Family Practice, 2019, 791–796
doi:10.1093/fampra/cmz021
Advance Access publication 10 May 2019

Qualitative Research

Women's appraisal of the management of vulvodynia by their general practitioner: a qualitative study

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Abstract

Background: Provoked Vulvodynia (PVD) is the most common cause of vulvar pain. General practitioners (GPs) are insufficiently familiar with it, causing a delay in many women receiving correct diagnosis and treatment. Besides patients factors, this delay can partly be explained by the reluctance of GPs to explore the sexual context of PVD and by their negative emotional reactions such as helplessness and frustration when consulted by patients with medically unexplained symptoms like PVD.
Objective: To gain insight into how women with PVD perceive and evaluate condition management by their GP, in order to support GPs in the consultation of women with PVD.
Methods: We performed face-to-face in-depth interviews with women diagnosed with PVD. The interviews were recorded, transcribed verbatim and thematically analysed. The Consolidated Criteria for reporting Qualitative Research (COREQ-criteria) were applied.
Results: Analysis of the interviews generated four interrelated themes: Doctor-patient relationship, Lack of knowledge, Referral process and Addressing sexual issues. Empathy of the GP, involvement in decision-making and referral were important factors in the appreciation of the consultation for women with PVD who were referred to a specialist. Because women were reluctant to start a discussion about sexuality, they expected a proactive attitude from their GP. The communication with and the competence of the GP ultimately proved more important in the contact than the gender of the GP.
Conclusion: Women with PVD prefer a patient-centred approach and want GPs to acknowledge their autonomy and to address sexuality proactively.

Key words: chronic pain, doctor-patient relation, dyspareunia, empathy, general practice, vulvodynia

Introduction

Provoked vulvodynia (PVD) is the most common cause of vulvar pain and is defined as 'vulvar pain of at least three months duration, without clear, identifiable cause, which may have potential associated factors' (1). These associated factors are, for example, fibromyalgia, mood and sleep disorders, fatigue, dyspareunia, micturition symptoms and irritable bowel syndrome (2,3). Despite the vulvar pain, up to 80% of women with PVD continue to have painful, unaroused intercourse, leading to a vicious circle with an exacerbation of vulvovaginal symptoms (4,5). This vicious circle, together

KEY MESSAGES

- Women with PVD regard competence more important than the gender of the GP.
- Women with PVD prefer a patient-centred approach.
- GPs should learn to proactively address sexual issues and explore this topic.

with the help-avoiding behaviour of women with PVD, is an important patient factor in maintaining the problem (6). In primary care PVD is likely to be misdiagnosed, partially due to an overlap of symptoms between PVD and vulvovaginal candidiasis, as well as the absence of physical findings on exam (3,7).

In the Netherlands, women need a referral by the GP in order to access to a gynaecologist. Unfortunately, most GPs lack knowledge and skills to diagnose and manage PVD when confronted with persistent vulvovaginal complaints, due to a reluctance to perform an adequate sexual history and examination (8,9), lack of time (10) or lack of an adequate training (11). Physicians' delay in diagnosing PVD has repercussions for the women who present themselves with symptoms of PVD. Often, three or more physicians had to be consulted before the diagnosis PVD was made and on average, it took 24 months for women to receive the diagnosis of PVD (6,12). Meanwhile, physicians initiated therapeutic interventions which were largely ineffective and sometimes worsened the condition (13).

PVD raises two barriers to GPs. Firstly, GPs might be hindered by the sexual context of PVD, as taking a sexual history and performing a vulvovaginal examination showed to be barriers for GPs in the diagnostic process of vulvodynia (8). Secondly, when faced with professional uncertainty during their consultations on PVD-like complaints, GPs showed negative emotional responses such as helplessness, discomfort, incompetence and frustration, analogous to their reaction concerning patients with medically unexplained symptoms (8). As this may influence the doctor–patient relationship, it would be helpful to gain insight into how GPs' responses affect women with PVD in order to improve and facilitate the diagnostic process and management of PVD in general practice. We have investigated how women with PVD perceived and evaluated the management of their complaints by their GP. Our ultimate aim was to derive information from the experiences and needs of women with vulvovaginal complaints to support GPs in diagnosing and managing vulvodynia.

