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EPIDEMIOLOGY & RISK FACTORS

Healthcare Experiences of Individuals With Persistent Genital Arousal Disorder/Genito-Pelvic Dysesthesia



Robyn A. Jackowich, MSc,¹ Stéphanie C. Boyer, PhD,¹ Samantha Bienias, BScH,¹ Susan Chamberlain, MD,² and Caroline F. Pukall, PhD³

ABSTRACT

Introduction: Persistent genital arousal disorder/genito-pelvic dysesthesia (PGAD/GPD) is a distressing condition characterized by persistent, unwanted sensations of genital arousal (eg, feelings of being on the verge of orgasm, and of lubrication, swelling, tingling, throbbing) that occur in the absence of sexual desire. Although PGAD/GPD is associated with significant impairments in psychosocial functioning, the healthcare (HC) experiences of affected individuals are not well understood.

Aim: The aims of this study were to examine the barriers to HC, the costs of HC, and the associations among HC experiences, symptoms, and psychosocial outcomes in those with PGAD/GPD symptoms.

Methods: One hundred and thirteen individuals with PGAD/GPD symptoms completed an online, cross-sectional self-report questionnaire about their HC history and experiences.

Main Outcome Measures: Self-reported HC barriers, and financial costs associated with PGAD/GPD HC. Validated measures of HC experiences (eg, comfort communicating with HC practitioners [HCPs]), and psychosocial (eg, depression, anxiety) and PGAD/GPD symptom outcomes.

Results: The majority of participants (56.6%) reported waiting at least 6 months to seek HC for PGAD/GPD symptoms. Those who sought HC approached many HCPs (46.0% approached 6+ HCPs). Several barriers to HC were identified (eg, lack of HCP knowledge of PGAD/GPD), and high costs were reported. A series of multiple linear regression analyses found an association between HC experiences, psychosocial, and symptom outcomes. Specifically, decreased comfort communicating with one's HCP was associated with greater depressive and anxiety symptoms.

Conclusion: High costs and numerous barriers to seeking HC for PGAD/GPD symptoms were identified, and discomfort communicating with an HCP about PGAD/GPD was associated with increased symptoms of depression and anxiety. These results highlight the need for more awareness of this condition in order to improve care for this population. **Jackowich RA, Boyer SC, Bienias S, et al. Healthcare Experiences of Individuals With Persistent Genital Arousal Disorder/Genito-Pelvic Dysesthesia. Sex Med 2021;9:100335.**

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Key Words: Healthcare Experiences; Persistent Genital Arousal Disorder; Genito-Pelvic Dysesthesia; Financial Burden; Barriers to Healthcare; Psychosocial Wellbeing

INTRODUCTION

Persistent genital arousal disorder/genito-pelvic dysesthesia (PGAD/GPD) is a distressing condition characterized by persistent, unwanted sensations of genital arousal (eg, feelings of being on the verge of orgasm, and of lubrication, swelling, tingling, throbbing, contractions) occurring in the absence of sexual desire.¹ Symptoms can be episodic, lasting for hours to days, or constant. They are described as intrusive, unwanted, and, in some cases, painful. PGAD/GPD was initially called “persistent

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¹Department of Psychology, Queen's University, Kingston, ON, Canada;

²Kingston General Hospital and Department of Obstetrics & Gynaecology, Queen's University Kingston General Hospital, Kingston, ON, Canada;

³Department of Psychology, Queen's University, Kingston, ON, Canada

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sexual arousal syndrome,”¹ but the name of the condition was later changed to “persistent genital arousal disorder” to reflect the *genital* rather than *sexual* nature of the condition.² More recently, it has been noted that PGAD/GPD may be considered a type of “genito-pelvic dysesthesia” (defined as an abnormal, unpleasant sensation) where the primary unwanted sensation is arousal.³ This newest terminology represents a more accurate description of the symptoms associated with PGAD/GPD (unwanted, unpleasant arousal sensations), which may help reduce misconceptions that PGAD/GPD is a condition of high subjective arousal/sexual desire. This change in terminology may also help to decrease the stigma associated with this disorder.

PGAD/GPD is estimated to affect approximately 0.6–2.7% of women,⁴⁻⁶ which may also be an underestimate, as many affected individuals report embarrassment or shame about their symptoms. Although research primarily focuses on women, there are a growing number of case studies of men with similar symptoms.⁷ PGAD/GPD can be associated with significant difficulties in activities of daily living (eg, socializing⁸) and psychosocial well-being, with individuals reporting high frequencies of depression, anxiety, and suicidal ideation.⁹

Despite the significant consequences of PGAD/GPD, research on this condition is minimal, and a treatment algorithm has yet to be identified.⁷ Given the lack of empirical information on PGAD/GPD, limited training is available to healthcare providers (HCPs), which in turn may influence the experience of individuals with PGAD/GPD symptoms seeking treatment and care. However, little is known about the healthcare (HC) experiences of individuals with PGAD/GPD symptoms.

The relationship between HC experiences and wellbeing has been well documented in patients with chronic pain and other conditions,¹⁰ including those who experience other forms of genito-pelvic discomfort. Other forms of genito-pelvic discomfort, such as vulvar pain, may serve as a useful framework for studying PGAD/GPD HC experiences, as similarities between these conditions have been previously noted.^{11,12} The patient-HCP relationship and communication between a patient and HCP have been associated with treatment satisfaction in women with provoked vestibulodynia (PVD; vulvodynia subtype characterized by provoked pain at the vulvar vestibule). In 1 study, almost half the participants with PVD reported that finding a trustworthy HCP was the most important aspect of their diagnostic experience.¹³ Women with PVD often report frustration with their HC experiences due to misdiagnosis, not being believed about their symptoms, or visiting multiple HCPs.¹³ Indeed, a third of women with PVD reported having had more than 15 appointments, or a period of more than 36 months between symptom onset and diagnosis¹³; this process can be financially costly to the individual and/or HC system.¹⁴ Fear of not being believed may similarly lead individuals with PGAD/GPD to delay seeking HC. Once engaged in the HC system, lack of HCP information about PGAD/GPD or misdiagnosis may potentially lead individuals to see multiple HCPs or to undergo multiple procedures,

exacerbating the psychosocial effects of this condition and resulting in a significant financial burden to the individual and HC system.

