Contemporary Sexuality- Update
July 26, 2006

Persistent Genital Arousal Disorder: What It Is and What It Isn't

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Bio:

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Introduction

Although persistent genital arousal disorder (PGAD) has only recently been identified and described as a problem (Leiblum & Nathan, 2001, 2002), it is probably not a new phenomenon in and of itself. The primary features of this arousal syndrome, namely persistent feelings of genital arousal occurring without an obvious precipitant and persisting for extended periods of time, despite one or many orgasms, were likely experienced by women in the past, but were not typically reported because of feelings of shame, guilt, or embarrassment. However, an unexpectedly large number of women are now acknowledging this complaint. This surge in disclosures is probably related to two factors. One is the more open attitude toward all aspects of female sexuality in general. The other is the publication of our original report about this phenomenon in particular (Leiblum & Nathan, 2001), and the subsequent establishment of an on-line support group

devoted to the condition. This article will review the history, subjective experience, diagnosis, and prevalence of PGAD, as well as recent research and the current understanding of etiology and treatment.

Terminology

Initially, the condition was referred to as "persistent sexual arousal syndrome" or (PSAS). However, we came to realize that a better name would be "persistent genital arousal disorder" or (PGAD) since the problem is not a sexual problem per se but rather a problem of unremitting genital sensations. Both terms are used in this article since the new term PGAD has not been officially adopted at this time and most of the published literature still refers to the condition as PSAS.

Historical Overview

Over one hundred years ago, Krafft-Ebing (1903) described a condition that resembles PGAD in some respects. In writing about nymphomaniac women, he noted:

> In the daytime the slightest cause will produce a crisis in which a veritable abnormal mental and sexual excitement, coupled with painful sensations (pressure, vibration, pulsation, etc.) in the genitals, torments them. Temporary relief comes in time in the shape of neurasthenia, which reacts promptly on the centre of ejaculation and readily causes pollutions in lascivious dreams, or some erotic crisis when awake. Full gratification, however, they cannot find any more than those of their unfortunate fellow-sufferers who abandon themselves to men (p.323).

Unlike PGAD, however, the so-called nymphomaniac woman could identify lascivious or sexual thoughts or fantasies and was apparently aware of subjective feelings of sexual excitement. Women with PGAD, on the other hand, report intense feelings of genital congestion and sensations that are typically unaccompanied by any conscious

awareness of sexual desire. In fact, sensations of genital arousal seem to appear without any sort of provocation and are experienced as strictly genital rather than truly sexual in nature. In an attempt to relieve the sensations, many women will engage in sexual behaviors with themselves or a partner, but paradoxically, sexual activities seem to reinforce the sensations or provide only temporary relief. Sexual activity rarely dissipates the feelings of genital arousal entirely.

Women's Experience of PGAD

In order to better understand how women experience PGAD, and how it impacts their lives, consider the following unsolicited descriptions:

> I am a 65-year-old woman who has been experiencing persistent sexual arousal which was quite baffling to me until the nurse practitioner found your article in the medical journal. I was about to lose my mind because when this started, my gynecologist just kept telling me that sexual desire was normal and kept smiling at me and saying don't worry about it which was quite infuriating. I kept telling him I had lived and had sex for most of my 65 years and this was quite different than any sexual desire I had ever experienced. It is so distressing as sexual activity does not stop it…Orgasms did not stop the constant tingling in that area. It is like having a bad itch and nothing or no amount of scratching stops it…When your every waking hour feels as though you are in the middle of sexual intercourse that never comes to a satisfying end it is a very terrible feeling. It is hard to concentrate on anything.

A 53-year-old woman wrote:

> I have been suffering with this condition intermittently for the past 20 years, but it has recently become worse now that I am in my menopause, I am 53 years of age. I have no conscious sexual desire at all, yet the feelings are persistent without any stimulation required. I have a partner who is very understanding but I am no longer interested in sex as I don't get any relief whatsoever. It is very difficult and upsetting as I feel it is affecting our relationship. I also feel so ashamed that I have these feelings that I am unable to discuss this with anyone else.

