

# Health seeking behaviours and treatments received by Australian women with vulvodynia: a cross-sectional survey

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## Research Article

**Keywords:** vulvodynia, vulvar vestibulitis, vulvar diseases, pelvic pain, dyspareunia

**Posted Date:** May 11th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-514547/v1>

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**Version of Record:** A version of this preprint was published at Australian and New Zealand Journal of Obstetrics and Gynaecology on August 31st, 2021. See the published version at <https://doi.org/10.1111/ajo.13423>.

# Abstract

**Background:** Vulvodynia is a condition characterised by pain in the vulva lasting more than three months and for which no obvious aetiology can be found. It affects around 8% of women and has significant negative impacts on quality of life. There is a paucity of research on healthcare management pathways and the use of evidence-based treatments in an Australian community setting.

**Aims:** To explore which healthcare professionals Australian women with vulvodynia seek treatment from, and which treatments are recommended, provided, or prescribed by these healthcare professionals.

**Materials and Methods:** A cross-sectional online survey was conducted from May 2019 to August 2019. Women were eligible to participate if they had been diagnosed with vulvodynia by a healthcare professional, were currently living in Australia, and were over 18 years old.

**Results:** Fifty respondents meet the inclusion criteria, with a mean age of 30.5 years. On average, respondents reported seeing four different types of healthcare professionals in the management of their vulvodynia, with general practitioners (GPs) (98%), medical specialists (96%), and physiotherapists (80%) being the three most commonly consulted. Most respondents reported seeing multiple GPs (>87%), multiple medical specialists (>77%), and multiple physiotherapists (50%). The most commonly prescribed interventions were pelvic floor down-training exercises (76%), topical (70%) and oral (70%) medication, and vulvodynia information (56%).

**Conclusions:** Australian women with vulvodynia seek help from several professionals and receive a variety of treatments for their pain. Of concern is many treatments that are being offered clinically have very little peer-reviewed evidence of effectiveness in vulvodynia.

## Introduction

Vulvodynia is a disorder defined by the International Society for the Study of Vulvovaginal Diseases as chronic pain or discomfort of the vulva lasting more than three months and for which no obvious aetiology can be found.<sup>1</sup> Although the exact cause of vulvodynia remains elusive, there is consensus in the literature that it is multifactorial, resulting from the interplay of biological, psychological, genetic, and/or environmental factors, including inflammation, infection, and poor psychological health.<sup>2-4</sup> It is not uncommon for women with vulvodynia to experience pain and other symptoms for years, with Australian women experiencing chronic vulval pain on average for 6.03 years.<sup>5</sup> Although evidence is scant, the lifetime prevalence is estimated at 8%, with this prevalence remaining constant up to 70 years of age.<sup>6</sup>

Treatment options for vulvodynia range from surgery, medications (topical and oral), pelvic floor physiotherapy, psychological counselling, sex and couple's therapy, dietary plans, and traditional,

complementary, alternative, and integrative medicine (TCAIM) modalities. Due to the disparity in vulvodynia presentations, not all treatment approaches will be beneficial for all patients,<sup>7</sup> and women often seek help from multiple healthcare professionals with little success in symptom reduction.<sup>3-6,8</sup> Results from a questionnaire study from Boston MA, USA, found that more than 60% of women with a history of unexplained chronic vulvar pain consulted with three or more different clinicians, and greater than 30% of respondents whose pain impacted on sexual intercourse visited more than five doctors.<sup>9</sup> This disjointed nature to assessment and treatment creates significant delays to effective management.

While there is peer reviewed literature that supports the efficacy of treatments for vulvodynia,<sup>10</sup> whether women with vulvodynia in Australia are being offered these treatments by their healthcare professional(s) is unknown. The types of healthcare professionals that women are seeking treatment from is unclear, as well as the number of different clinicians they are visiting. It is imperative this information is collected to ensure suitable treatments are being utilised to prevent these women, their sexual partner(s), and family from living unnecessarily with this condition. Therefore, this study aims to investigate the number and types of healthcare professionals that Australian women living with vulvodynia seek care from, and which treatments are commonly provided.

## Materials And Methods

An anonymous online survey was developed by the research team and hosted on the Qualtrics platform (Qualtrics Ltd). Women were eligible to participate in the survey if they were aged over 18 years, were currently living in Australia, and had a current diagnosis of vulvodynia from a medical or health professional. Women with self-diagnosed vulvodynia were not eligible to participate. Participants were recruited via a direct anonymous link to the survey, with the invitation to participate distributed across various vulvodynia specific groups and pages on the Facebook social media platform. The combined reach of these groups was over 5,500 people. The survey was open for three months between May 2019 – August 2019 and was promoted at fortnightly intervals.

Participation in the survey was voluntary and no identifiable data was obtained. The survey collected demographics (current age, age symptoms started, age diagnosed with vulvodynia, postcode, ethnicity, language spoken at home, medications used), and information regarding the types and number of healthcare professionals consulted and the treatments they offered. All data provided was from the participants themselves and required recall over the participants' entire time period of living with vulvodynia. A list of healthcare professionals was presented, and participants were asked to select which healthcare professional(s) they had seen in relation to their vulvodynia. Free text fields following each question allowed participants to add responses which were not present in the pre-populated list of healthcare professionals and treatments. The Pelvic Pain Impact Questionnaire (PPIQ) was included to assess the impact that vulvodynia had on the lives of participants.<sup>11</sup> The survey took approximately 15–30 minutes to complete, and a full copy of the survey can be found in Supplementary Material.

Although vulvodynia is prevalent in the Australian community, the condition has a significant diagnostic delay and many women fear seeking help for their pain which contributes to under-diagnosis of the condition. Due to the difficulty of accessing this population, a sample size of at least 40 women was deemed appropriate. This number was based on two previous Australian studies using similar methodology which recruited 40 and 60 women.<sup>5,11</sup>

Data were analysed using SPSS v24 (IBM Corporation). Missing data were not replaced. Descriptive statistics were presented as means, standard deviations and ranges for continuous data, or number and percentages for categorical data. Free text responses on the details of treatments prescribed and overall experience with the management of vulvodynia were categorised using an Excel spreadsheet (Excel 2016, Microsoft Corporation).

The study was approved by the Western Sydney University Human Research Ethics Committee, (H13154) (approved 7 May 2019).

## Results

A total of 71 survey responses were collected. Of those, 13 responses were incomplete and eight did not meet inclusion criteria. A total of 50 valid responses were included in the analysis. Table 1 outlines the demographic and vulvodynia characteristics of the respondents. The mean age of respondents was  $30.5 \pm 8.8$  years, with a mean age of symptom onset of  $20.3 \pm 8.2$  years. The mean age that respondents received a diagnosis was  $26.1 \pm 7.7$  years, meaning they experienced an average diagnostic delay of  $5.8 \pm 6.5$  years. Just over half of the respondents (54%) reported using medications to specifically manage their vulvodynia symptoms. The full details on medications and the proportion of respondents using them is available in Supplementary Table 1.

Table 1  
Demographics and vulvodynia characteristics of the survey respondents (n = 50)

Characteristic	Data
Age (years), mean $\pm$ SD (range)	30.5 $\pm$ 8.8 (18–56) <sup>‡</sup>
Postcode, n (%)	
Victoria	22 (44%)
New South Wales	14 (28%)
Queensland	8 (16%)
South Australia	3 (6%)
Western Australia	3 (6%)
Age of symptom onset (years), mean $\pm$ SD (range)	20.3 $\pm$ 8.2 (4–42)
Age of vulvodynia diagnosis (years), mean $\pm$ SD (range)	26.1 $\pm$ 7.7 (17–54)
Mean diagnostic delay (years), mean $\pm$ SD (range)	5.8 $\pm$ 6.5 (0–32)
Mean time spent with symptoms since vulvodynia diagnosis (years), mean $\pm$ SD (range)	5.0 $\pm$ 5.1 (0–20) <sup>†</sup>
Mean time spent with symptoms since onset (years), mean $\pm$ SD (range)	10.3 $\pm$ 8.5 (1–36) <sup>†</sup>
Use of medication to specifically manage vulvodynia, n (%)	
Yes	27 (54%)
No	23 (46%)
Use of antidepressant and hormonal contraceptive, n (%)	
Neither	21 (42%)
Antidepressant	5 (10%)
Hormonal contraceptive	13 (26%)
Both an antidepressant and a hormonal contraceptive	11 (22%)
† n = 49 (one respondent excluded due to missing data)	

## Pelvic Pain Impact Questionnaire (PPIQ)

Women reported that their vulvodynia impacted their daily life in the past month. Table 2 presents the summary data for the PPIQ for all included respondents. The highest scores of the PPIQ were those relating to tampon use (3.3/4), sexual intimacy (2.8/4), and mood (2.5/4). Women reported their vulvodynia having varied levels of impact on their life as all impact domains had responses across the full range of scores (0–4). The average impact score for all respondents, as rated on the PPIQ, was 2.0 ± 1.0 (out of 4).

Table 2  
Summary data of the Pelvic Pain Impact Questionnaire, presented from greatest to lowest impact (n = 50)

Question	Impact domain	Score (/4), mean ± SD
9	Tampon use	3.3 ± 1.1 <sup>†</sup>
10	Sexual intimacy	2.8 ± 1.6 <sup>‡</sup>
2	Mood	2.5 ± 1.2
8	Wear certain clothes	2.2 ± 1.7
7	Physical activity	2.1 ± 1.6
1	Energy	1.8 ± 1.5
6	Function in daily role	1.8 ± 1.4
3	Sleep	1.3 ± 1.4
5	Sitting > 20 minutes	1.3 ± 1.4
4	Stomach/intestinal function	1.2 ± 1.2
<b>Average</b>		2.0 ± 1.0
† n = 48; ‡ n = 40		

## Healthcare professionals visited

Table 3 presents the summary data on the types and numbers of healthcare professionals seen. On average, women reported visiting 4.1 different types of healthcare professionals. The most commonly visited healthcare professionals were general practitioners (GP), with 98% of respondents reporting visiting at least one GP. Of those who visited a GP, over two thirds (67%) reported seeing three or more different GPs. The second most consulted healthcare professionals were other medical professionals (medical specialists), with 96% of women reporting visiting at least one specialist. Of those who visited medical specialists, over half (56%) reported seeing three or more different specialists. The most commonly visited specialists were gynaecologists (94%), pain specialists (26%), and dermatologists

(20%). Other highly sought healthcare professionals included physiotherapists (80%), psychologists (46%), and TCAIM practitioners (36%).

Table 3  
Healthcare professionals visited (n = 50)

Healthcare professional	Total n (%)	Number seen	n (%)
<b>General Practitioner</b>	49 (98%)	1	6 (12.2%)
		2	10 (20.4%)
		3	11 (22.4%)
		4	8 (16.3%)
		5	3 (6.1%)
		>5	11 (22.4%)
<b>Other medical professional</b>	48 (96%)	1	11 (22.9%)
		2	10 (20.8%)
		3	5 (10.4%)
		4	5 (10.4%)
		5	5 (10.4%)
		>5	12 (25%)
<b>Physiotherapist</b>	40 (80%)	1	20 (50%)
		2	12 (30%)
		3	6 (15%)
		>5	2 (5%)
<b>Psychologist</b>	23 (46%)	1	13 (56.5%)
		2	8 (34.8%)
		3	1 (4.3%)
		>5	1 (4.3%)
<b>Sex therapist / relationship counsellor</b>	15 (30%)	1	14 (93.3%)
		2	1 (6.7%)

† Patients may have seen more than one TCAIM professional, therefore percentage total not equal to 100

TCAIM – traditional, complementary, alternative, and integrative medicine

Healthcare professional	Total n (%)	Number seen	n (%)
<b>Nutritionist / dietitian</b>	8 (16%)	1	5 (62.5%)
		2	1 (12.5%)
		3	1 (12.5%)
		4	1 (12.5%)
<b>TCAIM practitioner</b>	18 (36%)		
Naturopath	14 (77.8%) <sup>†</sup>	1	9 (64.3%)
		2	3 (21.4%)
		3	2 (14.3%)
Acupuncturist	8 (44.4%) <sup>†</sup>	1	4 (50%)
		2	4 (50%)
Herbalist	6 (33.3%) <sup>†</sup>	1	2 (33.3%)
		2	4 (66.7%)
Hypnotherapist	4 (22.2%) <sup>†</sup>	1	4 (100%)
Yoga therapist	1 (5.6%) <sup>†</sup>	1	1 (100%)
<b>Other healthcare professional</b>	2 (4%)		
Medical service hotline	1 (50%)	1	1 (100%)
Myotherapy (massage)	1 (50%)	1	1 (100%)
† Patients may have seen more than one TCAIM professional, therefore percentage total not equal to 100			
TCAIM – traditional, complementary, alternative, and integrative medicine			

