

Persistent Genital Arousal Disorder: A Review of Its Conceptualizations, Potential Origins, Impact, and Treatment



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ABSTRACT

Introduction: Persistent genital arousal disorder (PGAD) is a condition characterized by symptoms of physiologic (typically genital) sexual arousal in the absence of perceived subjective sexual arousal. The physiologic arousal can last hours or days, or it can occur constantly, and it does not typically remit after orgasm(s). The symptoms are usually described as distressing, intrusive, and unwanted.

Aim: To review the available literature on PGAD.

Methods: A literature review through April 2016 was undertaken using terms *persistent genital arousal disorder*, *persistent sexual arousal syndrome*, and *restless genital syndrome*.

Main Outcome Measures: The main outcome is a review of the conceptualization of PGAD, its prevalence, proposed etiologies and treatments, and its impact on psychosocial and sexual functioning.

Results: Much of the research on the potential etiologies and treatments of PGAD is published in the form of case studies. Several etiologies of PGAD have been proposed; however, a cause or causes have not been confirmed. A range of treatments has been explored primarily in case studies, from electroconvulsive therapy to oral medication, with variable success rates. Psychologically based treatments have been suggested but have yet to be evaluated. Online surveys have found initial evidence supporting the negative impact of PGAD on mental health and sexual functioning; however, more research is needed in this area.

Conclusion: Although PGAD was first conceptualized 15 years ago, it remains a very under-researched condition. Currently, little is known about its biopsychosocial correlates, etiologies, or successful treatments. Future research directions are identified.

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Key Words: Persistent Genital Arousal Disorder; Spontaneous Genital Arousal; Restless Genital Syndrome; Etiology; Conceptualization; Treatment

INTRODUCTION

Persistent genital arousal disorder (PGAD) is a condition assumed to affect primarily women, although there have been three published case reports in men.^{1,2} It is characterized by symptoms of physiologic sexual arousal (genital vasocongestion, increased sensitivity of the genitals and nipples, etc) in the absence of feelings of subjective arousal.^{3,4} These symptoms are not fully relieved with any behavioral act or over-the-counter remedy, and they are described as intrusive, unwelcome, unpleasant, and sometimes painful. PGAD often results in great

amounts of distress and is associated with feelings of shame, isolation, and suicidal ideation.^{3–6}

PGAD was first described in the scientific literature by Leiblum and Nathan³ in a series of five case studies of women with varied experiences and diverse backgrounds. Leiblum and Nathan originally termed PGAD *persistent sexual arousal syndrome* based on a specific group of symptoms (see below). They later changed this label to PGAD to reflect the *genital* nature of the condition and to prevent confusion with persistent *subjective* sexual arousal or desire.⁶ Even with this change, PGAD is still confused with hypersexuality on a behavioral level⁷; women with PGAD and hypersexuality report a frequent and intrusive need for solitary or partnered sexual activity. Despite this behavioral similarity, hypersexuality is characterized by high subjective desire for sexual activity, whereas PGAD is typically characterized by high levels of genital arousal in the *absence* of desire. However, the differences between these two conditions have not been explored empirically.

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Leiblum and Nathan³ originally proposed five criteria that represent PGAD:

1. Symptoms of physiologic sexual arousal (genital fullness or swelling and sensitivity with or without nipple fullness or swelling) that persist for hours or days and do not subside completely on their own;
2. These symptoms do not resolve with ordinary orgasmic experience and might require multiple orgasms over hours or days to remit (for some women, this might include spontaneous and intense orgasms different from deliberate orgasms resulting from sexual excitement and activity);
3. Symptoms of arousal are usually experienced as unrelated to any subjective sense of sexual excitement or desire;
4. The persistent genital arousal can be triggered not only by a sexual activity but also by non-sexual stimuli or by no apparent stimulus at all;
5. Arousal symptoms feel unbidden, intrusive, uninvited and unwanted, and the symptoms cause at least a moderate degree of distress.