Current Study

This study aimed to gather descriptive information about the HC experiences of individuals with PGAD/GPD symptoms to better understand the associations among PGAD/GPD HC experiences, symptoms, and psychosocial outcomes. This study also investigated the self-reported cost of HC and barriers experienced when seeking diagnosis and/or treatment for PGAD/GPD symptoms. We hypothesized that greater comfort communicating with HCPs, a more positive relationship with HCPs, perception of PGAD/GPD HCPs as knowledgeable, a greater proportion of PGAD/GPD HCPs perceived as helpful, and satisfaction with HC experiences would be associated with decreased PGAD/GPD symptom severity and better psychosocial functioning (ie, lower sexual distress, depressive, and anxiety symptoms).

MATERIALS AND METHODS

Participants

Participants were recruited online (via posts on Reddit, Twitter, and Facebook, as well as on online PGAD/GPD support groups with the assistance of PGAD/GPD patient advocates/administrators). Eligible participants were 18 years of age or older, fluent in English, and endorsed the presence (past or current) of PGAD/GPD. PGAD/GPD was defined as experiencing the following: (i) symptoms of physiological genital arousal that persist for an extended period of time (hours, days, months); (ii) the arousal sensations occur in the absence of sexual desire; and (iii) the arousal sensations that are unwanted, intrusive and distressing. These symptoms correspond with 3 of the criteria originally proposed by Leiblum & Nathan.¹ Participants were not required to endorse that (i) their arousal symptoms do not subside on their own or with orgasm, or (ii) there is not a specific trigger for their symptoms because some individuals with PGAD/GPD report that their arousal symptoms will sometimes subside naturally or with orgasm for very brief periods of time before the symptoms return, and others hypothesize a cause/trigger for their arousal symptoms (ie, use of antidepressants, see¹⁵).

Measures

Participants answered questions about sociodemographics (Table 1), PGAD/GPD symptoms, and HC experiences. Participants indicated which of the 5 Leiblum and Nathan¹ PGAD/GPD characteristics they had experienced and rated their average PGAD/GPD symptom severity (0 = Very mild to 9 = Very severe). In addition to the questions about HC experiences listed in Table 2, participants rated their average satisfaction with PGAD/GPD HC experiences, how knowledgeable they perceived their HCPs to be about PGAD/GPD, and the proportion of PGAD/GPD HCPs perceived to be helpful. An open-ended

Table 1. Sociodemographic characteristics (N = 113)

| | % (n) |
|--|------------|
| Location | |
| Australia | 7.1 (8) |
| Canada | 7.1 (8) |
| France | 2.7 (3) |
| Germany | 2.7 (3) |
| Other | 11.5 (13) |
| United Kingdom | 11.5 (13) |
| USA | 57.5 (65) |
| Ethnicity | |
| American | 37.2 (42) |
| Australian | 6.2 (7) |
| British Isles | 8.8 (10) |
| Canadian | 4.4 (5) |
| Eastern European | 7.1 (8) |
| Endorsed multiple ethnicities | 9.7 (11) |
| French | 2.7 (3) |
| Northern European (except British Isles) | 3.5 (4) |
| Other | 8.8 (10) |
| South American | 2.7 (3) |
| Western European (except French) | 8.0 (9) |
| DR | .9 (1) |
| Current religious affiliation | |
| Catholic | 4.4 (5) |
| Christian | 16.8 (19) |
| None/DR | 63.7 (72) |
| Other | 4.4 (5) |
| Protestant | 5.3 (6) |
| Spiritual, no label | 5.3 (6) |
| Education | |
| Some/all college/undergraduate degree | 43.4 (49) |
| Some/all graduate school/professional training | 35.4 (40) |
| Some/all high school | 15.0 (17) |
| Some/all trade school | 5.3 (6) |
| DR | .9 (1) |
| Occupation | |
| Employed full-time | 23.9 (27) |
| Employed part-time | 15.9 (18) |
| On disability | 15.0 (17) |
| On employment insurance | .9 (1) |
| Other | 10.6 (12) |
| Retired | 11.5 (13) |
| Student | 8.0 (9) |
| Unemployed | 11.5 (13) |
| DR | 2.7 (3) |
| Household income | |
| >\$60,000 (USD) | 47.8 (54) |
| <\$60,000 (USD) | 37.2 (42) |
| DR | 15.0 (17) |
| Biological sex | |
| Female | 92.0 (104) |
| Intersex | 1.8 (2) |
| Male | 6.2 (7) |

(continued)

Table 1. Continued

| | % (n) |
|---------------------|------------|
| Sexual orientation | |
| Bisexual | 9.7 (11) |
| Other-sex attracted | 75.2 (85) |
| Other | 7.1 (8) |
| Same-sex attracted | 7.1 (8) |
| DR | .9 (1) |
| Gender identity | |
| Female | 88.5 (100) |
| Male | 6.2 (7) |
| Other | 5.3 (6) |

DR = decline response.

text box was provided to describe any perceived barriers to seeking medical attention and/or speaking with their HCP about their PGAD/GPD symptoms.

Interactions With HCPs. Two subscales from the Patient Reactions Assessment questionnaire,¹⁶ which assessed interactions with one's primary PGAD/GPD HCP, were completed by participants: the Patient Affective Index (PAI) and the Patient Communication Index (PCI), assessing the affective quality of the relationship (eg, respect) and comfort communicating with their HCP, respectively. Each subscale has 5 items rated from 1 (Very strongly disagree) to 7 (Very strongly agree), where higher scores indicate a more positive interaction. In our sample, the subscales showed excellent internal consistency ($\alpha = 0.88$ and 0.98 , respectively).

Financial Burden. Questions pertaining to the average HC costs related to PGAD/GPD were modeled after Xie et al¹⁴ (see Figure 1). These questions were introduced with the following instruction: "For the following expense categories, please specify the average amount per month (in USD) you spend on the treatment or management of PGAD/GPD symptoms." The study was open to an international sample, and therefore a link to a currency conversion calculator was also provided. Participants were also asked to indicate the average number of days per month that they were unable to perform household chores due to PGAD/GPD symptoms.

