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The Evil Twins of Chronic Pelvic Pain Syndrome: Endometriosis and Interstitial Cystitis

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ABSTRACT

Objective: To determine the value in the initial laparoscopic and cystoscopic evaluation of avoiding the unnecessary delay in diagnosing the "evil twins" of chronic pelvic pain syndrome, endometriosis and interstitial cystitis.

Methods: We performed a retrospective review of 60 women ranging in age from 19 to 62. They underwent concurrent laparoscopy, cystoscopy, and hydrodistentions from January 1999 to October 2000. A gynecology and urology team performed these procedures in these 60 patients at a regional pelvic pain center in Northwest Ohio.

Results: Fifty-eight patients (96.6%) were diagnosed with interstitial cystitis by the presence of glomerulation and terminal hematuria according to National Institutes of Health criteria. A diagnosis of (active and inactive) endometriosis was found in 56 patients (93.3%). Biopsy-confirmed active endometriosis was found in 48 patients (80%). In the interstitial cystitis patient group (58), 54 patients had a diagnosis of (active and inactive) endometriosis (93.1%), and 47 patients had biopsy-confirmed active endometriosis (81%). In the group of 56 patients with a diagnosis of (active and inactive) endometriosis, 54 patients were found to have interstitial cystitis (96.4%). In the group of 48 patients with active biopsy-confirmed endometriosis, 47 have interstitial cystitis (97.7%).

Conclusion: Patients with chronic pelvic pain syndrome are very difficult to manage. Eighty percent were found to have endometriosis and had numerous previous operations. Many patients failed to respond to multiple therapies. In many cases, pain persists even after a hysterectomy. Through our study, we showed the high prevalence and association of interstitial cystitis and endometriosis, the evil twins of chronic pelvic pain syndrome. It is absolutely necessary to perform both laparoscopic and cystoscopic examinations concurrently with the patient anesthetized in the initial evaluation and treatment of chronic pelvic pain syndrome to avoid unnecessary delay in making the diagnosis of the evil twins, because chronic pelvic pain syndrome can be caused by either or both of these entities. It is very important to have the gynecologists and urologists working as a team in making an early diagnosis to resolve these chronic debilitating diseases.

Key Words: Endometriosis, Interstitial cystitis, Cystoscopy, Hydrodistention, Pelvic pain.

INTRODUCTION

Chronic pelvic pain is estimated to affect 1 in 7 women, or approximately 9 million women in the United States, with associated health care costs approaching $3 billion annually.[1] The vast majority of patients with chronic pelvic pain (CPP) do not seek treatment, and less than 20% consult a gynecologist. Approximately 20% to 40% of laparoscopies are done for CPP.[2]

In the gynecologic literature, chronic pelvic pain is associated with endometriosis in 30% to 87% of cases.[3-9] Endometriosis has been regarded as one of the most common causes of chronic pelvic pain that affects an estimated 5 million women in the US.[10] A definitive diagnosis of endometriosis requires an operative laparoscopy evaluation. Even with new advances in treatment of this disease, the rate of recurrence remains as high as 50%.[11] To make matters worse, it is considered a progressive disease in more than 60% of patients.[12] This often leads to numerous surgeries, including laparoscopies and even hysterectomies. Treatment of endometriosis-related chronic pelvic pain remains challenging to clinicians and the results have not been satisfactory.

Although endometriosis is very common, interstitial cys-

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titis, which is emerging as a more common disorder than previously recognized, should also be considered. It is estimated that as many as 2.5 million women in the US may be suffering from interstitial cystitis, and until recently, interstitial cystitis was underdiagnosed as a cause of CPP.[13] Several possible reasons exist as to why interstitial cystitis has not been recognized as the cause of pelvic pain. First, gynecologic teaching traditionally does not focus on syndromes originating from the bladder. Likewise, urologic and gastrointestinal training has not focused on pelvic pain syndromes.[14]

In this study, we verified the association of the 2 diseases in patients with chronic pelvic pain and suggest that laparoscopy and cystoscopy/hydrodistention should be performed initially to avoid unnecessary delay in making the diagnosis of the two most common conditions in chronic pelvic pain syndromes.

METHODS

From October 1999 to October 2000, 60 women from ages 19 to 62 presented to the Midwest Regional Center for Chronic Pelvic Pain with complaints including dyspareunia and dysmenorrhea, with or without urinary symptoms like urinary frequency, urgency, nocturia, hesitancy, and sensation of incomplete emptying for more than 6 months of duration. They all underwent a physical examination with findings including abdominal-pelvic tenderness, uterine tenderness, and bladder tenderness. Laboratory studies included negative urine cytology and urine and genital cultures. The gynecology and urology teams then performed concurrent laparoscopic, cystoscopic, and hydrodistention evaluations. Intraoperative laparoscopic findings were not revealed to the urologists at the time of surgery. The urologist performed cystoscopy and hydrodistention after the laparoscopic evaluation was completed.

