

1 **Exploring Healthcare Experiences of Women Diagnosed with Vulvodynia**

2 Original Article

3
4 Lauren Templeman¹, Judith Eberhardt¹, and Jonathan Ling²

5
6 ¹Teesside University, School of Social Sciences, Humanities and Law, Borough Road,
7 Middlesbrough TS1 3BA, United Kingdom.

8
9 ²University of Sunderland, Faculty of Health Sciences and Wellbeing, Chester Road,
10 Sunderland SR1 3SD, United Kingdom.

11
12 Corresponding author:

13 Dr Judith Eberhardt

14 Department of Psychology, School of Social Sciences, Humanities and Law, Teesside
15 University, Borough Road, Middlesbrough TS1 3BX. Phone: 01642 738651. Email:
16 j.eberhardt@tees.ac.uk. ORCID ID: <https://orcid.org/0000-0003-0745-178X>

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24

25 **Abstract**

26 **Background:** Although seeking diagnosis and treatment for chronic pain should be
27 straightforward, this is often not the case for those living with vulvodynia, who often
28 describe it as a battle, frequently involving misdiagnosis, dismissal, and gender-based
29 discrimination.

30 **Aim:** This study explored the healthcare experiences of women living with vulvodynia in the
31 United Kingdom.

32 **Methods:** As they are less explored in literature, experiences post-diagnosis and across
33 varying healthcare settings were specifically considered. Interviews were conducted with six
34 women, aged 21 to 30, to explore their experiences when seeking help for vulvodynia.

35 **Outcomes:** Through interpretative phenomenological analysis, five themes emerged: the
36 impact of diagnosis, patients' perception of healthcare, self-guidance and lack of direction,
37 gender as a barrier to effective care, and a lack of consideration of psychological factors.

38 **Results:** Women often experienced difficulties before and after diagnosis, and many felt
39 their pain was dismissed and ignored due to their gender. Pain management was felt to be
40 prioritised by healthcare professionals over wellbeing and mental health.

41 **Clinical Translation:** There is a need for further exploration of experiences of gender-based
42 discrimination of vulvodynia patients, healthcare professionals' perceptions of their own
43 capabilities in working with vulvodynia patients, and the impact of improving professionals'
44 training in working with these patients.

45 **Strengths & Limitations:** Healthcare experiences after diagnosis are rarely examined within
46 literature, with studies predominantly focusing on experiences surrounding diagnosis,

47 intimate relationships, and specific interventions. The present study provides an in-depth
48 exploration of healthcare experiences through participants' lived experiences and gives
49 insight into an under-researched area. Women with negative experiences of healthcare may
50 have been more likely to participate than those with positive experiences which may have
51 resulted in their overrepresentation. Furthermore, participants were predominantly young,
52 white, heterosexual women, and almost all had comorbidities, further limiting
53 generalisability.

54 **Conclusion:** Findings should be used to inform healthcare professionals' education and
55 training to improve outcomes for those seeking care for vulvodynia.

56 **Keywords:** Vulvodynia; vestibulodynia; healthcare experiences; female sexual dysfunction;
57 women's sexual health

59 Introduction

60 Vulvodynia is a condition characterised by persistent vulvovaginal pain that cannot
61 be attributed to any other cause. Pain may be generalised or specific to one area and can
62 occur unprovoked or only with physical contact ^{1,2}. Pain may be stinging, burning, or
63 stabbing and affects those of almost any age, including adolescents ³. Vulvodynia has
64 frequent comorbidities ⁴, often reduces quality of life and may disrupt daily functioning ⁵.
65 Sexual intercourse is frequently avoided with vulvodynia, raising challenges surrounding
66 identity, femininity, and intimacy within romantic relationships ^{6,7}. Those living with
67 vulvodynia have described feeling shame, frustration and isolation, and further associations
68 exist between anxiety, depression, and vulvodynia ⁸⁻¹¹.

69 The estimated lifetime prevalence of vulvodynia is 8-16% in the United States ¹²; no
70 figures for the United Kingdom (UK) exist. Prevalence may be higher than reported as many

71 avoid help-seeking out of embarrassment or belief that vulvovaginal pain is part of a
72 person's 'typical experience'¹³.

73 Despite its high lifetime prevalence, healthcare professionals often lack
74 sufficient knowledge to identify and treat vulvodynia, including some in the final stages of
75 speciality training¹⁴. General practitioners (GPs) describe feeling frustrated and helpless
76 when consulted by patients with provoked pain, expressing reluctance to explore the sexual
77 content of the condition¹⁵. Negative experiences seem frequent during the journey towards
78 diagnosis; women describe healthcare professionals as dismissive and stigmatising with
79 frequent misdiagnosis, often resulting in frustration, self-doubt, helplessness, and impaired
80 coping^{10,16–18}. Suggestions that pain is exaggerated or psychological may trigger distress in
81 patients^{18,19}. Referral to specialists, however, may not occur as frequently as expected¹⁸.
82 This has therefore led to an increase in self-education out of necessity for diagnosis in some
83 women, such as conducting online research to find knowledgeable physicians or to provide
84 their physician with information surrounding vulvodynia²⁰.