Psychosocial Outcomes. The Beck Anxiety Inventory (BAI;¹⁷) is a 21-item self-report questionnaire of anxiety symptoms. Participants rated the degree to which anxiety symptoms bothered them over the past month, from 0 (Not at all) to 3 (Severely, it bothered me a lot). The Beck Depression Inventory II (BDI-II;¹⁸) is a 21-item self-report questionnaire of depressive symptoms. Each item, rated from 0 to 3, measures a different symptom of depression over the past 2 weeks. Higher scores indicate greater symptom severity. In the present sample, the internal consistency of the BAI and BDI-II was excellent (both $\alpha = 0.93$). The single-item version of the Female Sexual Distress Scale (FSDS) was used to assess distress about sexuality.¹⁹

Table 2. Types of healthcare (HC) experiences and healthcare providers (HCPs) consulted about persistent genital arousal disorder/genito-pelvic dysesthesia (PGAD/GPD; $N = 113$) symptoms

| | % (n) |
|---|---------------|
| Length of wait prior to approaching a HCP about PGAD/GPD symptoms (in months) | |
| ≤1 | 24.8 (28) |
| 2 | 7.1 (8) |
| 3–5 | 11.5 (13) |
| 6+ | 39.8 (45) |
| Have not approached a HCP | 16.8 (19) |
| Number of HCPs consulted about PGAD/GPD symptoms | |
| >5 HCPs | 46.0 (52) |
| ≤5 HCPs | 41.6 (47) |
| 0 HCPs | 12.4 (14) |
| Types of HCPs consulted about PGAD/GPD symptoms | |
| Acupuncturist | 22.1 (25) |
| Biofeedback Specialist | 6.2 (7) |
| Clinical Social Worker | 12.4 (14) |
| Medical Doctor | 80.5 (91) |
| Not applicable | 10.6 (12) |
| Nurse Practitioner | 17.7 (20) |
| Other | 29.2 (33) |
| Physical Therapist | 48.7 (55) |
| Physician Assistant | 12.3 (15) |
| Psychiatrist | 31.9 (36) |
| Psychologist | 41.6 (47) |
| Sex Therapist | 19.5 (22) |
| M (SD) | |
| HC experience ratings | |
| Proportion of HCPs seen about PGAD/GPD symptoms perceived as helpful and understanding | 23.5% (30.24) |
| How knowledgeable they perceived their HCPs to be about PGAD/GPD 0 = No knowledge of PGAD/GPD to 9 = Extremely knowledgeable about PGAD/GPD | 2.29 (2.69) |
| Average satisfaction with PGAD/GPD HC experiences 0 = Not at all satisfied to 9 = Completely satisfied | 2.43 (2.69) |

HC = healthcare; HCP = healthcare practitioner; PGAD/GPD = persistent genital arousal disorder/genito-pelvic dysesthesia.

“Other” types of HCPs consulted included: Bodyworker, Chiropractor, Naturopath, Hypnotherapist, Psychoanalyst, and Sport Medical Service. Proportion of HCPs seen about PGAD/GPD perceived as helpful and understanding (decline response = 0); How knowledgeable they perceived their HCPs to be about PGAD/GPD (decline response = 14); Average satisfaction with PGAD/GPD HC experiences (decline response = 13).

Procedure

This study was reviewed and approved by the Queen's University General Research Ethics Board (GPSYC-847-17). Interested

participants were directed to an online survey hosted by Qualtrics software (Provo, UT, USA). The first page of the survey contained the letter of information and consent form. After participants responded to a question documenting that they gave their informed consent to participate in the study, they then proceeded to the 30–45-minute online survey. The survey was cross-sectional, and some questionnaires required retrospective recall (eg, recall of past HC experiences). Participants who declined to provide their consent to the study were re-directed out of the survey. Upon completion, participants viewed a debriefing form and had the option to enter a prize draw for 1 of 2 \$50 (CAD) Amazon gift cards.

Data Considerations

Before beginning the data cleaning process, the data from certain participants were removed (see Figure 2), for a final sample of $N = 113$.

Quantitative Analyses. Data were examined for missing values, normality, and outliers where appropriate. Where outliers were identified (values > 3 times the interquartile range), analyses were conducted with and without them; results did not differ meaningfully between these cases.²⁰ No missing data were imputed for sociodemographic or HC experience questions. On validated questionnaires with more than 15 items (BDI-II, BAI), if fewer than 15% of the items were missing for an individual, missing values were replaced with the individual's mean response on that questionnaire. If more than 15% of items were missing, then that individual's response was excluded from the analysis. Analyses were conducted using Statistical Package for the Social Sciences (SPSS) Version 25 (IBM Corporation, Armonk, NY, USA). A series of multiple regressions were undertaken to examine the relationships among HC experiences, PGAD/GPD symptom, and psychosocial outcomes. The data were checked to ensure they met assumptions for multiple linear regression. Alpha values (2-tailed) were set at $P < .05$. As PGAD/GPD HC experiences is a novel area of research, an a priori power analysis was undertaken to determine the sample needed to detect a medium effect size ($f^2 = 0.15$). G*Power version 3.1²¹ indicated that a sample of $n = 55$ was required for multiple regressions with 5 predictors and 80% power.

Qualitative Analyses. Thematic analysis was used to identify themes, inductively, from the open-ended question about barriers to PGAD/GPD HC.²² Two independent reviewers (R.A.J., S.C.B.) identified an exhaustive list of themes within the responses, and then used these 2 lists to create a shared codebook. Both reviewers then independently coded the participant responses for each of the 28 themes identified (0 = theme absent; 1 = theme present). The 2 raters had good reliability ($\kappa = 0.75$;²³). Ratings where they disagreed (3.6%) were discussed until consensus was reached.

