms and diagnosis in our survey population.[19] Still, many of the questions related to pelvic pain, general demographics, and questions about other symptoms were mixed in with those of special interest.

An advantage of the online survey is that, theoretically, respondent's complaints are not filtered through a physician-investigator's focused interpretation. A survey of a support group is an "outreach" approach to clinical data gathering, with the promise of communication with a concentrated group of self-reported sufferers. In a recent study published in *The American Journal of Medical Genetics*, Glayzer et al. recruited women with EDS or HSD (joint hypermobility) via social media to fill out a survey of comorbid conditions. As in our survey, results were compared with women in the US population at large. They found a higher rate of vulvodynia vs published incidence for the general population (50% vs 8%) in the EDS/hypermobility group, and high rates of fibromyalgia, TMJ dysfunction, and mast cell activation syndrome.[39] The same weaknesses of self-reporting were considered to be balanced by access to a large group of patients[40] with an uncommon condition. Indeed, Facebook now has billions of users and many thousands of medical support groups that are increasingly seen as a valuable resource for medical and public health investigations.[41] The ability to reach out to a group of PCS/PeVD sufferers directly is a new approach to this poorly understood entity.

The results of this survey study warrant a more formal evaluation of the prevalence of particular comorbid conditions in patients with PCS using more comprehensive and standardized questionnaires, within a controlled clinical trial setting. Surveys of support groups can generate hypotheses for future study. Given the similarity with findings from studies of chronic pelvic pain, our survey results emphasize the need to evaluate CPP patients more specifically for PCS/PeVD, as well as the comorbid conditions that show clear increased prevalence in this PCS group relative to the prevalence seen in surveys of the general population.

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Contributorship

SJS: author who conceived the study, MJS: author and editor who compiled data and organized manuscript, LES: author, BC: research assistant who helped to compile data, BHS: author and statistician who guided statistical methods, NK: author who assisted in compiling data, and PR: author and editor.

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