Methods

Design

We conducted a qualitative study to explore the experiences and needs of referred women with PVD. Given the personal and sensitive character of the subject, we preferred individual face-to-face in-depth interviews (14).

Participants

Purposive sampling was used to recruit women diagnosed with PVD. They were recruited by certified sexologists, gynaecologists and pelvic floor therapists. The inclusion criteria were:

- Age 18 – 0 years, Dutch speaking.
- A definitively established diagnosis.
- Consultation by a GP at least once prior to the diagnosis.
- The first visit to a GP, regarding vulvovaginal complaints, was less than 2 years ago (to minimize possible recall bias).

All participants were unacquainted to the researchers.

Procedure

Sexologists, gynaecologists and pelvic floor therapists were requested to inform their patients with PVD about this study, and to provide information about how to participate. Women were invited to participate regardless of the evaluation (positive or negative) of their experiences with their GP. After inclusion, a medical student (RS) and psychology student (MM), both female and experienced in discussing sexuality, interviewed the participants in a private setting of their own choice, e.g. in their own home. Prior to the interview, each respondent provided written informed consent and filled out a questionnaire with baseline characteristics.

Data collection

For the interviews, we used an interview guide based on literature and expertise of the supervising committee (PLe, PLu, TT, AL, and EL). The topics in the interview guide focussed on how women experienced and evaluated the diagnostic process and management of their vulvovaginal complaints by their GP. The interviews were expected to last on average 60–90 minutes and were recorded on tape and transcribed verbatim. After seven interviews, all authors (except RS and EL) performed data analysis, in which provisional themes were appointed and ambiguities discussed, allowing going back and refine themes of the interview guide, and addressing new emerging topics. Adjustments were made in querying in detail on the participant's specific experiences with their GP's communication and physical examination, concerning sexual issues. No new topics were suggested.

Data analysis

The transcripts of the interviews were thematically analysed (15). Three researchers (RS, MM and PLe [GP, sexologist]) coded all transcripts, using an inductive open coding strategy. Discrepancies in coding were discussed during face-to-face meetings until consensus was reached. We established a codebook with the software program MaxQDA. Saturation was reached in the last three interviews where no new themes were discussed. By combining codes related to the same phenomenon, conceptual themes emerged during discussion with PLe, MM, PLu (GP, experienced qualitative researcher), TT (GP, expert in uro-gynaecology), AL (GP, expert in gender and women's health) and EL (psychologist, sexologist, expert in women's sexual health). The Consolidated Criteria for reporting Qualitative Research (COREQ-criteria) were applied (16).

Ethical approval

Ethical approval was obtained from the Medical Ethics Review Board of the Amsterdam Medical Centre.

Results

Participants

About 200 sexologists, gynaecologists and pelvic floor therapists were approached to recruit potential research participants. Of them,

63 were willing to recruit which eventually led to 12 participants. See Table 1 for a summary of their characteristics.

Interviews

Analysis of the interviews generated four interrelated major themes (with sub-themes in parentheses): Doctor–patient relationship (Empathy, Openness); Lack of Knowledge; Referral Process (Decision making, Feeling dependent); and Addressing sexual issues (Reluctance, Taking initiative, Exploring, Gender).

Doctor–patient relationship

Empathy

A warm, kind, supporting and understanding approach as off the first contact was mentioned as an aspect of a good doctor–patient relationship, an important condition for the continuation of the conversation.

> That very first contact is very important. General practitioners should simply be able to put people at ease. The first time I got there, he took time to get to know me, so just: who are you, what's going on, so that was just a good start. (Respondent no.8, aged 31 years (R8, 31 yrs))
>
> Because even someone who doesn't know much about that condition but simply has the empathic basis or is almost curious about what it means to you, you would have had a very different conversation. (R12, 26 yrs)

The feeling of being taken seriously by the GP also influenced the quality of the contact with the GP, for instance when the GP took time to listen to the concerns and when the GP acknowledged the complaints.

> I think anyway because he always takes time. I never … I have this doctor from childhood, I've been with him all my life, um.. and, he is never in a hurry, which I like. (R2, 28 yrs)
>
> Make you feel like she's taking you seriously. That it is not that you come over for nothing. (R1, 25 yrs)
>
> Yes, because, yes, I also had other experiences with general practitioners. That I'm not taken seriously there, although it does have a considerable impact on your life, and that he did, yes, recognized it. What I especially liked is that he gave me the idea of 'well this is something we really need to do something about.' (R4, 24 yrs)

Table 1. Characteristics of study subjects

Respondent	*n*
Age in years	
• 20–25	5
• 26–30	4
• 31–50	3
Medical or psychological history	
• Anxiety or mood disorder	5
• Chronic pain	3
• Pelvic floor overactivity	2
• None	2
Education	
• (pre-)Vocational education	3
• Higher professional education	5
• University	4
Relational status	
• No steady partner, sexually active in last year	1
• Steady partner, sexually active in last year	9
• Steady partner, not sexually active in last year	2
Time between first consultation GP and receiving diagnosis	
• 2 years	4
• 1 year	2
• 6 months	1
• 3 months	5
Number of GP consultations	
• 1–3	5
• 4–6	4
• >6	3
Current severity of PVD[a]	
• 3–5	6
• 6–8	6

[a]Severity of complaints scores range from 1 (no complaints) to 10 (extreme complaints).

Openness

The GP being open about his or her own uncertainty about the diagnosis or management of the problem was valued as worthwhile and contributed to a feeling of reciprocity or equality. This openness may be valued as just as important as a GP being knowledgeable and competent.

> She said to me, well [name], I find this so bad for you, I have never heard of it, but I'm just going to find it out. That was just a very equal understanding that we had with each other from the first moment. And that makes it different. (R5, 27 yrs)
>
> And I don't mind that he is vulnerable like 'yes, I haven't seen that very often and it's a good thing, that is how it went', or that he says: ´these are good things to hear for the next people who will come´. [..] And it is not that he has made a mistake, I do not see it in that way at all. (R12, 26 yrs)

Lack of knowledge

Women showed disappointment about the lack of knowledge and professionalism of GPs. Especially in situations when GPs took actions without informing them well, such as prescribing anti-fungal medication or performing a speculum examination without good reason.

> Anyway, yes, I was just angry that it took so long and because she really didn't know what it was and didn't indicate that either. My doctor knew nothing more than 'fungal infections' while later my sex therapist was the first to talk about other things that could be the case. (R2, 28 yrs)
>
> I felt a bit like we were just doing something, trying things out, but he really had no idea where we were going. (R3, 22 yrs)

The doubt about the expertise of the GP was mainly demonstrated by the fact that women felt that the knowledge of the general practitioner was not sufficient.

> And then he came with that idea of 'stretching' [of my vagina] but then you just don't know anything about my sex life. So, then you don't listen well and you don't understand it. (R7, 35 yrs)
>
> The GP took me seriously, but in retrospect I think he didn't have the knowledge because every time I contacted him, a culture was taken and something was prescribed, so I felt taken seriously, but in retrospect this wasn't the way to make this diagnosis. (R8, 31 yrs)

Referral process

Women mentioned two sides of the same coin as important elements in the referral process: the feeling of autonomy in a shared decision-making process and the feeling of dependency in the absence of a referral.

Shared decision-making

Central to the appreciation of the relationship with their GP is the extent to which women felt they were involved in the decision-making process. This included any kind of partnership and reciprocity in finding a diagnosis or a good treatment. This reciprocity established a sense of being taken seriously and being involved.

> He has presented things and really involved me in what was going to happen. Figuring out together, gosh, what does this mean actually and what can be done with it. And afterwards I also like, even though he did not know exactly what it was, that he at least participated. (R8, 31 yrs)
>
> There was always the question, what do you think of it, or what do you think, or do you agree with it? There was always a counter-question. It never happened that he said, 'I'll refer you' or 'we're going to do that'. (R1, 25 yrs)

When the GP did not offer an effective treatment or referral, this made women feel that their complaints were not being taken seriously, about which women felt much frustration. This led to feelings of disappointment and anger.

> That man only said: this must resolve by itself! (R2, 28 yrs)
>
> And then she also said that maybe I should learn to live with it, I thought that was a bit crazy. And ehm, that also made me think I did not feel taken seriously. Because I really thought, well, hello, I'm 20! (R3, 22 yrs)

Feeling dependent

When the GP unilaterally decided that a referral was not in order, women felt dependent. In the case of the cited women, this led to delay of a proper treatment.

