Sexual Arousal Syndrome: A key symptom in case of pudendal neuralgia

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Mrs. X, 40 years old, presents since 12 months with urinary frequency, nocturia, urgency, dysuria, superficial dyspareunia, persistent sexual arousal syndrome and a severe bilateral perineal pain in sitting position (more on the right; average pain level 8/10). Since 6 months, she presents also with frequent gas incontinence and dyschezia (difficulty to empty her rectum). She has a foreign body sensation in the vagina (like a menstrual tampon) and contact with her underwear is painful. The 3 clinical signs of pudendal neuropathy are positive (abnormal pinprick sensitivity, painful Alcock’s canal, painful “skin rolling test”). Perineal descent measured with the Perineocaliper® was ≈ 0. The 3 right pudendal blocks she had were very effective for 2 weeks (disappearance of all the symptoms). In her history, we found she has had a kick in the coccyx in the past. She is employed and has to sit 6 hours/day. She is not a biker. The EMG exploration showed increased pudendal nerve terminal motor latencies at the level of the bulbo-cavernous muscles (5.2 msec on the left and 6.2 msec on the right side; normal: <5msec) and neurogenic traces at the level of the right bulbo-cavernous muscle. The warm and cold detection threshold test showed bilateral qualitative abnormalities (aftersensation and habituation mainly on the right side). Lumbo-sacral MRI was normal. Bilateral transperineal pudendal nerve decompression was done under pudendoscopy. The compression test done during surgery (simulate sitting position) showed a clear compression of the 2 nerves on the sacro-spinal ligament. We found an accessory branch of the left pudendal nerve included in the sacro-spinal ligament. It was freed by cutting the ligament between the main trunk and this branch. The table below presents the evolution with time of the different symptoms and clinical signs during the first 9 months after surgery. Before her last visit, she had a flare up induced by

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Pudendal neuropathy is a frequent disease in women. It can induce urinary (painful bladder, frequency, dysuria, incontinence), anal (proctalgia fugax, incontinence, dyschezia) and sexual (dyspareunia, sexual arousal syndrome) troubles. The frequently associated pain (called pudendal neuralgia) is located along the distribution of the pudendal nerve. It typically increases in sitting position and is reduced on a toilet seat.

It is quite easy to suspect the diagnosis of pudendal neuropathy using 3 clinical signs: abnormal pinprick sensitivity, painful Alcock's canal, painful "skin rolling test". We use EMG, warm and cold detection threshold evaluation and lumbo-sacral MRI to complete the evaluation. A positive block is also helpful to confirm the diagnosis and can sometimes cure the patients (here very effective during 15 days).

Sexual arousal syndrome (SAS) is one of the key symptoms of pudendal neuropathy. It is an unwanted and disturbing sexual sensation at the level of the labia or of the clitoris. The frequency of this symptom in the patient’s life is from quite rare (once a month or less) to persistent (nonstop). In our experience, SAS is frequent in case of pudendal neuropathy (28 % of the patients scheduled for surgery) and it disappears very often with its treatment.

After transperineal pudendal nerve decompression under pudendoscopy, intermittent SAS is reduced or cured in 86 % of the cases. For us, it can be used as a monitoring of nerve healing. In the case report, you can follow the improvement of SAS with time parallel to pudendal healing (improvement of all the other symptoms).

In the literature this symptom is also associated with a high incidence of Tarlov’s cysts at the level of the sacral roots. If Tarlov’s cysts are present it is very difficult to say if pudendal neuropathy or the cyst is responsible for SAS. Because it is less dangerous and easier to treat pudendal neuropathy than Tarlov’s cyst, we always try to treat this symptom like a consequence of pudendal neuropathy (U-shaped cushion, pudendal blocks, trigger points release and if necessary pudendal nerve decompression).

Persistent sexual arousal syndrome is the worse manifestation of this symptom. It can induce involuntary orgasms and is described by the patient as very disabling (sometimes more devastating than the pain). Usually, the physician is not aware of this problem and leaves the patient without a solution, or even worse, speaks about a psychiatric disease.

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The case report presented here was ideal (our first case of real persistent sexual arousal syndrome). Everything was classical. What to do if sexual arousal syndrome is isolated? If the clinical signs of pudendal neuropathy are negative?

If there is no Tarlov’s cyst to explain the problem? Would Tarlov’s cyst treatment cure sexual arousal syndrome? More research is for sure necessary to understand completely this strange but very frequent symptom.