And from yet another 63-year-old:

> I THINK I have a milder case of PSAS than any you describe ...mild* but still an unwelcome, intrusive, disturbing thing...a state of almost constant physical (but not psychological) "readiness"…. My FIRST thought was "now I KNOW how 16 year old boys feel"...that I was undergoing a testosterone increase. It felt SO chemical...so profoundly unrelated to any psychological increase of libido…I described it to my nurse practitioner a month ago as a case of "hormonal rape." We both laughed…maybe I laughed because it seemed to have somewhat subsided when I saw her but after a few weeks of its laying low, it's back...full time...no matter what I do. At first it was relieved by (easily achieved) orgasm(s) for a few hours. Now I know if I try to relieve it...it just comes back and I might just make it worse!

As these descriptions suggest, the genital arousal is perceived as uncomfortable and unwanted. So what are the specific characteristics of PGAD and how does it differ from normal awareness of genital sensations that many women experience and enjoy?

Diagnosis of Persistent Genital Arousal Disorder

In our original report describing a condition we initially called "persistent sexual arousal syndrome" (PSAS), Nathan and I (2001) described the features that seemed to characterize the five women we had seen, namely:

1. The physiological responses characteristic of sexual arousal (genital and breast vaso-congestion and sensitivity) persist for an extended period (hours to days), and do not subside completely on their own.
2. The signs of physiologic arousal do not resolve with ordinary orgasmic experience, and may require multiple orgasms over hours or days to remit.
3. These physiologic signs of arousal are usually experienced as unrelated to any subjective sense of sexual excitement or desire.

4. The persistent sexual arousal may be triggered not only by sexual activity, but also by seemingly nonsexual stimuli or no apparent stimulus at all.
5. The physiologic signs of persistent arousal are experienced as uninvited, intrusive, and unwanted.

In 2003, PSAS was included as a provisional diagnosis by an international committee of experts convened to recommend revisions in the nomenclature of women's sexual dysfunctions (Basson et. al, 2004). At that time, the disorder was defined as follows:

> Spontaneous intrusive and unwanted genital arousal (e.g., tingling, throbbing, pulsating) in the absence of sexual interest and desire. Any awareness of subjective arousal is typically but not invariably unpleasant. The arousal is unrelieved by one or more orgasms and the feelings of arousal persist for hours or days (p. 45).

More recently, we have identified another feature of the disorder, namely spontaneous orgasms that are seemingly unprovoked and intense. While some women find these orgasms pleasurable, the majority of women find them uncomfortable, distracting, and disturbing. For some few women, unprovoked orgasms may occur any time, during the day or night. They are often intense and numerous and may last for many minutes. Some women are so bothered and worried by these orgasmic "fits," which may resemble a kind of seizure, that they seek neurological evaluation.

In fact, a rare syndrome involving spontaneous orgasms has been identified before. In a case report in the *Lancet*, Reading & Will (1997) described a 44-year-old woman who was referred to a neurology clinic after a brief loss of consciousness. For the

last three years, she said she had experienced recurrent episodes, approximately once every two weeks, in which she would suddenly

> become aware of an internal, ascending feeling indistinguishable from an orgasm, lasting up to a minute. These orgasms had no definite triggers and were described as neither particularly pleasurable nor satisfying because they were out of control. On several occasions, she experienced an episode while she was driving and she had to stop the car. There were no other symptoms, no associated loss of consciousness, and no reduced awareness. (p. 1746)

In this rare case, an electroencephalogram revealed a right anterior frontotemporal epileptic focus. Using computed tomography, the physician identified "a large vascular abnormality on the right temporal pole with an area of surrounding gliosis." (p.1746) (Gliosis refers to the growth of abnormal tissue.) The authors noted that the "seizures" were due to a lesion on a cerebral artery. She was treated with carbamazepine (300 mg twice daily) and the episodes did not reoccur.

In our experience to date, MRI evaluation of women who report spontaneous orgasms, as well as persistent genital arousal, do not have obvious central pathology and there is no obvious explanation for their numerous and unprovoked orgasms.

Differences between PGAD and normal feelings of genital arousal

Not all feelings of unprovoked genital arousal are problematic. In fact, although not often discussed in the literature on female sexual response, it is quite normal for many women to experience sensations of unprovoked genital arousal throughout the day or week. For instance, one woman commented:

> I've always, as far back as I can remember, experienced what you are describing…becoming suddenly aware that I am "horny," "aroused" with

> no apparent provocation. When possible, I run for my vibrator…otherwise try not to pay attention and it goes away…it has never been so persistent that I would describe it as a "disorder."