RESULTS

Sample Characteristics

The average age of participants was 44.5 years ($SD = 15.5$, $n = 110$, range: 19 to 80). See Table 1 for further sociodemographic

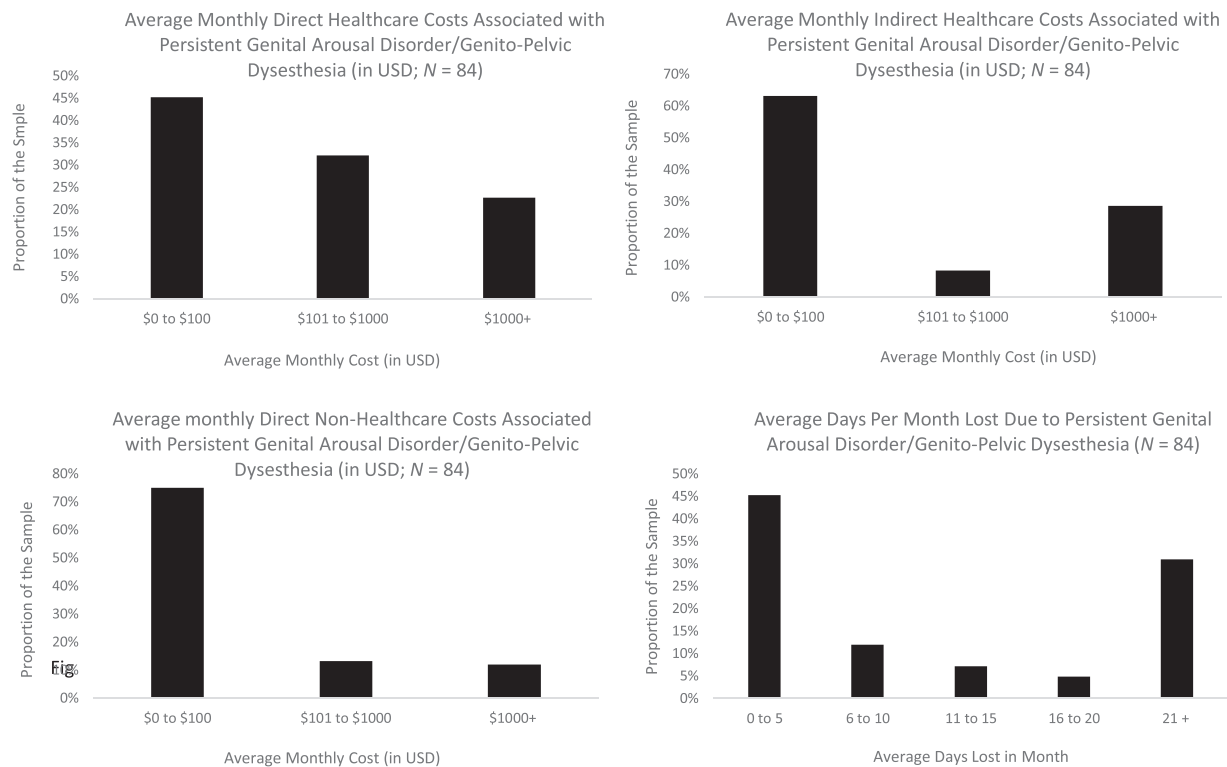


Figure 1. Self-reported average monthly healthcare (HC) costs (in USD) associated with persistent genital arousal disorder/genito-pelvic dysesthesia (PGAD/GPD). Definitions of HC cost categories were modeled after Xie et al. 2012. *Direct HC costs include:* Insurance Payments (Commercial insurance payments [ie, the amount paid by the insurer for office visits], hospitalization, and prescription medication) and Out-of-Pocket Payments (Payments for office visits, lab work, or diagnostic tests; surgical procedures, hospitalization, prescription medications, OTC remedies, or self-care measures as well as any other amount paid for medical care [ie, any invoice paid beyond the amount paid at the visit]). *Direct non-HC costs include:* Transportation expenses including travel costs and parking. *Indirect costs include:* Financial loss for work-related items (such as, sick leave, leave of absence, direct loss of job and unemployment) and Employers' Costs (payments made by employers to you for PGAD/GPD-related work loss [sick leave and leave of absence].) *Day lost per month:* days that participants were unable to complete their daily household chores.

information. The majority of participants (74.3%, $n = 84$) reported experiencing all 5 of the Leiblum & Nathan PGAD/GPD criteria,¹ while the remainder experienced at minimum the 3 necessary criteria for participation. The majority of participants indicated that they currently experience PGAD/GPD symptoms (88.5%, $n = 100$).

HC Experiences

Over a third of participants (39.8%, $n = 45$) waited 6 months or more after symptom onset to approach a HCP about their symptoms, and 16.8% ($n = 19$) reported never having approached a HCP (Table 2). Of those who had sought HC for PGAD/GPD symptoms, two-thirds (67.0%, $n = 63$) had received a formal diagnosis of PGAD/GPD from a HCP, and 20.4% ($n = 19$) waited over a year before receiving this diagnosis. Those who had approached an HCP reported consulting with numerous providers; with 46% ($n = 52$) of the sample consulting at least 6 HCPs about their symptoms. Medical doctors, physical therapists, and psychologists were the most commonly consulted HCPs.

Individuals with a diagnosis for their symptoms reported consulting a significantly higher number of HCPs about their PGAD/GPD symptoms (median = 6, $n = 63$) than those without a diagnosis (median = 4, $n = 31$), $U = 637.0$, $z = -2.74$, $p = 0.006$. Ratings of perceived HCP knowledge of PGAD/PGD, helpfulness, and understanding, as well as overall satisfaction with HC for PGAD/PGD, were low on average (Table 2).