85 Long waiting times and misdiagnosis can negatively affect mental health and delay
86 treatment further, when early diagnosis and treatment may be vital for positive outcomes
87 and distress minimisation^{21,22}. Post diagnosis, experiences vary. Some feel relieved their pain
88 is validated and are optimistic about treatment, while others lose faith, seeing vulvodynia as
89 a label used by physicians who do not understand the cause of their pain^{17,21}. Barriers to
90 treatment after diagnosis include high financial costs, long waiting times for appointments
91 and the need to travel for treatment^{23,24}. Healthcare experiences after diagnosis are rarely
92 examined within literature, with studies predominantly focusing on experiences surrounding
93 diagnosis, intimate relationships, and specific interventions¹⁷.

94 Experiences after diagnosis require exploration to examine whether interventions
95 are effective and to identify potential improvements to increase patients' quality of life. Few
96 studies have examined experiences within the UK context. As healthcare systems differ
97 across countries, experiences may differ within the UK, with its National Health Service
98 (NHS), in comparison to other countries ²⁵. One study conducted in the UK explored
99 experiences of diagnosis and replicated findings in the existing literature, describing
100 healthcare practitioners in the UK as lacking knowledge of vulvodynia and being dismissive
101 of the condition; however, as the primary focus was on the journey to diagnosis,
102 experiences after diagnosis were not examined ¹⁷. Understanding how patients' lives change
103 in response to diagnosis, and the treatment they receive, is critical for informing future
104 practice.

105 Research has explored experiences with specific healthcare professionals, but this
106 does not allow for an overall picture of the effectiveness of healthcare to develop; this is
107 particularly important as those seeking help for vulvodynia who frequently visit many health
108 professionals ^{4,20,22}. Canadian research in a vulvar diseases clinic found that a diagnosis was
109 difficult to obtain and that after diagnosis, barriers to treatment included costs, distance
110 and inadequate explanation of treatments ²¹. Few studies have sought to establish which
111 factors are relevant to the experience of women seeking help from for vulvodynia in the UK.
112 Furthermore, UK research has focused on experiences of diagnosis ^{10,17} or its clinical
113 management (e.g., ⁵) but not considered patients' experiences after diagnosis. Examining
114 vulvodynia patients' experiences post-diagnosis is important as it helps identify their care
115 and support needs.

116

117 The current study aimed to explore healthcare experiences of women living with
118 vulvodynia in the UK, examining experiences across healthcare. We built on existing work by
119 considering experiences after diagnosis, the implementation and benefits of psychological
120 approaches to patient mental health, care after diagnosis and patient experiences with
121 specialist vulval pain clinics.

122 123 **Materials and Methods**

124 ***Design***

125 An interpretative phenomenological approach (IPA) was adopted for this exploratory
126 qualitative study. IPA is used to understand lived experience of a phenomenon²⁶. Through
127 semi-structured interviews, participants shared their experiences in detail, increasing
128 understanding and allowing for further probing into the meanings constructed of healthcare
129 as necessary. This allowed the researchers to collect in-depth data on lived experiences,
130 understand the meaning participants assign to experiences within healthcare, their impact
131 and whether healthcare is felt adequate²⁷. The researchers interpreted and constructed
132 meaning from the participants' narratives to achieve understanding.

133 ***Participants***

134 Six participants were recruited, allowing for in-depth analysis of individual accounts
135 and the examination of patterns across cases²⁸. To be eligible to participate, women had to
136 live in the UK, be aged 18 years or older, and have been formally diagnosed with vulvodynia.
137 The presence of a clinical diagnosis ensured participants had not potentially incorrectly self-
138 diagnosed. Diagnosis had to be no longer than ten years and no less than six months ago,
139 allowing for adequate experience to reflect upon while minimising recall bias¹⁷. Any

140 subtypes of vulvodynia were acceptable, allowing for further exploration than existing
141 literature provided. As healthcare experiences may differ for adolescents²⁹, those aged
142 below 18 were excluded. Participants were also excluded if they were unable to speak
143 English, if they felt they would become distressed during participation, or if they were
144 unable to access an online call on Microsoft Teams, with in-person interviews being
145 impossible due to restrictions imposed by the COVID-19 pandemic and the resulting social
146 distancing regulations when data were collected.

147 Recruitment took place via a private online support group on the social media
148 platform Facebook, providing access to a difficult-to-reach population who may distrust
149 recruitment via healthcare-based methods¹⁹. Having obtained consent from the owner of
150 the Facebook group to recruit, a post was shared describing the study along with inclusion
151 criteria. Using convenience sampling, six female participants were recruited in total (five
152 others had expressed interest but did not participate, one individual was outside the period
153 of diagnosis, one did not attend the interview, and three did not respond after being
154 provided with further information).

155 **Materials**

156 As no published studies produced suitable interview schedules for our research
157 question, the interview schedule was constructed using existing studies and areas identified
158 for future research^{17,30}. The schedule was reviewed by two experienced qualitative
159 researchers who were not involved in the research. Questions such as 'How would you
160 describe the experience of receiving a diagnosis and care for vulvodynia?' and 'To what
161 extent do you believe healthcare professionals had a desire to help?' aimed to explore
162 participants' perceptions of diagnosis and experiences of healthcare when seeking help for

163 vulvodynia. Topics covered included the experience of diagnosis, experiences with specific
164 healthcare providers, care satisfaction, belief in healthcare competence, and exploration of
165 beneficial and unhelpful experiences. We aimed to unearth the impact of these experiences
166 and any beneficial aspects or areas requiring improvement. Prompts were used to probe
167 further depending on participants' responses.