Dr. Echenberg Answers Questions and Offers His Own Comments

What is PGAD (Persistent Genital Arousal Disorder) and how many suffer it on a global scale?

Although PGAD in women is uncommon (no one really knows the actual incidence of this disorder), I want to make it clear that PGAD is a sub-set of a much larger and quite prevalent group of disorders that together are called “chronic pelvic pain” (CPP) or “Complex Abdominal Pelvic Pain Syndrome” (CAPPS).

An estimated 30 million women in the US alone are diagnosed with chronic pelvic pain. Worldwide, CPP is estimated to affect 15 to 20 percent of all women of reproductive age (teen to menopause). Many studies have shown that at least 90 percent of CPP/CAPPS sufferers have some level of pain with sexually related activities – and my personal experience in treating women with CPP/CAPPS corroborates these statistics.

What leads women to develop CPP/CAPPS and its correlated disorder of Persistent Genital Arousal Disorder or PGAD?

There are five main root issues that can result in a woman developing PGAD. They include:

- Organ and structural “triggers” of the urinary bladder, such as Painful Bladder Syndrome/Interstitial Cystitis (PBS/IC);
- Lower bowel issues such as Irritable Bowel Syndrome (IBS) and Inflammatory Bowel (IBD);
- Gynecologic disorders such as endometriosis, vulvodynia, and vestibulitis;
- Previous accidents, surgeries and childbirth; and
- Sports injuries to the lower genital structures.

Is PGAD a sexual disorder, or a pain disorder?

PGAD is NOT a sexual disorder. PGAD is a pain disorder.

“PGAD is NOT a sexual disorder. PGAD is a pain disorder.”
~ Dr. Robert Echenberg

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Please explain the symptoms of PGAD.

A neuropathy is a condition that arises from traumas as well as dysfunctions of the body that cause nerves to “fire off” when they should not. When nerves are hypersensitive and fire off around the clitoris WITHOUT any sexual arousal or sexual thoughts, a woman feels a variety of sensations that may be linked to pleasurable clitoral (genital) stimulation but very quickly result in painful spasmodic contractions of the pelvic floor muscles and ligaments that mimic spasmodic orgasmic activity – except there is no pleasure and only a variety of different types of pain, including burning, stabbing, cramping, and worse.

Millions of women have various aspects of CPP/CAPPs, but only a small percentage of these have PGAD. In my opinion, all women with PGAD have pudendal neuralgia, and/or pelvic floor dysfunction (chronically tight or “hypertonic” pelvic floor muscles), and most of the women I have seen with PGAD also have combinations of bladder, bowel, and/or reproductive organ dysfunctions. An orgasmic response in these women with PGAD can occur independently of sexual activity. When these patients try to be sexually active, this too “triggers” off painful orgasmic responses.

Obviously when this spontaneously occurs in the daily life of a woman at work or in school or just when walking around, there is a tremendous embarrassment, shame, and anxiety, which ultimately increases depression, anger, frustration, and many other upsetting emotions.

This is all made worse when she is ridiculed or embarrassed further by her family, friends, and even doctors who do not understand any of these conditions and tell patients “they are lucky to be able to have multiple orgasms.”

What causes PGAD’s painful sexual response?

Symptoms of PGAD generally tend to involve pain deep within the pelvic floor muscles, and in and around the external genital region. Flares can occur regularly for periods of time, but patients can go months or even years without any of these symptoms. When flaring, even the slightest contact with clothing can hyper-stimulate the onset of painful spasmodic responses.

Does PGAD affect women of a specific age group?

In my personal experience, I have seen patients varying in age from teens to post-menopausal. The small amount of literature about PGAD places it more commonly in the late reproductive years (40s-50s).

Why do some doctors think it is hyper-sexuality, and what is the key to diagnosing it well?

In my experience, most doctors have very little education in human sexuality or in the rapidly evolving science of pain. Both of these subjects are still not considered to be worthy of teaching in any significant extent in our medical schools. PGAD is a confusing combination of symptoms that the vast majority of doctors and others just do not understand.

Is PGAD different than women who experience multiple orgasms?

YES, it is very different. Perfectly normal, healthy women have long been known to be able to achieve multiple orgasms with pleasurable sexual activity. PGAD is not related to normal pleasurable sexual response. It is a neurologic disorder related to how chronic pain is processed from the genital region to the brain.