Barriers to HC for PGAD/GPD Symptoms

Twenty-eight different barriers to HC for PGAD/GPD symptoms were identified (Table 3). The most common barriers were a lack of knowledge about PGAD/GPD within the HC community (46.0%, $n = 52$ "The doctors are not informed about PGAD/GPD, and there are few studies related to this"), HCPs not acknowledging the distress or impairment associated with PGAD/GPD symptoms (25.7%, $n = 29$, "I don't think she [the HCP] understood the severity of the impact on me of living with PGAD"), and participants' own emotional barriers to seeking

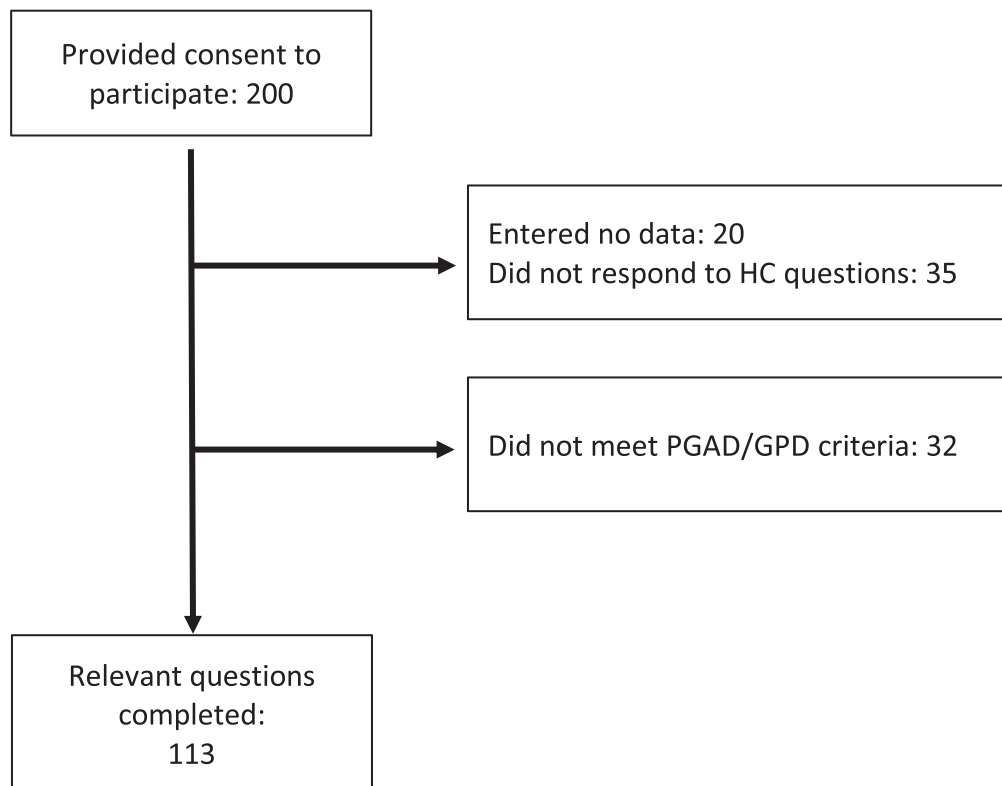


Figure 2. Flow chart illustrating the number of participants who completed each stage of the survey, and reasons for participant exclusions. Twenty respondents did not complete any questions following the consent page. Of those who provided consent, 35 were not included in the analyses because they did not respond to any of the HC experience questions (ie, they terminated the survey after completing the only the sociodemographic questions). Finally, 32 participants were excluded because the individual did not meet persistent genital arousal disorder/genito-pelvic dysesthesia (PGAD/GPD) symptom eligibility criteria. In total, there were 113 eligible participants: 13 participants that were eligible and completed the survey in part, and 100 participants that completed the survey in full.

HC (23.0%, $n = 26$, “Nervous and embarrassed about discussing this with my doctor,” “Shame”). Some participants additionally reported facilitative strategies for seeking HC in their responses, such as advocating for oneself to receive referrals and doing their own research into the condition.

Financial Burden

The majority of participants reported spending up to \$100 USD per month on PGAD/GPD HC (Direct HC costs: 47.6%, $n = 40$; Direct non-HC costs: 75.0%, $n = 63$; Indirect costs: 63.1%, $n = 53$; Figure 1). However, a notable number of participants reported paying an average of \$1,000 USD or more per month on PGAD/GPD HC (Direct HC: 22.6%, $n = 19$; Direct Non-HC: 11.9%, $n = 10$; Indirect: 28.6%, $n = 24$; definitions provided in Figure 1). A bimodal distribution was observed with respect to the frequency of being unable to complete household chores due to PGAD/GPD symptoms. Just under half of participants (45.2%, $n = 38$) reported being unable to perform household chores between 0 and 5 days per month, whereas 31.0% ($n = 26$) reported being unable to do so for 21 days or more in an average month.

HC Predictors of Symptom Outcomes

Multiple regression analyses were performed to determine if HC experiences (PAI, PCI, perception of HCPs as knowledgeable about PGAD/GPD, overall satisfaction with PGAD/GPD HC experiences, and proportion of PGAD/GPD HCPs who were helpful and understanding) significantly predicted symptom and psychosocial outcomes (BAI, BDI-II, FSIDS, PGAD/GPD symptom severity ratings; see Table 4 for the correlation matrix).

The anxiety and depression models were significant, explaining 26.2% (Adj. $R^2 = 0.211$, $F(5, 72) = 5.12$, $P < .001$) and 24.5% (Adj. $R^2 = 0.193$, $F(5, 72) = 4.68$, $P = .001$) of the variance in scores, respectively (Table 5). Lower comfort communicating with one’s primary PGAD/GPD HCP was a significant predictor in each model. The third regression model predicting sexual distress was significant, explaining 24.8% of the variance in sexual distress scores (Adj. $R^2 = 0.196$, $F(5, 73) = 4.81$, $P = .001$). Rating HCPs as more knowledgeable about PGAD/GPD ($\beta = 0.307$, $t = 2.41$, $P = .019$) and lower satisfaction with PGAD/GPD HC overall ($\beta = -0.383$, $t = -2.65$, $P = 0.010$) were significantly associated with greater sexual distress. Finally, the model predicting PGAD/GPD symptom severity scores was also