Another woman commented, "What those women described sounds pretty normal to me, but I never would have described my experience as a problem, nor as PSAS/PGAD. I always just thought I was horny."

Clearly, awareness of sensations of genital arousal is quite normal for some women and may be experienced as mildly pleasurable or mildly annoying. Such sensations may either trigger subjective feelings of sexual desire and sexual behaviors, or alternatively, may simply fade away—noticed but not acted upon. This is NOT a disorder. In contrast, the women who complain of persistent genital arousal do NOT find it pleasant or reassuring or enjoyable. In fact, we believe that in order to qualify for a diagnosis of PGAD, there must be accompanying feelings of distress, e.g., a self-reported rating of at least 4 on a 10-point distress scale.

Prevalence

The prevalence of PGAD is unknown. Since it is both embarrassing and often misunderstood, women tend to be reluctant to talk with their physician. When asked, however, most gynecologists will acknowledge having seen one or two cases over the course of their career. It is only since PGAD has been "named" and described in the literature that the condition has been legitimized and we have received an outpouring of letters and e-mails from women, young and old, pre- and post-menopausal. Again, it must

be acknowledged that not all women who describe persistent genital sensations qualify for a diagnosis of PGAD.

Recent Research

To date, there have been very few research studies on persistent sexual arousal. Recently, we published the results of our first attempt to identify features, triggers and interventions for this disorder (Leiblum, Brown & Wan, 2005). A 46-item questionnaire was posted on three Internet sites related to women's sexual health. The survey included demographic questions, medical and sexual history, characteristics of the arousal, triggers of arousal, treatment attempts and outcomes, and the advice received from physicians. This first published study was based on responses from 103 women. Since then, the questionnaire has been extensively revised and re-posted in the Internet. To date, surveys have been received from more than 400 women worldwide.

The majority of women complaining of PGAD tend to be in relatively good health, well educated, and in long-term relationships (Leiblum et. al., 2005). They are quite distressed about their condition, although there is a small minority reporting mild and intermittent arousal, rather than intense and continuous, who find the condition somewhat pleasurable. In fact, more recent data (unpublished) suggest that there are two distinct groups of women--those with genuine PGAD and those who have some, but not all, of the features of the disorder and who are only mildly distressed. These women do not qualify for a diagnosis of disorder.

When asked what stimulated the sensations of genital arousal, women described a host of possible triggers, some physical and some psychological:

- "Persistent sexual arousal began a few weeks after my cesarean section."
- "I alternated between Zyban (bupropion) and Paxil and believe my PSAS started while on Zyban as a rebound effect."
- "Beginning of PSAS coincided with cessation of periods."
- "Originally started following ectopic pregnancy and subsequent pregnancy with second child."
- "Persistent yeast infections"
- "The original cause, I think, was the accident and injury to my pelvis that I suffered in the summer of 2002. The first time I experienced PSAS was after masturbation a couple of weeks after my injury, which was also the first time I had done anything sexual."
- "Switching to different anti-depressants."
- "Possible original trigger--receiving many enemas as a child for years?"

Overall, respondents identified the following major groups of triggers: terminating or beginning a particular medication or hormonal regimen, intense sexual stimulation by self or partner, and emotional stress and anxiety. Sixty-three percent of respondents reported at least moderate distress as a result of their persistent feelings of genital congestion while 19% reported extreme distress. The strongest predictors of distress were intrusive and unwanted feelings of genital arousal ($p < .0001$), continuous symptoms ($p < .001$), feelings of unhappiness ($p < .03$), shame ($p = .0001$) and worry (p

= .01), reduced sexual satisfaction ($p < .004$), enjoyment of symptoms some of the time ($p = .01$), and relationship status ($p < .004$).

A second study (Brown, Leiblum, & Wan, 2005) examined the sexual functioning of 45 women with PSAS compared to 152 women with female sexual arousal disorder (FSAD) and 244 healthy control women. The Female Sexual Function Inventory (FSFI) (Rosen, Brown, Heiman, Leiblum, Meston, Shabsigh, et al., 2000) was used to collect data. PSAS women scored significantly *lower* than the control group on the total FSFI scale, as well as on the desire, arousal, lubrication, and orgasm subscales, suggesting *reduced overall sexual functioning and less satisfaction than the normal controls*. However, they obtained higher scores on the desire, arousal, lubrication, and orgasm subscales than women with FSAD.

