1. You specialize in raising awareness for and treating chronic pelvic and sexual pain. What might be some causes of these issues? Is this preventable?

In 2001, I was asked to design a fresh approach to assessment, diagnosis and management of female chronic pelvic pain (CPP). Too many young women were getting invasive diagnostic and therapeutic procedures that either were not diagnostic or in fact very misleading. I had already practiced Ob/Gyn for 35 years and thought I knew most everything about pelvic pain. However, my involvement into these issues soon began teaching me that the typical gynecologic reasons for pain such as endometriosis, ovarian cysts, adhesions, pelvic inflammatory disease, STDs, etc. were only the tip of the iceberg regarding CPP. I started going to conferences on generalized pain, reading pain journals, and gathering more and more information about the science of pain which has exploded over the past 10 to 15 years.

Several text books on CPP had already been published, and it was becoming more and more obvious in the research into pain that what we had been taught and what currently is still being taught in women's health training programs about pain assessment and management was greatly in need of catching up to the rapidly evolving research.

In short, what I found was that studies were indicating that CPP in women (and indeed men as well), was a much more complex array of multiple “triggers”, both visceral (bladder, lower bowel, and reproductive organs), and “somatic” (all of the rest of the pelvic structures) including all of the muscles, ligaments and nerves in the pelvic region.

As a matter of fact, I tell my patients now that even though I won the anatomy prize in medical school, I then spent the next 35 years delivering babies and operating on the reproductive organs, while “forgetting” that there were even nerves, muscles or ligaments in the pelvis.

Consequently, our program now is actually a pain management program for what has been described in the literature as a chronic regional pain syndrome (CRPS) of the pelvis. According to the International Pelvic Pain Society (IPPS) www.pelvicpain.org, CPP is one of the most common medical problems of women between the ages of 18 to 50 (affecting up to 15 to 20%). Shockingly, 61% of CPP remains incompletely or incorrectly diagnosed, and millions of women are referred from specialist to specialist and are often led to believe that the problem is “in their heads”.

Because we specialize in this type of pain, we see many serious consequences of delays in diagnosis, and women who have suffered for years and even decades with multiple issues, both physical and emotional. Importantly, close to 90% of CPP sufferers have some degree of sexual pain as well, thereby affecting their intimate relationships, causing increasing stress and more serious emotional sequelae. A great deal of this long term suffering and dysfunction can be prevented by much earlier awareness and vigilance on the part of young women themselves, their parents, and their health care providers even as their teenage years.

2. What are some treatment options for chronic pelvic pain? What about sexual pain?

Treatment options obviously depend on the specifics of the diagnostic assessment. We commonly see multiple “triggers” of pain in the pelvic region, but regardless of which diagnoses, our model in general is to:

- Find and treat the “triggers” – this could be any combination of urinary bladder, lower bowel, or reproductive tract dysfunctions (all visceral or organ dysfunctions) and previous histories of any number of physical or emotional traumas, such as sports injuries, childbirth, pelvic surgeries, or emotional, physical, or sexual abuse. Many of these traumas become permanently embedded patho-physiologically resulting in long term nervous system and muscle “memories”.
- Treat the chronic pain itself as the bottom line “diagnosis”. This will involve treating both long term neuropathic (nerve generated) and inflammatory pain (as in auto-immune disorders – which commonly are associated with chronic pain disorders).
- Treat the ever present myofascial pain and trigger points that are virtually always present as a result of the body’s natural sense of bracing or protecting itself. In this case the “core” muscles may already have been in severe spasm and “clenching” for years. This treatment involves specialized pelvic floor physical therapists.
- All modalities are used including topical ointments for vulvar and vestibular pain and inflammation, neurolytic pharmaceuticals for neuropathic pain, anti-inflammatory and acute pain medications to break the cycle of pain, anxiety, and spasm, specialized pelvic floor PT, massage therapy, mind/body relaxation techniques, bladder instillation treatments, peripheral nerve blocks, psychological counseling, and any other modalities that the patient finds helpful to relieve her specific pain symptoms.

3. Have you seen an increase in the rate of pelvic/sexual pain diagnoses over the past several years? If so, to what might you attribute this change?

Because I specialize in chronic pelvic and sexual pain, I certainly see increasing numbers of very severe women and even some men with these devastating conditions. Invariably we find that with a careful history (previously sent out lengthy questionnaire) and time spent on that first visit (often more than 2 hours), we realize, as does the patient, that she commonly could have been diagnosed much earlier in the course of her problems. I believe that these complex conditions have always been prevalent in medical practice, but I do know that I missed many of these diagnoses as a gynecologist due to my years of ignorance of how chronic pain integrates so closely and so often with numerous pelvic conditions.