Numbers of women may go through incremental stages of “under the radar” bladder and urethral sensitivities, along with early pudendal neuralgia symptoms, during which time they may initially feel more “arousal” intensity during genuine sexual activity. Later, their increased sensitivity begins to turn to an annoyance or a discomfort, and this can eventually lead to various descriptions of pain, burning, pressure, cramping, stabbing, and worse.

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At the same time, these women may discover that the pleasure sensation that has become more irritating may correlate with urethral and/or bladder sensitivity. In addition, a large number of the women we see with pain related to sexual activity often will tell us that they can achieve arousal and even orgasmic response, but that they “pay for it” with pain and cramping that may last for some days thereafter.

There may be a fine line between pleasure and pain in many of these chronic pelvic pain patients. If the pudendal nerve branches innervating the entire vulva are more and more “dialed up” in their signaling in association with a sensitive and tender urethra and bladder, then vaginal intercourse may turn from pleasurable to painful.

Also, many of our patients with painful bladder syndrome (PBS/IC) recognize that for years they have experienced an immediate need to urinate during and following deeper penetration intercourse. Many young women are taught to “pee” following sex to avoid “UTIs”, so they train themselves to empty their bladders before and after sexual relations. However, the research on PBS/IC clearly shows that a very high percentage of so-called “UTIs” following sex are really flare-ups of interstitial cystitis.

In addition, I have begun to suspect that the so-called “G Spot” in the anterior vaginal wall may indeed be the urethra itself. The “G Spot” which has been talked about for years has never been anatomically demonstrated. The female urethra courses down the midline of the front half of the vagina and can become significantly sensitive in a portion of IC/PBS patients. This urethral sensitivity might explain the pain/pleasure continuum that we earlier mentioned associated with PGAD. Vaginal intercourse cannot avoid urethral friction and may thus lead in these women to a state of arousal or hyper-arousal.

Is there any effective therapy for PGAD?

YES. PGAD is treated like other peripheral neuropathies and chronic pelvic pain disorders. Find and treat all “triggers” which may be pudendal neuralgia, IC/PBS and others, treat the pain adequately and always find a qualified pelvic floor physical therapist for the inevitable pelvic floor dysfunction or clenching.

There are medications such as anti-depressants, anti-seizure medications, beta-blockers, and even peripheral nerve blocks on the pudendal nerve that I have seen to be quite effective. Also, because of the secondary anxiety and depression, it is very helpful to utilize many different types of mind/body relaxation techniques. The more we learn about chronic pain in general, the better the research will be towards treating all of the genital pain syndromes.

With what other “sexual” disorders can PGAD be classified?

Because PGAD is a pain disorder, it influences all the other sexual disorders. If a woman is experiencing genital pain, it is obvious that she will also have diminished sexual desire and arousal, and that she will be less and less interested in allowing her body to be stimulated to any type of orgasmic response.

Is there any similar disorder in men?

It is not clear whether there is a similar disorder in men. Priapism is an uncommon disorder of unwanted non-sexual penile erection that can be painful, but is largely considered to be due to vascular abnormalities. Also it is not analogous to PGAD because that would have to be the occurrence of unwanted multiple ejaculations, and I do not know of such a disorder.

Nonetheless, in a few of the male patients in our clinic who also have IC/PBS, I have found at least several men recently who describe onsets of urethral sensitivities that feel to them as if they might have an ejaculatory response in totally non-sexual situations. There definitely needs to be further investigations about the various manifestations of pelvic and genital pain in men.

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Should PGAD be officially recognized in the next edition of the Diagnostic and Statistical Manual of Mental Disorders?

Based on what I have already stated, I think that PGAD should NOT be listed as a “mental disorder” at all. PGAD certainly can create mental and psychological problems in the individual with the problem, but I strongly disagree that PGAD is “all in your head.”

In Summary:

In the course of performing two- to three-hour evaluations with more than 1000 chronic pelvic pain patients, and listening closely to each of their stories, I have now started to realize that almost all PGAD patients I am now seeing have combinations of the symptoms mentioned in this article. There is, in my strong opinion, direct relationships to pudendal neuralgia, both with generalized vulvodynia and provoked vestibulodynia, as well as with the urethral and bladder sensitivities associated with PBS/IC.

It is my hope that in the future this disorder receives more recognition, and the sufferers of PGAD will find increases in medical awareness and expansions in treatment options to help them lead fuller and more pain-free lives.

Taking the Shame Out of Persistent Genital Arousal Syndrome (PGAD)
(Sometimes called PSAS, SAS – persistent sexual arousal syndrome or RGS - restless genital syndrome)

By Violet Matthews, BSN, RN

You may have seen the newspaper article on the woman who had 800 spontaneous orgasms a day...or a popular TV show episode in which a patient came to the ER having spontaneous orgasms, with the snickering and knowing glances of the medical professionals standing by. If you watch YouTube videos and news stories on PGAD you may get the idea that it is pleasurable or that PGAD patients are sexual freaks. These are serious misconceptions. It is time to create an atmosphere in the media and the medical community that allows patients with PGAD to obtain medical treatment without experiencing feelings of embarrassment or shame.

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What is PGAD?

In 2003, an international panel of experts described PGAD as arousal that is spontaneous, intrusive, and unwanted, in the absence of sexual interest or desire.\(^1\)

In a later study on PGAD, the participants had to meet at least one of these 5 criteria developed by the panel:\(^2\)

1. Involuntary genital arousal that persist for hours, days, or months.
2. The arousal does not go away after one or more orgasms.
3. The arousal is intrusive and unwanted.
4. The arousal can be triggered by nonsexual stimuli unrelated to sexual excitement or desire.
5. The cause cannot be identified.

(Sandra Leiblum, a leading researcher on PGAD later updated the criteria to include that the experience causes distress.)\(^3\)

An unidentifiable cause as listed in number five above may be true for some cases but there are many known cases of PGAD caused by pudendal neuropathy/neuralgia (PN). Dr. Jacques Beco, a pudendal neuralgia specialist, reports that “sexual arousal syndrome is frequent in cases of pudendal neuropathy (28% of the patients scheduled for surgery) and it disappears very often with its treatment.”\(^4\) Other physician researchers have confirmed that pudendal neuropathy is one of the causes of PGAD\(^5\) in both females and males.\(^6\)

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Since the pudendal nerve innervates the genital area and plays a major role in sexual arousal and orgasm, it is reasonable to conclude that damage or irritation of the pudendal nerve could cause sexual dysfunction such as PGAD. The pudendal nerve is named after the Latin word for shame. It is unfortunate that many patients with persistent genital arousal disorder feel shame. Thankfully, some physicians are beginning to recognize that patients with PGAD are not “mad” but that they have a medical condition.

That is not to say that PGAD does not take a huge toll on the psyche of the PGAD sufferer. Many patients with PGAD have considered suicide and many have had to quit their jobs because the illness is too distracting to be able to work. They have gone from being normal, happy, productive professionals to lying in bed with ice on their genitals and becoming isolated with a torturous disease, losing their income and many of their social and family relationships. Here are some statements that I have been told in my personal communications with PGAD sufferers:

“I would rather have cancer than PGAD; at least it would have an end.”

“If the medication I am taking had not taken away the symptoms, I would not want my life to continue.”

“I would rather be burned at the stake than have this illness.”

“It’s like being constantly raped, but with rape it would be considered an emergency and someone would come to your rescue. With PGAD, no one considers it an emergency.”

“It’s like constantly being molested.”

“It is the worst form of torture.”

“Even after I had a diagnosis of pudendal nerve entrapment causing PGAD, one physician wondered if I was a nymphomaniac. PGAD is incredibly humiliating and it’s not something you can easily talk to people about because it is so private. You are all alone.”

“PGAD is the worst symptom of pudendal neuralgia. It’s the worst thing I have ever experienced.”

“I’ve had both pudendal neuralgia and breast cancer requiring chemotherapy. Breast cancer was much easier to deal with than pudendal neuralgia.”

“It’s like being a prisoner of war with constant sexual torture.”

“I would rather never have another orgasm in my life.”

This is not an illness to make fun of or to dismiss as being insignificant. PGAD ruins people’s lives. It takes the joy out of living, and can lead patients to commit suicide. Some PGAD patients report that it is difficult for them to eat or sleep and they are unable to concentrate on reading or to think clearly due to the constant chronic sexual/physical distress.

What Causes Pudendal Neuropathy Leading to PGAD?

The causes of pudendal neuropathy leading to PGAD listed in this article are based on my personal communication with pudendal neuralgia patients who suffer from PGAD. (There may be additional causes including those listed in the peer-reviewed literature on pudendal neuropathy, pudendal neuralgia, and pudendal nerve entrapment.)

