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VISION

THE INTERNATIONAL PELVIC PAIN SOCIETY
Professionals engaged in pain management for men and women.

IPPS

THE INTERNATIONAL PELVIC PAIN SOCIETY

Complementary and Alternative Medicine and Web-Based Research

Recent surveys have found that roughly one-third of the population now use complementary and/or alternative medicine (CAM), people with chronic pain (CP) are among the most frequent users, and nearly 70% often don't tell their physicians (1 – 4). CAM therapies specifically for female chronic pelvic pain syndrome (CPPS) have not been systematically investigated. However, in the past 15 years, there have been some studies of biofeedback, acupuncture, hyperthermia, electrostimulation, and herbal and nutritional supplements for CP/CPPS (5).

Published findings from randomized clinical trials (RCTs) of CAM modalities are frequently inconclusive and often do not concur with the experiences in actual clinical practice. In real world settings, patients self-refer and their preferences may influence their outcome. Also, many CAM interventions are difficult to evaluate. For example, subject and practitioner blinding, finding a comparable placebo or sham procedure, defining and measuring outcomes that are meaningful to the patient, all are problematic. Furthermore, unless clinical trials include patients with co-morbid conditions, the results may not generalize to the general population.

Well-designed observational studies can reflect the conditions of actual clinical practice. They can be conducted over the Internet. Computer-administered questionnaires are well accepted (6, 7), and they appear to be equivalent to paper-and-pencil instruments (8, 9) on some factors. Some people disclose more on a computer form than they do in an interview or on a paper form (10).

Patients are using the Internet to get information about their medical conditions. Researchers are using it to conduct multi-site trials. Practice groups are creating web-based practice networks. Thus, the Internet can provide a research infrastructure linking patients with CAM and conventional researchers to collaborate and to answer such important questions as: who uses CAM, how CAM treatments affect the natural course of a disorder, and who gets better?

One such web-based tool is PROCAIM, http://www.procaim.org. PROCAIM was developed at UCLA to study the interactions among CAM and conventional therapies, symptoms, pain, stress and coping, mood and well-being among patients treated for CP, fibromyalgia, interstitial cystitis, and other chronic conditions. There is no need for physician involvement: the individual patient just enrolls and provides IRB-approved consent on-line. All responses are confidential. Other enrollment options are available if physicians wish to monitor their patients' responses. For further information about PROCAIM or CPPS, contact the authors.

Deborah Ackerman, MS, PhD
UCLA School of Public Health
Deborah.Ackerman@ucla.edu

Andrea Rapkin, MD
UCLA School of Medicine
ARapkin@mednet.ucla.edu

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The President's Perspective

To Lump or to Split?

John Steege, MD

Classical medical training teaches us to reduce a patient's list of diagnoses as much as possible: the principle of parsimony. A generation or two ago, pelvic pain was treated the same way. Imaging methods were limited, diagnostic access to the pelvis limited (prior to laparoscopy), and conceptualization of illness influenced by the mind-body split. At the risk of gross generalization, when organic pathology was not evident on pelvic examination, pelvic pain was attributed to psychological factors. Psychometric assessments found that as a group, women with pelvic pain had more depression and a higher frequency of personality disorders. When laparoscopy became commonplace and pathology was more often found, parsimony compelled labeling the pathology as the source of pain. Lumping happened. Indeed, some early pelvic pain clinics accepted only patients with a normal pelvis as visualized at laparoscopy.

We've come a long way from that time. Or, have we?

The past three decades have seen major advances in pelvic imaging, and the ready use of laparoscopy has allowed us to look at anatomic detail to the point of cataloguing minutia. In addition, our clinical perspective has expanded beyond the female reproductive tract to include surrounding visceral and somatic structures. As a result, we have accumulated a growing list of disorders, all of which might be pain generators in some women some of the time: peritoneal windows, uterine retroversion, hernias, non-pigmented endometriosis, pelvic congestion, ovarian vein varicosities, bladder glomerulations, levator spasm, myofascial trigger points, vulvar vestibulitis, irritable bowel syndrome, etc. Each of these maladies has generated its own list of treatments, some of them surgical. The true efficacy of some of these surgeries, together with the powerful placebo effect of surgery and the great difficulty of doing sham-surgery-controlled trials, has produced a devoted following for each procedure.

With each of these entities having its moment in the sun, each its champions, we have become splitters.

We would all love the opportunity to study pure populations of patients with each of these disorders, in order to characterize the typical symptom profile, develop diagnostic criteria based on history and physical examination, develop validated screening questionnaires, and conduct randomized double-blinded placebo-controlled treatment trials. So far, efforts to do this have been disappointing. For example, the PUF scale, designed to detect interstitial cystitis: a patient with pelvic pain can easily reach a high score without having any bladder symptoms at all. It may function well in a clinical population with only bladder symptoms, but in a more general clinical population, it loses specificity rapidly.

Enter the mathematician: if each of these disorders is its own independent entity, then the statistical probability of finding more than two of them in one person becomes miniscule.

Yet most of us regularly see patients with three or more of the above. The medical record reeks of alphabet soup: IBS, FM, CFS, IC, TMD, and others often listed in the same note. As diagnoses proliferate, so do treatments. Early genetic studies now suggest there may exist a neurophysiologic common ground for these problems: alterations of central neurotransmitter pathways that may link to symptoms in one or more peripheral organ systems simultaneously. Is this the neurophysiologic equivalent of Engel's "pain-prone personality"?

When do we reach the point that listing multiple diagnoses becomes detrimental to the patient, and not a help? How often can we really say that each of these syndromes is present in its complete form? Isn't it more likely that one or two are the initiators, and others chime in (in somewhat muted form) as time goes on, partly in response to medical labeling, partly due to genetic predisposition, and partly in response to a growingly negative set of expectations in the patient, reinforced by her interactions with the medical world?

Future treatments for chronic pelvic pain are likely to include many that are not organ-specific: posterior tibial nerve (PTN) stimulation and other neuromodulation techniques, kappa opioids for visceral pain, physical therapy with a general rehabilitation approach, and alternative therapies. Our challenge as clinicians is to integrate these approaches with well chosen, and hopefully limited, organ-system-specific treatments, in a thoughtful treatment plan. This plan must be presented to the patient with a positive approach, helping her to reach out for her own strengths, and pursue health, rather than see herself as the unfortunate statistical anomaly with multiple independent illnesses. Our role as healers may be better served by optimistic lumping (progressive parsimony?), rather than splitting that may serve to overwhelm the patient.

Join Us

Please join us in educating ourselves on how best to treat chronic pelvic pain. With your help, we can provide relief and a more normal lifestyle for our patients. For membership information, please call (847) 517-8712 or visit our website at www.pelvicpain.org.

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Mark Your Calendars!

IPPS Annual Meeting
October 16 – 18, 2008
Buena Vista Palace Hotel & Spa
Lake Buena Vista, Florida

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Thank you.

THE INTERNATIONAL PELVIC PAIN SOCIETY

Two Woodfield Lake
1100 E. Woodfield Drive, Suite 520
Schaumburg, IL 60173-5116
Phone: (847) 517-8712
Fax: (847) 517-7229
Website: www.pelvicpain.org

The International Pelvic Pain Society
Two Woodfield Lake
1100 E. Woodfield Drive, Suite 520
Schaumburg, IL 60173-5116