> So yes, I now realize that a GP, well, how do you say that, it's quite difficult, she is a young woman, but in terms of hierarchy it is just hard to be mature and put your fist on the table and that you say ...,yes you are dependent. (R7, 35 yrs)
>
> He said, you have to live with it because it's your age. In the beginning you just accept it because …, well, in our health center there are four doctors and I have been to all four. Yeah, and sometimes I also asked whether I could go to the gynaecologist, but that was irrelevant. (R9, 53 yrs)

Some women expressed low self-esteem and self-doubt about the significance of their complaints, particularly when the complaints recurred and no new avenues for diagnosis or treatment were being suggested.

> I always had the idea that it was me; like eh, I do not have to overdo and eh, the pain that will pass anyway. (R1, 25 yrs)
>
> A little that I thought, now I come back again with that, you know, that I thought, now I am really known as the girl who has a 'fungus-cunt' every time. So I found that at some point annoying, or that I had to call again, like okay, I have itching again, could you prescribe something for me? (R2, 28 yrs)

Addressing sexual issues

Talking about sexuality with a GP included a large number of distinct elements, which led to four sub-themes that are mutually dependent.

Reluctance

Women did not always start a conversation about sexuality, partly due to their own reluctance,

> Because she has asked during the examination of my belly of gosh "hey, do you have pain at ehm ... penetration". Then I said, no, no, no, there is nothing wrong. But the moment she sat right in front of me at the table, I certainly would not have said anything because then she also was looking at me. (R1, 25 yrs)
>
> It took a very long time before I even went to the doctor, because it is quite a big step to go to the doctor with such a complaint. (R3, 22 yrs)

Taking initiative

Most women appreciated the initiative of the GP in starting a conversation about sexual issues. This was seen as a basic competence of the GP as a professional. They expected discussing it as a normal issue and expected to be understood and supported.

> Because I always think yes, he listens to all these kind of stories all the time and um, I don't know, I just really see him as a good doctor and as a professional, so I am … he is needed for that. (R2, 28 yrs)
>
> [It was nice] that she could talk about it so easily and that it was not uncomfortable. (R6, 24)
>
> Yes, I prefer asking me a thousand embarrassing questions to establish a good diagnosis above avoiding it because it is uncomfortable. Yes, I would like that, and put you at ease as much as possible. (R10, 28 yrs)

Exploring

Women wished that GPs had asked more in depth questions to explore the sexual context further.

> If she had asked more than once, I might have had something like yes, maybe it should just be on the table. (R1, 25 yrs)
>
> No, I think it would have been good that he had tried to get out of it because he followed me closely [in my reserved attitude]. He asked if we enjoyed it or something like that, the question was also quite closed. And then I thought, yes, it is going well. But it is also logical that there is a bit more behind these complaints. (R12, 26 yrs)

Gender

Many of the participating women with PVD had no preference for a male or female GP in discussing sexuality, although initially some doubted about whether a male GP would make them feel at ease. Whenever there was a preference this was based upon them being familiar with the GP, regardless of gender. The communication with and the competence of the GP ultimately proved more important in the contact than the gender of the GP.

> Yes, I was just afraid that he would not go into that as an older man and it was nice that he did. (R4, 24 yrs)
>
> At that man I first thought of, yes, it is a man, but it was such a nice man and very patient and so and very knowledgeable, so I thought it was great. (R10, 28 yrs)
>
> Yes, I like a woman with this complaint. There is also a man in this practice but I actually asked for her. (R7, 35 yrs)
>
> I do not care if it's a man or a woman, if only he understands his job. (R5, 27 yrs)

Discussion

Main findings

Most participating women mentioned that the quality of the doctor–patient relationship and the level of knowledge about diagnosis and management of PVD, more so than the gender of the GP, is

important for the appreciation of the consultations concerning vulvovaginal complaints. When symptoms recurred or persisted and the GP was reluctant to refer or offer a new treatment, women felt dependent or frustrated. Some women expressed reluctance to bring up sexual issues themselves, but welcomed the GP initiating exploration of sexual issues during the consultation. They regarded this to be a basic competence of a GP. The male gender of the GP was not experienced as a barrier in the consultation or when sexual issues were discussed.