## Treatments offered

Women reported that different healthcare professionals provided various treatments. Table 4 presents the most frequently reported treatments received for vulvodynia offered by each type of healthcare professional. From Medical Professionals, including GPs, respondents were most likely to be offered medications. They were most likely to be offered pelvic floor muscle (PFM) down-training from physiotherapists, counselling from psychologists and sex therapists, dietary recommendations from nutritionists/dietitians, and a mixture of supplements, herbs, and dietary advice from TCAIM practitioners. The full list of treatments for each healthcare professional can be found in Supplementary Table 2.

Table 4  
Most commonly reported treatments offered by healthcare professionals

Healthcare professional	Treatment / Intervention	n (%)
<b>General Practitioner (n = 49)</b>	Topical medication	35 (71.4%)
	Information	28 (57.1%)
	Oral medication	26 (53.1%)
<b>Other medical professional (n = 48)</b>	Topical medication	35 (72.9%)
	Oral medication	35 (72.9%)
	Pain education	27 (56.3%)
<b>Physiotherapist (n = 40)</b>	PFM down-training	38 (95%)
	Dilators	27 (67.5%)
	Internal massage	23 (57.5%)
	Pain education	23 (57.5%)
<b>Psychologist (n = 23)</b>	Counselling	4 (13%)
	CBT	2 (8.7%)
	Pain education	2 (8.7%)
	Mindfulness	2 (8.7%)
	Sexual desensitisation	2 (8.7%)
<b>Sex therapist / relationship counsellor (n = 15)</b>	Counselling	6 (40%)
	Intimacy relearning	2 (13.3%)
<b>Nutritionist / dietitian (n = 8)</b>	Dietary recommendations	7 (87.5%)
	Supplements	3 (37.5%)
	Education + colonics	1 (12.5%)
<b>TCAIM practitioner (n = 18)</b>	Supplements	2 (11.1%)
	Herbs + dietary change	2 (11.1%)
CBT – cognitive behavioural therapy; PFM – pelvic floor muscle; TCAIM – traditional, complementary, alternative, and integrative medicine		

## Discussion

In this study, Australian women with vulvodynia reported seeing a variety of different types of healthcare professionals, as well as seeing often numerous different healthcare professionals within the same

healthcare field. Women were offered a variety of treatments by their healthcare professionals, with the most commonly provided being PFM down-training, topical medication, oral medication, and vulvodynia information.

Our respondents reported a prolonged delay between the time their symptoms appeared and the time they received a diagnosis. The mean diagnostic delay of  $5.8 \pm 6.5$  years is greater than what was reported in a population study of 85 women with vulvodynia who lived in the United States, which found 63.5% of women experienced a diagnostic delay of less than three years.<sup>12</sup> Respondents in the current study also reported their pain impacting multiple areas of their life, including tampon use, sexual intimacy, mood, and the ability to wear certain tightfitting clothes or underwear. The diagnostic delay and widespread impact of pain found in the present study is concerning, as women are living for unnecessarily prolonged periods with their symptoms. Although the diagnostic delay may be due to the time-consuming assessment procedures required in definitively diagnosing vulvodynia as it is a diagnosis of exclusion, a more probable reason may be due to a combination of poor awareness of the condition amongst the general public and inadequate training of healthcare professionals. It has been well documented that in the United States that clinicians are inadequately trained to address health issues of the genitals, especially conditions that may be associated with sexual dysfunction.<sup>13,14</sup> While no such research exists in Australia, it is possible that similar training deficits would be seen in Australian clinicians, as has been reported for other complex gynaecological conditions such as endometriosis.<sup>15</sup>