However, there is one factor that seems to be very significantly increased in more recent years. The numbers of pelvic and sexual pain in younger women have gotten even higher than before. We are finding that more and more of our patients under age 35 – 40 appear to include an increased history of participation in variable sports activities. Over the past 20+ years, girls and women’s sports have overwhelmingly become so common a part of the lives of our children, youth, high school and collegiate level young women.
In his recent book "Warrior Girls – Protecting our Daughters against the Injury Epidemic in Women’s Sports", author Michael Sokolove, an investigative reporter from the NY Times, found that since Title IX, the numbers of girls in sports has increased dramatically and the levels of training, managing, coaching, and parental knowledge of the physical risks involved in these activities has not kept up with prevention and early understanding of the consequences of the injuries that are commonly incurred, especially in the girls that do the same one or two sports throughout their young lives.

So we do see in our CPP and sexual pain program an increasing and significant percentage of histories of gymnastics, dance, cheerleading, soccer, basketball, volleyball, track and field, field hockey, etc. Lower extremity, pelvic, coccygeal, and low back injuries are also extremely common in all of these and other sports.

The typical prototype of the young woman who ends up seeing us years or decades later is a girl between her mid to late teens and mid 20s, who began having significant pain with her menstrual cycles; irritation, pain, or difficulty in inserting vaginal tampons; beginnings of increased frequency and urgency of her urinary bladder – maybe being treated for "UTIs" (bladder infections); IRS symptoms, starting to have pain, burning, or itching of her vulvar and labial lips – maybe being treated for multiple "yeast or other vaginal infections"; lower abdominal bloating and pain; intermittent back pain; and a history of striving for academic and/or sporting excellence. How common and typical these young women are! Not all of them will progress to severe pelvic and sexual pain, but these are the young people whose parents, coaches and trainers should be educated to watch more carefully at a younger age, and realize that these combinations of physical and emotional stresses and traumas, although only minor or “under the radar” issues at the time, could later result in more serious consequences. Add to these common events, the trauma of surgeries, childbirth, physical, emotional or sexual abuses that are so common in our society and one can see why such a large percentage (possibly up to 20%) of young women develops sexual and pelvic pain disorders.

4. In your opinion, why is there such a “stigmatized” stigma attached to this condition? Why are so many women afraid to speak up and/or seek treatment for their pain?

I have been working with a young woman who is a patient with these issues, and is also getting her Masters degree in art and design. Her thesis is asking this very question - what makes these issues so “stigmatized” in our society, and why is it so shameful for women to speak up and find the help that they so desperately need? She is in the process of developing a design for a poster that could be placed on college campuses and other places where young women gather, that would draw them in to have a better basic understanding of how all of these seemingly diverse elements in their lives actually are all possibly interconnected and could lead to or explain their already present sexual and pelvic pain symptoms.

Unfortunately, even if women are made more aware of these disorders and have started to “connect the dots” in their own heads, it does not make it any easier to break the general mores of our society, intimate issues of bowel, bladder, menstrual, and sexual function remain taboo subjects and are not only embarrassing to talk about, but are even difficult to find, explain to, and actually get help from many health care providers. Media exploitation of “happy and pleasurable sex and orgasm” dominate the exposure to all of us, but probably make these suffering young women even more isolated and sometimes “guilty” that they are not “normal”.

When seeking medical attention, these individuals have multiple reasons why they are not felt “listened to”. Multiple studies indicate that health care providers are less likely to “listen to” and “believe” – women compared to men – anyone with chronic pain – anyone with emotional “overlay” – anyone whose tests do not indicate the level of pain described – and anyone with sexual concerns. Even typical pain management doctors are not trained for or interested in pelvic disorders related to bladder, bowel, reproductive, or sexual dysfunction. So the list is long as to why these sufferers are reluctant to, and even when trying to, find it so difficult to get the help they need.

5. How can suffering with this condition affect a person’s relationships?

Susan Bilheimer and I wrote an entire book dedicated to answering this very question: “Secret Suffering: How Women’s Sexual and Pelvic Pain Affects their Relationships”. The paperback version of our book only recently became available and can be found on our website, www.secretsuffering.com. Susan, who is also a sufferer of CPP and sexual pain, is also getting a new website operational called www.invisibilityisnotthedocfinder.com. We developed a comprehensive survey which can be found on that site that will allow a better understanding of why and how the health care system responds as it does to so many of these pain and inflammatory disorders, such as migraine, TMJ, Fibromyalgia, CPP, and a whole host of other painful and inflammatory auto-immune disorders.

Obviously persistent pain in the genital and deep pelvic core is likely to be more devastating to a sexual partner than, for instance, chronic shoulder or knee pain. In many instances relationships fall and crumble under the burden of painful sex. We describe in our book that so many of these previously vigorous and athletic type women say that their coaches and trainers kept telling them to just “stretch it out, man up, and get back in the game”. We speculate that these young women, who have learned to play through their pain, ultimately learn to have sex through their pain.