Comparison with the literature

Regarding the theme of the doctor–patient relationship, our findings correspond to studies about medically unexplained symptoms, which found that the unexplained nature of the symptoms and how these symptoms are handled by their physician is often a source of frustration and helplessness for patients (17). In line with our results, studies showed that this frustration was also felt when patients did not receive empathy from their GP (18,19). Empathy, as well as treating the patient as an equal partner, is perceived as important attributes of patient-GP communication and its presence results in feelings of satisfaction, relief and trust, as also is described in our group of women (20,21). Greater practitioner empathy or communication of positive messages showed to have patient benefits for a range of clinical conditions, especially pain and conditions with a strong psychosocial context, which also is seen in PVD (22–26).

The need for acknowledgement and being taken seriously among the interviewed women is in accordance with other studies in women with PVD. They showed that many women felt judged, not listened to and not believed in their quest for diagnosis (27). As we showed, these frustrations also increased due to a lack of GP knowledge on PVD. Mostly, women were told that because no organic cause could be found the symptoms were of psychological origin. This led to feelings of shame or low self-esteem (27). Furthermore, our findings show, in accordance with other studies, that a patient-centred approach should also allow patient involvement in the decision-making on further steps in diagnosis and treatment (28).

Although some women and general practitioners were reluctant to address sexuality, discussing sexuality does not prove to be a problem to the women in our study provided that the GP initiated the discussion. This positive appreciation of a proactive attitude is also seen in other studies in primary care (29–32). For GPs, embarrassment proved to be an important obstacle to initiating a dialogue about sexual health, especially in case of a patient–physician gender discordance (9,29,33,34). However, gender discordance showed not to be an issue to most women regarding discussing sexuality, taking into account that these studies were conducted in the USA and Western Europe and limited to women in family and gynaecological practice, young women called for gynaecologic screening, and women with cancer (31,32,35,36). These results correspond to our findings.

Strengths and limitations

The study has several strengths. Firstly, experts made the PVD diagnosis, which increases the internal validity as far as it concerns the group that was referred to a specialist. Secondly, the fact that the in depth-interviews were done individually optimized confidentiality and may have increased the reliability of the data. Thirdly, the interviewers' gender, age and training in discussing sexuality may have benefited the quality of the data. Furthermore, the participants were heterogeneous with respect to education level, comorbid conditions, time between first consultation of a GP and receiving diagnosis, number of GP consultations and current severity of PVD. This provided a variety of possibly relevant issues. Finally, our research group consisted of professionals with a broad variety of expertise, thus considering themes from different perspectives.

Limitations of our study are the self-selection bias of our participants, which may have had a strong effect on their answers. It took 1 year to include women who were willing to participate. The participating women were referred by their GP and probably were ultimately satisfied about the way they had been treated. Had we been able to capture women interacting with the GP during consultation, or had we been able to interview women in this stage of the diagnostic process, women's experiences and needs may have generated other themes. Also, recall bias due to the retrospective character of the interviews may have limited the reliability of the women's accounts. Furthermore, two different interviewers, due to practical circumstances, conducted the interviews; differences in approach (and response of participants) cannot be excluded. On the other hand, this might also be a strength as it may have provided a variety of issues which is of benefit for the heterogeneity of the content.

Implications and future perspective

Three issues might need attention. First of all, GPs should improve basic consultation skills in which they show empathy and in which they involve shared decision-making on subsequent steps in diagnosis and management. Also, GPs should be educated about PVD and should be better able to differentiate between VVC and PVD (37).

Secondly, in addition to these skills, GPs should learn to proactively address sexual issues and explore this topic in some detail. Male GPs should not be concerned about the gender discordance provided that they apply the aforementioned basic consultation skills and knowledge.

Finally, it would be relevant to investigate whether improvement of communication skills and knowledge of GPs about PVD are effective in diagnosis and management of PVD, to what extent the GP is capable to treat PVD effectively and which elements in the management of PVD in primary care are beneficial to women.

Conclusion

Empathy of the GP and involvement in decision-making and referral were important themes in women's experiences with the way GPs manage persistent or recurrent vulvovaginal complaints. Because women are reluctant to start a discussion about sexuality, they expect a proactive attitude from their GP in this. The communication with and the competence of the GP ultimately proved more important in the contact than the gender of the GP.

Acknowledgement

We thank Mrs Chantelle Otten, Sexologist at Cabrini Medical Center, Melbourne, for her translation of the quotes from the verbatim.

Declaration

Funding: Dutch Scientific Society of Sexology
Conflict of interest: none.

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