Respondents reported seeing many healthcare professionals with, on average, 4.1 different types of healthcare professionals being consulted. The involvement of multiple healthcare professionals is a positive finding, as previous research has found that treatment is most effective when it addresses the woman's unique aetiological contributors for which each healthcare professional is specially trained in doing so.<sup>16</sup> However, women also reported seeing multiple of the same type of healthcare professional in their journey to find relief from their symptoms, highlighting a lack of continuity of care for many women. The need to see multiple of the same type of healthcare professional may be driven by the patient's dissatisfaction and poor perceived success with the treatments that these professionals offered.<sup>3</sup>

Very few treatments prescribed to respondents have demonstrated efficacy. Of the 74 treatments offered to respondents in the present study, only one treatment, cognitive behavioural therapy (CBT), has demonstrated efficacy through a randomised controlled trial (RCT).<sup>17</sup> Despite the known efficacy of CBT for vulvodynia, less than half of respondents reported seeing a psychologist, and only two reported receiving CBT as a treatment. This may reflect a potential referral gap; whereby primary practitioners are not referring women with vulvodynia to psychologists to receive CBT as an intervention.

Respondents reported being prescribed many treatments which have demonstrated inefficacy. Despite anticonvulsants being no more effective than placebo,<sup>18</sup> 16% of respondents were offered anticonvulsants as a treatment option. Similarly, previous research demonstrates poor outcomes associated with vestibulectomy and the potential for a vestibulectomy to worsen patients' symptoms,<sup>19,20</sup> however, 8% of respondents had undergone vestibulectomy as a treatment. Previous RCTs investigating

topical lidocaine, electrical stimulation, and biofeedback have demonstrated their inefficacy, however, these treatments were still commonly prescribed to respondents. These findings warrant further investigation to determine the clinical decision making of practitioners in the face of inefficacy data, and highlight the need for better science translation from clinical trials to clinical practice.

Overall, there is a paucity of research on the various treatment options for vulvodynia leaving few options upon which healthcare professionals can base their clinical decision making. Over half (54%) of participants reported receiving medical intervention, however, there is little evidence to support the role of oral or topical pharmacotherapy in vulvodynia management.<sup>10</sup> The role of conservative therapies offered by allied health and complementary medicine professionals is even less clear, with no supporting RCTs having been conducted. While some healthcare professionals may provide effective interventions for patients, further rigorous trials are required to determine the optimal management of vulvodynia to provide clinicians with a solid foundation on which to base their clinical decision making. It is not until this evidence base is provided that we can expect to see meaningful improvements in vulvodynia management on a population level.

The findings and implications of this study should be considered in light of the strengths and limitations of the study design. The anonymous nature of the survey is a clear strength, meaning respondents were able to answer questions where they felt comfortable, adding to the likelihood that responses were truthful,<sup>21</sup> increasing confidence in the results. The online nature of the survey may have biased the sample towards women who engage with online technology and social media. While 50 respondents appears to be a small sample, an a priori sample size was calculated at 40 respondents based on the lifetime prevalence rate of vulvodynia and the recruitment success of previous, similar research.<sup>5,11</sup> Future research could consider additional ways to recruit a greater sample to maximise confidence in results. The quantitative focus of the survey also meant that participants were not able to expand and provide reasoning behind their responses, such as why they visited multiple of the same type of health professional. Future research should look to expand on the journey that Australian women with vulvodynia take through the healthcare system, from both the patient and clinician perspective, to help better understand help-seeking and health-providing decision making.

Australian women with vulvodynia experience a long diagnostic delay and remain in pain several years after receiving their diagnosis. They visit multiple healthcare professionals in their search for relief and receive numerous treatment modalities. Very few of the treatments that women receive have demonstrated efficacy in the literature. There is a dire need for further high-quality studies to be conducted to help guide clinical practice in the use of multidisciplinary management and provision of evidence-based treatments to Australian women with vulvodynia. It is only when this high-quality research is completed that women will not only be able to find relief but find it in a timely manner.

## **Declarations**

## Acknowledgements: Contributions

None.

## Acknowledgements: Funding

No funding was received for this study.

## Conflict of Interest Statement

AM and JC: Nothing to disclose.

MA: As a medical research institute, NICM Health Research Institute receives research grants and donations from foundations, universities, government agencies, and industry. Sponsors and donors provide untied and tied funding for work to advance the vision and mission of the Institute. This survey was not specifically supported by donor or sponsor funding to NICM.

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