Table 3. Themes (28) identified within participant responses to an open-ended question about barriers to accessing healthcare (HC) for persistent genital arousal/genito-pelvic dysesthesia (PGAD/GPD) symptoms (n = 113)

| Themes % (n) | Examples |
|---|--|
| HC factors | |
| Lack of knowledge about PGAD/GPD within the HC community (eg, lack of HCP knowledge, research, evidence-based treatments) | 46.02 (52) "The doctors are not informed about PGAD, and there are few studies related to this," "It is not well known or understood" |
| HCP not acknowledging distress/impairment associated with PGAD/GPD symptoms. | 25.66 (29) "I don't think she [the HCP] understood the severity of the impact on me of living with PGAD," "Dismissal of symptoms as not being serious" |
| HCP perceived PGAD/GPD symptoms as an exclusively psychogenic condition | 12.39 (14) "I was told it's in my head," "it's been difficult to prove that I'm not imagining this because of some underlying psychiatric problem" |
| Misdiagnosis or lack of diagnosis | 10.62 (12) "I had to diagnose myself," "my psychiatrist considered that I had a manic break and hypersexuality" |
| Geographic location and availability of a nearby provider/HC service | 9.73 (11) "Almost no one knows about PGAD in my country" "I was living in the country, 4 hours away from the city" |
| Treatment ineffective or symptoms worsened | 8.85 (10) "She gave inaccurate advice in relation to exercises to avoid, which made my condition worse" "...health clinic didn't seem to consider that touch could be a real trigger" |
| Communication/language barriers | 7.96 (9) "I told him that I have a constant burning feeling in my genital area" "They don't speak English well enough to understand the material I provided from online sources" |
| HCP used humor when participant disclosed symptoms | 5.31 (6) "The doctor said he bet my husband loved it, and he wished his wife would get it" "Providers joking and not thinking of it as a problem" |
| "Gate keeping" (eg, a referral needed to receive specialized care) | 4.42 (5) "I had to seek a sexual counsellor at the hospital for 2 years before she allowed me to have access to the Pelvic Pain Team" "Need to get referrals to see specialists" |
| Misattribution of symptoms to a comorbid condition (including depression) or increased complexity of PGAD/GPD symptoms due to comorbid medical conditions | 3.54 (4) "Claiming it's part of being depressed" "other diverse genitalia barriers" |
| Long wait time for referrals | 3.54 (4) "It took a long time to get an appointment with OBGYN specialists after seeing my first provider" "Long waiting period for some healthcare providers" |
| No access to a regular HCP | 0.89 (1) "I had no personal physician" |
| Lack of effective team-based treatment | 0.88 (1) "When you have symptoms like PGAD you should have a team supporting you" |
| Participant factors | |
| Emotional barriers to seeking HC (eg, shame, embarrassment, hopelessness) | 23.01 (26) "nervous and embarrassed about discussing this with my doctor," "Shame," "it's extremely hard to talk about" |
| Cognitive barriers to seeking HC (eg, fear they will not be believed, treatments will not help) | 12.39 (14) "I thought she would think I was crazy and would not believe me," "she won't know anything so there is no point" |
| Own lack of knowledge about PGAD/GPD delayed seeking/accessing HC | 6.19 (7) "Unaware that this was a thing" "I just recently learned that there was a name to the feelings that I had" |
| Personal attributions about their symptoms | 4.42 (5) "I felt I was dirty, that it was my fault," "I thought everyone felt the same" |
| Emotions that came up from HC seeking (eg, anxiety, frustration) | 3.54 (4) "You have to keep explaining to multiple people, which can be frustrating" |
| Barriers related to social support system (eg, reluctance to disclose symptoms to others) | 2.65 (3) "I live with my mother, and she accompanies me to the specialist medical appointments [...] I don't want her to be there, or to even KNOW about anything like this" "A husband who doesn't understand the full extent of my PGAD" |

(continued)

Table 3. Continued

| Themes % (n) | | Examples |
|---|----------|--|
| Perception of HCP as uncomfortable discussing PGAD/GPD symptoms | 1.77 (2) | "Most docs reacted by laughing at me or not being able to look me in the eyes," "Doctor seemed uncomfortable" |
| Past negative HC experiences in general | 1.77 (2) | "I am not interested in seeing a neurologist, stemming from a bad experience" |
| Positive relationship with current HCP | 0.88 (1) | "I do not wish to change GPs as he is very understanding" |
| Financial Factors | | |
| Lack of insurance coverage/limitations in coverage | 7.08 (8) | "Insurance has not paid for any of my doctors or surgeries in connection to PGAD" |
| Cost of seeking private services | 3.54 (4) | "Spent thousands on flights and medical fees," "I spent many thousand out of pocket" |
| PGAD/GPD not a diagnostic code in the HC system | 1.77 (2) | "PGAD is not in the healthcare system. We have to say I have something else wrong with my pelvic region to get an MRI" |
| Loss of income/time due to HC seeking | 0.88 (1) | "Seeing doctors became a part-time job" |
| Social factors | | |
| Cultural/societal norms and discourse around sexuality and PGAD/GPD | 7.08 (8) | "A condition that is not known in my country," "The stigma of it in western society" |
| Other | | |
| No barriers | 5.31 (6) | "None" |

HC = healthcare; HCP = healthcare provider; PGAD/GPD = persistent genital arousal disorder/genito-pelvic dysesthesia.

Table 4. Correlation matrix among healthcare (HC) variables and psychosocial outcomes