168 ***Data Collection***

169 Online individual semi-structured interviews were conducted by the lead researcher
170 using Microsoft Teams. Those who contacted the researcher for further information were
171 informed of study procedures, risks and ethics information via an information sheet and
172 were provided with a copy of the interview schedule. If participants had no further
173 questions and were interested in taking part, they were emailed a consent form to provide
174 informed consent. Participants were offered 24 hours to consider participation before
175 providing consent. Opportunities were provided for participants to ask questions prior to
176 the interview, and they were reminded of their right to withdraw at any time. Interviews
177 took place in one session, lasted between 55 and 96 minutes, and were audio-recorded
178 before being transcribed verbatim by the lead author. All interviews were conducted by the
179 same interviewer. After participation, a debrief form containing information on data
180 withdrawal and available support was provided.

181 **Table 1 here**

182 ***Ethical Considerations***

183 Prior to conducting the study, ethics approval was obtained from the ethics
184 committee at the lead author's institution, complying with the British Psychological

185 Society's³¹ ethics guidelines. A copy of the interview schedule was provided before
186 participation so participants could examine whether they felt comfortable discussing the
187 topics raised therein. Strict adherence to confidentiality principles was observed throughout
188 the study and all data were anonymised, and pseudonyms were used. Participants were
189 informed before participation of their right to withdraw and that breaks could be taken
190 from the interview at any time, particularly as vulvodynia may cause difficulties sitting for
191 prolonged periods⁵. The lead author, who conducted the interviews, was attentive to
192 potential distress in participants and was sensitive when discussing experiences. Contact
193 details for mental health support and information were provided following interview.

194 **Data Analysis**

195 A critical realist epistemological position was adopted by the researchers, which
196 allowed for consideration of factors influencing participant experiences and the way in
197 which social structures influence behaviour and perceptions. Individual experiences must be
198 considered in relation to social structures influencing both those seeking help and
199 healthcare professionals involved; this is enabled through IPA, which is rooted in critical
200 realism³². IPA allows exploration of how individuals construct meaning from experiences
201 about the social world they reside in, such as experiences relating to healthcare³³.

202 Reflexivity was maintained throughout the research process to recognise and minimise any
203 potential biases and increase research validity. The lead researcher was a white British
204 female postgraduate student with first-hand experience of a vulval pain condition.

205 Relationships with participants were not developed prior to the study and the lead
206 researcher did not disclose her own condition or motivation for conducting the research
207 beyond her academic studies.

208 IPA was conducted by the lead researcher using guidelines outlined by Smith et al. ²⁸.
209 Data saturation was observed with the recurrence of similar thoughts and experiences as
210 interviews progressed, at which point data collection was terminated. Analysis involved
211 reading the interview transcripts several times, highlighting areas of interest, and rereading
212 them to add notes at descriptive, linguistic, and conceptual levels. Inductive coding was
213 used to manually derive codes from the data. These codes were categorised based on
214 similarities and relation to the same topic or underlying meaning to form themes. The
215 themes were clustered further to form superordinate themes. This was repeated for each
216 individual case, then superordinate themes were examined for patterns and consistency
217 across interviews. Physical copies of the codes and subsequent themes were used to assist
218 with categorisation and the development of further themes. Tables within Microsoft Word
219 also aided this process; no other software was used. The researcher kept an audit trail
220 during analysis to increase trustworthiness of findings. To ensure credibility of the themes,
221 researcher triangulation was employed ³⁴, with all authors checking the themes to ensure
222 they accurately reflected the data. Furthermore, all authors checked the analysis for
223 consistency and to ensure a lack of bias.

224

225 **Results**

226 Participants' ages ranged from 21 to 30 years, with a mean age of 24.83. Time since
227 diagnosis ranged from one to three and a half years. Self-reported ethnicity was
228 predominantly White British, with one participant identifying as Black Caribbean. One
229 participant identified as bisexual and the rest as heterosexual. Most participants had

230 comorbid conditions including mental health conditions, endometriosis, and fibromyalgia
231 (see Table 2).

232 **Table 2 here**

233 Participants' experiences revealed five superordinate themes around their
234 healthcare experiences (see Table 3): the impact of diagnosis; patients' perception of
235 healthcare; professionals' lack of knowledge and patients' need for independence; gender
236 as a barrier to effective care; and a lack of consideration of psychological factors.

237 **Table 3 here**

238 **The Impact of Diagnosis**

239 Participants were asked to describe their experience of diagnosis and care for
240 vulvodynia. While all participants described experiences prior to diagnosis as predominantly
241 negative, experiences after diagnosis varied. Three subthemes emerged in relation to the
242 impact of diagnosis: negative experiences prior to diagnosis, negative experiences after
243 diagnosis, and positive experiences after diagnosis.