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Our book describes in some detail how the current science of chronic pain fits into pelvic and sexual pain disorders and also tells the stories of a variety of individuals and often their partners as well, as to how they have coped with these issues. Many of our patients not only have sexual and relationship issues with their intimate partners, but often cannot sit, stand, or walk comfortably, and have to take many bladder or bowel breaks – so all of the other relationships in their lives are affected as well – in school, work, taking care of household and parenting duties, etc.

I write in the book what it is like to open a pelvic pain center and how pain management is so different than a routine medical practice. The majority of our patients just simply “want their lives back”.


This is the most important question of all. The answer is a resounding yes, but with many current qualifications. As in most disorders of health, the earlier in the development of these complex inter-related issues are diagnosed and treated adequately, the better the final outcome. Having taken care of perhaps over 800 severely affected individuals for close to a decade, we can say that we see significant improvement with pelvic and sexual pain disorders. Levels of pain drop from averages of about 7 or 8 out of 10 to levels of 3 or 4 out of 10 within 6 months. Quality of life indicators rise from about 3 or 4 out of 10 to 7 or 8 out of ten as well.

This level of success takes patience, time, and a team approach with each patient, including her own level of commitment. Most studies indicate and I agree, that for best success with any type of chronic regional pain disorder, it takes a team effort, takes time, and the use of multiple modalities. Truly “integrated” medicine is essential here. We are also showing that our successes are multi-racial, multi-ethnic, and multi-socio/economic, and even multi-gender in nature. A young man in his mid 20s was referred to our CPP program with sitting pain, urinary urgency, pain on urination, erectile dysfunction, constipation. He had been treated repeatedly by 3 different urologists for prostatitis, without relief. His diagnoses were Interstitial Cystitis and Pelvic Floor Myalgia. He had been unable to have sex with his wife for quite some time and their relationship was floundering. Within 4-6 months, with appropriate medications, diet, physical therapy and counseling, he was 80% improved, his wife conceived and they subsequently had their first child.

Space does not allow for me to talk more specifically about individual therapies, but our web site www.secretsuffering.com has resources for all of these described conditions. My hope is that soon the various residency programs and fellowships in pelvic health will be teaching more information about assessment, diagnosis, and treatment modalities for CPP and sexual pain disorders.

About Robert J. Echenberg, MD, FACOG:  

SecretSuffering.com

Dr. Echenberg did his undergraduate work at Brown University, medical training at Jefferson Medical College, and his residency in Obstetrics and Gynecology at the University of Michigan Medical Center. He began private practice in Bethlehem, PA in the early 1970's, became board certified, and soon realized that much of what he needed to know concerning women's health had not been taught in those otherwise excellent programs. He feels now that much of what he subsequently needed to know had to be searched for on his own.

Along with aiding women through more than 2500 pregnancies and deliveries, doing the usual gynecologic medical and surgical care on thousands of others, he became the first regional physician to become the medical advisor for LaMaze child birth classes, helped start the first integrated course in human sexuality at Lehig University, and worked diligently to advocate for women’s reproductive rights and child birthing options in Pennsylvania’s Lehigh Valley (Allentown, Bethlehem, and Easton). He joined the American Association of Sex Educators, Counselors and Therapists (AASECT), became involved with the American College of Nurse Midwives, and sponsored the first nurse-midwifery birthing center in the region, as well.

Dr. Echenberg's interests then expanded into parent-bonding infant, issues of attachment and loss, medical ethics, sexual dysfunctional counseling for his patients and their...
partners, and was even interviewed on national television for his involvement in one of the country's first support groups for families suffering early miscarriage. He later established one of the original and few community hospital peri-natal ethics committees in order to help families deal with the difficult decision making surrounding seriously ill and dying newborns. One set of his parents wrote "The Long Dying of Baby Andrew", following the tragic loss of their child, which helped to change policies of parental involvement in neo-natal intensive care units throughout the country.

Echenberg's passion for integrative care in women's health now continues with his creation of one of the first privately owned multi-disciplinary practices specializing in assessment, diagnosis and treatment of chronic pelvic pain (CPP). He feels that his collaboration with Susan Bilheimer, a sufferer of CPP, in the writing of "Secret Suffering: How Women's Sexual and Pelvic Pain Affects Their Relationships", the creation of their website www.secretsuffering.com, and now their work on www.invisibleillnessdocfinder.com, all continue his career choices in helping "women in pain". He also has been recently elected to the board of the International Pelvic Pain Society (IPPS – www.pelvicpain.org).

Read more of our expert interviews: