Persistent Genital Arousal Disorder – A Case Study

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Introduction

Persistent genital arousal disorder (PGAD), also referred to as persistent sexual arousal disorder (PSAS) and restless genital syndrome (RGS), was first described in 2001 (1)) although descriptions of possible PGAD have been found dating back to 200 AD (2). The diagnosis is not clearly defined however five criteria have been proposed:

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.

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Prevalence is unknown, most likely due to lack of disclosure. PGAD primarily affects women but cases of men have been described (4). The impacts of PGAD are immense affecting activities of daily living, causing pain and discomfort, isolation, feelings of shame and in some cases suicidal ideation.

References:

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Case Presentation

Thelma*, a 64-year-old woman diagnosed with multiple sclerosis (MS) in 2001, telephoned for advice. She described a feeling of constant sexual arousal localised to between her clitoris and vagina. The sensation commenced 6-7 years ago, to start with it occurred "a couple of nights" a week and was initially pleasant she "just didn't reach climax" although it did interrupt sleep. The sensation then progressed to become more constant and she "can't stand it" it's "not supposed to happen at my age" – Thelma met all the criteria for PGAD; although she didn't have physical signs of arousal as described in criteria 1, the sensation would fit as a physiological symptom. This prompted further investigation and review.

Co-morbidities: asthma, prolonged QT syndrome, depression, lumbar disc degeneration, recent ex-smoker.

*Thelma is a pseudonym – not her real name.

Aetiology

As a large number of pathways are involved in sexual function the aetiology of PGAD is likely to be numerable and subgroups may be plausible (5).

Assessments in most cases are normal. Possible causes to be explored if presented with a person describing PGAD are:

Possible cause:	Examples:	Thelma:
Pharmaceutical	Cessation or commencement of SSRI's	On antidepressants but not associated with onset of symptoms
Peripheral, Central Nervous System	Epileptic focus, hypothalamic dysfunction, Parkinson's Disease, restless leg syndrome (RLS) and overactive bladder, neuropathy or entrapment of pudendal nerve	MS
Meningeal cysts	Tarlov cyst	No
Vascular	Pelvic congestion syndrome	No
Hormonal	Onset of menopause, post hysterectomy	Menopause at age 38
Diet	Increased Soy	No
Psychological	PTSD, Sexual abuse	No
Socio economic	Conservative attitude to sex, Family/ religious beliefs.	No

Treatments

There is no trial evidence for the treatment of PGAD. Case studies document a number of treatment strategies including;

- Cognitive behavioural therapy (CBT)
- Botox
- Embolisation of vein
- Surgical release of pudendal nerve
- Treat depression
- Exercise
- Clitorectomy
- Electroconvulsive therapy (ECT)
- Transcutaneous electrical nerve stimulation (TENS)
- Pelvic floor physiotherapy
- Hypnotherapy
- Mindfulness
- Distraction techniques
- Various meds incl: Benzodiazepines, Anticonvulsants, Leuprolide

Conclusion

After reviewing possible causes Thelma's treating neurologist and I concluded that Thelma's symptoms were secondary to a spinal lesion affecting the neural pathways primarily the somatosensory pathways most likely from her relapse in 2011, when she had difficulty walking and a lateral burning discomfort in both legs.

Initial attempts of treatment were aimed at decreasing vascular flow, she trialled a bricanyl turbuhaler and labetalol with nil to minimal effect. Thelma also tried cooling techniques and lignocaine gel to no avail. Historically she has trialled different medications for dysesthetic pain with intolerable side effects so these were not retried. Interestingly her symptoms lessened post disclosure although this was not sustained.

Thelma chose to focus on her depression hoping this may also help with her PGAD unfortunately pharmaceutical trials have been complicated by her prolonged QT syndrome.

Thelma has recently been assessed by gynaecology who have recommended trialling leuprolide acetate, a potent gonadotropin-releasing hormone receptor (GnRHR) agonist , as it was effective in two cases studies.(6,7)

Discussion

Due to the pathology of MS PGAD is a potential symptom which is undoubtedly under-recognised. Although alluded to as a potential cause for PGAD in literature, I only found one other case of a person with MS which described a combination of RGS and RLS (8). Interestingly since I presented this case at the 2017 Multiple Sclerosis Nurses Australasia (MSNA) conference four MS nurses have told me of patients that appear to have PGAD.

MS nursing practice point

As nurses, we are in the prime position to identify this disorder in our patient population. Thelma has certainly changed my MS nursing practice, I now include a more in-depth discussion about sexual function particularly around genital sensation in all my assessments.

Acknowledgements:

- Thelma, for feeling comfortable enough to share her distressing symptoms and allowing me to present them.
- Dr David Abernethy, Treating Neurologist
- MSNA, for giving me the opportunity to share this case study

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