244

245 ***Negative Experiences Prior to Diagnosis***

246 Participants were asked to what extent they believed healthcare professionals cared
247 about them and wished to help. All participants described difficulties with obtaining a
248 diagnosis. Professionals were described as not being invested in women's diagnosis and
249 therefore a lack of progress was made towards receiving adequate treatment. This was
250 demonstrated in Emily's account:

251 *You're just so desperate for an answer and for someone to help you, but I was going*
252 *between different people and not really getting anywhere, and it was going on for*

253 *months and months and months and months... what do you do with that when*
254 *there's no one to help you? (Emily)*

255 Seeking diagnosis was experienced as a difficult, tedious process. Participants felt desperate
256 for healthcare professionals to listen and provide information and treatment yet were
257 frequently disappointed. Patients visited many professionals and described prolonged waits
258 for appointments, which often did not provide further direction once attended.
259 Professionals did not seem actively engaged in exploring solutions, and a lack of direction
260 was evident, resulting in feelings of helplessness with participants wondering how to
261 progress further without adequate support from healthcare:

262 *Pre-diagnosis, I was so frustrated... I felt like I was the only person who was really*
263 *trying to find out what was going on, or trying to find the best treatment, and I felt*
264 *like I was just being passed around. (Emily)*

265 Seeking diagnosis provoked frustration in participants. Many felt professionals were
266 uninterested in trying to understand the cause of pain or potential solutions. Healthcare was
267 perceived as uncaring, unsupportive, and directionless. Some felt they themselves were
268 their only advocate, in actively trying to understand and treat their symptoms.

269
270 Perceived dismissal was also a frequent complaint:

271 *I felt like they thought either it was in my head or I was being dramatic. (Angela)*

272
273 Angela felt professionals did not take her seriously, believing she was exaggerating or
274 overreacting to her symptoms. Many did not feel listened to by professionals, believing
275 professionals '*didn't care*' (Angela), with no interest in helping or prioritising the individual.

276 Suzanne described the process of obtaining a diagnosis within the NHS as
277 'impossible', believing those who received effective care were 'really lucky' (Suzanne). She
278 felt diagnosis would not have been achieved without luck, and factors beyond her control
279 were responsible. Luck was suggested as influential by many; another woman highlighted
280 how her access to supportive professionals was made possible because she

281 *...knew these doctors because they also worked in these hospitals... that's the only*
282 *reason I got referred to them... that's just pure luck. (Emily)*

283 Participants believed that effective care was due to the chance of professionals knowing
284 about other useful professionals or treatments.

285

286 **Positive Experiences After Diagnosis**

287 Participants were asked to recall any experiences that were particularly positive or
288 beneficial. Three participants found that their care improved after diagnosis. Some believed
289 this was due to access to the treatment that a formal diagnosis provided: 'It's [vulvodynia]
290 definitely improved because I'm being treated now (Emily).' Others identified the approach
291 professionals had taken as key to their positive experiences:

292 *That was really good actually 'cause she [...] recognised what I was going through,*
293 *listened to what I was saying, trial and error with the medication and if I didn't feel*
294 *like it was working, go back, not like just, 'Oh, I'll ring you in three months'.*

295 (Samantha)

296 Samantha valued her care after diagnosis as she felt she was listened to by professionals
297 and her experiences were validated. Her treatment was able to progress, and she
298 appreciated professionals planning for potential future barriers to treatment, providing
299 reassurance and considering her wellbeing, not leaving her without treatment while waiting

300 for appointments. Care was valued when it was proactive and considered her emotional
301 wellbeing.

302 For all women whose care improved after diagnosis, progress, validation, and
303 understanding were key to this experience. Specialist care was also identified as influential;
304 professionals '*really knowing their stuff*' was seen as making '*such a difference*' (Jennifer) to
305 the perceived quality of care. The knowledge specialists had, such as those within sexual
306 health clinics, was believed to facilitate diagnosis and treatment, making these professionals
307 more helpful than those lacking specialist knowledge.

308

309 ***Negative Experiences After Diagnosis***

310 Participants were asked to recall any experiences that were particularly unhelpful or
311 harmful. Not all participants found their care improved after diagnosis:

312 *I thought, oh flip, we're gonna get somewhere now, now that we kinda know what it*
313 *is... maybe things will change... whereas in reality that was kind of the end of*
314 *everything once I got the diagnosis then because they were just kinda like, yeah... we*
315 *don't really know what to do. (Angela)*

316 Angela was hopeful that a diagnosis would finally open doors to treatment options and her
317 experiences of care would improve, allowing for long-awaited progress, but this did not
318 occur. She felt healthcare professionals lacked knowledge and understanding of the
319 condition so were unable to provide further support to reduce her pain. She felt
320 professionals had little motivation to improve their understanding of the patient and of
321 vulvodynia, which hindered progress. Ineffective treatment provision was identified by
322 Suzanne:

323 *I think... she was thinking just, oh people usually use soap to wash so I'll give her*
324 *these to use instead of soap, but I was already saying I'm not using soap... it just feels*
325 *like they have these tick boxes... and no matter what you say they're just always*
326 *gonna give you the same things. (Suzanne)*

327 Women were often recommended ineffective treatments and felt dismissed when
328 informing healthcare professionals that they had already tried these, with no benefit. It was
329 believed professionals did not treat patients as individuals, offering generic treatment
330 suggestions regardless of women's personal circumstances when tailored treatments may
331 be more effective. Thus, patients had to adapt to the care offered, rather than being
332 afforded patient-centred care.

333

334 **Patients' Perceptions of Healthcare**

335 Participants were asked what health services they had accessed and how they would
336 describe their experiences with each. Within patients' perceptions of healthcare, two
337 subthemes emerged: perceptions of NHS care and perceptions of private care.

338

339 ***Perceptions of NHS Care***

340 Perceptions of the care provided through the NHS varied, with some participants
341 viewing this negatively, as outlined by Suzanne:

342 *On the NHS it's [me] fighting to say my pain is worthy of you spending your money on*
343 *my pain, you've gotta, like, sit there and convince them of how bad it is, and that can*
344 *be a really degrading, draining experience. (Suzanne)*

345 Some patients felt they had to prove their symptoms deserved healthcare spending,
346 which was experienced as humiliating and exhausting. The use of *'fighting'* emphasises the
347 exertion and desperation involved to try to convince professionals to take action.

348 Others viewed the NHS more positively, believing:

349 *There are really good people in the NHS... if you persist you can get the right*
350 *treatment, because [...] we're so lucky in this country to have a free healthcare*
351 *service, even if it is limited. (Samantha)*

352 Samantha was grateful for the NHS and felt its flaws could be overlooked due to the
353 benefit the healthcare system provided overall. She believed that with perseverance, caring
354 professionals who wanted to help could be found.

356 **Perceptions of Private Care**

357 Participants who had accessed private care were asked whether their experiences of
358 this care differed to that of public or NHS services. Several patients had resorted to private
359 care, which was mostly viewed positively. Multiple participants highlighted money as a
360 motivator for care providers:

361 *They're just straightaway more open to everything you have to say because you're,*
362 *like, the customer at that point so they want to do what you want, they want to keep*
363 *you. (Suzanne)*

364 Suzanne felt listened to and respected when accessing private care; professionals seemed
365 more considerate of her own treatment and diagnosis suggestions than with NHS care. She
366 believed that as private professionals were paid directly by the patient, they provided higher
367 quality care with access to more treatments than on the NHS in order to satisfy the patient,

368 thereby encouraging the patient to return. As the patient was paying for their own care,
369 financial barriers like those inherent in the NHS did not hinder treatment:

370 *It was the only way that I was able to access psychological support. (Samantha)*

371 Angela identified private care as faster and more proactive in exploring treatments than
372 NHS care:

373 *I was seen to by a lot more people and a lot more different things were tried.*

374 (Angela)

375 However, private care alone was no guarantee of effective care: the healthcare
376 professional's knowledge was vital. Women had to research to find the most knowledgeable
377 and suitable professional for them, as many professionals seemed to lack specialised
378 knowledge. Money alone was not believed to be enough:

379 *I think you have to research the person, it's not just that it's private... I imagine
380 there's lots of doctors privately who have no idea what vulvodynia is. (Suzanne)*

381

382 **Self-Guidance and Lack of Direction**

383 When responding to the question concerning the extent to which they believed
384 healthcare professionals cared about them and wished to help them, participants' answers
385 showed that there was a perceived need for self-guidance and a perceived lack of direction.

386 Two subthemes emerged: a lack of knowledge in professionals and patients' need for
387 independence.

388

389 **Professionals' Lack of Knowledge**

390 Participants were asked how confident they felt in healthcare professionals' abilities
391 to diagnose and treat vulvodynia. All participants identified healthcare professionals as
392 lacking knowledge, as highlighted by Nina, a medical student:

393 *Doctors don't seem to know what it is, so then they can't help you, so they need to ...*
394 *teach people at medical school, because I didn't get taught about it... that's why*
395 *people just keep getting pushed around to doctor after doctor after doctor, going*
396 *round and round in circles. (Nina)*

397 Lack of progress when diagnosing and treating vulvodynia was attributed to healthcare
398 professionals' lack of knowledge. Being a medical student herself, Nina remarked that
399 vulvodynia was not included in general education, and that this needed to change to help
400 improve care. Knowledge was believed to be key to effective care as it informed referrals
401 and treatment exploration.

402

403 ***Patients' Need for Independence***

404 Participants' responses to the question of how confident they felt in healthcare
405 professionals' abilities to diagnose and treat vulvodynia highlighted their need for
406 independence. As healthcare professionals were often not well-informed enough to
407 diagnose and treat vulvodynia, most women felt it was necessary to conduct their own
408 research into potential diagnoses and treatments. This was the case for Angela, whose
409 mother also happened to be affected by vulvodynia:

410 *[My mother and I] just kinda... had to... go about learning for ourselves because the*
411 *doctor that we saw obviously was not experienced enough to kind of give me any of*
412 *that advice, so a lot of it came from, like, reading studies... I pretty much feel like we*
413 *did their jobs for them. (Angela)*

414 As professionals were unable to provide effective guidance, Angela felt her care had
415 become her own responsibility. She felt she had to act as her own doctor and therefore
416 explored literature on vulvodynia to seek solutions herself. Negative experiences with
417 healthcare reduced faith in professionals' ability to help with the condition; Angela believed
418 the only way she would find solutions was if she was proactive. Emily echoed these feelings,
419 suggesting:

420 *You have to do your research and say... well, 'Is it this, or could it be this?'. (Emily)*

421 As some healthcare professionals were felt to lack knowledge, patients felt it was
422 their responsibility to try and get the most from their doctors.