- Exercise (including weightlifting, horseback riding, skiing, cycling, elliptical machine, step aerobics or a combination of these)
- Pelvic surgery
- Childbirth
- Pudendal nerve blocks

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What are the symptoms of PGAD?

While symptoms may vary from person to person, following is a list of symptoms associated with PGAD as reported in literature or communicated to me personally by PGAD patients.

- A constant feeling of being on the verge of orgasm, with or without genital engorgement.
- Spontaneous orgasms (including numerous spontaneous orgasms that may come in waves).
- Shocks that cause a feeling of painful mini-orgasms.
- Inability to sleep or concentrate on normal activities due to the constant feeling of arousal.
- Spontaneous arousal awakening the person from sleep, this may be associated with sexual or non-sexual dreams and awakening with painful orgasms.
- In women, a feeling of vaginal penetration.
- In women, a feeling of sexual arousal in the clitoris, labia, and vagina (in one or all of these areas) that may be accompanied by excessive vaginal wetness.
- Males may have spontaneous unpleasant and unwanted erections with ejaculation.
- The arousal is not relieved by one or more orgasms.
- The arousal may be accompanied by pain or itching or both.
- The arousal may be accompanied by a constant feeling of needing to urinate.
- The arousal may be increased by sitting or by stimuli that would not normally be associated with sexual excitement such as vibrations while riding in the car or from loud music.
- Sexual thoughts or non-sexual stimuli may cause a feeling of electricity or buzzing along the course of the pudendal nerve.
- Sexual feelings in other areas of the pelvis such as the anal area, low back, groin, or thighs.
- Extreme sexual arousal feelings with engorgement (feeling like you might explode).
- Throbbing or “sexual” toothache in genital area (may just be on one side).

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Treatments that have Helped Some Patients with PGAD that is Caused by Pudendal Neuropathy

There is not much scientific literature listing successful treatments for PGAD. The treatments listed below that have helped relieve PGAD symptoms are those that patients with PGAD have related to me personally, or they have posted on the Health Organization for Pudendal Education forum. (This is not an all-inclusive list, or medical advice. Treatments that are helpful for one person may not be helpful for another.)

**Oral medications (including combinations of some of these)**
- Tramadol (especially the extended release form)
- SSRIs antidepressants that have a negative effect on orgasm/libido including lexapro
- Tricyclic antidepressants
- Buprenorphine
- Lyrica or neurontin
- Cymbalta
- Tegretol
- Clonazepam to reduce anxiety and promote sleep
- Soma to relax the pelvic floor and promote sleep

**Topical ointments**
- 5% or 10% Lidocaine, including Emla cream
- Over the counter extra-strength vagisil (20% benzocaine)

**Ice**
- (Frozen balloons or condoms can be inserted vaginally – use one inch of rubbing or drinking alcohol in the bottom of the condom, then fill with water; or use ultrasound gel. Condom can be placed in a toilet paper roll to freeze it. This is not a medically approved treatment but some patients report it keeps them from going insane.)

**Vaginal suppositories - valium/elavil (5/15mg) vaginal suppositories**

**Pelvic floor physical therapy to release internal trigger points**

**Avoidance of tight pants/clothing**

**Avoidance of sitting**

**Relaxation techniques including cognitive behavioral therapy**

**Pelvic floor Botox injections**

**Pudendal nerve blocks (although in rare cases they may cause PGAD)**
- (Some patients have stated that this provided the most significant relief. Some patients report near cures although there are rare cases of PNE surgery causing PGAD temporarily or for extended periods of time.)

**Pudendal Nerve Decompression Surgery**

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Conclusion

PGAD is an extremely distressing condition. It is important for the entire medical community and the media to realize that it is a medical disease and to treat PGAD patients with dignity. PGAD sufferers need to be treated with the same sense of compassion as patients who have other serious illnesses because they are experiencing symptoms that are equally, if not more, distressing. Fortunately, there are physicians who are researching PGAD and becoming innovative in their treatment of PGAD patients.

For friends and family of patients with PGAD, do not allow your friend or loved one to become isolated. What they are experiencing is horrendous and they need all of the love and support you can give them. Often finding the right treatments can help them return to a normal life but they may need your help in finding those treatments, especially if they feel hopeless. Please help them to feel empowered and to find the treatments they need.


3 Sandra R. Leiblum, PhD. “Persistent Genital Arousal Disorder: An Update of Theory and Practice.” The Female Patient, 2009 May;34: 19-20.


