31

PERSISTENT GENITAL AROUSAL DISORDER

David Goldmeier, MD

Introduction

I am a physician working in sexual medicine and sexual health in the United Kingdom, largely in the National Health Service. Nearly 40 years ago, after gaining my full qualifications in these fields (including a doctoral thesis), I decided that I needed more experience in psychiatry. So for the next 3 years I worked full time in general psychiatry, as well as setting up a sexual dysfunction clinic along with a clinical psychologist. I have always felt that an eclectic approach to patients with sexual dysfunction yields the best outcomes. I therefore use medications, cognitive behavioral sexual therapy, and mindfulness-based sexual therapy in my practice.

I currently also teach postgraduates and medical students and am chair of the sexual dysfunction special interest group of the British Association of Sexual Health and HIV. I undertake clinical research at Imperial College London.

It is helpful for me and, I hope, for you to understand Persistent Genital Arousal Disorder (PGAD).

A Brief History

It has long been realized that men are generally penocentric and that if genital engorgement takes place subjective arousal follows closely. Women’s arousal is altogether more complex, so that genital engorgement and transudated lubrication can occur independently of subjective excitement. When the two are not contemporaneous, subjective arousal lags behind or is absent.

Up to and including Victorian times, satyriasis or nymphomania was perceived at the least as inappropriate in a woman. Many doctors (they were almost all men) considered hypersexuality as a psychiatric disease apparently underpinning “lunacy” in general. Lunacy in women, when it presented with a large sexual appetite, was feared. Physicians in the United States and United Kingdom treated these unexplained psychiatric states with a clitoritectomy.

For the whole of the 20th century, excessive sexual desire was thought to underpin nymphomania. Kinsey described such women in normative terms, but mania, hypomania, other psychoses, and illicit drug use were the proposed causes of this state.[1]

Early in the 21st century, Leiblum and Nathan, to their eternal credit, actually listened to what a group of women were saying about sexual arousal. The subjects reported unbidden feelings of persistent subjective genital arousal.[2] The authors initially reported this as persistent sexual arousal but later, when they realized that these unwanted feelings had nothing to do with sex, began to call it genital arousal.
Possible Etiologies

In 2005 Leiblum et al. reported very high rates of anxiety and past sexual abuse in their studies of women with PGAD.[3] They suggested that PGAD is produced and perceived by the following process. Women detect a spontaneous genital response that they appraise as negative or inappropriate. This enhances anxiety, which in turn increases sympathetic nervous system activity, augmenting the perceived genital response and narrowing attention to genital sensations even further.

In 2009 Waldinger et al.[4] advanced our understanding by suggesting that a majority of cases of PGAD were caused by a neuropathy of the pudendal nerve or its branch to the clitoris. This made a lot of sense to me: the sensory portion of these nerves delivers messages from erogenous zones. The brain seems to interpret abnormal firing of these nerves as sexual arousal. It should be noted that the sense of arousal is often accompanied by some sort of pain and partial anaesthesia, a distinctly different experience from ordinary sexual arousal.

Some Cases

The first person with PGAD I came across was referred from colleagues in Birmingham in 2005. She was in late middle age and had developed continuous genital arousal, accompanied by a high level of anxiety about her condition. The PGAD symptoms were partially and temporarily relieved by masturbation or vaginal intercourse. She had cardiac issues and a low blood pressure. My psychologist colleague and I felt there was a large psychogenic component in her case. Six years later we learned that she suffered (as indeed did her children and grandchildren) from Ehlers Danlos syndrome, a hereditary hypermobility syndrome that affects the heart and peripheral nerves. Colleagues and I published this case report.[5] My first meeting with Leiblum, at a Society for Sex Therapy and Research conference in 2007, led to our co-authoring a number of papers. A few years later I was consulted by a 17-year-old from Scotland. She found that each time she sat down to study for national examinations, she developed unbidden subjective genital arousal. She had never masturbated nor had sex with a partner. She had catastrophic associations with her PGAD symptoms including “being like this for ever” and “there is something very wrong with how my vagina is made.” Such desperation is consistent with articles in the lay press that report that some women with PGAD attempt or commit suicide.[6]

Who Presents With PGAD, and How Common Is It?

I see one or two new cases a week; almost all are women. An occasional man complains of feeling arousal in the penis, often in the absence of erections. I receive referrals from all over the United Kingdom, plus patients from mainland Europe.