| | BAI | BDI-II | FSDS item | Severity of PGAD/GPD symptoms | PAI | PCI | Proportion of HCPs helpful | Perceived HCP Knowledge | HC satisfaction |
|-------------------------------|------------------------|-------------------------------------|-------------------------------------|--------------------------------------|--------------------------|--------------------------------------|----------------------------|-------------------------|--------------------------------------|
| BAI | 1.00 <i>n</i> = 103 | 0.575 [†] <i>n</i> = 99 | 0.435 [†] <i>n</i> = 96 | 0.256 [†] <i>n</i> = 101 | -0.130 <i>n</i> = 85 | -0.304 [†] <i>n</i> = 82 | -0.144 <i>n</i> = 103 | 0.096 <i>n</i> = 89 | -0.022 <i>n</i> = 90 |
| BDI-II | | 1.00 <i>n</i> = 99 | 0.521 [†] <i>n</i> = 95 | 0.323 [†] <i>n</i> = 97 | -0.178 <i>n</i> = 83 | -0.419 [†] <i>n</i> = 80 | -0.176 <i>n</i> = 99 | -0.063 <i>n</i> = 87 | -0.219* <i>n</i> = 88 |
| FSDS item | | | 1.00 <i>n</i> = 96 | 0.184 <i>n</i> = 94 | -0.141 <i>n</i> = 84 | -0.320 [†] <i>n</i> = 81 | -0.192 <i>n</i> = 96 | 0.043 <i>n</i> = 86 | -0.270* <i>n</i> = 87 |
| Severity of PGAD/GPD symptoms | | | | 1.00 <i>n</i> = 101 | -0.237* <i>n</i> = 85 | -0.386 [†] <i>n</i> = 82 | -0.242* <i>n</i> = 101 | 0.014 <i>n</i> = 88 | -0.275 [†] <i>n</i> = 89 |
| PAI | | | | | 1.00 <i>n</i> = 85 | 0.561 [†] <i>n</i> = 82 | 0.044 <i>n</i> = 85 | 0.136 <i>n</i> = 83 | 0.382 [†] <i>n</i> = 84 |
| PCI | | | | | | 1.00 <i>n</i> = 82 | 0.279* <i>n</i> = 82 | 0.085 <i>n</i> = 80 | 0.343 [†] <i>n</i> = 81 |
| Proportion of HCPs helpful | | | | | | | 1.00 <i>n</i> = 113 | 0.216* <i>n</i> = 99 | 0.386 [†] <i>n</i> = 100 |
| Perceived HCP knowledge | | | | | | | | 1.00 <i>n</i> = 99 | 0.609 [†] <i>n</i> = 99 |
| HC satisfaction | | | | | | | | | 1.00 <i>n</i> = 100 |

BAI = Beck Anxiety Inventory; BDI-II = Beck Depression Inventory, Second Edition; FSDS = Female Sexual Distress Scale; HC = healthcare; HCP = healthcare provider/s; PAI = Patient Affective Index; PCI = Patient Communication Index; PGAD/GPD = persistent genital arousal disorder/genito-pelvic dysesthesia.

**P* < .05.

[†]*P* < .01.

Table 5. Results from 4 multiple regression models examining healthcare (HC) experiences as predictors of psychosocial and symptom outcomes in individuals with PGAD/GPD

| Variable | β | t value | P value | R ² |
|---|---------------|--------------|-------------|----------------|
| Model 1: Anxiety symptoms (BAI), n = 78 | | | | |
| PAI | -0.046 | -0.36 | .721 | 0.262 |
| PCI | -0.458 | -3.51 | .001 | |
| Proportion HCPs helpful | -0.166 | -1.43 | .157 | |
| Perceived HCP knowledge | 0.084 | -0.70 | .487 | |
| HC satisfaction | 0.180 | 1.29 | .202 | |
| Model 2: Depressive symptoms (BDI-II), n = 78 | | | | |
| PAI | 0.098 | 0.75 | .459 | 0.245 |
| PCI | -0.442 | -3.38 | .001 | |
| Proportion HCPs helpful | -0.132 | -1.13 | .261 | |
| Perceived HCP knowledge | 0.060 | 0.467 | .642 | |
| HC satisfaction | -0.112 | -0.77 | .443 | |
| Model 3: Sexual distress (FSDS single item), n = 79 | | | | |
| PAI | 0.068 | 0.52 | .604 | 0.248 |
| PCI | -0.239 | -1.84 | .070 | |
| Proportion HCPs helpful | -0.161 | -1.89 | .169 | |
| Perceived HCP knowledge | 0.307 | 2.41 | .019 | |
| HC satisfaction | -0.383 | -2.65 | .010 | |
| Model 4: PGAD/GPD symptom severity, n = 80 | | | | |
| PAI | -0.059 | -0.45 | .651 | 0.246 |
| PCI | -0.224 | -1.74 | .087 | |
| Proportion HCPs helpful | -0.260 | -2.25 | .027 | |
| Perceived HCP knowledge | 0.194 | 1.60 | .114 | |
| HC satisfaction | -0.177 | -1.28 | .206 | |

BAI = Beck Anxiety Inventory; BDI-II = Beck Depression Inventory, second edition; FSDS = female sexual distress scale; HC = healthcare; HCP = healthcare provider; PAI = patient affective index; PCI = patient communication index; PGAD/GPD = persistent genital arousal disorder/genito-pelvic dysesthesia.

BAI model results are presented with 2 outliers excluded.

significant, explaining 24.6% of the symptom severity variance (Adj. $R^2 = 0.195$, $F(5, 74) = 4.83$, $P = .001$). Higher proportions of PGAD/GPD HCPs seen as helpful and understanding was significantly associated with lower symptom severity scores.

DISCUSSION

The aim of the current study was to examine HC experiences of individuals with PGAD/GPD symptoms, including the financial costs and perceived barriers to accessing HC, and the association among HC experiences, psychosocial functioning, and symptom severity.

Accessing Care and Diagnosis

Overall, the majority of participants waited 6 months or longer to approach an HCP about their symptoms. Two-thirds of participants who sought HC for PGAD/GPD had received a PGAD/GPD diagnosis, though many (20.4%) waited over a year for this diagnosis. Approximately half (46.0%) reported consulting 6 or more HCPs about PGAD/GPD symptoms. The HC experiences reported by the present sample are similar to those described by individuals with other conditions of genito-pelvic discomfort. One recent study found that a third of women with PVD waited 36 months or more to receive a diagnosis,¹³ and those with other forms of chronic genito-pelvic pain similarly see many HCPs for the diagnosis and treatment of their symptoms.^{24,25}

A notable proportion of the present sample reported high direct and indirect monthly costs associated with PGAD/GPD symptoms (> \$1000 USD a month on average), similar to the high costs incurred due to vulvodynia.¹⁴ The majority of participants were located within a private HC system (ie, United States; Table 1), however, given that some participants in the present study are located within HC systems that are publicly funded (eg, Canada), and other participants had not actively sought care for their symptoms, the costs associated with PGAD/GPD symptoms are likely an underestimate of the overall associated financial burden. The high HC costs for some individuals may be due to individuals undergoing multiple HCP consultations, trying various symptom management strategies, undergoing expensive surgeries, or seeking care for a condition that, at the time of the study, was not yet recognized in any diagnostic manuals (recently included in the ICD-11 for women only²⁶). Future research is needed to examine which HCPs most often provide PGAD/GPD diagnoses, what specific treatments are undertaken for PGAD/GPD, and how effective are these treatments.

