PILOT STUDY

A pilot study of the prevalence of leg pain among women with endometriosis

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Summary   Radiating leg pain is a common symptom presenting in manual therapy practices. Although this symptom has been reported as a complication of endometriosis, its prevalence and characteristics have not been studied. We surveyed members of a national endometriosis support group with endometriosis using a self-administered, mailed questionnaire. The main outcome measures were the prevalence and characteristics of leg pain. Of 94 respondents, leg pain was reported by 48 women (51%), and was bilateral in 59% of these symptomatic women. The likelihood of experiencing leg pain was related to weight gain since age 18, age, and height. The most common treatments tried included exercise, over-the-counter medications, and massage therapy, all with variable results. These data support leg pain as a prevalent complication of endometriosis, and that the disease may affect multiple peripheral nerves. Manual therapists should remain aware to this possible etiology for radiating pain.
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Introduction

Endometriosis is the third leading cause of gynecologic hospitalization in the United States (Eskenazi and Warner, 1997). Despite the high health care costs and morbidity associated with endometriosis, the etiology of endometriosis has not been fully delineated. The pathophysiology likely includes hormonal, anatomic, genetic, and immune factors. Risk may be associated with factors that increase the volume, frequency, and duration of retrograde menstruation and promote implantation and growth of endometrial plaque (Oral and Arici, 1997).

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Women with endometriosis have been hypothesized to have a greater risk of chronic, cyclic leg pain that is independent of any referred dysmenorrheal pain. However, the prevalence of leg pain from all causes among women with endometriosis is unknown. A search of the literature revealed numerous case studies of sciatica due to endometriosis, and outcomes of surgical interventions that confirmed the origin of pain as from endometrioma on the lumbosacral plexus or intrapelvic sciatic nerve (Binkovitz et al., 1991; Bjornsson, 1976; Denton and Sherrill, 1955; Descamps et al., 1995; Dhote et al., 1996; Papapietro et al., 2002; Takata and Takahashi, 1994; Torkelson et al., 1988; Vaisberg, 1964; Yekeler et al., 2004; Zager et al., 1998). Leg pain was incidentally reported by >40% of the 4000 respondents to a survey by the Endometriosis Association (Sinaii et al., 2008), but specifics of the pain (location, timing, duration) were not assessed. These data suggest that endometriosis involving peripheral nerves is a common cause of leg pain in women. While the direct involvement of peripheral nerves has been referred to as "unusual" (Binkovitz et al., 1991) and "rare" (Dhote et al., 1996) (Torkelson et al., 1988; Yekeler et al., 2004), under-recognition of leg pain among women with endometriosis has been cited (Zager et al., 1998). This may be in part because the symptoms are similar to those often attributed to pathologies of the spinal structures, such as lumbar intervertebral discs, paraspinal muscles, and joints. Manual therapists are likely to encounter patients with leg pain due to endometriosis, and need to recognize this etiological possibility.

Because there had not been a formal determination of the prevalence and details of leg pain existing with endometriosis, we performed a survey designed to elucidate details about leg pain that may coexist or be caused by endometriosis.

Materials and methods

This research was approved by the Institutional Review Board of the Beth Israel Deaconess Medical Center.

Study population and data collection

The Endometriosis Association is a national support group in the United States that is focused on progress in treatment and research of endometriosis. A total of 306 members with the disease who resided in the geographic vicinity of Boston, Massachusetts were mailed a 4-page questionnaire to be completed and returned in a postage paid envelope. The time allowed from initial mailing to receipt of the final questionnaire was 3 months. No repeat mailings or other methods to increase response rate were employed. Because endometriosis is sufficiently validated by self reporting when a woman reports laparoscopic confirmation (Missmer et al., 2004), the first question asked was whether endometriosis had been confirmed laparoscopically. Women who did not report laparoscopic confirmation were not asked to complete the questionnaire and were not included in the results. The questionnaire then asked details of demographic and anthropometric characteristics, reproductive history, and pain symptoms. Those who reported suffering from leg pain were asked to provide details of their pain including clinical help sought and treatments attempted. In addition, they completed pain drawings.

Analysis of the pain diagrams was performed with acknowledgment of the limitations regarding the determination of the involved nerve(s), which is difficult even during clinical evaluation, particularly when deep pain is involved. As previously performed (Bove et al., 2005), we subdivided the leg into 4 regions: proximal anterior (hip to knee), distal anterior (knee to foot), proximal posterior, and distal posterior. Respondent marks within these boundaries were counted as noting presence of pain in this region of the leg.

Statistical analysis

Using SAS Statistical Software Version 8.2 (SAS Institute Inc., Cary, NC), we compared the distribution of demographic, anthropometric, dietary intake, and reproductive

Table 1 Characteristics associated with leg pain among responding women with laparoscopically confirmed endometriosis, compared to responding women without leg pain [$n = 48$ of 94 (51%)].

Participant characteristic	UV OR (95% CI)	p-value[a]
Time since diagnosis of endometriosis (years)	0.96 (0.91–1.02)	0.15
Current age (years)	0.96 (0.93–1.01)	0.09
Current height (inches)	0.87 (0.74–1.02)	0.08
Current weight (pounds)	1.01 (0.99–1.02)	0.39
Weight at age 18 (pounds)	0.99 (0.97–1.01)	0.49
Weight change since age 18 (pounds)	1.02 (1.00–1.04)	0.06
Current body mass index (kg/m^2)	1.07 (0.98–1.16)	0.13
Currently overweight (BMI $\geq$ 25 kg/m2)	2.07 (0.90–4.77)	
Body mass index at age 18 (kg/m^2)	1.02 (0.89–1.18)	0.73
Age at menarche	1.20 (0.85–1.69)	0.30
Ever used oral contraceptives	1.80 (0.40–8.07)	
Parous	1.00 (0.44–2.29)	
Currently pregnant or lactating	0.58 (0.09–3.63)	
Hysterectomy	1.02 (0.34–3.12)	
Postmenopausal	0.60 (0.23–1.56)	

UV OR = Univariate odds ratio, CI = Confidence interval.
[a] Two-sided Wald statistic p-value, test for linear trend.