It seems likely that PGAD is uncommon. However, in my unit we found 1 case among 100 successive young women who attended for a sexually transmitted disease screening.[7] Although 1% is not very uncommon, we feel that it is rarer than this in the general population and that we happened to come across a case by chance.

Web surveys indicate a wide age range (15–82) of women currently complaining of PGAD.[3] A number of my patients report that PGAD started in childhood and has persisted from then on.

A Personal Perception and Understanding of PGAD

Until I saw my first case of PGAD, I had seen only patients who had mania or hypomania, or who were high on drugs or alcohol, who reported high levels of sexual desire or activity. After the first descriptions of PGAD, I too had to listen carefully to what the patients were reporting. I realized that
some of these psychiatrically diagnosed individuals were not reporting high levels of sexual desire. Rather, they reported high levels of unbidden genital arousal that caused distress.

Nowadays, I look for PGAD when patients’ histories suggest:

1. Symptoms characteristic of sexual arousal (genital fullness/swelling and sensitivity with or without nipple fullness/swelling) or unpleasant genital sensations (dyesthesia) persist for an extended period of time (hours or days) and do not subside completely on their own.
2. Symptoms of genital arousal or dyesthesia do not resolve with ordinary orgasmic experience and may require multiple orgasms over hours or days to remit.
3. Symptoms of arousal or dyesthesia are usually experienced as unrelated to any subjective sense of sexual excitement or desire.
4. The persistent sexual arousal may be triggered by sexual activity and by nonsexual stimuli or may have no apparent stimulus.
5. Symptoms are experienced as unbidden, intrusive, and unwanted—that is, ego-dystonic.
6. The symptoms cause the woman at least a moderate degree of distress.

Is PGAD a symptom, a syndrome, or an infrequently recognized aspect of a number of associated conditions? The case report and Web survey literature on PGAD has not yet been able to answer this fundamental question.

Assessing Patients With PGAD

**Physical Associations**

Complaints of pain and altered sensation along with the PGAD point to pudendal/dorsal clitoral nerve neuralgia. Any associated altered bowel or urinary symptoms, as well as back or pelvic pain, should likewise alert one to pelvic neuropathic processes. There are a number of other rare associations with PGAD, including arteriovenous malformations and cysts compressing the sacral nerve root spinal outlet.

**Psychological Associations**

I always assess patients to exclude past unwanted sex, anxiety, depression, and obsessive-compulsive illness, as well as psychotropic medications and change thereof. Some psychotropic medications are known to rarely cause clitoral priapism.

**Management**

Almost every patient with PGAD needs a broad therapeutic approach. This usually consists of medication for neuropathic pain (e.g. amitriptyline), as well as cognitive therapy to challenge the patient’s ideas (e.g. “This problem will take over my whole life and make me a sex maniac”). Mindfulness both helps patients to decrease high anxiety levels and increases acceptance of distressing feelings. My colleagues and I reviewed the management of this state in 2013. Pelvic floor physical therapy is an important adjunct to treatment. Sacral or pudendal nerve blocks have been used successfully to manage some cases of PGAD.

**Follow-Up**

A number of papers have anecdotally described treatment outcomes. However, there are no controlled trials. It is important to assess whether the patient and her partner want to continue with an
active sex life or not. Most women in my experience are only too happy to have their genital arousal “switched off.” This can have negative effects on ongoing relationships, however.

**Controversies**

Not all persistent genital arousal is pathological. Leiblum and Chivers\(^9\) pointed out that some women report mildly persistent genital arousal that may come unbidden and may be distracting but not distressing. They may even report these sensations as welcome, particularly when they arise in a situation that can lead to masturbation or consensual sex. So it appears that PGAD has a range of intensity, and one cannot be sure where to draw the line between normal unexpected unexplained arousal, which might be managed with reassurance, and the pathological state, which needs a thorough workup and thoughtful intervention.

**Conclusion**

It is very likely that PGAD is not actually a new syndrome. Rather, what is new is its recognition and acceptance by health care professionals. I continue to wonder how women with this syndrome handled their symptoms in the past. My supposition is that they were labeled as having a delusion or a manic illness or being a surreptitious user of illicit drugs. Or maybe they just lived with their symptoms. I hope that when you deal with patients with this syndrome you will be able to add to our understanding of this intensely distressing condition.

**References**