Current Etiological Theories

At present, there is no consensus about etiology. Goldstein (2005) has suggested the following possibilities: 1) central neurological changes (e.g., post-injury, specific brain lesion anomaly); 2) peripheral neurological changes (e.g., pelvic nerve hypersensitivity or entrapment); 3) vascular changes (e.g., pelvic congestion); 4) mechanical pressure against genital structures; 5) medication-induced changes; and 6) psychological changes (e.g., stress), or some combination of these. Many cases appear to be idiopathic, and no definite etiology can be determined even after a thorough and comprehensive history.

It is likely that there are at least two subtypes of persistent genital arousal: one more related to neurovascular or neurochemical causes, and the other more related to psychological causes. The account of a 23-year-old woman serves as an example of how some cases of PGAD may have a psychological basis. She reported that certain words related to sexuality acted as a trigger for her feelings of persistent sexual arousal. She reported that her arousal "operates at a subliminal level at times so that while there seems to be no cause, there actually is." She went on to say that once when she was listening to a lecture about the social behavior of monkeys, "a strong feeling of arousal intruded and interfered with my concentration. I realized on reflection that the arousal started when the lecturer made a passing remark about the sex of the monkeys. It was just that word that triggered it." She also noted that anxiety could trigger her arousal and that the ensuing pelvic tension would become unbearable. For this young woman, the feelings of arousal were "constant and waves of orgasm-like (without the contractions) feelings would flood me. …I would feel physically hot; my knees would sometimes go weak and it seemed to interfere with my consciousness of what was going on around me for the duration of the feeling."

For other women, the condition clearly seems pharmacologically induced, either as a response to a particular medication, such as trazadone, or as part of a discontinuation syndrome.

SSRIs and PSAS

Several writers have wondered whether there might be a relationship between PGAD symptoms and the use of selective serotonin reuptake inhibitors (SSRIs), such as paroxetine (Paxil), sertraline (Zoloft), venlafazine (Effexor) or fluoxetine (Prozac). There have been isolated case reports and private communications from women noting that the symptoms seemed to be associated with the start of one of these anti-depressant medications and that discontinuation of the medication seemed to relieve the condition.

Sexual response is certainly influenced by serotonin, although data are conflicting as to whether it serves primarily as an inhibitory, excitatory or mixed agent. It may depend on which receptor subtype is stimulated. Although the incidence of sexual side effects associated with the use of SSRIs is quite high (30-40%), delayed rather than enhanced arousal and orgasms are typically reported. This delay is not surprising since SSRIs block nitric oxide (NO), decreasing smooth muscle relaxation and inhibiting genital blood flow, thereby enhancing arousal and the likelihood of orgasm (as opposed to a PDE5 inhibitor, like sildenafil (Viagra) which increases NO levels by inhibiting phosphodiesterase-type 5 enzyme [PDE-5]). Curiously, some psychiatrists have suggested that if pudendal nerve irritation is the cause of the persistent genital arousal, the use of selective norepinephrine reuptake inhibitors (SNRIs), such as venlafaxine (Effexor) or duloxetine (Cymbalta), or anti-seizure medications, such as valproic acid (Depakote), may be helpful (B. Saks, personal communication, September, 2005).

Given that the role of medications in both the genesis and treatment of persistent genital arousal is poorly understood, a careful drug history--both past and current--should be taken with all patients complaining of PGAD. Careful specification of the order of events, e.g., whether the onset of genital arousal preceded or followed the termination of a new medication, is obviously of critical importance.

Pudendal Nerve Entrapment and PGAD

While medications may trigger genital arousal in some women, for others the condition appears related to pelvic muscular changes or pelvic nerve hypersensitivity. These conditions may cause blood to become "entrapped" in the pelvic region. The pudendal nerve as well as the other nerves innervating the female pelvis (the ilioinguinal nerve, the genitofemoral nerve, and the iliohypogastic nerve) may be implicated. When blood becomes trapped in the genital area and/or there is a resulting condition of hypertonicity of the pelvic muscles, tremors or feelings of pressure in the genital area may result which may contribute to, or cause, feelings of sexual arousal.