Leiblum and others have modified these features only slightly since the first description of PGAD, and sometimes distress is considered a separate, sixth criterion.^{6,8–10}

Although Leiblum and Nathan are credited as being the first to label this condition and its presenting characteristics in 2001, descriptions of PGAD-like symptoms existed before 2001. Facelle et al,¹¹ in a review of PGAD, described half a dozen historical cases, spanning from 200 AD to 1994. The paucity of research on PGAD before 2001 could indicate that a novel factor plays a role in its etiology; alternatively, individuals might have been reluctant to discuss these concerns for fear of stigmatization, or the collection of symptoms might have just gone unrecognized. These questions remain unanswered because a consensus has yet to be reached on the etiology of PGAD.

ETIOLOGY

Although many etiologic hypotheses have been proposed, the cause or causes of PGAD remain unknown. It is likely not attributable to a single cause or biopsychosocial factor, and there may be subgroups of women within the PGAD group who develop the condition through a combination of factors. These hypothesized etiologies include central and peripheral dysregulation,^{5,12,13} vascular changes,¹⁴ meningeal cysts^{15,16} (most commonly Tarlov cysts), and pharmacologic,¹⁷ psychological,¹⁰ and dietary¹⁸ explanations.

Little is known about the frequency or validity of each hypothesized etiology, because the majority of this work is in the form of individual case studies. A summary of the individual case studies related to potential etiologies is presented in [Table 1](#).^{1,2,12,14,17–38} This summary includes the hypothesized etiology of PGAD, treatment modality undertaken, patient characteristics, and the investigators' operationalization of

treatment success. Assessments (physical, neurologic, cardiovascular, endocrine, etc) yielded no abnormal results in most cases; exceptions are described in the "symptom characteristics" column.

Women with symptoms of persistent genital arousal have been asked about their own causal attributions of the symptoms. In an online survey of 103 women with PGAD conducted by Leiblum et al,³⁹ participants indicated that sexual stimulation (n = 51, 49.5%), masturbation (n = 39, 37.9%), stress (n = 35, 33.98%), and anxiety (n = 30, 29.1%) were the most commonly reported activities associated with the original triggering of their symptoms.

Although many instances of PGAD have no clear physical cause, some cases of PGAD have an identifiable morphologic etiology.^{15,16} Komisaruk and Lee¹⁶ requested that women in an online support group for PGAD submit sacral magnetic resonance (MR) images to determine the presence of Tarlov cysts, which form on dorsal (sensory) roots and have been found to result in genital dysesthesias or paresthesias (abnormal sensations). Of the 18 women who submitted their MR images, cysts were present in 12 (66.7%). A separate study identified 11 women with PGAD symptoms in a cohort of 1,045 patients with spinal meningeal cysts; Tarlov cysts were the most common type of meningeal cysts encountered in the PGAD group (n = 8 of 11, 73%).¹⁵ Surgical treatment of these 11 women resulted in complete and lasting disappearance of symptoms in seven patients (64%) and significant improvement in symptoms in three (27%); only one (9%) reported no change in symptoms.¹⁵ These investigators believed that PGAD might be a previously undiscussed symptom of a compressed sacral nerve and noted that it is often present with other sacral radiculopathy symptoms, including pain (dyspareunia, sacral, perineal, and buttock pain) and bladder, bowel, and sexual dysfunction.¹⁵

PREVALENCE

The exact prevalence of PGAD is not known. A survey of a sexual health clinic in the United Kingdom found that 1% (n = 1 of 96) of women who agreed to participate in a brief questionnaire met all five of Leiblum and Nathan's 2001 criteria for PGAD, and 33% (n = 32 of 96) endorsed at least one criterion.⁴⁰ A study of health care providers who address sexual health concerns indicated that 20% to 25% have patients with symptoms at least partly consistent with PGAD.⁵ Another source estimated the prevalence of PGAD to be 28% of women presenting with chronic pelvic pain.⁴¹ Because chronic pelvic pain affects 2.1% to 24.0% of all reproductive-age women,⁴² the prevalence rate for PGAD would range from approximately 0.5% to 6.7%. Women experiencing PGAD might be embarrassed to present to health care providers or fear being potentially misunderstood (eg, being mistakenly diagnosed with hypersexuality), thus contributing to an underestimation of prevalence. Lack of awareness by health care providers also can lead to underrecognition of PGAD and subsequent failure to make the

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