423

424 **Gender as a Barrier to Effective Care**

425 Participants were asked whether they were listened to and treated with respect by
426 healthcare professionals. Their answers showed that they felt their own gender influenced
427 their healthcare experiences. Participants believed stigma associated with female health
428 conditions influenced professionals' perception of patients:

429 *I had to... make sure I didn't seem too upset by my problem because then I would*
430 *seem hysterical, but then also not seem too just, like, 'Oh it doesn't matter', because*
431 *then they'll tell you to go away and come back in six months. (Suzanne)*

432 Suzanne felt healthcare professionals judged her based on her gender; appointments were a
433 balancing act of appearing distressed enough to receive care, but not distressed enough to
434 appear as an 'overemotional crazy woman' (Suzanne) who was overreacting and allowing
435 her emotions to take control. Both assumptions would result in halted progress and
436 dismissal. Healthcare professionals had the power to refer patients, therefore pleasing these

437 professionals and maintaining appearances was seen as important in getting access to the
438 necessary specialists and treatment.

439 Women were surprised gender-based discrimination persisted within care as the
440 'hysterical woman' assumption appeared outdated and '*didn't seem very 2020*' (Suzanne).
441 Participants believed that healthcare ought to have progressed from such attitudes. The
442 influence of professionals' assumptions on the care afforded to women was expanded upon:

443 *Women's problems always seem to be taboo... misdiagnosed, and people just don't*
444 *believe them when they're in pain. (Nina)*

445 Nina felt attitudes towards women's health frequently impaired healthcare provision
446 for them, and misdiagnosis was a persistent issue. This was felt to be specific to their
447 gender, with professionals believing patients to be exaggerating or overreacting as they
448 were female and were therefore given inadequate care.

449

450 **Lack of Consideration of Psychological Factors**

451 Participants were asked how satisfied they were with how they had been treated
452 and the care that they had received, and whether the care and treatment they had received
453 had been beneficial. As part of their responses, some participants explained that they had
454 been referred to psychosexual counselling at their own or their physician's request, yet
455 none was provided despite the referral. Most participants felt professionals lacked
456 consideration of psychological factors and their overall wellbeing when accessing care for
457 vulvodynia:

458 *None of them have ever outrightly asked, how are you doing... how is this impacting*
459 *you emotionally and mentally... they're all just kind of trying to manage the pain side*
460 *of it. (Emily)*

461 Emily highlighted that she felt that healthcare professionals did not consider how she was
462 coping with the condition or how it impacted her wellbeing; professionals seemed only
463 interested in helping to reduce pain and disregarding how vulvodynia affected her quality of
464 life. This was echoed by Nina who claimed:

465 *Doctors need to just recognise that you're a person, you're not just symptoms. (Nina)*

466 Nina felt professionals viewed patients clinically, as something to fix, and not as a whole
467 person. She believed that this required improvement, that the physical, psychological, and
468 social impact of the condition should be considered and that professionals should adopt a
469 more caring, sympathetic approach and be more understanding of difficulties faced by the
470 patient. Participants believed psychological support would have been beneficial to their
471 wellbeing:

472 *That's something that probably really should be mentioned... if somebody's*
473 *experiencing chronic pain then surely one of the obvious thoughts would be, that*
474 *must be really upsetting for them, distressing for them, and, like, is there anything we*
475 *can do to help that as well. (Jennifer)*

476 Jennifer felt the impact of vulvodynia on quality of life should be considered and that
477 further, psychological, support may be necessary to aid coping.

478 To summarise, healthcare experiences were predominantly negative prior to
479 diagnosis. For some, care improved following diagnosis, for others it remained negative and
480 lacked direction. Some felt accessing care on the NHS was a battle, and so resorted to
481 private care instead. Others felt the NHS was doing its best and were grateful for care it
482 provided. Participants believed professionals lacked relevant knowledge, and many felt
483 doing one's own research was key to making progress in the diagnosis and treatment of
484 their condition. Patient gender was seen as influential in care provision. The influence of

485 psychological factors received little attention from professionals; participants believed this
486 would have been beneficial in improving their wellbeing.

487

488 **Discussion**

489 This study explored experiences of women with vulvodynia in the UK healthcare
490 system, before and after diagnosis. Previous literature found difficulties obtaining a
491 diagnosis, including in the UK, demonstrating dismissal of patients and a lack of progress in
492 relation to the diagnosis and treatment of their condition ^{16,17,22,35}. Our findings suggest
493 negative healthcare experiences persisted for some even after diagnosis. For some,
494 experiences improved after diagnosis as finding knowledgeable professionals meant
495 participants were listened to and treatment was effective and well-planned, offering hope
496 to women. For others, experiences remained negative, with patients lacking access to
497 knowledgeable professionals, and not feeling treated as individuals.