An endometriosis diagnosis was confirmed by biopsy, and the disease was treated by surgical excision. An interstitial cystitis diagnosis was made according to NIH guidelines, including the presence of glomerulation and terminal hematuria by either one of the urologists. The urologic procedure was carried out with sterile water under 80 to 100 cm of hydrostatic pressure; the bladder was distended for at least 2 minutes. The study results were then obtained from operative reports and chart reviews.

RESULTS

In the study group of 60 patients with chronic pelvic pain, 58 (96.6%) were diagnosed with interstitial cystitis with the presence of glomerulation and terminal hematuria by the urologists according to NIH criteria.

A diagnosis of endometriosis was found in 56 patients, whereas 8 patients (14%) had a history of endometriosis but with a negative finding in the current laparoscopy evaluation. Forty-eight patients (80%) had biopsy-confirmed active lesions at surgery. Over 80% of patients had both diseases at the same time.

Forty-five patients (75%) with chronic pelvic pain had irritable urinary symptoms. In the interstitial cystitis group of 58 patients, 45 (77.5%) had urinary symptoms; and in the endometriosis group, 43 (76.5%) had urinary symptoms. This finding indicated that at least 25% of all study patient groups had no urinary symptoms.

In the interstitial cystitis group (58 patients), 47 patients (81%) had biopsy-confirmed active endometriosis, and 7 (12%) had a history of endometriosis but a negative laparoscopy in the current evaluation.

In the group of 56 patients diagnosed with either a history of or active endometriosis, 54 (96.4%) were also found to have interstitial cystitis on cystoscopy and hydrodistention. In the biopsy-confirmed active endometriosis group of 48 patients, 47 (97.7%) had interstitial cystitis.

In the patient group with negative laparoscopy findings, the majority improved in their symptoms after a cystoscopy/hydrodistention, which indicated that interstitial cystitis could have been the cause of their pelvic pain and not endometriosis despite their previous history of the disease.

DISCUSSION

Patients with chronic pelvic pain syndrome are difficult to manage. Endometriosis has been considered the most common diagnosis in women with CPP. At least 80% of chronic pelvic pain is associated with endometriosis.[4-9] On the other hand, support for a laparoscopic diagnosis comes from data demonstrating that endometriosis can be found in 60% of asymptomatic patients[15] and that progressive disease exists in close to 60% of patients overall.[12] However, the definitive diagnosis of endometriosis

is still by laparoscopy.

Diagnosing endometriosis can sometimes be difficult and is also surgeon-dependent. Surgeons are urged to obtain a confirmed biopsy, and it will often remain unclear whether the implants or adhesions found at surgery are the specific causes of patients' pain. Therefore, even in the presence of endometriosis, suspicion of other causes of chronic pelvic pain is warranted, particularly in patients who do not respond adequately to treatment.

Although laparoscopic excisional surgery offers a better success rate in treating endometriosis,[16,17] it also requires a higher level of surgical skills. It is unfortunate that many patients might have inadequate surgical treatment that could lead to persistent and recurrent disease as well as with all of these variables, thus making the diseases difficult to manage. Many patients have gone through numerous laparoscopies and have had a hysterectomy yet still suffer from chronic pelvic pain.

Endometriosis involvement of the urinary tract has been reported in 16% of women undergoing a laparotomy for endometriosis.[18] Evaluating patients' urinary symptoms is part of the routine in our chronic pelvic pain center. As a result, a cystoscopy was performed on many patients with chronic pelvic pain therefore leading to our findings and conclusion of this study.

Interstitial cystitis has always been ignored as a major disease that causes chronic pelvic pain. In our study, we have shown through cystoscopy and hydrodistention findings that over 90% of chronic pelvic pain patients have interstitial cystitis. In addition, 80% of CPP patients have biopsy-confirmed endometriosis. Just by simple mathematical calculation, over 70% of chronic pelvic patients suffer from both diseases. If cystoscopy were performed in only 75% of chronic pelvic pain patients based on a positive finding from urinary symptoms, 25% of the interstitial cystitis diagnoses would have been missed. If cystoscopy is only performed later after a negative laparoscopy, not only do you put the patient through 2 separate anesthesia procedures but also a majority of patients (80%) with a diagnosis of interstitial cystitis would have been missed!