The feelings of arousal may not dissipate with masturbation or partner stimulation because the fascia surrounding the nerves trap the blood, thereby maintaining high levels of arousal despite one or many orgasms. In fact, the more insistent the attempts to relieve the congestion, by either self or partner, the more insistent or more continuous are the feelings of genital arousal.

In summary, at this time, all that can be said with certainty is that PGAD is a multi-factorial disorder associated with two major classes of factors: (1) neurovascular or neurochemical causes and (2) psychological/stress-related causes. For different women, each of these factors may interact in different ways and exist to varying degrees. Moreover, it is always possible that the factors currently maintaining the condition may be quite different from the factors initially giving rise to it. That is, if women become overly vigilant about monitoring or focusing on their genital sensations, they are more likely to be aware of subtle changes and may even tighten their pelvic floor muscles. Constant tightening and tension of the perineal muscles, coupled with feelings of anxiety, stress or concern about the cause of these sensations, could certainly exacerbate or maintain an undesirable physical state.

Treatment

While there is no generally accepted treatment that can be recommended, common sense interventions seem the most reasonable at this time. Initial use of anesthetizing agents to numb the area and provide some relaxation of the pelvic floor musculature is recommended. Since it may re-occur, treatment should focus on coping with rather than totally eliminating the complaint. Psycho-educational interventions, cognitive-behavioral therapy, and physiotherapy/stretching exercises all comprise aspects of this approach.

1) Psycho-educational: Women complaining of PSAS report extreme relief when they discover that they are not alone in having this condition—that the problem has a name

and that there is a support group which can provide sympathy and suggestions. Women should be invited to look at the on-line support group which may be found at http://www.psas-support.com/.

2) Identification of triggers: Determining triggers that contribute to or exacerbate the condition may be helpful. Distraction is very important. Redirecting attention AWAY from the genitals to something outside of the body is to be encouraged. Avoiding intense "heavy-handed" self-stimulation is sensible since it only contributes to greater genital vaso-congestion.

3) Pelvic Massage: Pelvic massage or stretching exercises may reduce or eliminate pelvic floor tension and break up whatever connective tissue strictures contribute to the condition. Consultation with an experienced pelvic therapist may be helpful as well.

4) Medication: Certain medications may alleviate (or paradoxically, worsen) feelings of genital arousal. Mood stabilizing, anti-seizure medications, such as valproic acid (Depakote), have helped some women, while others report relief with some of the SNRIs. Determining which medications, if any, alleviate the condition is often a process of trial and error.

Final Thoughts

It bears repeating that the majority of women who experience PGAD suffer considerably, and hence are vulnerable to any treatment that promises relief. While psychotherapy–from virtually any theoretical orientation--may be helpful in promoting insight, providing possible explanations, encouraging cathartic expression, and

contributing to stress reduction and self-soothing exercises, there are only a few psychotherapeutic "cures" reported (Hallam-Jones & Wylie, 2001). At the same time, it must be emphasized that any treatment that helps to reduce emotional stress and/or physical tension is to be encouraged. More research is clearly needed to investigate the etiology, cause, and treatment for this baffling and usually disturbing condition.

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Continuing Education Questions

1. Persistent genital arousal disorder is:

a. Another name for nymphomania

b. A common experience for most women

c. Enjoyable and sexy for most women

d. Distressing and worrisome

2. At this time, the most likely etiology of PGAD is:

a. Pharmacological

b. Neurological

c. Psychological

d. Unknown at this time

3. Research suggests that women reporting PGAD:

a. Have a history of sexual/physical abuse

b. Are well educated and healthy

c. Have a history of medical complaints

d. Have a history of somatization and hysteria

4. On the Female Sexual Function Inventory (FSFI), women with PGAD:

a. Score as well as healthy control women

b. Score lower than women with female sexual arousal disorder

c. Score between healthy control women and women with arousal disorder

d. Score higher than normal women

5. True or False: It is normal for women to experience sensations of unsolicited genital arousal that seem to come "out of the blue."

Answers:

1) Answer: d

2) Answer: d

3) Answer: b

4) Answer: c

5) Answer: True

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