498 Negative experiences before and after diagnosis may be due to professionals lacking
499 knowledge regarding vulvodynia. This issue was identified by participants and supported by
500 previous literature, where over 80% of junior doctors in the UK had never attended training
501 on vulvodynia ¹⁴. Specialist knowledge and access to resources in healthcare may influence
502 outcomes after diagnosis ¹⁸. As identified by participants, professionals with greater
503 knowledge and motivation to help may be more likely to contribute to positive experiences
504 with care. Participants spoke of the need to conduct their own research to make any
505 progress with obtaining adequate care, supporting the findings of prior literature. This may

506 be attributable to the lack of knowledge of vulvodynia within healthcare, leaving patients
507 having to direct their care themselves ²⁰.

508 Perceptions of UK healthcare regarding vulvodynia had previously not been
509 explored. In our study, private care was mostly viewed positively, and seen to be more
510 effective than NHS care. Some felt accessing care was a battle on the NHS, although others
511 were more understanding of the difficulties professionals faced and expressed their
512 gratitude for NHS care despite limited resources and staff shortages ³⁶. The battle for
513 funding described by participants echoes these perceptions, and wider issues within the
514 NHS combined with a lack of knowledge regarding vulvodynia may underlie this. The
515 generally positive view of private care may be due to the positive outcomes achieved when
516 accessing private care that were not achievable on the NHS, and more personalised
517 experiences with private practitioners. As participants paid directly for their private care,
518 they attributed these positive outcomes to private practitioners' financial gain which
519 functioned as an incentive to provide high-quality care. The literature suggests that
520 generally, private care is perceived as better than the public sector in terms of timeliness
521 and hospitality towards patients, but also that providers in the private sector may be more
522 prone to violating accepted medical standards and to have lower reported efficiency ³⁷. It
523 would be beneficial to establish whether this is the case for vulvodynia care specifically, in
524 order to determine if participants' experiences are in line with the experiences of the
525 broader population of vulvodynia patients.

526 Beliefs informed by gender-based discrimination highlighted in previous
527 literature^{17,24} were also reported in the current study; women felt their pain was dismissed
528 and ignored due to their gender. The tendency for women's pain to be less recognised in

529 healthcare, and a previous neglect of research into female reproductive health issues may
530 be responsible for this and may contribute to professionals' lack of knowledge of vulvodynia
531 ^{18,38,39}. Gender-based discrimination within healthcare may be rooted in the historic concept
532 that unexplained pain was psychological or normal as medical research focused on men's
533 experiences and often attributed women's problems to their own failings^{38,40}. Within
534 practice, training for professionals to raise awareness of vulvodynia and improve patient
535 outcomes and the delivery of care is needed. More generally, education of healthcare
536 professionals regarding gender-based discrimination could provide a foundation to
537 dismantle such beliefs and improve experiences of those seeking care. Furthermore, it
538 would be useful to explore professionals' perceptions and experiences; this would provide
539 an additional perspective and enable a more in-depth understanding of patients'
540 experiences of gender-based discrimination when seeking help for vulvodynia.

541 Women in the current study felt that psychological factors were insufficiently
542 considered within healthcare when it came to vulvodynia. Some women were referred for
543 counselling, yet accessing this was difficult, which echoes previous findings ²⁴. Pain
544 management was often prioritised instead of holistically considering wellbeing and mental
545 health, which participants believed would have been beneficial. This notion is supported by
546 literature highlighting the need for multidisciplinary, patient-centred practice ^{41,42}. However,
547 it is important to consider that increased resources are needed to offer multidisciplinary
548 care for vulvodynia ⁴³; the increased demands on available resources will need to be
549 balanced against the benefits of such comprehensive care.

550 ***Strengths and Limitations***

551 The present study was conducted with a sample of six participants. While this limits
552 generalisability of our findings, it is important to emphasise that the aim of IPA is to explore
553 participants' lived experience of a phenomenon, rather than to generalise findings to an
554 entire population ⁴⁴. As the current study was exploratory, the lived experiences of our
555 participants highlight the need for further research with larger numbers of participants.

556 A further limitation of the current study is self-selection bias; those with negative
557 experiences of healthcare may have been more likely to participate than those with positive
558 experiences and may have had greater motivation to share their experiences, potentially
559 overrepresenting negative experiences ^{17,23}. The low response rate during recruitment may
560 be explained by potential discomfort discussing a sensitive subject. Barriers to treatment
561 seeking such as embarrassment, fear of judgement and concerns surrounding privacy when
562 discussing a sexual issue may continue to be barriers to discussion outside of a clinical
563 setting ². However, reflexivity, a clear audit trail, and description of the analytical process
564 were used to establish confirmability and increase the trustworthiness of our findings. As
565 participants were predominantly young, white, heterosexual women, insights provided may
566 not apply to those outside this demographic, as experiences of healthcare may differ across
567 demographic groups ^{45,46}. Almost all participants had a comorbid condition, so findings may
568 only represent those with existing conditions alongside vulvodynia ⁴⁷. Furthermore, as
569 participants had a formal diagnosis of vulvodynia, they may have already had some trust in
570 the healthcare system and their views may not reflect those of women with vulvodynia who
571 remain undiagnosed. However, overall, our study allowed an in-depth exploration of
572 healthcare through participants' lived experiences, providing insight into an under-

573 researched area. Such work is a critical foundation to develop greater understanding of this
574 widespread, but under-diagnosed, condition.