The results of our study demonstrate the high prevalence and association of the 2 diseases, interstitial cystitis and endometriosis, the evil twins of chronic pelvic pain syndrome. Results of other studies have been similar.[19,20] It is absolutely necessary to perform both endoscopic examinations concurrently with the patient anesthetized in the initial evaluation and treatment of chronic pelvic pain syndrome to avoid unnecessary delay in making the diagnosis of the evil twins because chronic pelvic pain syndrome can be caused by either or both of the evil twins. It is very important to have gynecologists and urologists working together as a team in making an early diagnosis to avoid missing a chance to resolve these 2 chronic debilitating diseases. It may also serve to avoid some unnecessary future surgeries.

References:

1. Mithias SD, Kuppermann M, Liberman RF, Lipshutz RC, Steege JF. Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. *Obstet Gynecol*. 1996;87:221-327.

2. Reiter RC. A profile of women with chronic pelvic pain. *Clin Obstet Gynecol*. 1990;36:253-259.

3. Cunanan RG Jr, Ciurey NG, Lippes J. Laparoscopic findings in patients with pelvic pain. *Am J Obstet Gynecol*. 1983;146:589-591.

4. Kontoravdis A, Hassan E, Hassiakos D, et al. Laparoscopic evaluation and management of chronic pelvic pain during adolescent. *Clin Exp Obstet Gynecol*. 1999;26:76-77.

5. Ling FW. Randomized controlled trial of depot leuprolide in patients with chronic pelvic pain and clinically suspected endometriosis. Pelvic Pain Study Group. *Obstet Gynecol*. 1998;92: 1029-1032.

6. American College of Obstetricians and Gynecologists. *ACOG Practice Bulletin #11*. Washington, DC: American College of Obstetricians and Gynecologists; December 1991:1-14.

7. Koninckx PR, Meuleman C, Demeyere S, et al. Suggestive evidence that pelvic endometriosis is a progressive disease whereas deeply infiltrative endometriosis is associated with pelvic pain. *Fertil Steril*. 1991;55:759-765.

8. Carter JE. Combined hysteroscopic and laparoscopic findings in patients with chronic pelvic pain. *J Am Assoc Gyn Laparoscopists*. 1994;2(1, pt 1):43-47.

9. Ripps B, Martin D. Focal pelvic tenderness, pelvic pain and dysmenorrhea in endometriosis. *J Reprod Med*. 1991;36:470-472.

10. Ballweg ML. Public testimony to the U.S. Senate Committee on Labor and Resources, Subcommittee on Aging; May 5, 1993; Washington, DC.

11. Giovanni B. Recurrent endometriosis. In: Nezhat CR, Buttram VC Jr, eds. *Endometriosis. Advanced Management and Surgical Techniques*. New York, NY: Springer-Verlag; 1994:159-171.

12. Mahmood TA, Templeton A. The impact of treatment on the natural history of endometriosis. *Hum Reprod*. 1990;5:965-970.

13. Ratner V. Controversies that adversely affect interstitial cystitis. *Urology*. 2001;57(6, Suppl 1):89-94.

14. Kohli N, Sze HM, Karram M. Gynecologic aspects of interstitial cystitis. In: Sant G, ed. *Interstitial Cystitis*. Philadelphia, Pa: Lippincott-Raven Publisher; 1997:153-164.

15. Moen MH. Is mild endometriosis a disease? Why do women develop endometriosis and why is it diagnosed? *Hum Reprod*. 1995;10:8-11.

16. Winkel CA. Combined medical and surgical treatment of women with endometriosis. *Clin Obstet Gynecol*. 1999;42(3):645-663.

17. Redwine DB. Aggressive laparoscopic excision of endometriosis of the cul-de-sac and uterine sacral ligaments. *L Am Assoc Gynecol Laparosc*. 1997;494:540-541.

18. Williams TJ, Pratt JH. Endometriosis in 1,000 consecutive celiotomies: incidence and management. *Am J Obstet Gynecol*. 1977;129-245-252.

19. Clemons J, Arya LA, Myers DL. Diagnosing interstitial cystitis in women with chronic pelvic pain. *Obstet Gynecol*. 2001;97(4, suppl 1):S7.

20. Seitzinger MR. Correlation of endometriosis with interstitial cystitis. *J Am Assoc Gynecol Laparosc*. 2000;7(3, suppl 5):S57. Abstract 195.

Disclosure: Maurice K. Chung, RPh, MD, FACOG, ACGE and others involved in this study have no financial interest in any commercial device, equipment, instrument, or drug discussed in this article.