Perceived Barriers to HC for PGAD/GPD Symptoms

Participant responses regarding HC barriers may shed some light on the reasons for delays in HC access. The most frequently cited barrier was lack of knowledge about PGAD/GPD in the HC community. This lack of knowledge may result from the fact that PGAD/GPD is a relatively new diagnosis. There is still little systematic research on PGAD/GPD⁷ and, as noted above, PGAD/GPD is not included in many common diagnostic manuals. It is encouraging that newer editions may be more inclusive, as receiving a diagnosis for other forms of genito-pelvic discomfort is associated with positive impacts for patients (eg, validation, hope;²⁷). Furthermore, "arousal" is assumed to be a coherent construct that is wanted and pleasurable; few understand that there can be disagreement between the subjective and physiological components of arousal and that 1 or both components can be experienced as distressing.¹¹ The latter point is reflected in the second most common barrier cited by participants: HCPs not acknowledging the distress or impairment associated with PGAD/GPD symptoms. Similar barriers to HC are

frequently described by women with vulvodynia.²⁸ Participants' own emotions (eg, shame) about their symptoms were the third most commonly described barrier to care. Educational efforts (eg, #PGADfacts social media campaign) directed toward HCPs and members of the general public can serve to raise awareness of PGAD/GPD, which may, in turn, decrease the stigma associated with PGAD/GPD.

Association Between HC Experiences and Psychosocial Outcomes

The present study found a significant association among HC experiences, PGAD/GPD symptoms, and psychosocial outcomes. In particular, lower comfort communicating with one's primary PGAD/GPD HCP was a significant predictor of higher anxiety and depression symptoms. Unwanted arousal may be a difficult topic to discuss with HCPs, as suggested by participants' reported feelings of shame and embarrassment. Similarly, previous qualitative research on women with vulvodynia has highlighted desire for nonjudgmental validation from HCPs.^{29,30} Clinical consensus guidelines³¹ note that patients are comfortable disclosing information about their sexual functioning to HCPs, but they want the HCP to open the dialogue. These guidelines recommend that all HCPs communicate to their patients that they are open to addressing sexual concerns and reinforced the need for brief sexual well-being screening questions.³¹ Questions such as, "Are you sexually active?" and "Are there any problems?" or "Do you experience any genital discomfort or unwanted arousal symptoms?" may be enough to initiate the dialogue for individuals with PGAD/GPD and other forms of genito-pelvic discomfort to disclose their symptoms more comfortably with their HCP.³¹

Greater perception of HCPs as being knowledgeable about PGAD/GPD was a significant predictor of greater sexual distress. Greater knowledge about PGAD/GPD may include understanding the limited research on and lack of empirically-validated treatments for the condition, which may contribute to patient distress. Alternatively, given that this study is cross-sectional and the directionality of the results is not known, individuals with higher sexual distress may seek out knowledgeable HCPs.

Limitations and Future Research

Due to the online, self-report nature of the study, a major limitation of the study was the inability to verify participant diagnoses and symptoms with a clinical exam. It is possible that some individuals in the study were experiencing symptoms similar to those of PGAD/GPD but, in fact, would not be clinically diagnosed with PGAD/GPD (eg, pelvic congestion syndrome), which may lead to issues with data integrity. We aimed to reduce the impact of this limitation by using specific and detailed eligibility criteria based on the diagnostic criteria for PGAD/GPD. Although research is needed in

PGAD/GPD specifically, previous research has found high agreement between self-reported symptoms and clinical diagnosis for samples of women with other forms of genito-pelvic discomfort (ie, chronic vulvar pain^{32,33}). In addition, recruitment for the study was largely undertaken through online support groups that require new members to undergo screening of symptoms prior to entry into the group. While recruitment from support groups may have bolstered accurate identification of PGAD symptoms, it may also have introduced a source of bias (ie, greater distress and/or greater access to knowledgeable HCPs through other members). Future studies could consider using wider recruitment strategies to mitigate these potential biases.

Despite the fact that the online nature of this study allowed for the recruitment of more than 100 people with an uncommon condition, the study design relied on participants' retrospective recall and was cross-sectional. Future research utilizing a prospective, longitudinal design would allow for a more dynamic and causal understanding of the interactive influences of HC experiences and symptom outcomes. Although the qualitative analyses supplemented the quantitative data in a novel way, the qualitative data analysis was limited to second-order interpretations (ie, researchers' explanations of participant responses³⁴).

CONCLUSIONS

This study highlights barriers to accessing and receiving appropriate care for PGAD/GPD symptoms. Despite the distress associated with their symptoms, a proportion of individuals with PGAD/GPD appear to delay seeking care, while others consult numerous HCPs and face high financial burden related to their symptoms and treatment. There is a need for a better understanding of this distressing condition within the HC community, including improved accessibility of information about PGAD/GPD. HCPs should approach individuals with PGAD/GPD with respect and understanding, as perceived HCP communication may connect with broader physical and emotional outcomes.

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Corresponding Author: Caroline F. Pukall, PhD, Department of Psychology, Queen's University, 62 Arch Street, Humphrey Hall, Kingston, ON K7L 3N6, Canada. Tel: 613-533-3200; Fax: 613-533-2499; E-mail: caroline.pukall@queensu.ca

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STATEMENT OF AUTHORSHIP

Robyn A. Jackowich: Conceptualization (lead), Data curation, Formal Analysis (lead), Methodology (lead), Writing-Original Draft (lead), Writing-Review & Editing, Final Approval; Stéphanie C. Boyer: Conceptualization, Formal Analysis, Writing-Review & Editing, Final Approval; Samantha Bienias: Conceptualization, Data Curation, Formal Analysis, Writing-Original Draft, Writing-Review & Editing, Final Approval; Susan Chamberlain: Conceptualization, Writing-Review & Editing, Final Approval; Caroline F. Pukall: Conceptualization, Data Curation, Formal Analysis, Funding Acquisition (lead), Methodology, Resources (lead), Supervision (lead), Writing-Original Draft, Writing-Review & Editing, Final Approval.

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