575 Healthcare experiences in a sample more varied in age, sexuality, and ethnicity
576 require further exploration to examine if these experiences replicate across populations.
577 Women with vulvodynia with no comorbid conditions should also be considered in terms of
578 their experiences of healthcare and whether these differ from those of patients with
579 comorbidities.

580 **Conclusions**

581 Our findings highlight negative experiences within healthcare, gender-based
582 discrimination, and a lack of consideration for psychological factors in vulvodynia. These
583 findings could be used to improve healthcare professionals' education and training in
584 relation to vulvodynia in order to improve their awareness of these issues. Future research
585 should focus on exploring vulvodynia patients' experiences of perceived gender-based
586 discrimination in greater depth. Furthermore, healthcare professionals' perceptions of their
587 own capabilities in relation to working with vulvodynia patients and the impact of improving
588 healthcare professionals' training in relation to vulvodynia care warrant exploration. This
589 may help improve patients' experiences of help-seeking, thereby improving outcomes for
590 those living with vulvodynia.

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593 **Availability of data and material (data transparency):** Research data are not shared. The
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595 identifiability of participants, therefore unable to share on ethical grounds.

596 **Code availability (software application or custom code):** Not applicable.

597 **Authors' contributions:**

598 **First author:** Conceptualization, Methodology, Investigation, Writing- Original draft
599 preparation.

600 **Second author:** Supervision, Writing- Reviewing and Editing, Validation.

601 **Third author:** Writing- Reviewing and Editing, Validation.

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Question	Further prompts
How old are you?	
Where in the UK do you live?	
What is your sexual orientation?	
What is your ethnicity?	
What symptoms do you experience and what was your diagnosis?	
When were you diagnosed and how long have you experienced symptoms?	
Do you have any other relevant diagnoses?	
What was your experience of diagnosis?	Who diagnosed you? What did diagnosis mean to you?
How would you describe the experience of receiving a diagnosis and care for vulvodynia overall?	Why was this? Could any improvements be made? – if so, what do you believe would be beneficial?
What happened after you received your diagnosis?	How did that impact you?
What health services have you accessed regarding vulvodynia? If multiple, how would you describe your experiences with each?	What may have influenced this?
If private care was accessed, did your experience within private care differ to that of public/NHS services?	What may have influenced this?
Do you recall any experiences that were particularly positive or beneficial?	What made this so positive? What was the impact of this?
Do you recall any experiences that were particularly unhelpful or harmful?	What made this so unhelpful? What was the impact of this?
After diagnosis, did your care change?	Was it as you expected?
Have you ever been offered psychological based treatment, whether alone or alongside physical treatments?	Did you access it? If yes, was it beneficial? If not, is this something you would have considered?

Do you feel you were listened to and treated with respect by healthcare professionals? How does that make you feel?

To what extent do you believe healthcare professionals cared about you and possessed a desire to help? What is the impact of that? How does that make you feel?

How confident do you feel in healthcare professionals' abilities when diagnosing and treating vulvodynia?

Were you informed of how and why any tests or examinations would be carried out? Do you believe the treatment received was necessary?

Do you feel satisfied with how you have been treated and the care you have received? Has your experience influenced your perception of healthcare services?

Overall, has the care and treatment you have received been beneficial?

If relevant – How have you coped with the negative experiences you described?

Are there any changes you believe are necessary to improve care further? Are there any aspects of care that are more or less important than others?

If suggestions have been made – If these suggestions were adopted, what difference would that have made for you?

Has the COVID-19 pandemic impacted upon your experiences of healthcare? What is the impact of this?

Overall, is there anything relating to your experiences of healthcare regarding vulvodynia that you would like to add?

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724 **Table 2.** Participant Demographic Information

Code Name	Age	Diagnosis	Sexuality	Ethnicity	Comorbid Diagnosis
Jennifer	24	Vulvodynia	Heterosexual	White British	Vulval eczema
Suzanne	25	Vestibulodynia	Heterosexual	White British	Endometriosis
Samantha	27	Vulvodynia	Heterosexual	White British	Mental health conditions
Angela	21	Vulvodynia	Bisexual	White British	Mental health conditions

Emily	30	Vulvodynia (generalised and provoked)	Heterosexual	White British	Vaginismus, fibromyalgia, IBS, Ehlers-Danlos syndrome
Nina	22	Provoked vestibulodynia	Heterosexual	Black Caribbean	None

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Table 3. Themes and Subthemes emerging through Thematic Analysis

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Theme	Subthemes
Impact of Diagnosis	<i>Negative Experiences Prior to Diagnosis</i>
	<i>Positive Experiences After Diagnosis</i>
	<i>Negative Experiences After Diagnosis</i>
Patients' Perceptions of Healthcare	<i>Perceptions of NHS Care</i>
	<i>Perceptions of Private Care</i>
Self-Guidance and Lack of Direction	<i>Professionals' Lack of Knowledge</i>

Gender as a Barrier to Effective Care

Lack of Consideration of Psychological

Factors

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